

The balance we seek: A sequential narrative analysis of childhood cancer blogs

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Dissertation Committee

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Dedication

This work is dedicated to the families who generously permitted me to use their stories to help others understand the beauty of lives well-lived, even in chaos; and to all the children I cared for who are with me every day in spirit, and to their families. You are right: no one really knows how you feel unless you've been there, so it is important to tell the story.

Abstract

Purpose The research aimed to identify the narratives and themes about the experience of parenting a child with cancer, analyze the social interaction present in illness blogs created by parents of children with cancer and identify the reasons expressed by parents in the blogs for writing and publishing online.

Questions The following three research questions were posed: (1) What life stories are evident in blogs created by parents of children with cancer? (2) What themes are evident in the illness narratives contained in these blogs? and (3) What is the influence of author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer?

Method Nine illness blogs created by parents of children with neuroblastoma and five by parents of children with acute lymphoblastic leukemia found using modified snowball sampling, met inclusion criteria and proved sufficient to reach informational redundancy. Three narrative analytic approaches were used sequentially to analyze the illness blogs from different but concomitant perspectives: life story, thematic analysis and Narrative-in-Interaction narrative analysis. The Natural History of the Illness framework was employed to analyze blogs within the context of the diagnostic, treatment and off-treatment phases of the illnesses.

Findings The life story analysis of two blogs resulted in creation of two summaries of the parents' narrative of the entire illness experiences. Thematic analysis of all 14 blogs led to discovery of two major groups: thematic categories and performative acts of the authors. Five thematic categories were found in the narratives: uncertainty/uncertainty management; stress/stress management; burdens/gifts; change/constants; and public/private life. Performative acts by the bloggers included reflecting; reporting; expressing; advocating; archiving; and explaining. Analysis of author-reader interactivity identified two major thematic categories: co-

creation, defined as the process through which blogger and reader influenced each other and ballast, defined as the readers' efforts to support and affirm the blogger.

Conclusion The recurring theme in the blogs was the quest for balance between life's buffeting and steadying forces. Author-reader interactivity, one of the defining attributes of illness blogs, was found to strongly influence the quest for equilibrium longed for by these parents in significant ways. The findings suggest that attention to parent blog content by nurses and other health care providers is important in understanding the day-to-day experiences of parents with children with cancer and can contribute to improving family satisfaction with care and patient care outcomes including quality of life concerns.

Recommendations Research on illness blogs is expected to lead to the development of a middle range theory of online communication in illness. Parent narratives from these blogs will guide new research as nurses seek to discover greater understanding of family life with childhood cancer. Further clarification of the meaning of balance to parents and the influence of online communication during illness is needed. More needs to be known about the relationship between blogging and parental measures of uncertainty, anxiety and identity change in the experience of childhood cancer. Research into the relationship between parent contributions to the medical record and family satisfaction, patient care outcomes and the prevention of medical errors would also prove useful.

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CHAPTER 1

Background

Family life is changed fundamentally and permanently when a child is diagnosed with cancer. In everyday decisions, reflection, and activities, parents come to hold hope and despair together at once. Children carry on with playing, learning, living, all the while attempting to cope with cancer, or the risk of its relapse. The combined 5-year survival rate for all childhood cancers has improved from 58.2 percent in 1975 to over 81 percent in 2006, the most recent year for which data are available. The 10-year survival rate in 2007 was over 75 percent (Altekruse, et al., 2007). As a result, there is now more reason for hope than despair. Despite this, cancer remains the leading cause of death by disease in American children between infancy and 15 years of age. Over 10,000 new cases of pediatric cancer were diagnosed in children ages 0–14 years in 2007 (American Cancer Society, 2007). The incidence of childhood cancers, invasive cancer in particular, has risen (Altekruse, et al., 2007). There has been essentially no change in outcome for children with disseminated disease in 25 years (Garnett, 2005).

While statistics demonstrate improving outcomes in childhood cancer treatment, much remains to be learned about issues related to family quality of life during treatment stages. Research on quality of life during cancer therapy was recently highlighted in an Institute of Medicine (IOM, 2007) report as one of the blind spots that persists despite significant progress in cancer research in other realms. The report called for a redoubling of efforts to ease the psychosocial burdens associated with cancer diagnosis and treatment that have been neglected in the race toward the striking biomedical achievements that have occurred.

In the report, the IOM Committee on Cancer Care for the Whole Patient defined psychosocial health services as psychological and social services and interventions that enable

patients, their families, and healthcare providers to optimize biomedical healthcare and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health. The comprehensive IOM report offered a brief review of literature relevant to the use of online communication in illness. The locus of the family experience of cancer is not limited to the physical space of clinical settings. Increasing attention is being directed to research on alternate locations and methods that can support the provision of psychosocial services. The IOM Committee explicitly recommended assessment of the efficacy of “virtual peer support groups” that have recently increased greatly in number, especially since patients and families that are home-bound or geographically isolated can access these groups at minimal expense (IOM, 2007, p. 90).

Some of the virtual groups have taken shape from one of the new strategies for dealing with childhood cancer that families have adopted, i.e., the use of illness blogs. In these online narratives of the illness experience, parents express in rich detail what it is that adds to their success in surviving the experience, however they define success. They identify those elements of the experience that need to be improved. And for the first time, in real time, these individuals are describing life as parents of children undergoing treatment for cancer as they live it. In addition, they receive responses from and maintain relationships with family, friends, even strangers across many miles (Heilferty, 2009). To date, no research has been published on this new phenomenon of online writing and publishing stories about the experience of parenting a child through cancer diagnosis and treatment.

Parental experiences of childhood cancer

Treatment for childhood cancer has evolved into a mixed-blessing labyrinth of treatment options and unstable wellness states. Although the hope is always for cure, a large portion of the

child's cancer treatment life is spent in and out of the medical state referred to as no clinical evidence of disease (NED). Remissions and exacerbations become the frame of the roller coaster that has been used to describe life with childhood cancer (McGrath, 2002).

Cure rates for certain types of childhood cancers have improved; as a result, greater numbers of affected children and their families experience cancer as a chronic illness. With recent advances in childhood cancer care, a new illness trajectory has emerged that brings to the experience prolonged and complicated uncertainty, stress and image changes (Mishel, 1983; Young, Dixon-Woods & Heney, 2002; Alderfer, Cnaan, Annunziato, & Kazak, 2005).

There is now a greater urgency than ever to attend carefully to issues of quality of life. A question that has resulted is: while years have been added to life, has life been added to the years? Despite progress in nursing, medicine, sociology and psychology research in this area, there remains much to be discovered about parenting a child through serious illness. This wholly unanticipated, under examined and poorly understood existence between recurring crises and uneasy calm---between relapse and NED---must be attended to if any progress is to be made in the prevention of long-term negative psychosocial outcomes for the family, such as posttraumatic stress disorder (PTSD) (Barakat, Alderfer, & Kazak, 2006).

Studies of the experiences of families with a child living with cancer have shed light on significant negative events that can result from the disease, the treatment, or both. In a qualitative study of seventeen families with a child diagnosed with cancer, Björk, Wiebe and Hallström (2005) identified two essential themes from the interviews with family members: "a broken life world" and "striving to survive." The authors described the families' experiences of safety, security and certainties being replaced with fear, uncertainty, chaos and loneliness after the child's diagnosis. A diagnosis of cancer challenges the integrity of the family at large, as

well as its individual members' identities. The most significant untoward elements that have received serious scrutiny involve the impact on parents of the prolonged, episodic short- and long-term uncertainty; stress; and family and personal identity changes during and after childhood cancer (Mishel, 1983; Young, Dixon-Woods & Heney, 2002; Alderfer, et al., 2005).

In a seminal study, Contro, Larson, Scofield, Sourkes and Cohen (2002) interviewed sixty-eight family members of forty-four deceased children regarding treatment, transition to palliative care, and bereavement follow up. The authors found that parents appreciated being actively involved in making decisions. Honesty, clinical accuracy, compassion and availability were identified by parents as the most desirable healthcare provider traits. One of the most striking findings was the profound and lasting emotional distress experienced by parents from single negative events in the child's care. These events were found to haunt parents and complicate grief for years.

More needs to be known about the influence of healing relationships on a family's illness experience and decision making at different stages of the disease process before designing interventions (Kane, Hellsten & Coldsmith, 2004). At the same time that staggering investments are being made in medical advances in childhood cancer, arguments are being made for greater inclusion of research in nursing and psychosocial elements of care (Dixon-Woods, Young & Ross, 2006).

When a child's cancer recurs, families are offered many more diverse and complex options for treatment than when the child was first diagnosed. Often, Phase I or II experimental therapies with unknown outcomes and less likely benefit are offered in the hope of prolonging life when it becomes evident that a child will die at some point from the disease. Inspired by incentives from the National Institutes of Health, inequalities in funding for age-, disease- and

developmentally-specific research efforts are being addressed, making more options available than ever before for pediatric cancer treatment (Carlson, Reilly & Hitchens, 2004).

Despite recent advances in knowledge development on these phenomena, there remains a lack of evidence regarding the effectiveness of some of the psychosocial interventions now in practice in many centers. One explanation for this lack of evidence might be related to the complex nature of studying such a vulnerable population. Many of these families have one foot in the curative mode and one foot in end-of-life phenomena, with the ground underneath constantly shifting. Research will need to draw on constructs now being created to inform awareness of family life during all phases of childhood cancer care: curative treatment, survivorship and end of life. A need has been identified for more research into conflicts related to symptom patterns, perceptions of suffering, treatment decision making, as well the meaning families seek in the end-of-life experience (Stutzer, et al., 2005; Oeffinger, Martin, & Kremer, 2008).

In the report *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families*, the Institute of Medicine (IOM, 2002, p. 358) recommended several specific areas for future research, which included attending to the reports of children and families about their specific experiences within healthcare systems (preferably concurrent with that care), not just their global assessments of satisfaction.

Illness narratives

There is evidence that expression of stories of illness helps to reduce the psychosocial side effects of cancer treatment (Frank, 1998a; Kleinman, 1988; Sandelowski, 1991). Illness blogs are the online equivalent of illness narratives. The significance of the research reported here rests in the hope of acquiring new knowledge about life with childhood cancer from the

first-person accounts created by parents in illness blogs. The importance of narratives of illness, to those who create them and to those who read them, is the meaning, context, and perspective they provide for the individual's unique situation (Greenhalgh & Hurwitz, 1999). Research on the unique features of writing that separate illness blogs from other forms of illness narrative is central to understanding the theoretical benefits. Blogs are unsolicited and interactive. Parents start blogging and continue to blog for reasons that are unique to their circumstances. Illness blogs are the online version of personal journals, but with the interesting, though thus far unexamined dimension of interactivity from family members, friends and strangers who feel compelled to respond to entries in real time (McNamara, 2007). In addition to new knowledge about the life stories and illness experience-centered narratives found in parent blogs, new insight was found in this study about the effect on parents' illness experience. The sense of solidarity resulting from the immediacy and reciprocity characteristic of this author-reader relationship was one of the main findings.

Attending to the stories promotes a sense of empathy and trust between practitioner and patient, honors family members' identities and allows for the construction of meaning on both sides. Illness narratives can also provide essential diagnostic clues and context for caregivers (Greenhalgh & Hurwitz, 1999; Young, Dixon-Woods, & Heney, 2002).

Illness blogs

Evidence of challenges to a satisfactory quality of life during treatment for childhood cancer appeared in the vivid descriptions in the online narratives created by parents about the experience. In both public and password-protected online forums, parents expressed deeply felt emotions, reaching out to family and friends, sharing clinical details with readers, and receiving solace. These online journals, or illness blogs, defined as frequently modified web pages in

which dated entries are listed in reverse chronological sequence, were first seen in 1996 (Herring, Scheidt, Bonus & Wright, 2004). Illness blogs have been recognized as the textual narrative of illness experiences (McNamara, 2007; Heilferty, 2009).

A recent query using blog search engines Google and Technorati provided thousands of responses to the search terms “child and diagnosed with cancer;” “diagnosed with neuroblastoma” (a cancer mainly affecting children); and “child and diagnosed with leukemia.” In addition to these publicly created and maintained blogs, many more password-protected sites exist on services like CaringBridge and CarePages. CaringBridge is a nonprofit organization offering free personalized websites to those wishing to communicate with family and friends during significant life events. CarePages is a privately held business that works with hospitals to provide blogging services to patients and family members (Aleccia, 2008).

Despite exponential growth in blog development and use in recent years, blogging continues to suffer from an image problem—that of the typical blogger as “a web-obsessed male telling the world what he had for lunch” (Gordon, 2006, p. 32). The image is changing as the genre is refined, as it gains broader acceptance, and as research interest in online writing proliferates across disciplines. From journalism to literature and healthcare, the blog is gaining recognition as a completely new genre of authorship and readership. For the family members in this study, blogging served as a forum for the exchange of ideas, experiences, and knowledge. Blogs appeared to relieve suffering by helping individuals maintain close relationships despite separation and by aiding in the formation of new relationships, regardless of temporal or geographic proximity (McNamara, 2007).

More and more hospitals are making personal web pages available to families on which they can journal, post pictures or family news, and link to cancer support websites. These blogs

are filled with details about what families expect, hope for, and witness as the childhood cancer experience unfolds. In the clinical setting, not enough time is spent listening to patients' stories (Rallison & Moules, 2004). Much has been learned in this study from the deeply personal yet widely accessible narratives of these lived experiences.

Parents seek information from many sources in attempting to decide on the right approach for their child's care. The Internet is playing a greater role in providing families with information on available clinical trials, the experiences of other children and families in similar situations, logistical arrangements for travel and communication with leading healthcare providers. Parents have reported a constant and profound struggle to balance the hope for cure with the reality of the impact of experimental therapies on the child's life and wellness (Carlson, Reilly & Hitchens, 2005).

Significance to nursing

The significance of the research was tied to one of the essential functions of holistic nursing: to tend to families' stories of the illness experience (Thomas & Pollio, 2001). Nowhere are childhood cancer stories being relayed more broadly, more vividly and in such detail than in the parent blogs that were examined. Owing to their continuous physical presence with patients during hospitalizations and with the advantage of having the most time with families, nurses are uniquely positioned to explore illness experiences in depth. Nurses have historically been in the best position to attend to what families often say they want: to be heard, in addition to being treated. Turning attention to illness blogs has expanded nursing's definition of data to include this unsolicited, broadly published yet deeply personal writing on the illness experience. It is imperative that the child's and family's existence be understood within the context of their world view (Woodgate, Degner & Yanovsky, 2003).

Narratives resulting from qualitative research involving interviews with family members about the experience have been used to educate professional caregivers, by creating a window into family challenges, successes and truly supportive professional helping behaviors (Woodgate, 2006; Woodgate, Degner & Yanofsky, 2003). For clinicians new to nursing practice, exposure to illness stories, especially first-person accounts, can facilitate the development of skills required to build meaningful, therapeutic, caring relationships (Minden & Gullickson, 2004). Storytelling can promote empathy, socialization and acculturation, i.e. into the culture of illness and family suffering during illness (Sharts-Hopko, personal communication, January 10, 2008). Memorable narratives can encourage reflection on the principles of nursing practice. Nurse educators can use illness stories to help students translate empathy with individual stories to understanding of those for whom they care (Minden & Gullickson, 2004). For researchers, the study of narratives can provide a frame of reference for holistic, patient-centered approaches to the acquisition of new knowledge. Reading, listening, and attending to family stories of illness help to generate new hypotheses and challenge conventional wisdom (Greenhalgh & Hurwitz, 1999).

Statement of the problem

Research to date on the experiences of parents living with childhood cancer has focused on parental decision making; hope; uncertainty; stress; as well as child, parent and family quality of life or coping (Hinds, 2004; Hinds, Burghen, Haase, & Phillips, 2004; O'Neil, 1996; Stewart, Pyke-Grimm & Kelly, 2005). While members of the healthcare team have concentrated primarily on exploring research questions and answers within the context of hospital and outpatient settings, families have begun expressing intimate narratives of the lived family experience of childhood cancer online in blogs, with readers able to respond. An emphasis on

exploring psychosocial aspects of the experience using traditional research methods has led to an accumulation of knowledge about pathologic responses, maladjustment, stress levels, and emotional decompensation. The current snapshot of the family struggling with cancer treatment and side effects, obtained in clinic and inpatient visits, creates an incomplete picture. Yet these snapshots of experience are employed every day in clinics in the assessment, interventions or evaluation of care.

Little is known about the day-to-day experiences of parents living with a child who has cancer. The problem addressed by the present research was the lack of understanding on the part of professionals about parents' experience with childhood cancer.

Research purpose

The purpose of the research was to explore, describe, and analyze these online narratives in the hope that knowledge generated would amplify the voices of these vulnerable families. The research aimed to identify the themes about the experience and the social interaction present in blogs created by parents of children with cancer and to identify the reasons expressed by parents in the blogs for writing and publishing online.

A strong sense of solidarity that emerged from years of working with families affected by childhood cancer and from reading blogs created by them inspired the present research. "The reality of human solidarity, which is a benefit for us, also imposes a duty" (Pope Paul, 1967). In the context of the research, the virtue of solidarity is understood as that professional and moral duty to attend to families affected by life-threatening illness in response to the abundant privilege received in caring for them.

Solidarity here is defined as that unique position of the researcher standing with the storytellers, as witness to the daily lives of families affected by childhood cancer. In the present

blog analysis, solidarity was expressed in the research activities associated with it: meaningful presence, patient advocacy and change agency. To stand with these families is to situate their stories at the center of care.

Analysis of illness narratives can contribute to a broader understanding of the ways in which parents are living with childhood cancer. Illness blogs are the online expression of parents' experience of the illness (Heilferty, 2009). This study of parent blogs about their child's cancer will be significant to the degree that it can add a new dimension to the snapshot that will honor the families' stories. Ultimately, it is hoped the results can inform nurses, physicians, and others about the expression of life embedded in the parents' online writing on the experience of parenting a child through cancer.

Before the creation of new interventions based on the limited information clinicians glean from brief interactions in the hospital or clinic setting, outside the family's living context, a deeper understanding of the experience in the family members' own words is needed. In illness blogs, families are sharing their stories in detail for the entire world to read. It is hoped that strategies to improve some aspects of care for these families will come when their writing about the experience is better understood.

A sequential application of three narrative analytic approaches was used to analyze the illness blogs from different but concomitant perspectives: life story, thematic analysis and text-in-interaction narrative analysis (Polkinghorne, 1995; Georgakopoulou, 2006; Riessman, 2008).

Research questions

The narrative analysis of parent blogs about living with childhood cancer was designed to answer the following three research questions: (1) What life stories are evident in blogs created by parents of children with cancer? (2) What themes are evident in the illness narratives

contained in these blogs? and (3) What is the influence of author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer?

CHAPTER 2

Review of Literature

As medical outcomes have improved for children with cancer over the last few decades, more information has been discovered about the experience of living with the illness. This review highlights research related to the parental experience of childhood cancer. A search of the literature to date revealed one general and two specific areas of concentration that have guided the research: first, experiential research on parenting during treatment for childhood cancer in general; second, study of the effects of the stress of the experience on the parents and family; and third, study of the effects of the associated immediate and prolonged uncertainty. The review of research on parenting through childhood cancer in general, and research on stress and uncertainty particularly, are organized by study type and presented in chronologic order. Next, a review of literature pertaining to research on illness narratives, and in particular on illness blogs is presented. Lastly, the conceptual framework that guided the proposed research is explained in relation to the chosen sequence of narrative methods.

Parents' experience of childhood cancer

The review of published literature on the experience of parenting a child through cancer found 1980 as a significant turning point in healthcare professionals' research on the topic. It was in this decade that research on the experience began to change as childhood cancer treatment changed and outcomes for many of these cancers improved dramatically (Van Dongen-Melman & Sanders-Woudstra, 1984). In their review of the literature on psychosocial aspects of childhood cancer, especially the impact of the disease and treatment on the child and family, Van Dongen-Melman and Sanders-Woudstra (1984) highlighted results from studies of parents' reactions. Despite improvements in treatment outcomes from the late 1960's to the late 1970's,

there was no evidence that parents had moved away from linking a diagnosis of cancer with death. A call for parent education and sensitivity to what the authors referred to as parents' anticipatory mourning was part of the conclusions drawn. In addition, several connected but distinct elements were noted in the early literature on the topic: uncertainty, stress, hope, professional caregiver attitudes toward parents, pressures on the marriage, coping behavior, adaptation and concurrent stresses. The authors suggested a change of research focus in this area away from loss as a central phenomenon toward the emotional aspects of living with the disease.

Methodological problems found in the early research by Van Dongen-Melman and Sanders-Woudstra (1984) were a lack of integration of the apparent disparate but related concepts that might facilitate a better understanding of the complex processes at work. Inconsistencies in measurement techniques used to study the same concepts were also noted, in addition to bias in sample selection, incomplete descriptions of sample groups and inappropriate design and use of research instruments. Suggestions for the future included study within a theoretical model with an emphasis on coping as a central area of concern, a view of research participants as normal families under stress rather than as a group of abnormal individuals, and an examination of characteristics that might explain responses to cancer.

Child psychologists Kazak and Nachman (1991) used pediatric oncology as an example of childhood chronic disease to explore research published on families' experiences with illness. Bronfenbrenner's social ecological model served as the frame for viewing the research first from the child's experience, outward in concentric rings that encompassed settings and environments that affect the child i.e., the siblings, parents and families of the ill child, out to the social support networks i.e., educational systems, healthcare system and policy/societal attitudes. Research on parent reactions was found to be influenced by personality, previous experiences with illness,

caretaking, family-of-origin issues and the interaction of individual and family members' predispositions toward functioning. The authors identified general concerns, gender differences and coping styles as the three main areas of research on parents. Further refinement in theoretical models and integration of the expanding body of research with new, family-centered interventions were suggested (Kazak & Nachman, 1991).

Qualitative research on parental experience of childhood cancer

In their report on a longitudinal study of family reaction to childhood cancer, Martinson and Cohen (1988) described fifteen themes that emerged from the analysis of data derived from interviews with parents of children diagnosed with cancer in 1978-1979. Themes identified included being unprepared for the diagnosis and the need to regain a sense of normalcy quickly to fear that the cancer would recur and that a sibling would develop the disease. The use of a longitudinal design and inclusion of data from parents of children who survived and parents whose children had died added knowledge about the spectrum of families' lives with cancer over time. Interventions suggested by the data included helping parents develop skills that would help them explain the child's illness or death to siblings; providing continuous access to nursing services for survivors and their families, and helping parents develop assertiveness skills required for obtaining needed treatment and care information. Interestingly, Martinson and Cohen suggested a longitudinal analysis within families to add further levels of analysis of responses to cancer over time. The proposed study of illness blogs that contain months or years of writing about the parent experience is consistent with this recommendation.

"Restructuring reality: Family strategies for managing childhood cancer" (Clarke-Steffen, 1997) stands as a seminal work in the research on the family experience. In this report of a longitudinal, prospective, grounded theory study of thirty-two members of seven families who

had a child recently diagnosed with cancer, the core process in which families were found to engage involved six main strategies: (1) managing the flow of information; (2) evaluating priorities; (3) shifting priorities; (4) changing future orientation; (5) assigning meaning to the illness; and (6) managing the therapeutic regimen.

The findings were found to exemplify the Family Management Style theorized by Deatrick, Knafl and Guyer (1993) in which a common goal of the families was the normalizing of life within the context of illness, or the creation of a new normal. Two interventions spontaneously recommended by parents in the study were to include support for parents from healthcare providers in the form of answering all questions using everyday terms and to make knowledgeable advice available 24 hours a day with freely accessible phone support (Clarke-Steffen, 1997).

In a grounded theory study by Van Dongen-Melman, Van Zuuren and Verhulst (1998), parents of children successfully treated for cancer were found to continue to experience profound losses after treatment ended, although the anxiety and stress at this time was not likely to be expressed by the parents or understood by relatives and friends as such. This sense of mourning over the possible death of the child was mediated and limited by the survival framework, i.e. the propensity toward emphasis on ever more hope and concentration of effort toward survivorship, complicating its expression further. Also of note was the notion discovered here that a combination of coping strategies appears efficacious, but in this respect the authors called for more research. New information obtained provided insight into which late consequences can be expected in parents at the end of treatment, indicating a possible unattended period of transition in which anticipatory guidance might be helpful (Van Dongen-Melman, et al., 1998).

Dixon-Woods, Findlay, Young, Cox and Heney (2001) collected parent narratives through semistructured interviews to determine how parents felt about the diagnostic experience with childhood cancer, how the process affected them, and whether these narratives had implications for early diagnosis and referral of childhood cancers. One of the motivations of the authors was concern over delays in diagnosis and treatment related to the healthcare system in the United Kingdom. The authors took a grounded theory approach to data analysis. Their results revealed new information about the experience of parenting a child with cancer. Specific attention was drawn to the great complexity of issues faced; the underestimation of the importance of the pre-diagnosis period of stress and identity challenges; and the institutional roadblocks faced. In addition, the description of 'long disputes' versus 'short disputes' over care decisions identified differences in the way parents managed part of the experience.

In a phenomenological study of sixteen parents of twelve Australian children recently diagnosed with acute lymphoblastic leukemia (ALL), McGrath (2002) found the initial stage of treatment to be highly stressful with parents often overwhelmed by the experience. Three main emotional states were noted to predominate: the stress of uncertainty; the shock of uncertainty; and a feeling of being trapped in an unpleasant emotional roller coaster ride. Honesty from healthcare professionals, an opportunity to share feelings and an affirmation of the harshness of the situation were reported as helpful in dealing with the perception of feeling overwhelmed (McGrath, 2002).

In a subsequent phenomenological study, McGrath, Patton and Huff (2005) reported on interviews with family members of children recently diagnosed with a different type of cancer, acute myeloid leukemia (AML). The results revealed similar struggles among the two groups of families in regard to disruption of normalcy and the effort to regain balance.

A third phenomenological study of the experience of childhood cancer conducted by McGrath and Phillips (2008) revealed that families affected by lymphoma, the cancer diagnosis of interest in the study participants had a somewhat different experience than participants in earlier studies. They reported more intense expressions of stress; provided more descriptions of a high degree of stress related to invasive procedures; and experienced feelings of isolation and insufficient access to information related to the relative rarity of lymphoma. In addition, family members reported further feelings of isolation related to the notion that the outcome for their child was much more hopeful than for children with other types of cancer, so parents expressed a sense that their families' suffering was trivialized.

Grinyer (2004) reported on a follow-up study of parents' narratives of their experiences related to their young adult child's cancer. Four years after the start of the research and after publication of several reports related to it, including a book, parents were invited to write narratives on the impact of the diagnosis of cancer on family life. Grinyer described the genesis of the idea and the methodological background in detail. "Narrative correspondence" was chosen as the method for data collection and was defined in this study as email, handwritten letters and telephone conversations responding to written calls (in newsletters and journals) and personal calls (from health professionals) for the narratives. Part of the purpose of the study was to ascertain the effects of participating in emotionally demanding research. Although a significant portion of the report described the significance and challenges of the approach along with potential for harm and cautions about ethical treatment, more detail on the method of analysis of the data would have added to its structure and understanding. Themes found in the parents' narratives were: the 'therapeutic effect of writing,' 'continued pain,' 'the book [Grinyer's published text on the earlier research (Grinyer, 2002)] as a lasting memorial,' 'ability

to read the book;’ and ‘the launch and workshops.’ (Parents had been invited to the book launch and to workshops following it.) In her conclusion, Grinyer found expressions by the parents about the process of writing, specifically in the method in which parents retained control over when, how, and where and the medium by which they responded, to be beneficial to parents on many levels.

Björk, Wiebe and Höllstrom (2005) reported on a phenomenological study of families’ lived experiences when a child is diagnosed with cancer. Seventeen participating families (17 mothers, 12 fathers, 5 patients, and 5 siblings) were interviewed at three time points during the cancer experience: just after diagnosis; during treatment; and after completion of treatment. Two essential themes were identified from the analysis of the interviews: “a broken life world” and “striving to survive.” Everyday life stability was replaced by fear, chaos and loneliness. Family members described efforts of striving to feel hope, to have a positive focus, to gain control and to feel close to other people. Björk and colleagues suggested the important role nurses might have in helping families deal with the cancer experience and in diminishing chaos since the data highlighted the dependent role parents assumed within the healthcare system.

Woodgate’s (2006) narrative inquiry of the family experience of childhood cancer was based on interview data collected from 39 children with cancer and members of their families. The purpose of the analysis was to describe how childhood cancer shapes a child’s and his or her family’s way of life as depicted in the narratives that they constructed. Interpretive interactionism was the guiding frame of reference, and the author differentiated between two types of interpretive interactionism: the first being the foundation for grounded theory, a method in which findings are meant to be presented formally and toward development of a theory; and the second, which involves the use of narratives to highlight the uniqueness of every

story. The narratives were collected from 39 children and members of their families (parents and siblings). The findings included a ‘core narrative:’ that ‘life is never the same;’ and identification of the themes of ‘shared and unique losses,’ ‘moving forward, moving on,’ and ‘It is never over with...always a waiting game.’

The study lent support to Clarke-Steffen’s (1993) finding that a diagnosis of childhood cancer fractures reality in the lives of children and their families, causing a need to develop new coping strategies to cope with life with cancer. Although every family’s experience with childhood cancer was acknowledged as unique, some similarities were identified in the narratives created in the study: the requirement inherent in the experience that all families confront the possibility of the death of the child; a pervasive sense of loss in many aspects of life; and that the cancer narrative did not end when the child completed treatment. The continuing narrative included an unsettling realization that cancer and the fear of recurrence would always be part of their lives (Woodgate, 2006).

A narrative analysis of data collected in a case study of a South African couple’s journey of coming to terms with their child’s cancer revealed the positive influence of a social support group in the management of parental uncertainty within the context of chronic life-threatening childhood illness. Their story was noted to support the idea that chronic conditions follow an uncertain course that changes over time and can only be appreciated retrospectively (Papaikonomou, 2007).

Quantitative research on parental experience of childhood cancer

Researchers from the University of Amsterdam compared parents’ emotional reactions to cancer treatment in relation to whether or not their children were in the state of remission or relapse. Eighty-four mothers and seventy-nine fathers of eighty-four children with cancer (43 in

remission, 41 in relapse) were asked to complete the Beck Depression Inventory; the State-Trait Anxiety Inventory; and the Situation-specific Emotional Reaction Questionnaire. In addition, parents were asked to identify their main concerns about their child's illness from a researcher-created list of concerns in five categories: (1) the child's future in society; (2) the child's psychological functioning; (3) the child's physical functioning; (4) the child's survival; and (5) child-rearing difficulties (Grootenhuis & Last, 1997).

The mothers and fathers of children who had relapsed reported more feelings of helplessness ($p < .001$) and uncertainty ($p < .001$) than parents of children in remission. They also reported their fears concerning their child's chances of survival more often than parents in the remission group ($p < .05$). Mothers of children who had relapsed reported significantly more depression ($p < .001$) and anxiety ($p < .001$) than mothers in the remission group and more than fathers in either group. The problems of fathers, embodied primarily in physical symptoms, of children who had relapsed were revealed only with an illness-related questionnaire chosen by the researchers to look beyond emotional concerns. Based on these findings, Grootenhuis and colleagues recommended careful psychological monitoring of those parents with children who relapsed.

British researchers Fotiadou, Barlow, Powell and Langton (2007) compared the characteristics of optimistic parents of children with cancer and optimistic parents of healthy children; and the relationship between optimism, anxiety, depression, life satisfaction, coping and subjective health perception in parents of children with cancer and parents of healthy children. One hundred parents of children being treated for cancer at a United Kingdom (UK) Regional Cancer Centre were compared to 117 parents of healthy children on the variables of interest. Parents of children with cancer were found to have higher levels of anxiety ($p < .001$),

depression, ($p < .001$), optimism ($p < .001$), satisfaction with life ($p < .001$) and subjective health perception ($p < .05$) than the parents of the healthy children. Optimism was positively correlated with satisfaction with life, subjective health perception, anxiety and depression in both groups. The authors concluded that the importance of optimism in relation to psychological distress in parents of children with cancer should be highlighted as a target for planning interventions.

Using procedures identical to a study published 10 years earlier (Noll, 1995), researchers from Ohio compared parents of 49 children with cancer and 49 healthy classmates using measures of adjustment an average of 18 months post diagnosis (Gerhardt, et al., 2007). Between-group differences were converted to effect sizes for each study and were compared to assess for similarity or difference in results. Mothers of children with cancer reported significantly more anxiety ($p < .001$), less family conflict ($p < .001$), and more social support ($p < .05$) than controls. Fathers did not differ between groups. Effect sizes were small for most comparisons of parental distress, family environment, and social support. Social support had little effect on distress. Despite the 10-year gap between the two studies, agreement on group differences was high. In both studies, the researchers concluded that parents of children with cancer exhibited significant resilience during treatment. It was suggested that future replications and meta-analytic work may be helpful in this area.

Role-specific qualitative studies

Mother-focused research. A grounded theory study of United Kingdom mothers' experience of having a child with cancer, characterized as 'parenting in a crisis,' was reported by Young, Dixon-Woods, Findlay and Heney (2002). These authors have called attention to the inability of 'criteria of psycho-social normality, coping and adjustment' to address in a meaningful way the experience of parenting a child with cancer. Themes identified in analysis

of interviews with twenty mothers included (1) biographical shift; (2) proximity and confinement; (3) ensuring children's cooperation with treatment; (4) maintaining children's physical well-being; (5) emotional work: managing emotions; (6) emotional work: communication with children; and (7) guardians of biography. Several useful concepts noted in this study could be the foundation for future research. New information included the concept of "engulfment" or the sense of inability to separate oneself from the suffering of the child; altered mother roles; reordered meaning and diminished control; negotiation of cultural discourses about motherhood; and threatened and disrupted biographies with the associated grief and loss issues. Limitations unique to this study noted by the authors were the failure to address the issue of gender separately from child age, something felt to be influential; and the inability, due to lack of resources, to triangulate the data with interviews of fathers or other close family members (Young, et al., 2002).

The perceptions of caregiving demands were investigated by the research team of James, et al. (2002). The multicenter study funded by the Pediatric Oncology Group (POG) and the Association of Pediatric Oncology Nurses and conducted by advanced practice nurses at nine POG member institutions, asked open-ended questions that were part of the Care of My Child with Cancer (CMCC) questionnaire, a research instrument under development at the time of publication. The analysis of responses to the open-ended questions revealed negative physical and emotional health as the most frequently reported effects on parental caregiving.

Two types of assistance found to be most helpful by caregivers included timely education about their child's health status and emotional support from family members, friends and others. Of the 153 caregivers (all mothers, according to summary information in table format, though this was unstated in the text) who returned the questionnaire, 98% responded to the six open-

ended questions at the end. The authors identified key features that were found to be meaningful to caregivers in the childhood cancer experience. Examples of these features included the importance caregivers placed on the care evident in the delivery and the accuracy of information given regarding their child's health, and the expressed desire to have the same care providers over time (James, et al., 2002).

In a phenomenological study, Vickers and Parris (2005) also made a unique contribution to the understanding of the challenges of parenting a child with complex needs in "Towards ending the silence: Working with women caring for children with chronic illness." The authors' efforts to draw attention to the significant and growing problem of mothers' conflicting roles and responsibilities related to their chronically ill child and work life constituted an important first step in an area deserving greater attention. This study was included in this review because mothers of leukemia patients were included as participants.

New knowledge created included the fact that the women were expressing feelings and experiences of working and caring for the first time; the idea that others may contribute to these women's 'silence;' and the notion that rather than slipping into self-doubt, as suggested by Jack (1991) as the theory of 'Silencing the Self,' these women expressed the intent and ability to persist in speaking and acting from a position of 'moral rightness.' Recommendations for development of flexible workplace policies, a need for recognition of women's challenges by their partners, fellow workers, friends and family; and enabling and encouraging women to speak out about their reality were derived from the findings (Vickers & Parris, 2005).

In a longitudinal study of thirty-two mothers' experiences of caring for a child with acute lymphoblastic leukemia (ALL), British psychologists Earle, Clarke, Eiser and Sheppard (2006) conceptualized 'building a new normality' as both important and difficult to achieve. These

researchers added their voices to those who have portrayed the literature as incomplete in reporting parent experiences. By reiterating concerns that research focused on ‘problem’ or psychological indicators, e.g., stress or coping, fill only a small part of missing knowledge, the authors emphasized the significance of including the study of life from the families’ perspective. Semistructured interviews for this study focused on the impact of the illness and treatment on daily life.

The movement toward a ‘new normality’ was found to occur as a process of evolution over time. The results were discussed within the time frame of the study, namely Time 1 (3-4 months after diagnosis); Time 2 (15 months after diagnosis); and Time 3 (27 months after diagnosis). The contradiction noted by these mothers of children with cancer, that a ‘normal life’ was deemed very important, but difficult to achieve, and that this persisted over time, suggested to the authors that a more realistic set of expectations be offered families after the diagnosis (Earle, et al., 2006).

Father-focused research. Chesler and Parry (2001) used a variety of data collection methods to study the experience of fathers of children with cancer. While the authors initially worked from a framework of five types of parental stress in the childhood cancer experience identified in previous research, a framework of the influence of gender emerged from the data of this study. This study uncovered important new information about gender identity, gender role and the broader cultural and social structure in which the experience takes place.

Data for the study were collected from multiple “research and action efforts” conducted over the twenty years from 1978-1998. Data from surveys of several hundred parents were used to identify parents for interviews who expressed interest in participating in interviews. In addition to interviewing 52 fathers, Chesler, himself the father of a childhood cancer survivor,

conducted workshops for 115 fathers of children with cancer. All data from the interview transcripts and workshop transcripts or field notes were compared, and when no significant differences were found, were pooled together to create a data set from 167 fathers. Examples of elements of the experience that were considered unique to fathers include the traditionally held notion of pressure to be the ‘rock’ of the family; the pressure related to continuing to work through the experience; and the loss of male friendships due to distance or lack of understanding. Interestingly, though portrayed in the study as uncommon, was the support for the idea of positive transformation being one of the perceived benefits of the experience (Chesler & Parry, 2001). Implications for practice included the potential benefit of the use of a variety of strategies that reach fathers in multiple settings and a call for changes in the structure of work and clinical settings. Suggestions for future research included examination of some of the incentives for and barriers to participation in research; and comparison of mothers’ and fathers’ experiences.

An area that has been neglected in research on parenting children through cancer is the experience of rural families. As tertiary care, especially pediatric oncology diagnosis and treatment, becomes increasingly a metropolitan phenomenon, parents with a child diagnosed with cancer who live many miles from a major city face unique challenges. Scott-Findlay and Chalmers (2001) explored the experience of being or having a child with cancer in a rural geographic area in their descriptive qualitative study of ten Canadian families. In all, twenty-five family members, who ranged in distance from the tertiary center from 39.2- 285.8 miles, were interviewed. Eight themes were identified in the analysis of data: (1) our diagnosis story; (2) trying to destroy the enemy; (3) away from our home; (4) living at a distance from our ‘hope’; (5) life is different, but we must go on; (6) the support of others; (7) our whole family is affected; and (8) our wishes. An important new focus was the notion of rural parent as “gatekeeper” and

“expert.” In addition, the authors emphasized the dilemmas these families faced as distinct from those of families closer to the treating institution in at least two ways. First, results showed added complexity regarding decision making when the child is sick; and second, the results revealed the difficulty in assessing and dealing with different skill levels of the professionals caring for the child locally (Scott-Findlay & Chalmers, 2001).

McGrath and Chesler (2004) reported on phenomenological research with ten fathers undertaken as part of a longitudinal study of the parental experience of having a child undergoing treatment for acute lymphoblastic leukemia (ALL) in Australia. Findings suggested that these fathers experienced extreme emotional pain and distress; that stereotypical perceptions that men do not cry are false; that work represents a ‘time out’ from the emotional strain; that fathers’ anger played a role in the emotional strain; that acceptance facilitates coping; and that fathers are concerned about the impact of the treatment experience on the family’s sense of normalcy. Recommendations from the results were targeted toward ‘supportive interventions,’ but with just ten participants, reached a bit far beyond the scope of the study findings. While it was logical to suggest, based on the findings, that fathers should be given the opportunity to engage in discussion with other men about their roles and coping strategies, it was premature to suggest that in the future, special attention should be paid to the issue of ‘anger’ based on the analysis of ten Australian fathers. Certainly, a call for further study was suggested from the findings, but a jump to recommending interventions seemed a large leap to make based on this study’s findings.

Parental uncertainty during childhood cancer

Qualitative research

In the longitudinal qualitative study of family transition to living with childhood cancer mentioned earlier, Clarke-Steffen (1993) identified uncertainty as a major contributing factor in the diagnosis phase and in the “new normal” that emerges. From the “not knowing what it was” to the attempts to manage uncertainty by attempting to derive meaning from the illness, certain healthcare provider behaviors and strategies were identified as helpful: assistance with information-seeking behaviors; providing information; coordination of information dissemination; and assistance with uncertainty management.

Multiple dimensions of uncertainty that arise after the diagnostic uncertainty resolves were identified in a grounded theory study of parents of ill children by Cohen (1993): existential, etiologic, treatment, situational, and biographical. Existential uncertainty represented the parents’ struggle to make meaning in the change in their identity. Uncertainty regarding the cause of the illness was labeled etiologic uncertainty. Questions concerning the appropriateness and composition fell under the category of treatment uncertainty. Uncertainty that shifted with unexpected events was labeled situational uncertainty. The final dimension identified by the researchers was biographical uncertainty when participants expressed experiencing a changed life once the child became ill. From the search for meaning of the illness and its inherent threats to decision-making capacity, personhood, spirituality and adaptation, families face unimaginable challenges when a child is ill. Cohen found that the ambiguity can become a “second chronic illness” for those dealing with prolonged periods of uncertainty and suggested assistance with the management of uncertainty may be the most significant contribution clinicians make in helping families cope.

Cohen (1995) returned to the data from the grounded theory study (1993) to explore events noted to precipitate increased parental anxiety by triggering a heightened awareness of the uncertainty concerning the child's survival. The events found in the data that triggered this awareness were (1) routine medical appointments; (2) body variability; (3) keywords and provocative questions; (4) changes in the therapeutic regimen; (5) evidence of negative outcomes; (6) new developmental demands; and (7) nighttime. Parents were found to learn to manage their responses to uncertainty by trial and error as well as by intentional acts. In some instances, professionals were noted to have increased the intensity of anxiety when parents employed two common strategies, trying to live one day at a time and trying to retain as normal a life as possible, when these were misinterpreted by the professionals as denial (Cohen, 1995).

Woodgate and Degner (2002) explored data collected in Woodgate's dissertation research in search of an understanding of the experiences of childhood cancer as it pertained to the family experience of uncertainty. A critical eye was evident in the literature review with the authors' noting that one of the shortcomings of Mishel's uncertainty construct was its questionable relevance to the childhood illness experience. This issue has since been addressed in both qualitative and quantitative study (Mishel, 1983; Mishel, 1988; Santacroce, 2002). Data collection for this longitudinal study took place from July 1998 to December 2000 and was accomplished through open-ended interviews and extensive participant observation at a variety of times and in a variety of settings. The findings validated previous research findings of parents' and families' experiences of uncertainty. The researchers identified 'coming to know what to expect' and 'taking one day at a time' as two of the seven strategies parents found helpful in reducing uncertainty and helping them cope. In research done since the development

of the Parental Perception of Uncertainty Scale (PPUS), Stewart and Mishel (2000) recognized that even more influential than uncertainty might be the management of that uncertainty.

Australian nurse researchers De Graves and Aranda (2008) conceived a model of uncertainty at relapse of childhood cancer from the results of their ethnographic exploration of the experiences of families during the experience. Twelve families (12 mothers; 5 fathers; and 3 children with cancer) chose to participate in multiple in-depth interviews over 6.5-13 months. The most significant finding was the profound impact of uncertainty, consistent with Mishel's conceptual model (1988), but for one distinction. The family members in this study did not consider their uncertainty as a danger *or* opportunity, but as danger *and* opportunity. The authors found that for these families, uncertainty created the possibility for hope; and that families fluctuated between two states of reality: hoping for a cure and contemplating the child's death.

Quantitative research

Thus far, research into uncertainty has highlighted its theoretical relationships to family coping, distress experiences, parental role attainment and long-term family system function. The most recent review of published research on parental uncertainty found a mix of qualitative studies and quantitative explorations. Although parents' uncertainty concerning their children's illnesses was found to be well-described as a significant stressor, sparse quantitative evidence was found to confirm a relationship between uncertainty and parents' psychological distress (Stewart & Mishel, 2000).

In a descriptive correlational study of late psychosocial effects in parents of children who survived cancer, uncertainty and loneliness were found to be the most frequently reported problems. Characteristics such as being a mother, low self-esteem, no religious affiliation,

chronic disease in a family member other than the affected child and concurrent stressors increased the risk of late problems (Van Dongen-Melman, et al., 1995).

Sterken (1996) described the relationship between uncertainty and coping patterns in fathers of children with cancer. Thirty-one fathers completed the Parental Perception of Uncertainty Scale (PPUS) and the Jalowiec Coping Scale. The age of the father, age of the child and the length of time since diagnosis were positively correlated with paternal uncertainty ($p < .001$) and negatively correlated with coping ($p < .05$).

In a correlational study, Santacroce (2002) examined the relationships between uncertainty, anxiety and posttraumatic stress symptoms in 15 parents, i.e., 12 mothers and 3 fathers, of children recently diagnosed with cancer. The PPUS, the STAI and the Reaction Index (RI) were completed between 4 and 8 weeks after diagnosis. Surprisingly, parental uncertainty scores were not high. The author posited that the instrument may not have fully indexed all the uncertainties these parents might have experienced. The few African-American parents in the sample did have significantly higher levels of uncertainty than other parents, but the small sample size and the homogeneity of the sample did not permit generalization.

Mu, Ma, Hwang and Chao (2002) used a Chinese-language version of the PPUS, the Pearlin Mastery Scale and the State-Trait Anxiety Inventory (STAI) to explore relationships between known demographics, the sense of mastery, the perception of uncertainty and the experience of anxiety in eighty fathers of children in Taiwan with cancer. The researchers found that paternal perception of uncertainty was positively related with paternal anxiety ($p < .001$) and negatively associated with a sense of mastery ($p < .01$). Multiple regression analysis for factors influencing paternal anxiety revealed that paternal education levels higher than or equal to university and the perception of uncertainty were related to the degree of paternal anxiety,

accounting for 25% of the variance. This suggested that better educated fathers with higher uncertainty may be at risk for higher anxiety in caring for their child undergoing cancer treatment than fathers with less education.

Parental posttraumatic stress/posttraumatic growth and childhood cancer

Quantitative research

In studying posttraumatic stress symptoms (PTSS) and general distress in parents of children with brain tumors, Fuemmeler, Mullins and Marx (2001) posited that reliance on emotion-focused coping strategies and perceived illness uncertainty would be associated with PTSS and general symptom severity. Eighteen mothers and ten fathers completed the Posttraumatic Stress Diagnostic scale (PDS), Brief Symptom Inventory (BSI), Ways of Coping (WOC) checklist and PPUS. Results indicated that both illness uncertainty and emotion-focused coping contributed to the variance noted in general distress.

Yeh (2002) researched gender differences of parental distress experienced by Taiwanese parents whose children were being treated for cancer. A Chinese version of the Parenting stress index/short form (PSI/SF), Symptom checklist-35-revised (SCL-35R) and the Marital Satisfaction Scale were completed by both parents of 164 children being treated. Mothers were found to have significantly higher levels of distress than fathers. Mothers and fathers whose children were diagnosed in the 2 months before completing the questionnaires were found to have higher levels of depression, anxiety and global stress than those whose children were diagnosed more than 2 months prior to survey completion. In addition, these parents reported significantly greater marital dissatisfaction than other parents. The findings of the study supported the need for close psychological monitoring and adequate support of parents, especially at the time of diagnosis.

Fuemmeler, Mullins, Carpentier and Parkhurst (2005) compared levels of posttraumatic stress symptoms (PTSS) and general distress in forty-seven parents of long-term survivors of cancer to those of a group of thirty-one parents with a child with another chronic illness (Type 1 diabetes mellitus). In addition, the researchers examined three factors that have been associated with increased distress and PTSS: social support, coping style and parental uncertainty. Using the results of parental responses to demographic and illness questionnaires, as well as the PPUS, PDS, BSI, Social Network Reciprocity and Dimensionality Assessment Tool (SNRDAT) and Ways of Coping Checklist, the authors found no evidence of illness-specific impact of illness uncertainty or emotion-focused coping on either PTSS severity or general distress. Limitations cited by the authors included the lack of measurements over time, a small sample size, the illness-related variables not examined (late effects and child cognition); the limited number of fathers participating; the influence of mother-father dyads (both parents were invited to participate), the homogeneity of the sample, low response rate and selection bias.

In several correlational studies, posttraumatic stress symptoms have been reported by parents of children undergoing treatment for cancer and in parents of childhood cancer survivors, suggesting a need for greater attention to and prevention of the effects of the perceived stressors (Alderfer, et al., 2005; Norberg, Lindblad, & Boman, 2005; and Pöder, Ljungman & von Essen, 2008). In addition, a new body of research is developing among pediatric oncology researchers centered on posttraumatic growth that highlights the positive changes that result from negative life events (Barakat, Alderfer, & Kazak, 2006). New instruments have been developed that attend to parents' and children's resilience and so-called 'benefit finding' behaviors (Phipps, Long, & Ogden, 2005; Phipps, 2007).

Solicited illness narratives

Since illness blogs can be classified as online diaries, this genre of unsolicited writing was explored for completed research through a search of the databases Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline and Sociological Abstracts from 1990-2008. The search returned no results for the terms “unsolicited writing and childhood cancer.” Extensive research has been done on the therapeutics of *solicited* writing exercises in relation to healthcare and outcomes (Gidron, et al., 2002; Duncan, et al., 2007; Schwartz & Drotar, 2004).

Schwartz and Drotar (2004) analyzed prescribed written narratives by parents of children with cancer and by a control group of parents of healthy children to identify emotional and cognitive processes related to physical and psychological health outcomes. Outcome measures included depression and anxiety; long-term mood; health-related quality of life; and physical symptoms. A decrease in negative emotional states together with an increase in cognitive processing was found in the experimental group from the first three-day writing sessions to the second, four months later.

Duncan, et al. (2007) found reductions in posttraumatic stress symptoms, but not in depression in measures taken at an interval of one month between sessions of guided disclosure writing by parents of children with cancer. Gidron, et al. (2002) found that when compared to controls, family practice patients who completed guided disclosure writing reported lower symptom levels at three months from study start. In addition, participants made fewer repeat clinic visits during the three and fifteen month follow-up periods.

One report of unsolicited writing was found in the literature search. In a study of health promotion and quality of life in chronic illness, adults with multiple sclerosis completed

questionnaires. Of the 811 surveys returned, 205 included unsolicited comments by the respondents. Content analysis of the narrative writing revealed four major categories that suggested an apparent need to share more than the questionnaire permitted: (1) dialogue with the researcher, (2) completing the context, (3) living with MS, and (4) survey as intervention (Clayton, Rogers & Stuijbergen, 1999).

Illness blogs

Blogging is unsolicited, first-person writing by individuals or a group of individuals, published online and posted in reverse chronological order for others to read and react to that includes opinion, descriptions of experiences, reporting of events and/or commercial exchange of ideas and products (Blood, 2000; Herring, et al 2005; Heilferty, 2009). Illness blogs are used to express the experience of illness and to connect with readers via the Internet. Attributes of illness blogs that were found in the literature included the unsolicited, first-person online narrative nature of the writing. In addition, these narratives are created during illness by patients or family members and include frequent entries in reverse chronological order that are archived. These blogs are often linked to other blogs and websites. Illness blogs involve a high degree of author-reader interactivity, possess a beginning, middle, may or may not have an ending, and can either be publicly accessible or password-protected. They are published for multiple audiences in 'real time' and are created in the context of the illness or can be a regular blog that transforms into an illness blog at diagnosis. One defining characteristic of illness blogs is the blogger's unique 'from me to the world' perspective. While listservs and other chat formats rely on user-to-user interaction to sustain dialogue, bloggers are creating monologues that do not require, but do welcome comment from readers (Heilferty, 2009).

Theoretical definition. An illness blog is the online expression of the narrative of illness. It permits an exchange of information, ideas and emotions between affected and unaffected persons; family and strangers joined in the story of an illness experience to help the affected manage and cope with the stress, uncertainty and identity changes that accompany illness.

Operational definition. Most broadly described as online journals or diaries, blogs are easily and regularly modified web pages, posted in reverse chronological sequence that can be commented upon by readers, and may include links to other websites or blogs and more recently include images, either still or moving (Australasian Society for Computers in Learning in Tertiary Education, 2006; Blood, 2002; Gordon, 2006; Herring, Scheidt, Wright & Bonus, 2005). Illness blogging is unsolicited, first-person writing by individuals on the topic of illness, published online for others to read and react to that includes opinion; descriptions of experiences; reports of events and feelings and perhaps the exchange of treatment information.

Review of illness blogging research

Early attempts to analyze online communication on the topic of illness consisted of examinations of listservs, chat rooms, online support groups and other media of conversational modes (Klemm, 2008; Orgad, 2005). Pitts (2004) conducted the first exploration of online illness narratives and examined 50 personal webpages, (the precursor to blogs) that had breast cancer as a primary theme. Interestingly, Pitts first questioned whether the subject of study was ‘people’ or ‘representations.’ The content analysis revealed information about the uses of the Internet and online writing, as well as the meaning assigned to the concepts of sickness, healing, recovery and survival, among others. In the end, both ‘people’ and ‘representations’ were understood to be the object of understanding the new medium for finding and sharing medical information and experiences; the creation of peer support networks; constructing bodies and

selves in virtual space; and the impact of the feminine political voice on the topic of illness within the context of society and culture.

In another exemplar of research into online illness narratives, Orgad (2005) explored the online discussions among patients and family members for themes related to the experience of breast cancer and the meanings assigned to concepts such as support, stress, coping, and adaptation. The researcher framed the message board posts as storytelling, with expositive, event and concluding features. But the researcher found that analyzing text of computer-mediated communication (CMC), that is, the posts on online breast cancer message boards, did not answer completely the fundamental question of how individuals made use of the Internet during illness. Orgad went on to explore the experience ethnographically by email interviews with willing participants. In so doing, a more encompassing narrative was created by incorporating the 'what' of the CMC content along with the 'why' and 'how' from the interview data.

Serfaty (2004) identified co-production as a unique structural feature of blogging. Traditional diaries are composed in private, and if published at all, are published as a body of work, with a beginning, middle and end. In contrast, online diaries call on readers to actively participate in the creation of the text by commenting on entries and providing advice and feedback for the author. This relationship of the author with the diary's reader was identified as a new phenomenon.

In a study of women's online writing about the breast cancer experience published in the communications literature on the subject of illness blogging, McNamara (2007) found that self-expression, writer-reader interactivity and control over the narrative were strongly influential in the ability of bloggers to make meaning out of the breast cancer experience.

Despite the increasing research interest in blogs and the practice of blogging in some disciplines, a significant lack of attention to blogs created by cancer patients and their families or friends was noted by information science researchers Kim and Chung (2007). In the only quantitative study to date on illness blogs, the authors used cluster analysis techniques to classify cancer blog users' demographics, blog use and perceptions of blogs. Invitations to participate in a survey were offered to the authors of 153 individual English language personal blogs containing the word 'cancer' in the title over three months in 2006. The dominant demographic group across clusters was highly educated Caucasian females, a new understanding of blogger characteristics compared to findings in previous research that had found blogging to be a predominately young male activity (Pew Internet and American Life Project, 2006). Blogs were found to be used more for sharing emotional support and personal stories than medical knowledge, consistent with previous studies (Kim & Chung, 2007). Although the authors recognized the limitations of small, convenience sampling, this first attempt to understand the practices and needs of cancer bloggers, added significant knowledge toward understanding of blogging during illness. Of note is the lack of information about illness blog practices and utility during illness within the healthcare disciplines.

Sociologists Clarke and van Amerom (2008) analyzed blogs of 45 men and 45 women who self-identified as depressed for differences in descriptions of the experience of depression. English-language blogs were found by entering the term "depression blogs" into two Internet search engines one day in 2006. Several million hits were returned, so blogs were read before selection for inclusion in order to assess the perceived 'richness' of the content. The first 45 authored by each gender that included enough data to be analyzed were included. Using content analysis, manifest and latent data were identified and categorized. Manifest analysis found that

more men than women referred to pharmaceuticals and self-harm; and more women than men referred to psychotherapy. The majority of authors were found to be in their twenties. Analysis for latent themes revealed three differences in men and women who blogged about depression: more men than women expressed a sense of acceptance of biomedicalization of the illness experience; linked depression to world events; and included references to violence. More women than men were found to link depression to family or other interpersonal relationships.

The authors made no claims that their results held broad authority in the wider population of people with depression. In addition, they referred to a commonly discussed limitation of Internet research: there is no way to verify the ‘truth’ of the postings found in blogs. But when considered alongside the criticism of interpersonal qualitative research in general, that data are never fully verifiable, Internet research is really not exceptional in this regard.

Conceptual frameworks

Four conceptual frameworks guide the present research: Ricoeur’s theory of narrativity; Bluebond-Langner’s Natural History of the Illness; Mishel’s Parents’ Perception of Uncertainty in Childhood Illness; and Geogokopoulou’s approach to Narrative-in-Interaction. Each framework’s connection to the proposed research is described, together with the proposed narrative analytic method to be enlisted.

Ricoeur’s theory of narrativity. Ricoeur’s (1979, 1991) theory of narrativity as the mode of expression of temporality emphasized plot as the structure of narratives and identity as reconfigured by narrative. Ricoeur believed that expression of temporality and identity could be known only indirectly through cultural signs such as symbolic mediations such as metaphors and other literary representations of the concrete and narratives of daily life. For Ricoeur, analysis of narrative plot is not merely the examination of the structure of narrative, but also makes

distinctions between historical and fictional narratives and possesses temporal structures that bridge the gap between narrative and temporal inquiry.

Review of life history methods. One approach to analysis of illness blogs as life narrative might be to examine them in light of Bruner's (1991) ten features of narrative: (1) narrative diachronicity (Ricoeur's 'human time'); (2) particularity; (3) intentional state entailment (where 'agency presupposes choice'); (4) hermeneutic composability; (5) canonicity and breach; (6) referentiality; (7) genericness; (8) normativeness; (9) context sensitivity and negotiability; and (10) narrative accrual. These ten elements mean in general terms that the narrative places an event in a certain time, with particular details. The author holds ownership over the choice of included details, makes sense of the sequence and content of the narrative and the truth of the substance. Narratives include references to other individuals or narratives; are universal enough as to be understood in a general way; can impose or represent norms agreed upon by the receiver; fit within a larger context, and can be added to and edited over time.

It is the perpetual construction and reconstruction of the past that forms canons that permit the recognition of breaches, and in so doing, make it possible to interpret them. Bruner viewed life narrative as experience and memory organized in story form. Researchers are never able to verify online narratives and stories empirically; rather, it is verisimilitude that is relied on to relay individuals' experiences and memory. It is the narrator's construction of reality that is the subject of study.

Another approach to illness as life story relies on the twenty points presented by Smith and Watson (2001). The authors define autobiographical or life narrative as an historically situated practice of self-representation, and view the approach to the autobiographical telling as a performative act. In so doing, researchers must attend to the meanings of authorship; culture;

historical transformation from the narrative; the autobiographical 'I'; models of identity; plotting; temporality; audience and addressee; coherence and closure; memory and meaning; the therapeutics of writing; claims of truth; authority; voice; experience; embodiment; agency; relationality; knowledge; collaborative aspects; and ethics.

Polkinghorne (1995) held that life history is constructed by the researcher. Where other methods of narrative analysis rely on the work of both narrator and researcher to coconstruct the story, life history is the retrospective coming together of a series of events marked by segments of time that explain, in a coherent way, a range of disconnected data elements in interesting and explanatory ways. Polkinghorne suggests the possibility of the expression of a 'living story,' one that is described and analyzed as it is happening. Plot forms the narrative structure, and cognition is understood to be either paradigmatic or narrative.

In paradigmatic cognition and analysis of narrative data, individual words name concepts; events and themes are classified and categorized; movement is toward derivation of a theory from the data. In narrative cognition, episodes with similar plots within longer stories are viewed side by side for comparison and contrast; when analyzed through narrative cognition, the outcome of narrative data is a complete story, with the plot discovered or developed by the researcher. This understanding assists in viewing the collected series of entries in an illness blog as data that might be discovered to possess a larger scope of narrative beyond the accumulation of the everyday. Polkinghorne's paradigmatic analysis of blogs yields something more like an understanding as illness narrative, with location of themes common among a set of blogs. However, for the purpose of this research, it was the narrative analysis of blogs toward the generation of a story-by-researcher that yielded a coherent particular view of one entire blog as a complete story.

To guide researchers, Polkinghorne restated a set of seven evaluative criteria created by Dollard in the early 20th century. These criteria call on the researcher to (1) include a description of the cultural context in which the story takes place; (2) attend to the embodied nature of the protagonist; (3) recognize the importance of significant others in the protagonist's life; (4) concentrate on actions and choices of the protagonist; (5) consider the historical continuity of the characters' past experiences, habits, etc; (6) remember that the outcome of the study is the generation of a story bounded by a temporal period and including identification of a *dénouement*; and (7) make the generation of the researched occurrence plausible and understandable.

The life history approach to narrative analysis was the first employed in the present research, guided by Polkinghorne's vision of one narrative exemplar and Ricoeur's theory of narrativity, in this case a blog rich with detail about parenting a child with cancer that tells the story of the parent's life as lived during this experience.

Bluebond-Langner's "The Natural History of the Illness" framework. In the book *In the Shadow of Illness*, sociology researcher Bluebond-Langner (1996) shared the Natural History of the Illness framework. This set of concepts guided the second analytic treatment of parent illness blogs. The Natural History of the Illness was developed when the researcher observed and reported on the behavior of patients with cystic fibrosis and their family members over time across the illness trajectory. The author noted that the critical changes in the social and emotional life of the family from the time of diagnosis to death were tied closely to the chronology of the clinical course. In online illness narratives, blogs appear to chronicle the hopes, fears, obstacles and successes that occur in relation to life during treatment with similar periodic demarcations. The Natural History of the Illness framework informed this consideration and analysis of illness blogs by establishing the understanding of illness blogs as unique

narratives of the experience of illness, that is, that narrative and time are intimately and inextricably linked. When examined within the framework of the Natural History of the Illness, illness blogs can be seen to embody the myriad predictable and sequential responses patients and family members have over time to the intrusion of the illness on their daily lives. The strategies for managing the stress, uncertainty and identity changes that accompany an illness experience from the time of diagnosis through treatment to cure, chronicity or death, were evident in illness blog writing and in the exchange between author and reader-responders. Guided by the Natural History of the Illness framework, an experience-centered thematic analysis was undertaken as the second analysis in the present research.

Review of thematic analytic approaches to illness narratives. As illness blog use has proliferated internationally, researchers in several disciplines have begun to examine this form of expression and communication in varied ways. Sociologists seek to understand narratives as both a means of expression and as an interaction between storyteller and reader. In *Narrative Analysis*, Catherine Riessman (1993) explicated the ideological underpinnings, practical usefulness and implementation of the narrative method. She views a person's story as a complete body of discourse, mismanaged and misinterpreted when broken down to component parts. The story can be summarized, but if it is to be understood wholly, it should not be compartmentalized.

Riessman (1993) cited linguist Labov (1982) and physician Mishler (1986) as strong influences. The purpose of narrative inquiry is to see how respondents impose order on the flow of experience to make meaning of events and activities in life; to ask not 'why tell a story?' but 'why tell a story that way?' In this way, the stories become autobiographies. Despite significant conceptual and methodological diversity, Riessman identifies key concepts, debates and

interpretive dilemmas. Narratives are categorized either as habitual (events that repeat without a peak in action); hypothetical (depiction of events that did not happen); or topic-centered. The second and third sequence of proposed analysis examined illness blogs as topic-centered, thematically-linked ‘snapshots’ of events.

Structural elements of significance include the style, language, setting, and interview context. There are four levels of interpretive decision making in narrative inquiry. After attending to the phenomenon or question, consideration must be given to how to facilitate narrative telling in interviews. Appropriate transcription methods for the study purposes are next, and last is the analytic approach that best matches the research purpose. Validity is viewed from the standpoint of the ability of the story and its analysis to persuade, to be considered plausible, to be “checked” by the storyteller, to be coherent, and to have pragmatic use. Narrative analysis is not appropriate for use with large numbers of “nameless, faceless” subjects. The slow and painstaking methods require attention to subtle nuances, organizations of responses, and understanding of context (Riessman, 1993).

In a review of research from the mid-1980s to the mid-1990s, another sociologist, Hydén (1997) found the following: (1) a proposal of three kinds of illness narratives, i.e. ‘illness *as* narrative, narratives *about* illness, and narrative *as* illness; (2) the potential benefit of illness narratives; (3) problems with organization of illness narratives; and (4) the social context of ‘telling’ and its influence on the narrative. Temporal influences on these types, functions and forms link illness narratives to the social and cultural context in which they are created. Hydén’s typology defines “illness *as* narrative” as the expression of the experience of illness and its impact on a person’s life. “Narratives *about* illness” are those that convey knowledge and ideas about the illness, as in discussions among health professionals about the patient’s illness. Hydén

defined “narrative *as* illness” as the occasion of narrative generating illness, e.g. a situation in which a patient is unable “to use the medium of narrative to connect experiences with particular events” such as the incomplete narrative created by some with mental illness (Hydén, 1997, p.55).

While acknowledged to be in its infancy, the study of illness narratives seems to serve several functions: to construct an illness experience; to reconstruct life history; to make disease and illness understandable; and to collectivize the illness experience. This makes it possible to examine the phenomenon from different vantage points: as sociocultural construct; as a transformation and expression of bodily suffering; and as the narrator’s attempt to construct the world, to find his or her own life-work or life context (Hydén, 1997).

Atkinson (1997) published a severely critical essay on the work done by Frank (1998b) and Kleinman (1988) in regard to narrative analytic methods. Atkinson asserted that the emphasis on attending to every individual story as complete in itself views the stories in a social vacuum, or blind alley. When all stories are celebrated, they can only be understood in terms of the individualized view of the self. This self-mythologizing was described as a total failure to use narrative to achieve serious social analysis (Atkinson, 1997). In response to this criticism, Frank (2000) wrote that it is in the telling of stories that meaning is assigned. Selection of a method presents a quandary to narrative researchers, Frank asserted, because claims to analyze another’s story presume that it is the analysis that matters, when he believes it is the ill person’s story that has the power to move, motivate or change the reader (Frank, 2000).

Psychologists have tended to view illness narratives from the standpoint of therapeutics, i.e., as a means for individuals to improve mental or even physical health through solicited expression of everyday personal experiences. The large body of research, first conceptualized by

Pennebaker (2002), regarding the personal benefits of writing about the illness experience has led to many quantitative studies of relationships between writing and symptom management, including even health promotion and illness prevention (Daiute & Buteau, 2002; Lepore, Greenberg, Bruno & Smyth, 2002); Lumley, Tojek & Macklem, 2002)

In *Narrative Knowing and the Human Sciences*, psychologist Polkinghorne (1988) examined narrative as a human effort to make experience meaningful. The aim of the study of narrative meaning is to make explicit the operations that produce its particular kind of meaning, and to draw out the implications this meaning has for understanding human existence. Discourse is the foundation for study of narrative knowing. Narrative understood as discourse can expand understanding beyond mere words or sentences. A discourse is a unit of utterance, an integration of sentences that conveys a larger meaning.

In her report on one electronic narrative of illness, McLellan (1997) described important elements of online narrative structure and content, characterized the virtual communities relevant to the formation of such narratives, and suggested how it and similar texts might illuminate the illness experience. The structure she found was embodied by a series of journal-style entries authored by the father of a teenager undergoing treatment for leukemia in a daily chronicle of events related to life as a parent of a child with cancer. Responses posted by site visitors were in turn responded to by the author, creating a quasi-dialogue. Included in the online narrative were laboratory test results that illustrate wider changes in quality of life, advice from posters to the blog, and metaphors that helped readers imagine the experience.

Relationships between diary author and audience are redefined when published online. The author becomes receiver of others' reflections and responses. Readers become co-authors when posting a message for the author and subsequent readers to process. The reader-author

communication becomes central to the understanding of the meaning that online diaries create for the author and for the reader (McLellan, 1997).

The value of such narratives is in the creation of community for people in need of connectedness often without the ability to be physically present with others. For healthcare professionals, the unguarded expression of feelings and responses to treatment can provide desperately needed insight into patient experiences outside the context of the clinical setting. The recent proliferation of online illness narratives allows many more voices to be heard than ever before. McLellan (1997) cautioned student researchers against over interpreting online diaries for fear of going beyond their original intent.

Nursing has arrived late to the phenomenon, an irony given that it is nurses who have been attending to illness narratives the longest. Sandelowski (1991) presented narrative as a framework for understanding the subject of narrative knowing, and the interviews that are created in the process. She placed the “storied nature of human interpretation” (p. 162) and its analysis at the center of inquiry. In regard to techniques, she differentiated between the assumption of language as structure, which necessitates verbatim transcripts including pauses, false starts, asides, etc.; and language as vehicle for communicating information that might be understood through constant comparison in the service of generating grounded theory. Interviews or self-graphed story lines are the means of data collection, and analysis identifies those ways in which individuals organize their stories, explain their situations and solve problems. A story must have ended or an event must have happened, for the narrative to be created. A story has a beginning, middle and end; only then can it be told, analyzed and understood (Sandelowski, 1991). It is here in which the inquiry of online narratives navigates

into uncharted waters, since most blogs are reflected on during the event, are a series of connected events and have no true 'end.'

One of the more straightforward depictions of narrative inquiry as a distinct method of qualitative nursing research was written by Duffy (2007). It is defined as a form of qualitative research that uses the collection of stories as its source of data. These stories can be told by individuals about themselves, or can be told by others about them, that is, autobiographical, biographical or some combination of both. Duffy uses the terms narrative and story interchangeably. Here, narrative is concerned with sense making, meaning making, constructions and reconstructions of identity. How well a story is put together and how the person makes sense of things are more important than the 'truth' in any positivist sense.

Duffy explained the method of narrative inquiry clearly and succinctly. There is first the question, limited in scope and identifying the narrator from the outset. Data collection is accomplished through purposive sampling and face-to-face interviews whenever possible; follow-up interviews when necessary; collateral interviews when possible; solicitation of pictures, poems, drawings, etc. with their meanings illuminated by the interviewee; and examination of related historical or documentary sources (Duffy, 2007). One potentially enlightening source of data missing from Duffy's discussion of data collection sources are the online narratives being created by patients about their illness experiences.

This is addressed directly by Robinson (2001) in an essay that creates a model for ethical use of unsolicited first-person narratives from the Internet as a rich source of data. Advantages to using online narratives include influence of anonymity on the depth of feeling expressed, the therapeutic effect of 'just writing it down,' and the urge of some to reach out to others online to express the joy and satisfaction of caregiving. A clear and simple algorithm is offered to

enhance understanding of situations in which Institutional Review Board approval might be necessary. Trustworthiness of online data depends largely on its use. Whether information from the Internet can be used as the sole source of data or as a supplementary source of data is determined by the research question, the phenomenon of concern, and the scope of the inquiry (Robinson, 2001).

Data analysis of narratives takes four forms: (1) structural, in which the words and phrases used are examined; (2) psychological, the method employed for the purposes of the proposed study, aimed at understanding the person's attempts at meaning making; (3) identity development, focused on the ways outside stories influence the person's sense of self; and (4) artistic or aesthetic, in which narratives are understood as a universal form of art where the goal is to solicit purely emotional responses to the stories (Duffy, 2007).

Sakalys (2003) expands the understanding of the importance of illness narratives in nursing as having two therapeutic powers: increased self-awareness through enabling reflection and formulation of experience; and attachment of persons to others. Holistic nursing practice warrants attention to the potential of narrative as a caring/healing modality that can help patients restore personhood, coherence and connectedness (Sakalys, 2003).

Skott (2002) interprets and presents expressive metaphors from patient illness narratives to illustrate the cancer experience as a weave of uncertainty, obscurity and the search for consolation. These metaphors are construed as giving access to patients' perceptions of cancer as a deep threat to the self. Patients feel fear and ambiguity although the culturally valued themes are maintaining hope and morale even in the face of serious illness. The personal, new and equivocal metaphors, for example, chemotherapy as 'enemy' equal to the disease itself, are

an imaginative projection of experience created by narrators to find consolation and to overcome solitude by articulating experience and ultimately strengthening identity (Skott, 2002).

Methods of conducting narrative analysis of online writing range from those that engage participants in the research to those that examine and analyze online text as a corpus alone; and from isolated quotes analyzed for thematic elements to online diaries as complete stories.

Essential to the understanding of online narrative as unique is the necessary consideration of time, place and person: interactive authorship in real time in Internet spaces.

The duality of both narrator identities and narrative genres is the inspiration for the use of multiple methodological approaches in the study of illness blogs. Bloggers are users of a new technology. Bloggers are practitioners of the traditions of diary writing, but the form now possesses the added dimension of interactivity. Blogging is a new understanding of publishing. The blog is at once a new and old medium for communicating experiences, identity and meanings; and bloggers are at once practicing traditional and innovative expression of experience. Blogs are collaboratively produced and possess an unwritten code of conduct; bloggers are aware as they write that they will receive comments on their writing almost immediately. These features require careful consideration and negotiation by the authors and readers-responders of what to include and what to omit, which relates strongly to the community being built and the norms being upheld (McNeill, 2005).

The concept of illness narrative has evolved as the genre has broadened. Much of its understanding began with Kleinman (1988) and Frank (1995). The addition of the work on pathographies by Hawkins (1999) expanded the definition of illness narratives to include unsolicited memoir writing on the illness experience. Illness narratives are generally considered to be stories of illness solicited, transcribed, then analyzed and coconstructed by researcher and

narrator. This, then, is considered a ‘whole story’ that can be analyzed. Online illness narratives will require a different type of analysis in this regard, as they are unsolicited and contained within a larger narrative being composed in the present.

Riessman (2002) claimed that narrative analysis allows for the systematic study of personal experience and meaning. Fraser (2004) conceived of eight steps in narrative analysis, from ‘hearing’ and transcribing through to publishing. Interestingly, the author maintained, as one step in the process, the importance of ‘scanning across different domains’ of experience to achieve a fuller understanding of phenomena. The unique nature of illness blog makes this genre the first unsolicited first-person writing on illness published, even broadcast, that is publicly available. Illness blogs are real-time documentaries of life with illness as decisions are made, treatments are experienced, and life is lived. A blog represents a wholly new type of self-expressive narrative that encompasses the interpersonal, social and cultural contexts of the larger life.

In illness blogs, the author is narrator of events and experience, responder to comments, parent, victim, and family and community member at once. These multiple positions infuse the writing with meanings that change over time and as events happen and are reacted to. The subject is written about in the present, as an immediately past event, a more distant past series of events and with the future always in mind. There exists in illness blogs the same openness of time and identity changes, flexibility and reflexivity as in traditional illness narratives. Such a complex process as illness blogging, with diverse applications, meanings and levels of communication calls for a comparably complex and flexible method of analysis.

For the thematic analysis of blogs as illness narratives, with Riessman (2008) as guide, it was possible to examine and describe the texts of blogs thematically as expressions of the

perceived experience. Where Tamboukou (2008) considered teachers' narratives from a genealogical perspective with attention to gender influences and power, the aim of the present research was to describe thematic elements and patterns in illness blogs as events unfold from the time of parents' first description of diagnosis through decision making and treatment to cure or death. Like Tamboukou's attention to the small things or 'insignificant details' she found in the genealogical approach to women teachers' diaries, this analysis attended to the 'small things' to find patterns of coping with illness.

By analyzing parent blogs as narratives of illness with attention to choices about what is said, what is left out, the temporality of expression, the author's shift in positioning, the coherence and contradictions, and even the multidimensional conceptualization of space, it was possible to construct new knowledge of living with illness from a body of writing by parents from a wholly new medium. Conceptual isolation of the portion of parent blogs pertaining to the illness helped to place temporal, event and presumably some semblance of experiential boundaries around the narrative of the experience. This permitted an exploration of the themes pertinent to understanding the aspects related to the healthcare of these families.

Mishel's Parents' Perception of Uncertainty in Childhood Illness (PPUCI) theory.

Developed by nurse researcher Merle Mishel, the Parents' Perception of Uncertainty in Childhood Illness (PPUCI) theory offers insight into parents' experiences of serious childhood illness. It is anticipated that the PPUCI theory will play an important role in explaining some of the results expected in the proposed study. A review of Mishel's work as it pertains to the study follows.

In research on the experience of parenting a child with cancer, the pervasiveness and influence of uncertainty has emerged in the literature as constant accompaniment in the chaotic

concert that integrates treatment life and the rest of life. Uncertainty has been characterized as an essentially neutral element, subject to appraisal (Mishel, 1988). For some parents, uncertain futures are alternately accepted in hope, as brief respite from the oppression of negative possibilities and unwelcome stressors that surface over the trajectory of the child's illness. Mishel (1983) named diagnosis, symptoms of illness, healthcare providers, family systems, consequences and management of uncertainty as focal points in understanding the causes of parental uncertainty in acute childhood illness. In her writings on uncertainty in chronic illness in childhood, Mishel (1983) cited illness status and progress, cause of the disease, an inability to find patterns in illness, "learning to live with" uncertainty and the quality of provider information as the most influential elements.

Uncertainty was defined as the inability to determine the meaning of events and it occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes (Mishel & Braden, 1988). Illness uncertainty was described as a perception that hampers clear appraisal of events and limits coping (Mishel, 1983). Four stages were identified on the path from uncertainty to adaptation. Antecedents to uncertainty, such as symptom pattern, event familiarity, education and social support were named as influential elements. The second stage is the appraisal of the uncertainty as either a danger or an opportunity. That is, the uncertainty may be the preferable state if the outcome is negative (Mishel, 1988). A weblog entry by the mother of a child with cancer illustrates this phenomenon:

Our lives turn in very vicious cycles with this horrible monster. When things are *bad* [italics added] we always know what to expect and there are no surprise [sic] or disappointments and all we want is for her to improve and when things are

good we constantly worry about when the next shoe will drop and what is coming around the corner when we should be just enjoying the good times. Its [*sic*] a balance I have not yet mastered but getting better at [*sic*] (Adams, 2006).

The third phase in the processing of uncertainty involves the coping efforts either to reduce the perceived danger or maintain the positive effects of viewing the event or circumstance as an opportunity. If the coping strategies employed are effective, the fourth and least understood area of uncertainty, adaptation, or some movement toward a new feeling of normal, or balance occurs (Mishel, 1988).

Georgakopoulou's Narrative-in-Interaction conceptual approach to narrative analysis. The fourth and last framework that will guide the third narrative analytic approach to parent illness blogs is Georgakopoulou's (2006) Narrative-in-Interaction frame. This Greek sociologist has positioned analysis of talk-in-interaction as going beyond canonical narrative interpretation in three paradigm shifts. In approaching narrative as an interactive expression that encompasses deeper levels than 'coconstruction' and can be conceived as multivoiced communication, according to Georgakopoulou, a new theory of genre should ask how generic representations get situated and become relevant in the microcosm of specific instances of communication. The smaller aspects of the narrative, i.e., improvisation; contingency; contradictions; and fragmentations that are generated through interactivity were deemed to be equally worthy of investigation as the grand narratives with the attendant emphasis on coherence, structure and totality. In addition to discussing new theories of genre and a 'celebration of the micro as paradigm shifts, Georgakopoulou called into question the recent contextual and interactional turn toward a quest to identify narratives as better or worse, more real or more relevant, when identity is understood as discursively emergent and achieved. This stands in

contrast to work by Ochs and Capps (1996, p. 32) who claimed that “we develop our selves [*sic*] through the stories we tell and if we tell them with others, then we are a complex, fluid matrix of coauthored selves.”

Examination of illness blogs as narratives-in-interaction has several benefits. First, without this perspective of inquiry, the relevance of the ongoing exchange between author and reader-contributor would be underappreciated as a unique aspect of illness blogging. It is expected that analysis of this ongoing exchange of micro-communications will illustrate the proposed significance of the interactivity and interrelatedness of author and audience, a wholly new dimension, and as conceptualized here, a distinct phenomenon within the practice and genre of blogging. Walker’s (2004) characterization of distributed narratives rejects the notion of narratives as ‘things’ in favor of ‘connections’ that should be analyzed with new conceptualizations of time, space and authorship. Blogs are ‘open’ narratives that flip Aristotle’s dramatic unities of time, space and action over with an emphasis on *distribution*. Blogs are serial narratives told over time. The ‘where’ of blog space raises more questions than answers: stories take place within a larger story; there are links to other stories; the author and readers never ‘meet;’ stories take place and are documented in many places; people ‘find’ them in varied ways. Authorship, the last of Walker’s distributive unities, is marked by fragmentation, multiplicity and ephemeral qualities. Seale’s (2004) notion of narrative incitement plays an important role in blog writing, as expression of one story inspires related stories between and among author-readers. In addition, it is expected that looking closely at the narrative of interaction during blogging will add some understanding as to why broadcasting might be essential to the author, that is, why blogging and not diary writing? Several pertinent questions arise when reading illness blogs that can best be answered by isolating the parts of the narrative that contain

interaction. What does support come to mean to both parties? Are there perceived benefits of the interaction that make blogging the preferred method of expression? How are subsequent entries and the narrative overall changed by the influence of reader-responders? What are the qualities of the author-reader relationship? How is the author-reader relationship, if indeed one exists, situated in cultural contexts?

Returning to the text of illness blogs with special attention focused on the exchanges between readers and the author added another dimension to the understanding of the phenomenon at hand. While it was conceivable that the interaction of reader-response and author-response would become apparent during thematic analysis of the blog as a whole, because interactivity played a key role in the narrative, recognition of the exchanges as a separate phenomenon highlighted their unique influence on the larger narrative.

Table 1, a comparison of the narrative dimensions considered during application of the three methods, was created to delineate distinctions made between the life story approach (whole blog); thematic analysis of blogs as illness narrative (segments of blog); and narrative-in-interaction (author-reader discourse). Nine narrative dimensions were considered during each sequence of the blog analysis: the focus of analysis; narrative segments; temporality; subjects; author positions; agency; performative acts; audiences; and coherence, each described briefly in table 1. Early in the thematic analysis, the performative acts of the bloggers were recognized as sufficiently significant as to require separation from thematic content. In this way, the reason for writing was examined as a distinct phenomenon of interest. Authors shared details of an event or feelings about circumstances, but often also explained the reason the writing, i.e. why it was so important to include particular details in the narrative. Thus, performative acts were those

elements of the narrative that answered the reader's questions about the purpose of blogging and represented the expression and reception of the author's intention and meaning.

Table 1. *Narrative dimensions considered during the sequential narrative analysis*

<i>Narrative Dimension</i>	Life story	Thematic analysis of blog as illness narrative	Narrative-as-interaction
<i>Focus of analysis</i>	Plot, identity	Illness experience	Author-reader interaction
<i>Narrative segment</i>	Whole blog	Illness-defined segments	Author-reader discourse
<i>Temporality, i.e. segment of time</i>	Open-ended; self-determined	Bounded by illness and treatment phases	Alternatively immediate and once-removed from events
<i>Subject of the narrative</i>	Parent's life; work; faith; milestones; finances; sleep; food; relationships	Life during illness and treatment; decision making	Support; encouragement; opinion; faith
<i>Author position</i>	Author; editor; self; parent; child; sibling; friend; community member; citizen	Parent of ill child; parent of well siblings; spouse; "nerve center"/information filter; journalist/reporter of events	Author-reader-responder; receiver of support/commentary; center of communication hub
<i>Agency, i.e. ownership of the narrative</i>	Primary ownership of story; individual within culture/family/community	Individual member of medical subculture; lobbyist for increased funding/media attention; fundraiser; illness community member	Member of online community; leader of blog 'followers'
<i>Performative act, i.e. what the narrator accomplished in the writing</i>	Documentation of life; stress management; documentation of identity issues	Documentation of illness experience; Lobbying efforts; Communication of specific illness and treatment details; uncertainty management	Broad publication of experience; Information seeking; Uncertainty management; receive and offer support; diminish isolation
<i>Audience</i>	Self; others	Self; others	Others
<i>Coherence, i.e. does the narrative makes sense over time?</i>	No unified/stable self; sequencing patterns; plot evolution	Specified sequential markers: diagnosis; treatment; 'evidence of disease'; cure; hospice; death	Intermittent/inconsistent communication; Plot?; varied sequence; not under author control

From a theoretical perspective, the use of three approaches in sequential fashion enabled more flexible reading practices and a more inclusive and comprehensive understanding of illness blogs. Smith and Watson (2001) summarized the complex interconnectedness of various theories that have a role in the proposed research:

Theorizing performativity, [i.e., the expression and reception of narrative] contests the notion of autobiography as the site of authentic identity. Theorizing positionality [i.e., the narrator as authority] with an emphasis on situatedness, contests the normative notion of a universal and transcendent autobiographical subject, autonomous and free. And theorizing dialogism [i.e., the multivoiced narration] contests the notion that self-narration is a monologic utterance of a solitary, introspective subject (Smith & Watson, 2001, p. 146).

Understanding narrative, time and identity and their connectedness occurs through researcher commitment to the ‘hermeneutic circle of explanation and understanding’ (Ricoeur, 1984). By analyzing illness blogs using three distinct yet theoretically congruent methods it was possible to achieve a broader, deeper understanding of the subject, identity and meaning derived from these life narratives of experience and interaction.

Conclusion

To answer the three research questions posed within the four frameworks necessary to guide the interpretation and analysis in a systematic and logical manner, three narrative methods were proposed to understand parent illness blogs more fully.

CHAPTER 3

Method

In this chapter the narrative analytic approach employed to answer the research questions about illness blogs is described. The research aimed to answer the following three questions: (1) What life stories are evident in blogs created by parents of children with cancer? (2) What themes are evident in the illness narratives contained in these blogs? and (3) What is the influence of author-reader interactivity expressed in illness blogs on the experience of parenting a child through cancer? The plan for blog selection and analysis is described, as are consent procedures and the plan for protection of participants.

Sequential approach to narrative analysis

A three-step sequential narrative analysis of parent blogs about childhood cancer was employed. First, a life story approach was undertaken, in which one parent's blog was analyzed to create the story of the parent's life during the child's cancer treatment. Second, a thematic analysis of several blogs was performed in an attempt to discover common thematic elements across a number of participants' experiences, their reports of illness events and actions they take regarding their care for their children. Lastly, blog narrative-in-interaction was analyzed to search for unique and influential features of the interaction of the parent blog author with readers who respond by posting comments, often in turn responded to by the author. The three approaches served to isolate and illustrate in relief the experience of parenting a child through cancer as expressed in blogs.

Blog selection

The purposive sample of parent blogs included publicly accessible, English language blogs created and authored by parents that contained descriptions of life with a child who had

undergone treatment for acute lymphocytic leukemia (ALL) or neuroblastoma in the last 5 years or who was currently undergoing treatment for these types of cancer. For the purposes of this study, “child” was defined as someone younger than eighteen years of age. Selected blogs included blogger contact information and descriptions of events related to the child’s cancer diagnosis and care. Parent blogs excluded from analysis were non-English language blogs and blogs created by parents of children with other illnesses.

Blog selection for the first analytic approach was achieved by an Internet search, using blog search engines Technorati and Google Blog Search for a purposive sample of one richly descriptive blog created by the parent of a child with ALL and by the parent of child with neuroblastoma that was analyzed using the life story method. Criteria for selection included descriptions by the parents of events surrounding the prediagnostic, diagnostic, treatment and off-treatment phases of the child’s cancer experience and public accessibility of the blog. Since the blogs analyzed in the life story approach would also be included in the second and third analytic sequences, these two blogs also needed to include at least one reader comment for every blog entry. Blogs selected for life story analysis were the two that contained the greatest number of entries and richest data after initial reading of all selected blogs and consultation with doctoral committee members. From these two blogs, narratives of the lives of the authors-parents affected by childhood cancer were created in the tradition of Polkinghorne (1988). The resultant life story incorporated the general demographic and personal information shared by the blogger, with identifying information removed or changed to protect participant privacy.

The search terms expected to yield results most appropriate to the needs of the research are “diagnosed with acute lymphocytic leukemia/leukaemia (ALL)” and “diagnosed with neuroblastoma.” In a preliminary search for blogs of interest, it was noted that each of the blogs

in blog directories contained the phrase “[child’s name] was diagnosed with [the type of cancer] in [month or year].” This seemed to be one way for the blogger to introduce both the child and the topic of the blog to the readers. By using the chosen phrases, most returns pertained primarily to childhood cancers. Two different types of childhood cancer were represented. Due to the disparate nature of each type of cancer and the associated treatment, examination of narratives of life with these two cancers provided insight into family life during treatment that differed in important ways. Sickness and disease trajectories can serve as meaningful time markers when illustrating stories of illness (Sandelowski, 1999). Generally, the onset of symptoms of and treatment for leukemia is rapid and intense, usually with early diagnostic and treatment plan clarity and presumably positive outlooks for successful treatment. Neuroblastoma illness and treatment generally includes lengthy periods of uncertainty characterized by alternating periods of being free of evidence of disease followed by relapse and further treatment, with less certain and much less optimistic predictions for successful treatment. Together, analysis of two types of illness blogs within childhood cancer enhanced understanding of areas of similarity and difference in the parent experience. Support exists in narrative research literature for inclusion of, and accommodation for, greater variety in sampling rather than less (Riessman, 2008).

Parents of nine children with neuroblastoma and five children with acute lymphoblastic leukemia consented to participate in the research by replying to an email solicitation. In research involving children, even indirectly, as in this case, the obligation to solicit assent to the research from the child must be considered. Since blogs selected were publicly accessible, with the parental value of strict privacy presumed to be less than consequential and in light of the efforts

being undertaken to make personally identifying information anonymous, assent from the child was not solicited.

In addition to the first two blogs selected for life story analysis, an additional eight blogs by parents of children with neuroblastoma and four blogs by parents of children with leukemia were selected for thematic analysis (for a total of fourteen). In order to be included in the thematic analysis, these blogs had to contain parent writing that readily revealed demarcations in diagnostic and treatment phases during the child's cancer experience. Blogs were analyzed as individual units of illness experience expression and in relation to one another to identify thematic and linguistic similarities, consistent with Riessman's (2008) method of thematic narrative analysis. In analyzing blogs using Riessman's approach, narratives that became data were organized into categories of themes. Blogs were analyzed until a stable set of concepts were evident (Riessman, 2008). Thematic analysis continued until no new categories were found. Sandelowski (1986) described this as the movement toward informational redundancy.

Blog text was copied and pasted onto a Microsoft Word document. Names included in the analysis were excluded or changed to enhance privacy protection. The documents were saved in password-protected files located on the researcher's secure personal-use laptop. Copies of the files were saved on a password-protected external disk drive, stored in a locked cabinet in the researcher's home. The researcher and committee members possessed the passwords. The text of entire blogs, including comments by readers, was the transcript to be analyzed.

Sequential narrative analysis

Data, i.e. the narratives, were collected by copying blog content onto Microsoft Word documents totaling 15,479 pages, once photographs were deleted. First, blogs created by parents

of children with neuroblastoma were read through without note-taking. One blog was selected for the life story approach to analysis as outlined in the explanation of the method.

To maintain a coherent flow of reading and interpretation, the thematic analysis of the neuroblastoma blogs was undertaken after the life story analysis. To that end, a second reading of the same blogs with note-taking (in the margins, using the “comments” feature of Microsoft Word), identified thematic categories. This process was followed by a third reading, this time of just the thematic categories and the associated blog entries,. Thematic categories were isolated and organized according to temporal frames and outlined. The outline was used as a guide in the creation of the final text as small narratives were positioned as examples of thematic categories relevant to the second research question.

The same system was applied to the reading and interpretation of comments posted to the blogs by readers of the neuroblastoma blogs to answer the third question. Both the thematic and narrative-in-interaction methods, the second and third approaches, were undertaken until a set of stable concepts was identified and used to theorize across cases. The two methods share this common objective, but were employed using different frameworks that served to guide the selection of blogs. While the three approaches to narrative analysis discussed possess some theoretical and methodological incongruence, rigid attention to the execution of the analysis in the specified sequence added rigor and depth of understanding.

Once the neuroblastoma blog analysis was complete, attention turned to the blogs created by parents of children with leukemia. With these, the reading and interpretive process was identical. First, one blog was selected for the life story approach. After that story was created, the thematic analysis and comment analysis proceeded. Time from consent and initial transfer of

blog content to saved documents through to completion of the reading and analysis was just over one year.

To facilitate coherent reading, the following chapters will present the analysis of the blogs in the order of the research questions posed rather than in the order they were identified and analyzed. That is, chapter 4 will address the first question: What life stories are evident in blogs created by parents of children with cancer? The question is answered by the presentation of the life story analysis of the selected neuroblastoma blog, then the analysis of the selected leukemia blog.

The answer to question two (What themes are evident in the illness narratives contained in these blogs?) is reported in chapters 5, 6 and 7 in the form of narratives of the diagnostic, treatment and off-treatment phases. The thematic analysis of the neuroblastoma, then the leukemia blogs, will be reported, as organized by the analytic framework discussed earlier, i.e. the Natural History of the Illness (Bluebond-Langner, 1996).

The influence of author-reader interactivity, the focus of the third research question (What is the influence of author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer?) is reported in chapter 8. Analysis of the comments posted first on the neuroblastoma blogs, and then on the leukemia blogs is reported.

By looking at illness blogs using this three-step sequential analysis, i.e., (1) life history; (2) thematic analysis of blog as illness narrative; and (3) narrative-in-interaction, focused and broader understanding of the online expression of childhood cancer resulted. Table 2 delineates the steps taken in the sequential narrative analysis.

Table 2. *Sequential narrative analysis of parent blogs*

Method of narrative analysis
<ul style="list-style-type: none"> • IRB application and approval • Inclusion criteria <ul style="list-style-type: none"> ○ Blogs created by parents of children with leukemia ○ Blogs created by parents of children with neuroblastoma ○ Selected blogs must include event descriptions of prediagnostic, diagnostic, treatment and off-treatment phases of cancer care ○ Selected blogs will possess at least one reader comment per blogger entry ○ Selected blogs will be publicly accessible ○ Blog entries from the first to the most recent prior to consent will be included in analysis ○ Blogger contact information available on blog • Exclusion criteria <ul style="list-style-type: none"> ○ Non-English language blogs ○ Blogs created by parents of children with other illnesses ○ Password-protected blogs • Data collection/storage and consent <ul style="list-style-type: none"> ○ Internet search for illness blogs (ten by parents of children with ALL; ten by parents of children with neuroblastoma) of sufficient depth and narrative elements to be used for life story creation; thematic analysis and narrative-as-interaction ○ Search terms: “diagnosed with ALL” or “diagnosed with leukemia/leukaemia ” and “diagnosed with neuroblastoma” ○ Email bloggers for consent to use blog for analysis ○ Print and save blog text with pseudonyms/remove or anonymize other personally identifying information on password-protected Word document saved in 2 password-protected locations • Life story narration <ul style="list-style-type: none"> ○ Read/Reread selected transcripts (one blog re: ALL; one blog re: neuroblastoma) ○ Organization of data into coherent developmental account (plot) of author’s life and description of life with childhood cancer ○ Test plot development for contradictions with major events and actions ○ Final storied account (Outcome =generation of a life story) • Experience-based thematic analysis <ul style="list-style-type: none"> ○ Read transcript (5 ALL; 9 neuroblastoma total) at surface level looking for, taking notes on and highlighting phrases or words that indicate experiential processes that surround an event ○ Reread transcript looking for statements that relate to larger concepts (experience of parenting through cancer, uncertainty, stress) ○ Classify these brief narrative accounts into thematic groups or categories ○ “Information redundancy” (Sandelowski, 1986) will signify completion of analysis • Narrative-in-interaction analysis <ul style="list-style-type: none"> ○ Return to same transcripts ○ Read, then reread looking for, taking notes on and highlighting themes related author-reader interaction ○ Special attention to the “communicative how” and the influence of the interaction on subsequent blogging ○ “Information redundancy” (Sandelowski, 1986) will signify completion of analysis

Life history approach. The life history approach to narrative analysis was the first employed in the proposed sequence of interpretations. The approach exposed the narrative elements to illuminate the parental experience of childhood cancer in a new way. Guided by Ricoeur's theory of narrativity, one blog from each of the two types of cancer of sufficient depth and core narrative elements was analyzed in the method of life history creation conceptualized by Polkinghorne (1988).

This approach permitted cocreation of two complete narratives, by a parent of a child with ALL and by a parent of a child with neuroblastoma, through emplotment of life and treatment events described in the blog. The goal of exploration was to reveal life as a parent of child with cancer *by* the parent. This was accomplished by reading the blogs from the first entry forward in time to the last entry immediately preceding the day of consent. During a second reading, narrative elements in the data began to be identified. By the third reading, organization of data into an emerging thematic plot was achieved. This developing plot informed the researcher in a snowballing pattern of inclusion of gathered data. As analysis moved from separate event narratives toward the creation of a final storied account, plot development was tested for contradictions with major events and actions reported in the blog. "The final story must fit the data while at the same time bringing an order and meaningfulness that is not apparent in the data themselves" (Polkinghorne, 1988, p. 16). The life story of parenting a child through cancer is reported in Chapter 4 in the third person. When the life story approach for the first two parent blogs was complete, the thematic analysis of the remaining blogs (nine by parents of children with neuroblastoma; five by parents of children with ALL) was undertaken.

The second and third sequence of proposed analysis examined illness blogs as topic-centered, thematically-linked 'snapshots' of events.

Thematic analysis of blogs as illness narratives. The thematic analysis examined the portions of blogs created especially for the purpose of expression of ideas, events and consequences of living with cancer treatment. Entries were examined in temporal order consistent with the illness trajectories. The role of parents of children with cancer, as subjects, with common experiences who have chosen to write on the topic, was explored across the temporal order of disease process and treatment or what Bluebond-Langner (1996) called the Natural History of the Illness.

Selected blogs were read first from beginning to end, i.e., from the first entry to the most recent prior to consent. Words or phrases that described processes that surrounded the emergence of an event related to the illness or treatment were highlighted. The aim of the second and subsequent readings was to look for statements that related to larger concepts such as those outlined as part of the parent experience of childhood cancer in the literature review, namely solicited reports of parental experiences of childhood cancer, uncertainty and stress. Each reading resulted in increasing levels of specificity regarding classification of statements and narratives into thematic groups. Consistent with Riessman's (2008) approach to thematic analysis of narratives, the report of results maintained the integrity of the stories told by bloggers through preservation of sequence and inclusion of narrative voice. Segments of blog entries that illustrated the thematic categories identified were included and are described in later chapters.

The process of overreading, a practice well-documented in the study of literature, was used to analyze indirect statements and areas of omission in parent blogging. Overreading is the placement of attention by the reader on authors' areas of emphasis, inconsistencies, endings, repetitions and silences to enhance identification of important concepts or themes (Poirier & Ayres, 1997).

Narrative-in-Interaction approach. The third and last approach to analysis of parent blogs about childhood cancer was the exploration of the interaction between the blogger and readers. This approach is an application of Georgakopoulou's (2006) principles of understanding the influence of communication on the interpretation of meaning of events, actions and reactions. This third analytic approach was accomplished by returning to the same blogs examined using the thematic analysis approach described above. This time, the blog comments were read for exploration of themes that expressly relate to the interaction between blogger and reader-responder and its influence on subsequent writing and on the illness experience in general. Although this third approach was similar to the second, the distinguishing feature was the central focus of attention, i.e., identification of themes related to communication rather than experience.

Returning to the text of illness blogs with special attention focused on the exchanges between readers and the author added another dimension to the understanding of the phenomenon at hand. While it was conceivable that the interaction of reader-response and author-response would become apparent during analysis as illness narrative, because it was known in advance of the research that interactivity would play a key role in the narrative, recognition of the exchanges as a separate narrative highlighted their potentially unique influence on the larger narrative.

Selected blogs were read from the first entry to the most recent post prior to consent, with attention placed this time on what Fina and Georgakopoulou (2008, p. 384) referred to as the "communicative how," i.e., the interactional features and language details in narrative tellings. In a second reading, sequential mechanisms, or those elements of the story that influence the sequence of the narrative interaction, were highlighted. Finally, the function of the narrative

interaction was explored for its relevance both to the author and to the reader-responder. Themes related to the influence of comments on bloggers' subsequent writing and on the illness experience are reported in Chapter 8.

Ethical considerations

Before beginning research into lives complicated by illness, it was imperative to assess and explore potential ethical dilemmas that were inherent in or might result from the work. The duty to attend carefully to ethical treatment of the writing about the experience is derived from the perspective of solidarity with families living with childhood cancer. Institutional Review Board approval was obtained before study initiation.

A recent review of literature on ethical treatment of Internet research participants revealed three basic approaches. First, an open-source approach that treats publicly accessible Internet content as 'fair use' and as such not subject to privacy or copyright issues. Second, a Humanities approach that views published Internet writing as literature whose authors need not be contacted for permission to appraise the work. Lastly, some support can be found for consideration of authors of illness blogs as human subjects, entitled to protection of privacy and autonomy (Heilferty, 2011).

Given that the chosen framework for conceptualizing the research was a sense of solidarity with the authors derived from an ethic of care, the duty to justice and respect for persons demanded the 'human subject' perspective. The combination of the vulnerability of the authors of blogs (as well as other affected family members, not the least of concern being the child with cancer); the perceived and legally protected ownership of the narrative and images; and the potential for misinterpretation of the stories all raised the level of sensitivity and caution required to attend to these stories with an abundance of caution. Narrative analysis was selected

as the method of choice for its dedication to analysis of illness narratives as ‘bodies.’ The narratives were appreciated within the larger contexts of the illness and of the families. Families often declared a strong desire to have cancer viewed as *part* of their lives; so, too, will these illness blogs be viewed as *part* of families’ narratives.

Out of a sense of respect for persons, in the human subject model of ethical research conduct, only blogs created by parents who gave informed consent to research were included in the analysis. Once a blog was selected for potential inclusion, individuals were contacted by email for consent to have their blog included in the analysis from the date of consent backward chronologically to the first blog entry date. The email address was obtained from the parents’ blogs. The letter emailed to parents soliciting consent to participate can be found in the Appendix A.

CHAPTER 4

Life story analysis

Life story analysis

The two life stories that follow were created after reading the blog entries from mothers of two children, one treated for neuroblastoma and one treated for acute lymphoblastic leukemia. These stories are temporally bounded by the illness frame. The choice of blog to analyze was limited only by the bloggers' inclusion and exclusion of life elements. Both of these were chosen, in the method of Polkinghorne (1995), for the quantity and depth of personal revelation of events and reflection; and for the high degree of inclusion of family life narrative.

Leigh

Introduction

Ginny, Leigh's mother, blogged about Leigh's neuroblastoma since her diagnosis in 2002 at age 6. Leigh is 14 years old now, cancer free and in the 9th grade; eight years and still writing. In the early days Ginny referred to the site as her CaringBridge webpage. As the language of online writing evolved, later in the writing she called it a blog, identifying herself as a blogger.

In this first phase of the narrative analysis of blogs created by parents of children with neuroblastoma, Ginny's blog, "Leigh's Spot," was analyzed by associating the smaller stories told each day with the story of the blog as a metanarrative. This is in keeping with the research purpose of examining both the large and small context of stories relayed by parents about the two illnesses chosen for study. As with most blogs, each entry had a purpose; each might stand alone as a story within the larger narrative. Blogs are intended, after all, to send messages small and large, not merely to record daily events, reactions and feelings. The writer is interested not just in documenting, for this could readily be accomplished in diary form, but also in broadcasting.

Ginny stated at the outset that the blog's purpose would be to tell Leigh's story. As she wrote, she revealed details about her own life; her experience of parenting a child through cancer; and living a changed life. She marked time as "before cancer" and "after cancer" finding meaning in the experience in a metaphor she created after treatment was finished: "Cancer was the cloth that polished our family and made our love shine" (Leigh, mother, 2/24/08).

Ginny introduced the story's characters over time. The beginning of the blog entries gave background information about the family in the early days of Leigh's illness. Readers learned about Dave and Virginia (Ginny), Leigh's father and mother, in the series of emails sent to family and friends. Until the time Leigh was diagnosed with neuroblastoma, the family made a life 'on the road.' Dave and Ginny ministered in word and song in churches across the country. Dave is a minister in the Assembly of God church. The family members: Dave, Ginny, Martin and Leigh (age 11 and 6, respectively, at the time of Leigh's diagnosis in 2002), lived in an 'RV' that was pulled by a full size truck. In the blog, Ginny made repeated reference to living in 375 square feet of living space for all their married life. The children were raised on the road, with Ginny providing home schooling.

Ginny is a Christian singer/songwriter whose passion for writing is expressed in varying formats as the story evolved. When singing on the road was no longer an option due to Leigh's illness, she sang locally. When singing locally became problematic due to her own illness, she turned to writing of different sort: her literary style on the blog developed thematic and symbolic qualities not present in the early writing. She also adopted the identity of 'writer' as she sought to have her stories published locally and nationally.

Dave spent his elementary school years in Hawaii where his father was stationed as a fighter pilot. (Interestingly, Leigh chooses a family trip to Hawaii for her Make-A-Wish.) Dave

grew up wanting to be a fighter pilot like his father, but “flunked the physical.” He graduated from the University of North Carolina with a Bachelor of Arts in Economics and a minor in Philosophy. Dave became a minister after secular life proved unfulfilling. His contribution to the blog ends shortly after Leigh’s cancer treatment begins, when Ginny became the sole author. He characterized Leigh’s cancer in early blog entries as a “furnace of affliction” (for him) that caused him to reevaluate his plans and ambitions. He wrote of having had a vision of becoming a “high profile minister” but left that behind as he attempted to regain personal and professional balance at the start of her treatment.

Ginny’s stated purpose in blogging changed over time. In the early writing she used the blog as “an outlet for expression of her feelings and experiences.” She wanted to document for readers what it is like to live with childhood cancer. Later, she expressed wonder at the number of people who have followed the story and continue to read and contribute comments. Ultimately she identified the readers as the reason for her writing. She came to know them and to rely on them; to be informed by them and comforted by them. She responded to their questions about and concern for Leigh and eventually for her own health.

She became increasingly curious about them over time, asking for some basic demographic information. She learned that only three men are regular followers. By 2007, there were readers from all 50 states as well as other nations. By the end of 2008, visits to the site numbered more than 1,000,000. During a particularly troubling time, when Ginny had a breast cancer scare, readership jumped from its usual 1,000 visits per day to 2,694 one day and 4,414 the next. Just the increase in the number of people reading brought comfort. The blog readership grew from people she knew personally to include people she had never met but who were affected directly and indirectly by neuroblastoma, as well as other people who had “just

found” the blog. Six years after treatment, Leigh’s “favorite nurse” who cared for her on the day of transplant (a very memorable day for affected family members) reconnected with the family and remains in touch even after having relocated to her family home in Canada. When Ginny decided to create a new, second blog that would contain personal storytelling unrelated to neuroblastoma, as well as provide some income through advertising revenue, she made a commitment to readers to maintain “Leigh’s Spot” for three reasons: as a “legacy” to their experience; to “provide education” for families in similar circumstances; and as “a place for long time readers to connect” (Leigh, mother, 4/29/09).

In addition to the personal importance of the author-reader relationship, Ginny also wrote of another need fulfilled by blogging: to validate and receive acknowledgement of the experience. It was clearly important to her and she was grateful for comments that express readers’ identification with her thoughts, fears, joys and wishes. In her writing, she seemed comforted to find people with whom she believed she had much in common.

The blog began with early emails that Ginny posted to report progress in deciphering Leigh’s earliest symptoms: intermittent and unexplained fevers and joint stiffness that at first come and go, but became increasingly problematic and ever present. These early emails were posted in the blog to provide readers with background information necessary to understand subsequent events. This prediagnostic phase of the story was integral to understanding the narrative as time passed. For Ginny, any unexplained fever and pain Leigh experienced remained the sounding alarms for worry that pervaded the entire narrative.

Prediagnosis

Dave and Ginny had been married twenty years when the story began. The RV rested in the parking lot of what Ginny refers to as their “home church” in Raleigh NC. At this time,

Leigh's symptoms were being evaluated in Winston-Salem NC, Ginny stayed with her there, while Dave and Martin remained in the RV, commuting back and forth to the hospital for visits.

Ginny's writing in the days when a diagnosis had yet to be confirmed included escalating anxiety about the increasingly complex and worrisome testing being done without answers. Daily communication regarding each scan, each lab or scan result positioned the reader in a state of suspense similar to that endured by the parents. Ginny expressed frustration with the obstacles to resolution of the problems and delays in discovery while care providers tried to put Leigh's symptoms together into some meaningful pattern. Fear became the main feeling expressed as the answers became apparent. A tumor found on her adrenal gland and pathology results led to a diagnosis of neuroblastoma. A new series of questions arose. After the prolonged period of uncertainty about the cause of Leigh's fevers and pain, it was Dave who wrote of the devastation of the diagnosis. Plans for upcoming concerts and other commitments were cancelled; plans were made for Martin to be cared for by friends.

Ginny's writing quickly moved from reporting to a mix of information dissemination, revelation of feelings and reflection. Details about events; her beliefs about the future; her feelings about it all; and the description of the experience of watching one's six year old go through the treatment for cancer were all part of each day's blog entries. At first Dave reported on his reactions and feelings as well, but once treatment started, the writing was done by Ginny, roughly two thousand pages from 2002 to September 2009 when data collection for this study ended.

Diagnosis

Details of the plan for treatment, the meaning of survival statistics and plans for the necessary significant adjustments to the family's current lifestyle were all described alongside

Ginny's vivid expressions of her feelings about it all. Desperation, fear, hope, stress, gratitude, a changed sense of priorities all appeared, sometimes in the same day's entry. When Leigh was diagnosed and Ginny remained at her side at all times, Ginny wrote of her transition to a 'new ministry.' She adopted the notion that she had been called now to minister to her daughter, and accepted her former ministry as temporarily lost to her. Immediate concerns regarding Martin's schooling, lost income and travel from where the RV is parked in a church parking lot to the distant hospital all were addressed in short order. The family's highly developed ability to adapt, honed to a fine skill from many years on the road became an asset in making and changing plans on the fly.

As Ginny wrote of the feelings and experiences related to Leigh's cancer, she told Leigh's story and used Leigh's words to convey the profound changes and deep effects of the illness, but it was her own feelings and experiences that emerged as the central feature of the blog. She told Leigh's life story during treatment. More than that, she shared her own reaction to it; her view of how she, Leigh and the rest of the family were changed by the experience. It is Leigh's Spot, but in the telling, ultimately it is Ginny's version of family life with cancer.

Why a blog when a diary might suffice, if this is a phenomenon of writing as expression of feelings and events? Ginny answered this at several key points in the story. The early despair and feeling of isolation as the realization that Leigh has neuroblastoma, a childhood cancer with an exceptionally poor prognosis, abated when she shared with readers the persistent intrusive visions of Leigh's funeral that preoccupied her thoughts during some of the worst days. She received solace, encouragement, even some minor financial and other material aid from readers over the course of these 7 years. She frequently expressed her gratitude to readers who

commented in support, writing that these forestalled her sense of loneliness at a time when there was not much they were finding in common with others.

Treatment

Details of the treatment plan were shared, followed by her and the rest of the family members' reactions, physical, emotional, and spiritual. Expressions of feelings of desperation, frustration, hopelessness, fear, anxiety were juxtaposed with coping strategies in the summary of each entry. These included requests to readers for prayers; movement toward acceptance of what was unchangeable as a 'new normal;' living life one day, even at times one moment at a time; the use of psychotherapy; expressing gratitude for the good she found in their lives, even the positives brought by cancer, e.g. a renewed appreciation for small gifts in every day that were overlooked before; the marking of time by reflecting back on how far they had come once treatment began; the marking of progress in diagnosis or treatment anniversaries as time moved on and treatment ended.

Leigh's treatment consisted of months of chemotherapy followed by a stem cell rescue (referred to as "transplant" in the blog) at Duke Children's Hospital using her own cells harvested earlier in treatment. The chemotherapy and radiation immediately preceding the rescue was intense, obliterating her bone marrow function. She remained in the hospital for 5 weeks, then she and Ginny rented an apartment across the street from the hospital for several more weeks so that Leigh remained close for follow up visits and any emergency care required. Leigh attended physical therapy to regain muscle strength lost during the prolonged period of bedrest. Ginny was now a full time mother/nurse, providing care for Leigh and her complex medical devices,—her nasogastric feeding tube and central venous access device—providing

total parenteral nutrition and enteral feedings, and monitoring her safety and wellbeing for any signs of infection, obstruction, or other problems.

Ginny documented weeks of pain, protective isolation, restlessness, nausea and loneliness in the blog. She also wrote of those efforts by staff, friends and volunteers that meant the most in surviving the hospitalization: home-cooked meals; a hair stylist who visited every two weeks for both patients and family members; free food delivered from national chains and local restaurants; volunteers who joined the children in their rooms so parents were able to step away for a bit; volunteers called “best buddies” who were matched with one patient, visited for several hours each week and followed them through treatment and beyond; arts and crafts for the children; and parent support groups and counseling available.

Challenges faced included the ever present fear and acknowledgement that for children with neuroblastoma, relapse is not an ‘if’ but a ‘when,’ the cruel irony of the certainty of this juxtaposed against the powerlessness inherent in the uncertainty of when it might occur and the inability to prevent it. The statistics they were quoted at diagnosis were reiterated in both a positive light (since, so far, she had overcome them) and as a threat of an impending reality. For Ginny, the unwelcome imagery that appeared from time to time of the things she imagined Leigh will miss was disturbing to distraction: wedding, wedding dress, life as bride, mother and professional. Even with survival to adulthood, the potential for Leigh’s infertility meant not only no children (‘of her own’) for Leigh, but the potential for no grandchildren for Ginny.

In addition to the immediate losses, there were anticipated losses to be counted as well. Cancer had caused them to change everything: employment, living arrangements, schooling for both children, and their financial plans. Cancer was a “thief,” Ginny wrote, but in the place of those things taken by the disease and its treatment, unexpected gifts emerged. A deeper sense of

gratitude surfaced ‘after cancer’ that they thought was already fully realized in their lives ‘before cancer,’ rooted in their religious practice and belief system. Ginny wrote of being impressed daily with Leigh’s courage and will to maintain as normal a state of life as possible. She took pride in her own inner strength to vigilantly attend to what she called her “new ministry,” giving herself over to total care for Leigh, even when she had been sleepless for days. She wrote of her appreciation for the new community of support that developed as she shared her needs with readers online. For the first time, she wrote, she discovered the comfort of allowing others to help.

Off treatment

Once treatment was completed, residual uncertainty about the degree to which Leigh’s cancer had been eradicated was ever present. Some disease was present even after transplant, but remained stable without progression, a sign of hope as they waited for the oral chemotherapy to finish the job. Dave and Ginny sought an evaluation by nationally known neuroblastoma specialists (of which there are just a few at present). They flew to a major neuroblastoma center in New York City using the services of corporate flight donations. The evaluation of Leigh’s current state of disease meant she was not a candidate for the experimental treatment the parents had hoped would eradicate her disease, so the family returned home after this short stay with Leigh to continue on oral chemotherapy and to have her disease monitored.

By the first anniversary of Leigh’s diagnosis, her parents decided to move into a house in Raleigh while they tried to maintain as regular a life as possible. Subsequent scan results declared her disease still present but “stable,” meaning no changes have been seen in the scans done at three month intervals. For the family, a ‘new normal’ developed. As scans and oncology clinic visits became less frequent, a nervous settling in period occurred as the family

sought to regain balance. Ginny wrote of being delighted at the diagnosis of Leigh's first 'normal' childhood illness since neuroblastoma—swimmer's ear—after so much time spent worrying about life-threatening events. Everyday life became populated with more normal childhood activities, but Ginny expressed intense feelings of fear each time a week of surveillance scans neared. The simultaneous hope for the best while preparing for news of relapse wore on her, reaching a peak during the meeting with Leigh's oncologist who for over a year had been able to tell them her disease is stable, then eradicated.

During this period, time orientation in the telling moved from present, when Ginny told of daily happenings; to past, with her reflections on traumas and growth during treatment; to future, full of hope, but cloudy at best. Frequent retrospective reviews of older entries were included. These signified important ties to present events and served to remind her to be thankful for the present. It is in this time that Ginny began to see herself as a writer.

Communication with physicians was a frequent topic of Ginny's writing. She appreciated the oncologist's approach to care that she interpreted as understanding "that treating cancer is not only about saving a life, but also about living a life." At times she expressed frustration with the delay in receiving results of scans as anxiety increased with passing days. She unlocked what she referred to as "the code" of the delivery of results when she realized she receives "bad news by phone and good news by email," and became increasingly anxious when calls came from the hospital.

As early as a few months after transplant Ginny wrote of cancer survivorship issues, or cancer treatment-related sequelae. In these early days, Leigh had a high-frequency hearing deficit; persistent toe-walking gait; chronic thrombocytopenia requiring regular gamma globulin infusions; low memory scores and slow visual processing on a neuropsychological examination;

and slowed height growth. On some of these issues, knowing many of her readers were parents in similar situations, she solicited advice from readers about their experience with late effects.

A little over two years from Leigh's diagnosis, Dave was appointed pastor of a church about 30 miles from Raleigh. The family found a home and settled into life with Dave as pastor, Ginny as church secretary, and both children enrolled in the Christian Academy associated with and operated by the church. This became representative of the degree to which everything for this family had changed from continual motion to permanent settlement, with Leigh's disease as the core element with the potential for profoundly changing family dynamics.

Ginny's blog entries became fewer as news about Leigh's illness became rarer. She was grateful for these 'no news is good news' phases but the fear of relapse remained a component of her reflective writing.

Relapse

At one of the follow up visits four years after being diagnosed, the news came that a scan has shown relapse of her disease in an extremity. Ginny expressed renewed despair. The machinations in the expression of decision making leading up to treatment for the relapse highlighted vividly the anguish experienced by parents as they accepted responsibility for choosing among several available options, all with uncertain outcomes. The initial overwhelming sadness gave way to hope as subsequent scans show response to the oral chemotherapy treatment they had decided upon, the same drug she had taken in previous phases of treatment.

The family found hope in Leigh's own perception of her illness and its relapse. As she struggled to find meaning in her suffering during transplant, Leigh told Ginny that she knew God had a purpose for her cancer: "God put me on Earth to make people smile." At relapse, she told

her mom that God must have a purpose for this, too. Ginny had just returned from outside her clinic exam room where she heard Dave telling Leigh's story to another family. She told Leigh that "God is already using you" to teach others. At the same time, Ginny wrote of being troubled by intrusive thoughts of hopelessness, uncertainty and doubts about a future with Leigh alive.

Off treatment

Within a few months, scans showed that the disease was again arrested and Ginny's writing expanded to include broader issues of living with uncertainty and the late effects of treatment. The fear experienced from the time the routine scans were scheduled until the meeting with the oncologist to review the results appeared again and again in Ginny's writing. She described the five or ten minutes of polite 'chat' at the start of the meeting as being heard "as if he is speaking a foreign language" and she was unable to concentrate until she heard that the scans were clear and the rejoicing could begin. Her approach to the management of this scan anxiety was outlined as well. She vowed repeatedly throughout her writing to live each day, each moment at a time. She called this approach hitting the "play" button, not the "rewind" and not the "fast forward" buttons to remember to remain in the present.

In addition to the episodic but persistent fear of relapse, the assessment and management of Leigh's late effects of treatment dominated Ginny's writing about Leigh's illness over time. After being a concern for years, Leigh's endocrine levels returned to normal, allaying for a time Ginny's worry about Leigh's fertility. Another late effect was the finding of a delay in height growth. This, along with her hearing deficit, seemed particularly cruel in her eyes as, to Ginny, they represented visible lifelong signs of cancer's mark.

Post traumatic stress from the persistent fear of relapse was evident in one story Ginny told of waiting for a call from the oncologist with scan results. Ginny reached the limit of

patience and sat with Dave at the kitchen table, tearful and fearful, with the tissue box and tissues strewn on the table. When Leigh, twelve at the time, came down from her room and saw the table, she immediately thought the phone call had come and she had relapsed. Her parents reassured her that no call had come yet, that her mom had just been feeling overwhelmed with the fear of it all. The moment took on so much meaning for Ginny that she posted a photo of the kitchen table scene with the tissues, box, water glasses and cell phones on the blog.

Ginny wrote often of the ways family members used humor to cope with the residual stress related to Leigh's treatment. Family games nights and participation in as many 'normal' activities as possible were described in detail and with delight. Inside jokes about baldness and other side effects of treatment brought a sense of closeness and support. A cape worn by Leigh at one of the low points of treatment transformed her into "Vomit Girl," (she named herself) the oncology unit's superhero.

Ginny conjured categories of sadness in living with childhood cancer. She identified "big sorrows, small sorrows and collective grief." In early the days, one of the hardest parts was being separated from Dave and Martin during treatment. Later, it was "the not knowing that's so hard." As her sense of belonging to the community of cancer families grew over time, she discussed a "collective grief" shared by all when they read of children who relapsed or died. In seven years blogging, Ginny made reference to 10 children who experienced relapse of neuroblastoma and 23 who died from the disease, 10 of those in a four week span in 2004. She called this cumulative loss the "holocaust of neuroblastoma" and identified with other parents describing them as "my people." She was particularly upset when reading about children who relapsed or died more than 5 years after treatment, as this forced her to contemplate the possibility of Leigh's death again and again.

The feeling that “you can never get away” from the fear of cancer’s return was another of the sorrows. By 2005, three years from diagnosis, waiting for scan results during a time of relative wellness was seen as “the very worst part.” She repeatedly referred to “sobering moments” as in the time she asked the audiologist a simple question about hearing loss in neuroblastoma patients 10 or 15 years after treatment. She was taken aback by the hesitant and quiet response from the audiologist that “we don’t have data on kids that far out” and its inherent meaning: there are not enough children surviving the disease long enough to be evaluated. Even simple questions became emotional land mines.

The occasional direct quotes from Leigh provided insight into Ginny’s profound sadness over some of the losses experienced. In one example, she told the story of completing the camp form with Leigh a few years back. One question on the form asked what things on their body (devices, tubes, etc.) related to cancer. Leigh told her mom to write, “All I have are scars. Just scars.” The poignancy of the moment was not lost on Ginny.

The challenge to avoid panic with the minor pain Leigh reported from time to time, reminiscent of her prediagnosis symptoms, was monumental. Ginny named this as one of the chief difficulties in the post treatment phase. When Leigh reported pain “where my adrenal gland used to be,” Ginny forced “external calm” in the midst of “internal fretting.” Even mild symptoms that come and go were troubling as parents struggle with when and which physician to call for advice.

Ginny’s vivid use of imagery painted pictures for readers. She referred often to the cancer journey, especially the time of transplant, as the “valley of the shadow of death.” She was gripped periodically by the “familiar claw of fear” when Leigh had a new unexplained pain. Neuroblastoma was the thief, the executioner, the beast. The battle against it was compared to

Star Wars. Leigh's time away—at camp, with relatives—reminded her “of the permanent absence called death.” After a fun day away at an amusement park with Dave, Martin and Leigh, she returned home to write a blog post about the terror she experienced on the roller coaster. She hopped on without thinking too much about it, she wrote, then panicked as the ride intensified and she experienced all the highs and lows of Leigh's cancer ‘ride’ in three minutes. She is taken by surprise at being overcome with emotion. Not until she began to think about writing the blog post did she recognize the roller coaster as metaphor.

“Small sorrows” was the term Ginny gave to the late effects of treatment and other sadness cancer brought that pervaded the everyday despite feeling grateful that Leigh is alive. When Ginny wrote of these survivorship issues they were often ticked off as on a list and the cumulative effects seemed to add to her burden of watching her daughter suffer the “small sorrows” or surplus suffering (Clarke & Fletcher, 2004). In the next sentence, she would acknowledge the blessing of having these issues to be concerned about, and would express her understanding that readers may think her ungrateful, but as she stated from time to time, the blog had come to be the place where she can express these thoughts without reservation.

Leigh's hearing loss was raised as a concern from time to time, but it was not until she developed speech problems that her parents acted. At first, a neurologist was consulted who prescribed an MRI of her head to rule out a brain tumor, a possibility after cancer treatment. She went through an EMG and intensive speech therapy. She subsequently received a hearing aid, something her mother had been resisting for years. When Leigh expressed enthusiasm about all she hears with the aids on, Ginny expressed regret for having postponed getting this help for her. On reflection, she recognized Leigh's limited growth and her need for hearing aids as problematic less for Leigh than for what they represented to Ginny and the rest of the world—

cancer as thief, robbing her of ‘normal’ childhood development. With every new milestone Ginny revisited the ways in which cancer had robbed Leigh of something. Each entry that began this way ultimately ended with naming a gift Leigh or her family experienced that replaced what had been lost by cancer.

All of these late effects and the potential for more were monitored at regular intervals. By 2007, five years after diagnosis, visits were scheduled annually. Reading Ginny’s blog gives insight into how much is asked of these families even at this late stage. From October to December 2007, Leigh had appointments to see a neuropsychologist, a pediatrician, an oncologist, an occupational therapist, a nurse practitioner, an endocrinologist, a pulmonologist, a cardiologist and was scheduled for a whole-body nuclear scan, bloodwork and bone-age radiography.

Occasional stories of disappointment stood in contrast to the main narrative mood that portrayed her family as “fairly wonderful (We are!)”. In one story of disappointment, well after Leigh completed treatment, she shared her feelings with readers about the fact that both children neglected to mark her birthday with a gift. She was shocked at their ungratefulness and after trying to hide her hurt feelings, became tearful and plagued with guilt at becoming emotional over the slight. Readers responded in two ways. Some offered an outpouring of identification with her dilemma. Others delivered reprobation for having been so selfish and suggested she grow up. In her determination to maintain a positive mood on the blog, naysayers were furthermore asked to email her directly with their suggestions and the negative comments were removed from the guestbook.

One area that Ginny rarely mentioned was the financial circumstance of their lives. Readers learned only that medical insurance seemed to remain constant during the time of

Leigh's treatment, with a premium being paid of \$1,000 per month. Even during periods of unemployment, no mention was made of a lack of coverage. Ginny stated in one entry that they were left with several thousand dollars in medical bills. The only other discussion of finances related to treatment was at the time of the visit to New York City to discuss experimental therapy, which would have cost \$300,000 uncovered by their insurance.

A blog like any other

It is striking that in the end Ginny's story turned toward reports of routine daily events, reflections on these events and past experiences, and the offering of the occasional recipe in response to readers' requests. Leigh's wellness was integrated into daily life, albeit with the mention from time to time of the cloud of fear that periodically overshadowed life.

Leigh's illness began to be integrated into the 'new normal' life of the family. Milestones were accepted as lost or celebrated as achieved; late effects of treatment were recognized and dealt with; Dave's job changed again; moves were contemplated; and through it all Ginny recognized her own development as mother, wife, and writer. There were health setbacks for everyone in the family, the most significant of which was Ginny's diagnosis with COPD, even though she never smoked. Her travel through diagnosis and treatment in some ways paralleled Leigh's journey and she described looking to Leigh for inspiration in handling the challenges. Leigh took on the role of comforter to a small degree, showing Ginny positive effects of having invested so much energy and emotion in Leigh during treatment.

Dave decided that being a pastor for a church and administrator for a K-12 Christian school proved too stressful, so left this position to find a church where he can be pastor only. This move resulted in a protracted period of unemployment and inspired questions from readers about the relative suddenness of the change. Ginny assured blog readers that he had not been

asked to leave and that the decision was less sudden than it might have appeared in her writing. Months later, with Dave and Ginny taking on temporary secular jobs for very brief periods on and off, the family eventually relocated to coastal NC where the Assembly of God regional leadership helped Dave find a church in need of a pastor.

As Leigh's off-treatment phase went on, when scans and other tests were to be arranged only in the event she became symptomatic in the future, Ginny's writing expressed feelings and descriptions of normal life events (Martin's high school graduation and college entrance, house hunting, Ginny's health issues, etc.). These reports of daily life in transition from a family with a sick child to more 'normal life' were enlightening as Ginny seemed to seek out and highlight these normal experiences to share in contrast to the stories of disease and treatment. During this time there is evidence of particularly enthusiastic pleasure in and an insightful gratitude for normal worries and normal successes that came from the knowledge of the power of what the family had gone through.

Ginny wrote frequently and lovingly about Martin. Early in her writing she seemed to make a point of including news about Martin in every entry to combat the concern she expressed about his feeling neglected during Leigh's most intense treatment times. He was twelve when Leigh was diagnosed and is twenty now. His every milestone and achievement was documented and celebrated in the blog. Readers came to know him as well as they seemed to know Leigh, Ginny and Dave. Ginny wrote of pride in him, concern over the neglect he experienced during Leigh's treatment, enjoyment in his company as he grew and changed through adolescence, and the loss she experienced as he left for college. Around the time he turned 19 his car needed repair and he had no job since he attended college full time; so Ginny asked readers for what she called "pay back time" for this cancer sibling who put up with so much over the years. For his

birthday, Ginny asked readers to send cards with a just a couple of dollars to let him know he was appreciated. Readers already had been sending cards and gifts to Leigh and Ginny over the years, so within the context of the author-reader relationship that developed over time, the request made sense. Readers indeed responded, sending food, cards and money in an overwhelming show of affection.

Leigh decided she would like to be an author when she grows up and began contributing reviews of her favorite books for the blog readers to enjoy. Ginny's portrayal of Leigh's orientation toward the future was always positive and upbeat. The summer of 2009 was the first since diagnosis that Leigh had no appointments. Ginny declared this her first "medically liberated" summer. In another event that signified a move away from her identity as "cancer kid," Leigh's application to the summer camp for children with cancer is not accepted, which Ginny understood to mean she reached a "cutoff point" now that she had been there five years in a row.

Ginny eventually decided to preserve Leigh's site as the 'cancer' blog and started a new, second blog for writing about 'normal life' in which her development as a writer is evident. She felt able to set goals for herself again. This time, goals related to singing and songwriting evolved into goals related to writing for publication. As time passed and Leigh remains healthy, Ginny's writing took on a noticeably greater future orientation.

Isabelle

Similar to Ginny's blog, Molly's blog was the synchronized narrative of three stories in the life of a family: the story of Isabelle, Molly's daughter with leukemia; the story of Molly herself; and the story of life with childhood cancer. She relayed the details of Isabelle's cancer, its treatment and the family members' reaction to events, all the while chronicling Isabelle's childhood development. While Isabelle, her illness and its treatment occupied a large portion of the narrative in the early entries, later, Molly shared more about her own life and her reactions to the experience. In the end, the cumulative narrative of the near daily entries resulted in a vibrant and colorful monologue on living with childhood cancer, in this case acute lymphoblastic leukemia (ALL).

In addition to Isabelle and Molly, other important characters of the story were Isabelle's older brother Cole, age four at the time of Isabelle's diagnosis; Isabelle's father and Molly's husband, Jeff; and a host of family and friends, most living nearby. These key figures would be referred to by Molly repeatedly in the blog as "the village." This characterization embodied ever deeper meaning as treatment progressed.

Isabelle was diagnosed with ALL in December 2005 at 22 months. In January 2006, her mother began writing in CarePages, a webpage sponsored by hospitals. CarePages, like CaringBridge and other blog creation websites, give family members the opportunity to create a blog, post pictures and receive messages from readers. Isabelle's mother continued writing throughout her daughter's treatment for and eventual recovery from leukemia. By September 2009, the time of the last blog entry included in this study, Isabelle's treatment was complete and she remained without evidence of disease.

Treatment for leukemia differs from that for neuroblastoma in significant ways [National Cancer Institute (NCI), 2010a]. For children with leukemia, hospital lengths of stay are typically shorter, though they may be equally numerous; side effects of therapy are intense for shorter periods; treatment, delivered mostly on an outpatient basis, has been standardized after decades of clinical trials. Researchers have achieved a long-term event-free survival rate of 80% for children between 1 and 18 years of age (NCI, 2010b). After an intense 2-4 week inpatient stay, the remainder of the first year of treatment for ALL requires frequent outpatient oncology clinic visits. All told, treatment for ALL takes three years. Families live with the ever-present potential for hospitalization for management of treatment side effects.

Many families are told, as Molly wrote, to expect the treatment phase to feel like a ‘rollercoaster.’ While this might be applicable for those types of childhood cancers that involve alternating periods of ‘no evidence of disease’ (NED) and relapse or recurrence, children with ALL typically attain remission early in treatment and spend most of treatment phase disease - free. In truth, for the families in these blogs about life with ALL, the illness trajectory might be better compared to a bungee jump: a fall from a precipitous height followed by smaller and smaller bounces to a soft landing.

What was unique about Isabelle’s CarePage among the other blogs about children with leukemia included in this study was the volume and depth of information included by her mother about personal and family details. The other four included treatment details, requests for prayers and other help, etc., but it was impossible to recreate the whole of family life from the stories shared. Molly’s expansive writing and extensive reflection painted a vivid picture of the family living with and through the illness.

Early in the blog, entries were composed mainly of facts about Isabelle's symptoms, the early signs of alarm that her parents reacted to, and details about location, testing and the management of these symptoms. Entries did not include many introductory personal details. It seemed the author, at least in the early writing, assumed an audience of friends and relatives who were well known to the family. As the narrative expanded from the narrow focus of the illness and its treatment, the reader sensed a recovery of balance and a turn toward a life that had integrated leukemia and the hope for survivorship.

From the early broadcast of the events in the diagnostic and early treatment phase of Isabelle's leukemia, her mother's narrative included stories rich with illustrations, both narrative and photographic. By the end of the blog, entries were not merely intended to announce events, small and large, but expanded to include much more reflection on the series of events that had occurred and the effect of leukemia and its treatment on family life.

Interestingly, Molly composed a few entries she would later describe, with regret and with an apology to readers, as 'pathetic.' Only three or four of these were found in the hundreds of entries over the four years of blogging studied. Each time she stated these came from 'the other journal' or 'a secret journal, kept to record expressions of feelings deemed too personal to share. In one entry she shared feelings of being unable to handle the "torment" she witnessed in other patients' experiences. She told the story of a 16 year old hospital roommate of Isabelle's who moaned, shouted, and then screamed that she did not want to live as she struggled with intense pain. Molly shared this story to illustrate frustration with her feelings of helplessness and the challenge that came when two year old Isabelle asks difficult questions on the subject of pain and sadness.

Molly is a native Southern Californian, raising a family in the same area in which she was raised. Few personal details were included about Isabelle's father, Molly's husband, Jeff. Although she mentioned his work at a restaurant, his role there was not described. Readers learned he is Canadian when Molly wrote that his parents came to town from Toronto, where he grew up. No explicit expressions were found that described their socioeconomic background, but indications of a middle to upper income level could be gleaned from demographic and material details.

Jeff was consistently mentioned as one of the people who took turns staying with Isabelle when she was hospitalized or went to clinic. Many stories were noted about the loving relationships between Jeff and each member of the family. They travelled together, and periodically Molly mentioned a night out, a weekend away or some other special time set aside for just the two of them. Molly described him as her pillar of strength.

Isabelle's brother Cole, older by 2 years and her only sibling, was described by Molly as innately sensitive to the feelings and needs of others. He was often characterized in blog entries as a comfort to his ill sister, especially during hospitalization, bringing a sense of normalcy to the situation. Molly wrote of continually monitoring the emotional state of both children, but especially Cole, for signs that his sister's illness and treatment might be affecting him. She wrote often in early entries about the need for help with attending to both children, with requests that readers "TOC" or "Think of Cole" on particular days.

Molly wrote about her work as a master's prepared special education psychologist in a local public school district. She described work with children with autism as central to her identity before Isabelle's illness. In March 2007, she returned to her office to interview candidates for her position, from which she resigned shortly after diagnosis. Upon seeing her

desk for the first time in 16 months, she found evidence of a life turned upside down: unopened holiday presents on her desk, photos, to-do lists on the bulletin board and other remnants from the days immediately before diagnosis in December 2005.

By the end of the portion of the blog studied, Molly returned to work part time after one attempt to do so about 18 months after diagnosis made her realize she was not yet ready. She cited an inability to concentrate and a lack of empathy for the families with whom she worked as reasons for the unsuccessful attempt at returning to work. Nearly 3 years later, with treatment complete and both children adapting well to life after cancer, she returned to work again. This time she described feeling more confident and better able to concentrate and empathize with students.

Molly identified several strategies for managing the stress and chaos induced by the experience, even in the early days of treatment. She set goals for each week; in some entries she named goals for the next day, or the next clinic visit, etc. She repeatedly referred to writing as an act of self-expression and self-preservation. The significant role played by “the village” in helping her manage stress and maintain a sense of control was clear throughout the narrative.

Molly’s requests for help were specific and direct when she made them. The nature of “the village” made this necessary only occasionally. This was due, at least in part, to Molly’s clear communication in the third blog post about whom to call for updates and with offers of help. She listed names and contact information for individuals from each area of her life: work, family, and what she referred to as mommy-friends and high school-friends.

After the initial hospitalization for diagnosis and the start of treatment, a member of “the village” stayed overnight with Isabelle, alternating nights with Molly and Jeff. At the same time, if Isabelle’s parents were away from home at the hospital or working, the village took care of

Cole. The village became a local mass of support, in word and in action. Over the three years of treatment, Isabelle was hospitalized 21 times and required 57 visits to the outpatient oncology clinic. Molly counted nearly 200 lab draws. Molly regularly informed readers of times likely to induce high stress to solicit companionship for herself or for Cole in her absence. At every visit to the clinic except two, a friend, or family member accompanied Molly and Isabelle.

Molly frequently expressed gratitude to members of the village and other readers. One extraordinary gesture was referred to several times. Early in the treatment phase, a friend volunteered to manage medical insurance communication for the family, a significant burden and source of surplus suffering cited by most families in this study.

One of the ironies described by all the bloggers in the study was the contradictory feelings experienced when treatment ends: a mix of relief and terror. Molly named her fear of relapse “Luke,” the elephant in the room (a play on the word leukemia). In one entry toward the end of treatment, she described her relationship with Luke the elephant. She wrote that she and Luke had learned to coexist and that over time, he was becoming less of a presence in her life. In another entry, Molly referred to Luke when reflecting on how best to manage the children’s questions about leukemia coming back. Luke became a permanent resident of what Molly and other parents referred to as life “AC” or after cancer.

Molly seldom made explicit reference to faith and religion, but on one occasion shared her thoughts on the subject:

I would call my approach to faith, eclectic. Part prayer to a generic God I refuse to name, a standby mantra of “it always ends up working out” and “this too shall pass,” a candle lit, a little hair color, the serenity prayer, a glass of water under my bed, some sage burned, yoga breathing, aromatherapy, mani-pedi, Ambien, sighing, rocking, a reading

here and there from the psychic persuasion, worrying and of course, writing. You put it all together; add supportive friends and family and voila. A recipe for survival! (Isabelle, mother, 12/22/08)

Just once in the 4 years of writing studied, when the number of comments being posted to the blog was lower than usual, Molly called out to readers for more of the messages she had come to count on for support. She was rewarded with a steady rate of response to all her subsequent entries after that. When addressing readers directly, aside from reporting events and family members' reaction to them, she alternated between requests for assistance or prayers and thanks for all the support and for writing.

Ultimately, Molly's blog was a narrative about fortitude, survivorship and personal and family growth. Each blog entry contained some evidence of what the family endured; their methods for coping with the uncertainty, fear and stress; and lessons on the definition and meaning of requesting and receiving support, both in person and in action. In a reflective entry on the third anniversary of the day of diagnosis, Molly summarized Isabelle's diagnostic phase and commanded readers to know the signs of childhood cancer, to insist on answers, to trust instincts and to demand tests be done.

The new normal Molly described at the end of treatment accommodated her fears of relapse and allowed for more frequent joyful occasions. Regular entries in which she reflected on the memories created, evidence of personal growth, and the identity changes that resulted from the experience were posted on significant days. Entries on birthdays, the anniversary of the diagnosis and holidays were particularly poignant, but some evidence for the occurrence of PTSD and posttraumatic growth were found in entries written on routine days when powerful

memories or feelings, sometimes negative, sometimes positive, interrupted the routine of a normal day.

Similar to Leigh's story, Isabelle's was fundamentally about the whole family, about her mother's efforts to cope with the ordeal, and about highlighting the challenges and the joys that are inherent in the experience.

CHAPTER 5

Blog analysis: Diagnostic and early treatment phase

The research question as originally proposed (What themes are evident in the blogs?) proved expansive and daunting during analysis of the illness blogs. One hundred thirty eight narratives in the neuroblastoma blogs in five thematic categories were analyzed. Consistent with narrative methods, redundancy was the limiting factor in the collection of stories for analysis (Riessman, 2008). For this report, narratives were selected that uniquely illustrated the thematic categories identified.

Fifty-eight narratives from the leukemia blogs in the same five thematic categories were identified. The reason the number of stories identified as significant for analysis in the leukemia blogs was lower than for those in the neuroblastoma blogs is twofold. First, the leukemia blogs were shorter overall; and second, stories with similar themes were excluded from analysis at the point of redundancy.

With such a large number of narratives (selected from 15,400 pages of text), many themes were isolated within the stories told. Narratives about stress, uncertainty and identity or life changes predominated, as anticipated in study preparation. Additional thematic categories were identified as well (Table 1). These thematic categories have imbedded in them stories with related themes. Interestingly, narratives of attempts to *manage* the uncertainty and stress; and of the *positive* effects of change were just as prominent. In most of these blogs, regardless of disease type, the use of positive imagery and control of negative thoughts and forces counterbalanced the negative events associated with the illnesses. This cyclical attempt to move toward equilibrium was consistent throughout the narratives as bloggers attempted to maintain balance the ride on the roller coaster that for so many authors represented the illness trajectory.

An additional aspect was underappreciated in the preparatory phase of the research: the performative acts of the authors. Not only did themes become apparent, but questions about the purpose of the writing arose during the reading: Why did the bloggers choose to write? And why write a blog? What were parents trying to accomplish? Explicitly or implicitly, parents answered these questions in their writing. The performative act of blogging itself became an important part of the consideration of the narratives. Examination of thematic elements in isolation from the form and purpose of expression would limit the understanding of the effect of blogging on the family experience (Atkinson, 2009). One hundred fifty-one stories illustrating the performative acts of the authors were identified in the analysis. Fifty-two stories highlighting the performative acts of the parents of children with leukemia were identified. Illustrative narratives on bloggers' purposes will be reported here.

Parent blogs were read through completely once. During a second reading, key narratives were highlighted with notation in the margin using thematic labels. A third reading, this time with concentration on the themes noted, made categorization into smaller groups possible. Each reading was done within the time frames of pre-diagnostic/diagnostic/treatment/off-treatment phases of the child's illness. Originally intended to separate the time during which families described the days before having an official diagnosis, 'prediagnostic' lost its meaning in most of the blogs. In truth, over time, the line between pre-diagnostic and diagnostic phases became blurred to the point that coherence dictated labeling the time as diagnostic.

After the third reading, the performative act of writing by the authors was set aside for consideration in isolation from the themes (Table 1). This analysis will be discussed in Chapter 8.

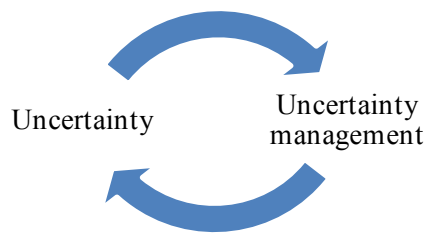
Report of the thematic analysis will proceed in temporal order, beginning in this chapter with the diagnostic phase of the illnesses. Chapters 7 and 8 will depict examples of significant narratives identified in the treatment and off-treatment phases the illnesses. The narratives of thematic categories identified will be reported first. The report of the performative acts identified, with illustrative narratives, will follow. Comparison and contrast of narrative elements of the nine neuroblastoma and five leukemia blogs will be discussed in Chapter 9.

To facilitate reading, minor spelling or typographical errors by the bloggers have been corrected; grammatical errors remain. The authenticity of the authors' narratives was best preserved by presenting full length blog posts in some instances. To aid coherence, formatting of quoted text was made uniform. Identifying information has been eliminated to the degree possible. Where necessary to promote understanding, names were changed as promised in the consent to participate. Each thematic category is introduced by a symbol representing two related themes in the parents' quest for balance. This visual cue aims to ease reading by separating the five thematic categories listed in table 3.

Table 3 *Blog analysis: thematic categories*

The matic categories
Uncertainty/Uncertainty management
Stress/Stress management
Burdens/Gifts
Change/Constants
Private/Public lives

Thematic Categories: Diagnostic phase



Uncertainty

Five of the nine neuroblastoma blogs began after the diagnosis was made, but four blogs began with the story of events immediately preceding the diagnosis. Information about symptoms was included relative to uncertainty and the measures being taken to solve the mystery. Signs of neuroblastoma can be vague, slow to present themselves and difficult to differentiate from symptoms of some of the most common childhood illnesses. Symptoms such as intermittent abdominal and leg pain, especially in very young children, are difficult to monitor and quantify. For some children in these blogs, weeks passed before a definitive diagnosis was known. Parents' writing about this prolonged period of uncertainty included expressions of feelings of unease, panic, shock, disbelief and despair. Descriptions were included of early attempts toward information gathering regarding the illness and treatment.

(Cindy) The history Right before Memorial Day, Cindy started feeling a little under the weather. She had a runny nose, and seemed irritable, so we figured maybe a bug or an ear infection. At this point we thought Cindy had a virus of some sort.... We went through a couple of days of this, went to the doctor, it wasn't an ear infection, and she seemed to get better. A week or so later...our wonderful pediatrician and friend, Dr. D..., didn't find anything obvious going

on, but after listening to Cindy's "owie (sp?) belly" and "owie head" complaints decided to get X-rays done of both. We got the results back and found out that her sinuses were impacted and infected. Finally we figured it out. We got some strange news also. The x-rays showed a calcification in the intestines...Cindy's doctor scheduled an ultrasound of her tummy just to be sure. We would have the ultrasound in about ten days. Unfortunately, that was as fast as it could be done. We got her on some antibiotics and a couple of days later she started to complain of severe tummy pain....We assumed that she might have some problems with the antibiotic so the doctor put her on a new antibiotic a couple of days later....During this period we noticed that she started limping a bit on her right leg but still running around like you would expect of a 2 year old. This occurred over a two day period and we had assumed that she had fallen and she was a bit sore. Cindy told us that her **right** (this becomes significant later) knee was hurting. Friday June 20th, Lesley came home from work for her usual daytime lunch with Cindy. Cindy would not stand and walk. Every time Lesley would try and set Cindy down she would pull her legs back up. Lesley immediately called the doctor and myself and the next thing we knew we had a 1:30 appointment at the doctor's office. The doctor...manipulated Cindy's right hip and she cried out in pain. We convinced Cindy to walk across the floor and noticed her limp was more pronounced. The doctor ordered more tests of Cindy including a hip ultrasound and x-ray....An appointment was made for us later that afternoon at the outpatient clinic and we drove straight there....The doctor called later that night and told us that they were waiting on some of the tests and that we should bring Cindy in at

10:30 the next morning to check out the progress and go over the results. The next morning we got Cindy up, she would not eat breakfast and had no interest in her morning cup of milk with daddy. We went to the doctor's office. [The doctor] called us back into [her] office and there we stood in shock as we learned that Cindy's left (yes, I said left) femur had some inconsistencies. The bone appeared "moth eaten" a characteristic of some type of cancer, perhaps neuroblastoma, or quite possibly a bone infection. Cindy was lying on the carpet underneath my chair rolling around giggling and playing.

We were in shock. Our doctors were wonderful and did a great job breaking some very bad news to a now very sad family. They made every effort to get the ultrasound of her belly immediately but could not convince anyone at that time to come in to do the ultrasound. They let us leave out the doctor's side door as we fought to keep in our tears....Lesley and I put Cindy in the car and turned on her favorite Elmo DVD and we stood at the hood of the car hand in hand bawling. We got in the car and called our family and friends to get help to figure out what to do.

By the time we got home Cindy had fallen asleep for her afternoon nap and we put her in bed. It was a mad dash to the phone book and we called every hospital and clinic that had ultrasound equipment in the metroplex. Each one was either closed or the radiologist was on call and would only see patients admitted to the ER. My mom...came over, and together with the advice of friends and doctors, and we devised a plan.

When Cindy woke up we did not feed her or offer her anything to drink. We drove her straight to the ER and told her over and over that her tummy had an owie in the hope that she would repeat it to the ER nurse. We knew we had an emergency but we did not know how to get her past the nurse. Luckily, when we got there Cindy was in clear discomfort and agitated. We got past the ER nurse and waited another hour or two to meet with ER doctor. It is almost funny now but once I mentioned "moth-eaten" bone to the doctor it became a flurry of activity. Phone calls were made, doctors were consulted, tests were ordered and at 11:30 Saturday night Cindy was admitted to the Oncology Department.... I want to point out at this moment that it was Cindy's pediatrician... that helped us get this resolved so quickly. For that we are extremely thankful. We now knew we were most likely dealing with neuroblastoma, or possibly lymphoma, but we would wait to see what our new oncologist would say.

The BLURRRR

The next few days followed with x-rays, bone scans, CT scans, blood tests, urine tests, biopsies and the usual rounds of pokes and prods. Some were hard for Cindy - like the x-ray machine and bone scan. But many were ok for Cindy - like the CT scan (or Cindy tunnel) and the blood pressure machine (hug machine). Overall she was pretty resilient. It was all of this that led to her final diagnosis (Cindy, father, retrieved 10/16/09).

Uncertainty management

Writing in the diagnostic phase broadcast clinical information and requests for prayers or help to family members and others quickly and efficiently. Parents expressed an awareness of

the need for family and friends to know about illness events. Plans for short term management of the illness and for the care of siblings and other family concerns were noted. Posts during this time were brief but frequent, often twice or more per day to report on the diagnosis; results; surgery progress; pathology; and the degree of metastasis, if present. The burden of delivering bad news to readers was also evident in the writing, as when “odds of survival” were reported.

Cindy (diagnosis) Cindy has been diagnosed with Stage 4 Neuroblastoma, High Risk (more information on the Neuroblastoma page). While this is a really nasty cancer, it has been well researched and documented over the last couple of decades. She has a primary mass of Neuroblastoma tumor in her abdomen (3” x 6”) with metastasis (spread) to her left femur, and the tip of her right shoulder and two lower vertebrae show as “hot spots” with a bone scan (no evidence on x-ray). Her bone marrow was tested and also shows evidence of cancer. Once more test is pending that may show more evidence of cancer.

I realize this all sounds very nasty but there is good news. Neuroblastoma is incredibly receptive to chemotherapy. People are beating it everyday. It goes to show that the right combination of love, prayer, wisdom and medicine can make miracles happen.

Remember, you are reading the beginning of one of the greatest success stories of our time.....(Cindy, father, retrieved 10/16/09)

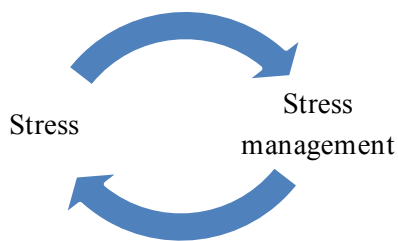
Emphasis on descriptions of events and the medical management plan at this stage of the illness seem to be the most prevalent means of uncertainty management expressed by parents.

Business plan The biopsy on Tony's tumor and bone marrow came back positive for Neuroblastoma, so the chemotherapy treatment started right away. (This is a treatable cancer.) His protocol (treatment schedule) is a 21 day cycle: 3 days of chemo, 18 days off, then start again. The 21 day cycle is the *ideal* schedule, but cannot be followed if Tony is sick, has low blood counts, or has any sort of infection. We have to be flexible! During March/April Tony will be admitted to the hospital for 45-60 days for a radiation treatment and stem cell replacement. Chemo will pick up again following that and will continue through Dec 2005. Hopefully Tony's cancer will then be GONE!...How are we doing? I know that's the question on everyone's lips. We're doing fine... as fine as any family can be when faced with a life threatening disease. I've told this to a few of my friends, but I'd like to share it with everyone: when you *think* about something like this happening to your child your mind plays the "what if?" game over and over, and you go through all kinds of scenarios and make yourself crazy. But now that I'm that mom with the child who has cancer, I've found that instead of doing "what if?" I think my mind has made this into almost a business plan. There are a series of things that have to be done in order to get Tony cancer free. And that is the goal and the primary focus. There is no time for "what if?" and there's no place for it. It's as simple as that (Tony, mother, 11/13/04).

The chaos of managing life with childhood cancer, especially in the early days posed a challenge to a sense of control in parents used to planning.

Living with pencils ...the case manager here on our unit said we were going to have to start living one day at a time. Sometimes one hour at a time. This is going to be hard for

me the habitual planner and even Jason who loves to have planned out things like vacations years in advance. However I think it will be a great life lesson for all of us to live in the moment. The past two weeks have already shown us what is truly important in life. We focus on so many details while what is really important is the loved ones in our lives. So pens are to be thrown out. We will live with pencils. And try to live one day at a time. Please pray for us. This is going to hard (Lucy, mother, 12/13/08).



Stress

During the diagnostic phase, stress was found to be multifactorial in the blogs. Waiting for the relief of the child's discomfort; results of scans and tests; and the diagnosis itself also induced stress. Descriptions of feeling overwhelmed and isolated from the rest of the world were found.

How are you? Ginny and I got a two and a half hour break when my folks came tonight. We went out to eat and to the mall. It was good to get away from "it." We strolled and held hands, the very picture of yuppiness, but inside something has changed. As I wandered through the fancy stores perky sales persons would approach me saying: "how are you?" I came very close a couple of times to shouting "my daughter has cancer, and you?!" Fortunately my mother (and my wife) taught me a few social graces, so good sense prevailed. I told Ginny about it

and she said "it's good that you controlled yourself, others don't deserve to be punished just because you are hurting." What an incredible, wise lady God has given me (Leigh, father, 5/28/02).

Waiting: It is 9:15pm and we still haven't heard from the oncologist regarding the results of the MIBG scans over the past 3 days. We have called the "on call" service two times and the farthest we got was speaking with the on call doctor who had no clue what was going on with Jeremy. We want the results of this test...we were told we would be called tonight not only for results, but to have the plan for Monday. The waiting is agonizing, frustrating, and really unfair. Add this to the stress of having to watch Jeremy endure another scan today without sedation. Although painless for him physically, he cries throughout the whole scan unaware of why he is being strapped down and put into a confining tube. As you can tell, spirits are low tonight. He is still up and upset at this hour, he has only slept about 1 hour all day. He is agitated, overtired, and is experiencing painful constipation....Our little world is so vastly different than what it was just two weeks ago. That is difficult for me...I'm overwhelmed by everything and just keeping praying "strength for today God and hope for tomorrow." (Jeremy, mother, 1/30/09)

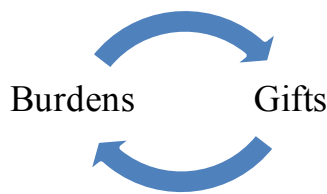
Stress management

In the blogs, managing the stress of the diagnostic period was centered on making and adjusting to a specific plan, often set by the medical team. Parents who prided themselves on not needing help were forced to recognize the need to accept help from a variety of sources.

Seeking/accepting help: We are currently trying to put together support "teams" to organize groups for the many areas for which we need help. Walt put it best when he said that he is learning to swallow his pride and accept help. We are graciously accepting help on behalf of our children (Jeremy, mother, 1/26/09).

Focus on the plan permitted a feeling regained balance and control in an otherwise out of control time. Information seeking regarding the illness and its treatment became a chief priority for one or both parents, although this often induced more stress as the ominous nature of the prognosis became clear.

A plan to keep him motivated It has been a rough week for Dman. He is getting tired of all of the medicines and pains that come along with low counts and fevers. He will be getting more platelets today, they gave him blood again yesterday. Danny has helped us come up with a plan to keep him motivated to get through all of the treatments that he will have to face. After he is done with all of this, including NYC and the monoclonal antibody treatments, he wants to learn how to snow ski. Fortunately for him, I grew up skiing in PA and somehow managed to ski for about 20 years without doing any major damage to myself or anyone else. So, we will hopefully be able to keep him focused on the job at hand, and when the going gets tough, we will talk about the snow, skiing, and how much fun it will be (Danny, father, 7/18/02).



Burdens

Narratives of the burdens of the uncertainty before and during the time the diagnosis is being made were found to center on feelings of disbelief, uncertainty and a profound shift in perspective. In a blog post created to relay the events of the first days of diagnosis and treatment, one mother reflected on receiving and trying to make meaning of information.

A complete lifestyle change We also officially started chemo today. They did a dose of Vincristine and Dexamethasone. Both of them work on killing the Leukemia cells. We also got what they call our road map for the next month. It is basically the schedule of what chemos they do on what days. The treatment for Leukemia is very different than how I have always thought of cancer treatment. Here is the very basic breakdown... It is a complete lifestyle change. However, today after a rough morning for Jason and I the cloud began to lift a little and we started to see a little more clearly and actually hear and understand the doctors more.... I know it sounds nuts but I really kept waiting for someone to walk in and tell us the annoying med student screwed up our blood work and she didn't really have leukemia. That instead it was a cold and to go home, cuddle on the couch and she would be as good as new in a couple of days. But that never happened.... We signed off on the release feeling it is important to find a way to stop this disease. It was a 9 page book practically that they went over and had to be signed. It sounded a little

bit like "WAA WAA WAH big word I didn't understand WAA WAA WAH please initial here" - they just had to be talking about someone else's child was all that I could think.

Dr. P... told us that she would keep repeating all the info until it made sense. She said a big part of this hospital stay was education in addition to treating Lucy. She promised they would take it all in baby steps and before long we would be rattling off the big words too. She really is wonderful (Lucy, mother, 12/3/08).

Acceptance of the illness was seen to occur gradually, as reflected in this post, created shortly after coming home from the hospital for the first time since diagnosis:

It breaks my heart While it has been great to be home, I think it has sunk into us today how long this journey will be, probably not all the way, but more than earlier. We placed as such a huge milestone on coming home from the hospital, as if once we got home everything would be good, but really it is just day 16 of her journey through chemo. As I watched her struggle today with the side effects all I could think of was there was no way to take this away from her. I couldn't promise to make it better or stop it, all I can do is hold her and console her. That sucks. I want to promise her next week she will want to go outside and play when it is beautiful like it was today. How do I explain to a 7 year old that it will stop but not till after she turns 10 and even then she will be followed for years. There were several times today when she also showed signs of knowing how long this process will be and it breaks my heart. I realize there will be days where she is feeling a lot better, however right now they seem so far away (Lucy, mother, 12/20/08).

Gifts

Even in what parents described later as the most stressful time of the illness, burdens were countered with an emphasis on positive thoughts. The assurances of support from family

and friends through prayer, presence and in material ways; the actions and caring behaviors of the healthcare team and even for fateful events that led to diagnosis sooner than later were all counted as blessings.

God's grace It is IMPOSSIBLE to look back on the events of the last month and not see God's grace sprinkled throughout this journey. With each day's events, I can't help but find incredible encouragement in the assuredness of God's grace from scripture, but how amazing to see it working in our lives. We are desperately trying to cling to this as we continually deal with feelings of sadness, anger, fear, and doubt. I wanted to share with all of you some of these miracles as a witness to God and His grace:

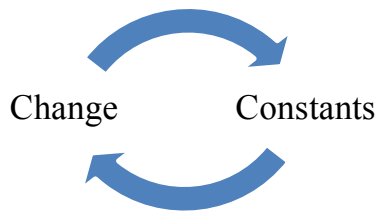
1. After our Dec23rd appt with the developmental specialist, Jeremy was given a diagnosis of cerebral palsy. The doctor set us up with an appointment for an MRI of JUST Jeremy's head for Jan21st. As the weeks went on and Walt and I studied more about CP, it just didn't seem like Jeremy. We both had an instinct that this was not what was wrong with Jeremy. I felt compelled to call the doctor and ask that they also do an MRI of the spine. The secretary was VERY reluctant to even ask the doctor, she told me several times it was not going to show anything for a kid with CP. I persisted. I called back two times and finally she agreed to run it by the doctor. They finally said they would do it if the insurance would okay it.
2. Up until Jan1st, we had Univera insurance. The first time the doctor submitted just the brain MRI to the insurance, they denied it. After Jan1st, we had to switch to Preferred Care. At this point, they submitted the request for both the brain and spine. We were okayed without any problem for both tests.

3. It is unimaginably horrifying to think of what would have happened if #1 and #2 above hadn't happened. We have been told that the tumor on Jeremy's spine could have caused paralysis at anytime. Had we not insisted that the spine be captured by an MRI, we would have never known about the cancer....If we hadn't switched insurances, we would not have been able to get the spine MRI done, at least not for quite sometime.

It is impossible for us not to see our God at work in Jeremy's life. It is easy for us to be mad, we are mad. It is easy for us to be scared out of our minds, at times we are paralyzed by fear. But, we are committed to seeing God's grace in Jeremy's life and to share that with others. May he be a living testimony of God's goodness that is available for all who believe (Jeremy, mother, 1/26/09).

Another mother reported events while highlighting the encouraging news shared in all the leukemia blogs at some point: that if a child has to get cancer, this is the one to get.

The best cancer to have Once they took the blood and tested it - it was confirmed that she has ALL or Acute Lymphoblastic Leukemia. This is the best cancer to have if you are going to have any cancer. It is the most treatable and most successful. It is also in her favor that she is a girl and between the ages of 2-10. After this was confirmed and pinpointed down to ALL she had to go into surgery to place a port in her chest, this will be where all of her chemotherapy will go through. She also had a spinal tap, to see if it was clear and that no leukemia was invading her central nervous system (brain), it was clear! After all of this was done Courtney went to recovery. Soon after she had to go and get an EKG of her heart to see how it measured before we started chemo....(Courtney, mother, 9/9/06).



Change

Narratives of change during the diagnostic period included both positive and negative elements. Work and child care changes sometimes necessitated a realignment of living arrangements and financial priorities. Medical insurance became a prime factor in decisions regarding changes in parent work; mothers remained with the ill child; risk for infection precluded attendance at child care centers; and siblings were affected by the upset to the balance of daily life.

Appreciation for the newly found time to spend with the ill child was expressed. A renewed sense of the parents' meaning to the child and family was evident in some blogs.

My new ministry In the past 8 days or so, I've only been away from her about 5 hours. I told Dave, "Leigh is my new ministry." While it seems very strange to not be on a church platform, or traveling, singing, writing, ministering in churches, etc. I view this "ministry chapter" as every bit as important. For example, when she was in the holding room before surgery last Tuesday, I was sitting in a wheelchair with her on my lap, comforting her as she cried. One of the attendants put a warm blanket over us and as he did, I began quietly singing my song, "Like A Blanket" to her. As I heard her crying stop I thought of all the hundreds of times I'd sung that song to many congregations all over the country. But I knew

that there was never an audience more important or special as that little audience of one. It is a privilege to minister to her (Leigh, mother, 5/26/02).

At the same time, change also meant a reordering of priorities that placed the children, ill and well, at the center of decision making.

How cancer changes things It's amazing how cancer changes things. I remember (with regret) times when we were back in the trailer, on the road, always frantic, always going and Leigh would say, "Mommy, will you play with me? Mommy, will you read to me?" There were a good number of times I did that but there were many other times when the laundry to be done, the song to be written, the letter to be typed and the errands to be run called my name so loud that I neglected the important in order to do the urgent. When she and I are tucked into that bed together, and all the wires and medical equipment are casting their scary shadow of uncertainty over our future together, storytime becomes more than a book read together-- storytime becomes sacred time. Every moment, every word, every breath is precious--not just for a family with cancer but for every family, everywhere (Leigh, mother, 6/11/02).

The change most frequently noted in the writing was described as living a 'new normal' life, manifested similarly in each blog, at each phase.

New normal Adjusting to life during treatment...dad back to work...living in pencil Well, today is the first day of some new normalcy. Jason started back to work today. His company has been so great in working with him through the initial stage. We are so lucky to not have the concerns that so many families do about work. Also, Abbie is off to school. So Lucy and I are home alone and my goal is to try and get some sort of schedule

in place. The case worker at [the hospital] chuckled yesterday when I mentioned that and reminded me to do it in pencil, however I'm pretty flexible and don't get too stressed by change, so we will see how it goes (Lucy, mother, 1/8/09).

Constants

Writing about those values, characteristics and abilities that remained constant through the early period of stressful change seemed to bring reassurance and comfort. A steadfast belief in the child's mission and purpose, based in faith, was found in the writing. Even early in the illness, gratitude became the cornerstone for seeing a way forward through the challenges ahead.

A big task at a young age Mimi is very strong in God's eyes, to be given such a big task at such a young age. I can only imagine what God has in store for her in her years to come!!! We have so much to be thankful for in this situation. We are blessed with a great support system, not only in each other but also with our friends and family (and the outpour of support from strangers too!). We will not have to explain to our crying daughter why her friends can't come over, or why they cannot come visit her because they are sick. We will not have to see her cry because she is too tired and weak to ride her bike down the sidewalk. And, we will not have to explain to her why her hair is thinning and falling out. Nor will we have to try to help her understand why some people just do not understand what it is like to be sick. God bless the parents who have had to do these things, I am not sure I would be strong enough (Mimi, mother, 3/27/07).

Performative Acts: Diagnostic phase

The activities in which authors participate in the act of blogging were separated conceptually to answer a question raised repeatedly in the analysis, i.e. why did the author write?

Table 4 lists the main functions identified.

Table 4 *Blog analysis: Performative acts*

Performative acts
Reflection
Reporting
Expression
Advocating
Archiving
Explanation

Reflection

The frenetic activity of the diagnostic phase seems to have left little time for reflection by the parents in these blogs. Indeed, reflection seems to elicit feelings of despair and fear to the point that some parents settle into a practice of taking things one day at a time, even one minute at a time.

Managing identity change Today I started to get just a little claustrophobic and panic stricken, looking at my future and what it holds. I just see countless days and weeks and months in a hospital; my days of travel and ministry and music and writing (where I've gotten so much of my identity and worth) are like echoes from another world. In this new world that God has put me in I've decided to stop taking things a day at a time and have begun to just take them a minute at a time (Leigh, mother, 6/11/02).

Reporting

The blogs were full of reporting on events at this stage. Communication of information seems to be the main purpose of writing at this time as results and treatment details remained the

focus. Events of the day and the child's or parents' reaction to them predominated. Also included were descriptions of the parents' attempts to integrate the illness into their lives.

Finally diagnosed ... We have been through a whirlwind of events since I last emailed (oct. 27) so let me get you updated if you're not on my Mom's list!...Know that we all are actually doing well under the circumstances.

Tony was finally diagnosed around Friday with a rare childhood cancer called Nueroblastoma. All of the sickness he has displayed since (we think) last April from colds to constipation to fevers, etc. were caused by this cancer. It is very difficult to diagnose due to the symptoms up until it really displays itself with fever, limping, anemia. Tony had a blood transfusion, bone scan, CTscan, MRI, several blood tests, urine test, xrays, and heart ultrasound in the course of three days to determine his illness. It's been crazy.

Tony underwent a surgical biopsy, cathider placement and bone marrow biopsy this morning. Everything went exactly the way it should have. (Thank you for your prayers!) Tony came out of surgery around 11:00...He's very exhausted, but doing great. Little trooper! The biopsy will be read by pathology and his diagnosis will most likely be confirmed as Neuroblastoma sometime tomorrow.

As soon as the diagonsis is confirmed Tony will start chemotherapy treatment (like tomorrow). We have a schedule from Tony's Oncologist, Dr. Moody, that outlines his chemo treatments and other procedures through December 2005. Dr. Moody has been very frank when it comes to Tony's diagnosis and we have every confidence in her and the plan for Tony's fight against this cancer. She is familiar with this cancer and has treated it many times before. We were even able to meet

a 16 month old boy. ..., just down the hall from Tony who is going through treatment right now for this cancer. He looks great and is doing well.

We are scheduled to come home hopefully on Friday if everything goes right with his first chemo treatment. (I feel like I'm writing this as a third person. It's all very surreal.)

I'm tired and need a good nights' sleep. Again, Thank you for your prayers, your thoughts, your generosity. We can't Thank you all individually right now, but know that you are all keeping us strong and will continue to do so as Tony fights the big fight through next year. As always, we'll keep you all updated (Tony, mother, 11/2/04).

One parent illustrated the importance of attending to the child's powerlessness and integrity in an entry about pain control.

She is in control So yesterday started out rough. They finally got her a morphine pump which she can control the pain meds she is getting. This has been fabulous. Before she would get meds that would knock her out for an hour, then she would be great for about an hour and then she would hurt waiting for more for 2 hours. Now she is getting a lower dose, which makes her more alert, but she is getting it at a more regular basis. Most importantly though she is in control.

Those of you who know Lucy well know that this is VERY important to her. She is very much one who likes to organize and control things. All the time she is organizing things at home and taking charge. Sometimes it is a very sweet quality and sometimes it has been a challenging quality. Many times when we have butted heads in the past (and there have been a couple) I have reminded myself that the streak of independence and being

strong willed will serve her well in the future, even if it did mean sometimes it made life a little hard now. I just never expected her to need it this soon in life.

However, I have realized over the past day how much it is important that she has control. Especially when so much is out of her control. It is hard for me to give up some of it as her mother since I want to take care of her. Also, I believe she may have inherited some of that quality from her mother. (OK, I admit she has inherited A LOT of the quality from her mother. Are you happy mom and dad? I admit it.) But when she has exerted that control it has helped tremendously (Lucy, mother, 12/5/08).

Entries from the mother, whose stated intention all through the years of subsequent blogging was solely to inform, included a story with a high level of detail.

This has not been a fun month Amelia had her 4th chemo treatment on Wednesday, February 22nd. The results from the bone marrow test she had done on Feb. 15th showed that she is in remission from the bone marrow. She will get another bone marrow test and spinal tap test on Wednesday, March 1st to make sure she is in remission at a molecular level. They expect she will be and then she can enter her next phase of treatment. This is an "induced remission" she is in. Her blood sugar levels are still high so we are treating her for diabetes. We have to check her blood sugar levels 4 times a day and then give her 2 insulin shots a day. She does not like this. Hopefully the diabetes is a side effect from the steroid she is on this month. She will be able to stop the steroid next week and then we will be able to know more. The steroid also makes her eat a TON and gives her mood swings. Needless to say, this has not been a fun month. But we are getting through it and Amelia is being a trooper. We are all confident that things will only continue to get better (Amelia, mother, 1/23/06).

Expression

During the diagnostic phase, expressions of frustration, shock, sadness and powerlessness predominate in the parent blogs. Feeling torn between work and home; among meeting the needs of spouse, ill child and other children; between watching the child endure the pain of procedures and the need to obtain results, all found expression in the parents' writing.

Sadness; 'Keeping it real' I would be lying to you all if I wrote tonight and told you all of my positive outlook, my sense of peace about this whole thing...So, I'm keeping it real here. I feel sad, sad from the top of my head to the tips of my toes. I feel scared, scared beyond anything I could have ever imagined. I feel torn, torn between my home, my family and the hospital and the battle ahead. I always said that when Allie was born, just 3 months ago, that my heart now was made up of 4 pieces. One of the pieces of my heart is sick, and I hate the fact that I can't just pick him up and make it better.

That is the real me right now. That being said, a good friend told me today that despite all the bad that surrounds us right now, God's promises for us don't change!...The MOST important thing anyone can do for Jeremy is PRAY!!! We pray for small things like safe travel, help with each procedure, guidance for the doctors. We pray for HUGE things, like total healing for Jeremy. Please join us in praying for Jeremy...(Jeremy, mother, 2/1/09)

A father expressed frustration with insurance coverage and other financial pressures.

Helps to vent I spent three exhausting hours with the financial aid people and a social worker. It felt like a proctological exam (Ginny did not edit this letter!) in letting them see into all of our personal business affairs. They said that middle

class people who pay their bills and keep low credit card debt get hit the worst in times like these...bingo. Our insurance does not cover any out patient visits or outpatient medicine. The costs could overwhelm our middle class lifestyle. The financial aid people are trying to get some assistance for us from medicaid and social security. Please pray with us for wisdom, favor and patience as we deal with the agencies. Please know that I am not fishing for donations in writing this. It is all part of the grief of this journey and it helps just to vent it in a letter (Leigh, father, 5/28/02).

Normal life came to be compared to a roller coaster by these bloggers, some of whom shared internalizing this from discussions with healthcare providers. This mother of a child with leukemia likened life with childhood cancer to a yo-yo.

Sorry for the somber display of emotions Well, her ANC is 3500. Way high enough to go ahead with chemo tomorrow and you would think I would be happy or relieved. If her ANC were not high enough I know I would be disappointed. Yet, I sit here downtrodden and disappointed. I would be lying to say I'm not. I know she needs this last 4 weeks in her system and I know the sooner we start, the sooner it's over with, but still I ache. It may not make sense to you, but knowing what's in store for her tomorrow makes me sick. And you get greedy for a few more days of normalcy before the storm hits. She's perfectly potty trained since she came home from the hospital, walking better, jogging a bit, riding her pink trike, best of spirits and then. . .

I'm being negative, but at least I know it. Sorry for the somber display of emotions. Thank God the worst of this is almost done. The yo-yo ride is making me nauseous (Isabelle, mother, 1/24/07).

For some parents, faith brought meaning to life with childhood cancer. One mother wrote nearly every day of the more than three year experience. At the start of each of these entries, she included a verse from the Bible or other inspirational text that exemplified her feelings or the provided inspiration in dealing with the events she went to report. For her, the blog was a place to post prayers as well.

Amen Please Lord Jesus save my son from leukemia make his body well, keep him from pain--show us a mighty miracle. Please I beg you to put his leukemia into remission.

Help my little boy rest tonight, snuggled up in your out stretched arms. Please give us all a peace that surpasses all understanding. In JESUS name- Amen (Kevin, 6/29/07)!!

She also identified Jesus as “the Great Physician,” a reference made by several parent bloggers. In fact, this mother placed Jesus in the position of influencing the computer that would decide the child’s randomization in the treatment protocol.

God’s role in randomization On the 18th we go into PICU for the big round of Chemo, Spinal Tap and Bone Marrow Biopsy. Once this is completed all of the tests will be sent to the Children's Oncology Group. We should find out what treatment group we will be placed in on or about the 24th of July. This is called Randomization. It is suppose to be decided by the computer.

OK--whatever. WE KNOW GOD HAS ALREADY DECIDED WHAT GROUP KEVIN NEEDS TO BE IN AND JESUS WILL TELL THE COMPUTER WHAT TO PICK!!!!Praise God that we believe in HIM and not a computer!!! (Kevin, mother, 7/11/07)

Archive

Many parents expressed the intention to preserve the experience by preserve their writing; for some, to remember events and for others, to give to the child later in life. This extended, vivid retelling of a mother-daughter discussion powerfully illustrates the stress both individuals endure.

To share and to make a book I don't have any medical news, but I wanted to share the most heartfelt conversation that Lucy and I had last night and the reason I can not sleep. I plan to eventually print off all of these journals and make a book for Lucy to chronicle her journey and don't want to leave this out. However, also this is probably not something great for those friends of hers that read the posts so parents, please read first and decide if you really think your child needs to know this or can handle it.

...Last night we had a very sincere conversation where she shared with me how much she had really thought about all of this. We were discussing Bryson next door. He is a little boy that Lucy has never met. They are both on restrictions and can't leave their rooms....So, Lucy and I were talking about the fact he is a big Mario Kart fan like her and they even make a Wii version of Mario Kart....I was telling her that he would possibly be off restrictions soon and maybe they could play....She was excited and then asked "Is he bald?" I matter a factly said "yes". She nodded and we went back to discussing the Mario Kart.

She then told me about how she knew she could die from leukemia. She said she also knew she wouldn't die, but that kids do die from this. She said that she is so glad that her heart didn't break in half at the beginning and her bones didn't break, because then she would really die. (She had always described the pain in her bones as they were breaking

and one night she had horrible chest pain.) She was so matter of fact about the whole thing. Very sincere! She told me she was glad she was at [this hospital] since at some hospitals she would probably be dead. She said at least here they cared about her and asked her questions. I think she is referring to her visit to [a local hospital]. She has commented several times about how they didn't listen and almost laughed at her. Which they sort of did.

She said she knew she was going to have to fight hard and couldn't wait till she could have energy to run with her friends and play. She said she just wanted to be ME again!! My heart was breaking, but we just sat and quietly discussed that she wasn't going to die. That it would be a long fight but she was still her and not someone else. She talked all about the fact that though we talk about a garden it is really cells she needs. She even could tell me all about which ones. I talked to her about why she was so tired all the time right now. It was amazing how much she knew.

Then we talked about her hair. She is so beautiful. It is tough on her. She said she is ok with losing it if she can kill the leukemia, but she said she was concerned that people would laugh at her. She talked about that some kids are bullies and would say stuff even if it wasn't nice and they shouldn't....She said she wants to get a wig, but is scared it will fall off and people will laugh. I told her she could wear hats too, but she is still scared Mr. Jordan won't let her. At one point she said that maybe she would get like the kids here and just go bald. She said everyone would laugh but that she could try. I didn't know what to say. Other than that she would be beautiful either way. She told me I had to say that because I was her mom. So she asked that when we get out of here we get a wig

lined up early so she doesn't have to worry about it. They have given me all the resources but I was dreading doing this. However I will now get it lined up immediately.

She is also so concerned she is going to lose her good friends. She said that she knew people wanted to come see her now but she said she didn't think they would once she didn't have hair and was sicker. She has even noticed though she is confined to her room with the door shut that most of the other patients on this floor get a lot fewer visitors than she does. She is scared her friends will decide this is too much. I told her that her true friends won't do that. I found it hard to tell her the life lesson we all learn eventually but much later than 7 and that is that true friends will stick beside you through thick and thin and those people may not be the ones she considers her best friends now. She said she knew that but she still wants her best friends now. It was interesting how much she knew which friends were having a hard time dealing with this and may not be able to handle it long term. It was also interesting how she said some people are sending her stuff right now but won't be there in a couple of months....The whole conversation was so touching and insightful. I have always known Lucy was a very deep thinker and I am so happy she shared with me what she was thinking. I have laid awake most of the night overwhelmed with the conversation. At 33 I have never dealt with issues such as these and to think a 7 year old is processing it and dealing with it breaks my heart. Also, it kills me that all I can do is tell her that we are in this together and that I will be here through everything to make it as easy as possible. She touched me when she said. "Mom, I know you will never leave me!"

She also wanted details of what life will be like at home. What clinic would be like?

What meds she would have to take? She wants to go home by Christmas but said she

knows she may not and was ok with that. I told her Santa would find her and she said she wasn't worried as long as we were here.

What a brave little girl she is! I love her so much and wish I could take it all away.

Sorry I unloaded this morning but I just wanted to share what an insightful and brave 7 year old I have. (Lucy, mother, 12/14/08)

Explanation

At the time parents begin writing, they explain several aspects of the illness experience: the purpose of the blog, which evolved with the illness experience itself; the specific needs they have that readers might be able to meet, especially prayer requests for specific events or results to occur; and the types of and reasons for the many tests and procedures that the child experiences.

Blog purpose 1: for the author; for other parents; and for Cindy at 18 Hello and welcome to my diary. I think I should probably offer a disclaimer to those of you who do not know me very well. I am irreverent, sometimes egotistical and most definitely sarcastic but ultimately I am a normal average human being. I have three purposes for this diary. First, this is therapeutic for me. It allows me to get out my feelings and deal with my own pain. As a result, I am better prepared to care for Cindy, to care for my wife and to care for my family. Secondly, as a parent of a child with cancer it is my hope that this may help other parents in the same situation. I know that I am searching for the “right” way to feel and I am beginning to understand that there is no such thing. For you other parents I hope you find some comfort in my words and feelings knowing that there is someone out there that feels the way you do. Lastly, this is my gift to Cindy on her

eighteenth birthday.

I will write how I feel and what I think. It won't be appropriate or polished and definitely not politically correct. I have no intention of swaying opinions or influencing people. It is my words and how I feel. It might make you happy. It might make you sad. Knowing me, it might even make you mad. But it will make me feel better and hopefully it will give me the strength to deal with my own pain. At this point I really don't want to discuss this diary. I don't want to know that you are reading it. It is still a little too personal and close. So please do not talk to me about it but if it makes you feel better then I am glad.

So here we go.....(Cindy, father, 6/21/03)

Blog purpose 2: to keep family and friends up to date I've been saying I'm going to do it for a while, and tonight I finally am starting! Blogging...I'm certainly no expert at this, but I think it is an important thing for me to do. This blog will keep friends and family up to date on Jeremy's progress. It seems clear that we have a long road ahead of us as we seek out a diagnosis, prognosis, and treatment for Jeremy. You will be able to check in on how things are going by reading my posts. Even more importantly, Walt and I believe in the power of prayer! For that reason I will be giving specific requests for prayer. Please pray for Jeremy! We know that God loves him even more than we do (thanks Julie for reminding me of that) and that He is holding Jeremy in the palm of His hand (Jeremy, mother, 1/14/09).

Early frustration was evident in this entry from the mother of child diagnosed a week earlier who uses the roller coaster metaphor for illustration.

Roller coaster A couple of days ago, Dr. M... sat down and explained that the treatment of cancer is a Roller Coaster. He said the goal was to try and keep the highs and lows from going to one extreme or the other. We haven't found that balance yet, however today was very much a roller coaster.

Abbie is feeling much better, but not good enough to go to school. So she went to a neighbors to play so Dave could come stay with Lucy and I. Which I needed. I was falling apart. Needless to say this morning was AWFUL. Lucy felt like crap. I woke up feeling awful and down and it went down hill from there. A lot of the emotions of this disease hit this morning. I was tired and looking at we are on day 6 of chemo treatments and we need to get to over 800 was depressing. In addition, Lucy seemed depressed. She spent most of the morning either asleep or with a blanket over her head. She REFUSED to take her medicine for over 5 hours. She cried, she was in pain. It was horrible. I was also having a hard time pulling it together. I was mad. Really mad. I realized that though this maybe a great hospital I HATED IT HERE! Lucy and I wanted to go home. We wanted to rewind a week and go back to being a normal kid. Enough of my pity party but it was a big pity party. I told Jason earlier he was going to have to write tonight because all I was going to be able to say was CANCER SUCKS!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

(Lucy, mother, 12/8/08)

The same mother finds understanding in the other metaphor offered by the physician, that of a garden in need of weeding. In subsequent posts, the mother returns to the metaphor to use as a measure of perceived progress.

Weeds in the garden ...[The physician] compared this to a garden being overtaken by weeds. He said that the weed start overtaking the garden and then kill all the flowers and

anything in it. So the process of chemo will be to kill the weeds completely out of the garden and to then let flowers grow. We just have to make sure we keep the weeds out completely.

So basically we have a group of unruly teenagers that keep inviting their no good crazy teenage friends over to party. They have destroyed the house. We now are going to have to kick them out and make them GROW UP!!!!!! I always knew I was dreading the teenage years and now we get to deal with them sooner. And I will admit I LOVE THE ANALOGY!!!!

I also love the idea of a garden....we are going to make sure her garden grows only the most beautiful weed free garden of Lilies. :) So he was wonderful and comforting (Lucy, mother, 12/3/08).

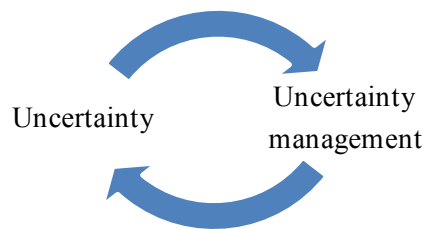
As the treatment progressed, the writing seemed to take on more and different meaning. In the next chapter, discussion of the thematic categories and performative actions of the authors are examined in the context of life during the child's cancer treatment.

CHAPTER 6

Blog analysis: Treatment phase

The thematic analysis of parent writing about life during the child's therapy found the authors continuing the quest for balance between the elements of the thematic categories: uncertainty/uncertainty management; stress/stress management; burdens/gifts; and change/constants. Analysis of narratives written during treatment rendered another thematic category: seeking a balance between maintaining a sense of privacy and the newly acquired public relationships with readers.

The matic categories



Uncertainty

Despite the long illness trajectory of neuroblastoma, parents wrote that it was impossible to “get used to” the uncertainty. Even when parents described having accepted and adjusted to the plan, the uncertainty caused by repeated treatment interruptions or delays due to unexpected adverse effects or prolonged myelosuppression caused fear of disease progression and death.

The not knowing Two days ago, I was getting ready to take her to the hospital for her checkup as well as to see if they had any more news about her recent symptoms.....Suddenly it occurred to me that I hadn't yet gotten Leigh's blanket (it ALWAYS accompanies us to the hospital) so I went to her room and retrieved

it from her bed. When I carried it out to the kitchen, she stopped chewing her Wheaties and was quiet for a moment before requesting rather matter-of-factly, “Mom, when I die will you please put blankey in my grave with me?” I froze for a moment and then did my best to put on a calm smile and said, “Is that what you’d like, Leigh?” “Yup” she replied, and went back to her cereal bowl. Is this the long good-bye? Conversations over what to put in her grave? Crying over Butterscotch and his paper bone, lovingly drawn by our sweet Leigh? Some people may chide me for my lack of faith, and say that I should just believe that she will live and she will. However, I know countless parents who have believed with all their might and yet their children are lying in a casket right now with their special toys and their precious blankies.

I read the statistics, I know the probable prognosis of her disease. On the flip side of the coin, I do believe in healing. I know that in the course of history, many thousands of people have been healed....If Leigh lives to be ninety-five, I will be so grateful. If she dies while she’s young, while she can still fit into my lap for snuggle time, I will be grateful for the time we’ve had. But the not knowing. The long good-bye. The wait for the phone to ring and a doctor’s words to shatter my world....I look at the symptoms she’s been experiencing lately and wondering if they are the beginning of the end. And then I look at the symptoms she’s been having lately and wondering if they’re nothing at all. It’s the not knowing that’s so hard (Leigh, mother, 4/17/03).

Waiting for results of scans and lab tests inspired unnerving vacillation between positive and negative thinking.

Stupid evil disease Still waiting. We were hoping to hear about the marrows yesterday but in re-listening to the message that Dr. E. left us she said it would probably be Thursday or Friday before we heard from her again. Waiting is a funny thing. One moment you focus on all of the positives and the next minute you are considering all of the irrational conspiracy theories of why you don't know anything yet. You wonder why is it taking so long. Did they find something and are waiting to tell us anything pending further review? Are they waiting to tell us because they want to give us more time to have happiness before they unleash the news from hell? Is it so bad or so odd that she is waiting to tell us until she has consulted with others and developed a plan? Is she waiting to tell us when we will be there in person. Is she waiting for a time when Lesley and I will be together? What is going on?

My mind then jumps right back to the rational side as I evaluate all of my scary thoughts....After all, this is Dr. E. we are talking about. She is a part of our family. We admire and respect her so much we named our child after her. We did it because we thought her honesty, kindness and dedication (wow, those words to even come close to describing how strongly we admire her) were of such amazing caliber that we wanted our family to be constantly reminded of her incredible qualities. We have honored Elly with the gift of that name as we can think of no better person in the world that can serve as model for the traits that we think are most important in a human being. So, given that, how can I sit here and debate conspiracy theories in the back of my head?

It is this stupid evil disease. It is the fear. It is the unknown (Cindy, mother, 8/24/05).

Early in the treatment phase, children with ALL are classified according to their body's response to the first month of treatment. Knowing this led several parents to place a significant emphasis on this for the power of this label to be associated with better outcomes.

Child as 'rapid responder' By Wednesday we have to be under 5% leukemia cells in the bone marrow in order to be considered a "rapid Responder". Rapid Responders do a lot better in treatment and have a much better prognosis long term and much less of a chance of relapse. If she is not below 5% then they will have to intensify her treatment. At least this is my understanding right now. The doctors and nurses do not think it will be any problem reaching under 5% by Wednesday at all. However, I'm a little nervous (Lucy, mother, 12/15/08).

Uncertainty management

Writing about attempts at maintaining control, the primacy of their decision making, the independence valued as a family unit within the healthcare system appears during this phase as families attempt to regain balance. Hope was often identified as the way to manage the uncertainty that caused so much distress. Parents hoped for the best while preparing for the worst. There were 'small hopes' that centered on immediate events such as good news about lab or scan results; that the child would be able to participate in an important family or school event. The 'big hopes' enabled forward movement through the despair and fear to achieve family goals. Hope became the foundation for dwelling on the positives so as to diminish the uncertainty.

Hope Today we hope for a couple of things. One, that the results of the stem cell collection are good. We want a lot of stem cells. Second, we hope to hear back about the results of the bone marrow aspiration. We want to hear that they could not detect any neuroblastoma cells. I don't know how realistic that is but I am hoping for it anyway. When she was diagnosed, I believe, they said she had about 60% neuroblastoma cells in the marrow on the left side and about 20% on her right. A reduction would be great, because that is a sign that the chemo is working. To go to 0% would be phenomenal. So, as usual I am hoping for the best but prepared that it might not be the case. Third, we are hoping to have her new catheter removed. It will take about fifteen minutes of us holding her down while Dr. E. slowly removes it. I know Cindy will not be happy but hopefully we can get that done without too much of a temper tantrum. Lastly, we hope to go home. Boy, wouldn't that be nice (Cindy, father, 7/31/03).

The metaphor of “hitting the play button” (as opposed to the fast-forward or rewind button on a media player) permitted peace of mind during times of particular turmoil.

Keep hitting the play button In the meantime, we will wait. We will keep on hitting the “play” button every day, trying not to “rewind” too far into the past, trying not to “fast forward” too far ahead into the future. For now, I feel deep peace in the midst of great sorrow. I am in a quiet, comfortable hotel room with my precious girl three feet away, happily and contentedly reading one of her beloved books (Leigh, mother, 7/8/06).

Living one day at a time—for 8 years The old cliché for our position is: "Take it one day at a time."

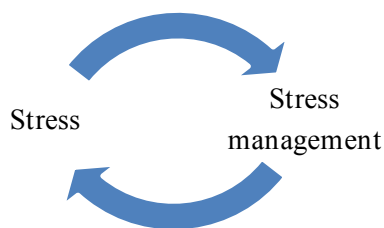
Now, we have more or less lived that way for almost 8 years, BUT, you really don't live ONE day at a time. There are always days, or weeks or months that you string together in your head because of treatment plans, testing schedules, trips, or school or whatever. Now, I find myself literally looking to get through ONE day without a major problem or medical development. I find myself at night, wanting to go to sleep with the knowledge that he will be OK until morning and that nothing bad will happen during the night. This is a most unsettling mindset that I have not experienced in many years. Probably back during transplant, there were thoughts like this, and that was a much more dire medical scenario. Now, we find ourselves facing unknown demons that do not show up on scans or in blood tests. We find ourselves praying for more than a cure. We are also praying for peace in his mind, so that he can get the most out of life. (Danny, father, 12/24/07).

Seeking information on treatment options, consultation with disease experts, and "doing all we can" were all actions parents described as comforting during periods of uncertainty.

I do better with all the info...Anyhow, given that it's been 18 months now since her diagnosis, I felt compelled to ask Dr. F. "if she were not on study, would she be getting anything different right now?" My thought was that perhaps there is a new study or new drug appropriate and obviously Jeff & I would pull her off study so she could participate. Dr. F. assured me that the current study is still the newest protocol. That's good news. Then I asked what her risk of relapse is today, percentage wise. She couldn't answer

that.... We've been told from the beginning that Acute Lymphoblastic Leukemia has an 85% success rate.... Today I asked F. what that means for the other 15%? Do they die? Do they relapse? Do some die, some relapse. The answer is that "they are doing something else." Either they didn't survive or relapsed and are doing repeat chemo, or went straight to stem cell transplant. The data doesn't differentiate between them. They just aren't in the cured group. The other thing that she mentioned in passing, but stood out in my mind because I hadn't thought of it quite this way, is that "as a whole there is an 80-85% success rate, but that doesn't mean the individual."

Ugghh! Mid-way through this conversation, I sensed her hesitation and said, "are you wondering why I'm asking this?" She said, "Yeh!" I explained that I do better with all the info. and then I can process it and hopefully set it aside. Otherwise, my imagination is often worse. So there it is, the good, bad and the ugly (Isabelle, mother, 8/28/07).



Stress

Stress during treatment was portrayed by the bloggers as one of the most disturbing components of the process. For parents and children alike, 'firsts' were particularly stressful. Acknowledgement of this phenomenon by staff and even the parents themselves helped gain some perspective on future events and the best way to handle them.

Mistakes by healthcare providers seemed to be described in circumspect and without castigation for the most part, especially if the mistake was followed by an apology and a promise

to account for and work to correct the error. In a few instances, treatment of the families by private health insurance company representatives on the other hand was stridently condemned for inaccuracies, delays in agreement to cover specific treatments or tests, and outright misrepresentations. These criticisms are discussed later in the result section as a mode of action taken by parents through their writing, but must certainly be understood as adding an already heavy stress burden.

Firsts, and the story of a mistake Cindy's first doses of chemo this round went off without a hitch. We had our usual "first night back at the hospital" problems with Cindy but we have become quite accustomed to dealing with her change in behavior....I am guessing that "firsts" are always going to be pretty frightening as we journey down this road. I had assumed when this whole mess began that these treatments would get easier and easier as time went by but, in retrospect, I think I was wrong. I would guess that I was just as scared yesterday as I was when we were first diagnosed. I don't want to mislead, this journey has become more bearable with almost every day that has gone by. It is the new procedures that seem to reignite the worry. This may sound contradictory to what I have said before but, in my case, it is more frightening now because of the knowledge that I have acquired. When we first started this mess I learned a lot about Neuroblastoma and I prepared myself for the worst, given her condition. Knowing that there were successes in this field and having a complete trust in my heart for the doctors and nurses, I was assured by the technical expertise of those that surrounded us. I didn't know why many of the drugs were being given to my child and I had no understanding of the importance of proper dosing, order, and

procedures. Since then, I have become aware of all of these intricate details and I am rather paranoid that everything is being administered correctly. I would hate to be one of our nurses because, now, we truly do have the knowledge to be dangerous. I think much of our increased fear is due to the mistakes made last week in recovery. Although I know it was not one of the nurses on our floor, and although I respect them greatly, and although they have never given me any reason to think any differently, I find myself double checking everything. I can feel the anxiety well up inside me anytime they come through the door. It, quite simply, isn't their fault but they are continuing to pay the price for a mistake that one nurse made in recovery and, in many ways, so am I. It is really pretty funny because, at the time it occurred, I really wasn't that mad. I knew they were human and I knew mistakes could be made. I was always a little weary of the staff in anesthesiology, surgery, and recovery for many reasons. They didn't seem as caring as our oncology nurses. Many didn't appear as technically proficient either but they certainly gave off an aura that they thought they were. Some even seemed to look down upon us. They also seem overworked. (You would not believe the volume of kids that go through the surgery center.) So, given this, I could see how a mistake could be made. I wish it wasn't on my daughter but, nevertheless, I could understand. My concern at the time was that they took responsibility for their actions, they fixed my daughter, and that they reevaluated their procedures to help ensure that it would not happen again to another child. All of which, it appeared that they did. So, it was easy for me to forgive. I just

wish I could forget. It would make life so much easier. In this sense, ignorance could be bliss. However, the stakes are just too high (Cindy, father, 8/8/03).

During the treatment phase of living with neuroblastoma the worry over scan results was the most common stressor. Even as the disease became stable or in remission, the worry over upcoming scans was ever present in the blogs. Nerve-wracking, jumpy and scary were some of the words used to describe the feelings.

Narratives found centered on the loneliness, the sense of isolation experienced, but also the comfort of knowing other parents in similar circumstances shared these feelings. The follow up testing for neuroblastoma involves lab work and scans that take as much as four to five days to complete, with another one to two days for final reports to be available to parents. The entries leading up to and during 'scan week' were full of stories of stress, particularly if the child was experiencing symptoms of any kind. Rumination on the 'what ifs' predominated the pre-scan entries. Some parents identified this as problematic and decried the interruption of daily life caused by images of relapse. Others viewed contemplating the likely treatment scenarios if the scans showed stable, progressive or no disease as a means to gain control and predict the future.

Scanxiety ...Since we have been home it is so easy to forget about the cancer world. Yes we have the daily care of Jeremy's Broviac and the constant reminders when looking at his scars. But we are home, no appointments for a while, and I guess I should feel really content. I just don't. I am struggling with this whole "monster under the bed" feeling that at any moment it will come crawling out and attack us once again. The parents who are in the monitoring phase call it "scanxiety"...all of the anxiety and fear that is wrapped up in the scanning and waiting phase....(Jeremy, mother, 4/26/09)

Reliving past stressors proved important for parents to share as they attempted to deal with unwelcome recurrences.

PTSD Fever worry After lunch I got a call from daycare that she was warm again so I called Omaha to see how they wanted to handle it. As we had discussed earlier today they wanted to run blood work to make sure she doesn't have an infection from her port.... It was like a bad dream, we heard the EXACT same thing today that we heard four months ago when we were trying to get her diagnosis. "Looks like a virus", "lets give Tylenol or Motrin", "let's watch it for a few days", etc. It was a very crappy feeling to be in the same room hearing those same words :-(....I was hoping to celebrate her birthday without any thought about the scans, probably wouldn't have happened either way (Mimi, mother, 7/24/07).

Unexpected moments of anticipatory grief caused additional stress in daily life when things were going relatively well.

Anticipatory grief 1 I had an out-of-the-blue “grieving for Leigh moment” last week when I was taking Martin to the orthodontist. All the way over there he was talking about college, trying to decide if he should go to a year of community college first and then transfer to a university or just go straight to a university....After dropping him off at the office, I sat out in the van to wait for him. It was a beautiful fall day and I was listening to songs on the radio and happily humming along, just enjoying a few moments of respite in my hectic life. And then all of a sudden, in the space of a half a second, I was bawling, just absolutely bawling. (If I’ve learned just one thing on this journey it’s that grief never seems to send an advance warning that it’s coming!) The thought had just

slammed into my brain that maybe the bottom line with the whole “college dilemma” was that Martin should opt for community college simply because he would still be able to live at home and have more time with Leigh. If the statistics hold true and she is indeed living on borrowed time, wouldn’t it be terrible for him to live 500 miles away and only see his sister a couple times a year? I thought, “He needs to cram in all the ‘Leigh time’ he can because one day when he comes home from college, she may not be here....” (Leigh, mother, 12/11/06).

Anticipatory grief in the face of impending death forced unrelenting stress into new forms.

Every minute of every day It's a guessing game trying to figure out what to do to save our son. What treatments he can weather, how to tweak them to work best for Tony. There is simply no plan in place for kids with recurred neuroblastoma - because the cure hasn't been found yet. This is in our minds every minute of every day (Tony, mother, 2/4/08).

Anticipatory grief 2 Tony's birthday party is this weekend. Melinda has pulled out all the stops and has organized an Indiana Jones adventure for the kids....It also isn't lost on us the significance of what this birthday represents and how for all practical purposes it will be Tony's last. While hope remains, reality also has a place at our table, and I find myself increasingly looking at the calendar and our scheduled vacation in early August and wondering if I should move it up (Tony, father, 6/25/08).

Stress management

Each of the blogs contained stories illustrating stress management strategies, but each parent writing had a different approach. For some, superstition and the use of good luck items or mantras brought a sense of peace and control.

Expect miracles Do any of you look back on things you have said or done and think "how did I know that THEN!? I...found a silver bracelet I bought for myself the week that Mimi was born....It said..."Expect Miracles". I found this, read it, and had to sit down. How did I know a year ago that this phrase would mean so much to me now? It is something like this that reminds me that God works in mysterious ways. After Mimi was born I put the bracelet away, and was going to save it for her - never to look at it again until she was older...or so I thought! Here I sit today - proudly wearing this bracelet again to remind myself to not only believe but EXPECT miracles!...(Mimi, mother, 6/8/07).

Don't upset the cosmic karma Lesley is petrified - probably more so than I.... She has this habit of believing the worst will happen. It is this "If she thinks it will happen then it won't" syndrome....That is minor compared to the weirdness I relive to keep neuroblastoma from dawning our door. In fact, I have to drive the same way to the hospital every time for scan week so that I don't upset the cosmic karma. I have been known to turn around when I have gone a different way and start all over. (Okay, maybe I am not known for that but I have done it.) In fact, I do all kinds of stupid things to protect our world from neuroblastoma. I still wear the hospital bracelet from when Cindy was diagnosed in June of 2003 because the only time that it has come off was in October of 2004 when we had the questionable relapse. I refuse to be confident about Cindy's health at anytime

because the times that I have been confident she has been diagnosed with cancer and I can tell you for sure that it is usually when things are going really good in life that bad things happen....I don't know that I really believe in any of these things. I know before I was touched by neuroblastoma I was never this superstitious....(Cindy, father, 8/21/06).

Still others imagined cancer at different age to be relatively more difficult, e.g. when parents wrote of how much more difficult they imagined having an older child or a younger child with the disease would be. This narrative thread was so prevalent in the blogs, the term 'developmental relativity' has been applied.

Developmental relativity 1 Another thing he did while he was up there was to go and stand outside Rm. 5202, Leigh's old room. From the picture on the door he saw that the current "resident" looked to be about seventeen or eighteen years old....As a mother, I can't imagine how much more complicated it would be to have an almost-adult son going through cancer treatment—the privacy issues alone would be tough for both mother and son. It was so much "easier" to have a 7-year old child of the same gender to care for in those long months of hospitalization. My hat is off to those cancer parents who are juggling the challenges of caring for older children (Leigh, mother, 9/26/07).

Developmental relativity 2 ...As you walk down the hall, you can't miss that look, like a deer caught in the headlights, of a newly diagnosed family. As a seasoned parent, we try to offer advice and comfort, knowing that when we walked in those shoes, no words could remove the fear and anxiety that consumed us. The one family has a very young child (about 1 yr. old), and she expressed

her frustration with not being able to communicate with the baby about what was going on. I could only offer my observations of having met many families with children diagnosed at a variety of ages. The very young ones can't tell you where it hurts, and you can't easily explain what is happening to them. But, a year or two from now, they will not remember any of this. The 3-6 year olds, can communicate a little bit better, can understand some of what is happening, but they too are at an age where treatments can get overwhelming. The older children, 7 and up, they can understand a lot of what is happening. They can even help in determining plans of action. Unfortunately, they will remember this and they know how to manipulate the parents when they need to. My overall conclusion is: THERE IS NO GOOD AGE FOR A CHILD TO GET DIAGNOSED WITH CANCER!!!!!!!!!!!!!!!!!!!!!! (Danny, father, 11/6/02)

Rereading previous posts in the blog reassured parents that things would get better.

Rereading for reassurance ... On many occasions I had worried that I wasn't doing a sufficient job at Daddying. One of the hardest things about this journey for me is my inability to comfort her when she seems to need it most.... I had to reread my diary to remember that this would get better. I went back to our first hospital stay and relived the first few weeks after diagnosis. It was good to see that although she was never sure of what she wanted, when it was all said and done, she felt tremendously loved. She became my baby girl again....(Cindy, father, 11/9/04).

Getting together with other parents, in person or online brought some relief to the stress.

In addition to communication with readers on the blogs, membership in neuroblastoma listservs and communication by email seemed to be other ways for families to connect.

Helps me cope ...more importantly, I find that participating on the NBLAST list helps me cope....My favorite part of posting is when I receive a private message from the experts. You would be surprised at what I get. Sometimes it is kudos. Sometimes it is another argument. More often than not, it is one of them making fun of my stance on something. There are 3 of them in particular that keep me laughing in the background. First off, they all fundamentally disagree with each other. So, regardless of what I post, I am going to get a little bit of everything. Hopefully, if I have done my homework (I have learned to double-check), there aren't any corrections. There are always differing opinions and the funny thing about it is that they are all absolutely right, each and everyone of them. One is always mad that I am focusing on a dead horse, one is always providing me support through medical articles and one is always telling me that, although technically correct, I am off my rocker and I should be focusing on something else. The irony is that who is telling me what is constantly changing. Who would have thought that this is what I would be doing. Finally, and the most important part, is all of these people deeply care about our kids and are fighting tooth and nail. Helping others and pushing the envelope makes it easier for me to cope with my own stress and worry....(Cindy, father, 12/3/07).

Humor was identified in the writing as a means to distract family members from the stress as well, so funny stories are interspersed with the more ominous narratives.

Single events like these can sustain you forever. ...it certainly was not a stellar treatment day....All of that seems much too depressing so I have decided to share a funny first day story. I was really paranoid about making Cindy look beautiful. I knew that without her mother there all eyes were on me. I knew Lesley had her spies making sure I was doing my job. She had to be dressed correctly (if not cutely) and perfectly coifed. I was prepared with detangler and comb in hand. I wasn't playing games. I did her hair when we left and, realizing her hat could cause problems, I carried a comb and bottle of detangler in my back pocket. In fact, as soon as we got there I did her hair again. Marie was our nurse for the day. She is one of our usuals. Cindy was glad to see her and gave her a big hug while she was hooking up her noodles....All of a sudden Cindy looked up at Marie and then looked over at the detangler. Cindy grabbed the detangler and looked straight at Marie. "Marie you should use this, it will make it so your hair is not so crazy and it will help to get the tangles out. You want some?"

Marie has an afro.

See, although some days your purpose may seem awful, single events like this can sustain you forever (Cindy, father, 2/15/06).

With relapse a real possibility with every set of scans, neuroblastoma parents wrote of the comfort found in having a plan in place for treatment if needed.

Having a backup plan So, having heard of this back up plan, we are much more at ease with the knowledge that we may be at or near the end of our run with this current chemo. Having a backup plan makes getting through the day much, much easier (Danny, father, 7/18/07).

One mother attended a support group, though it was composed of a more generic population of affected individuals that may have been helpful. The group is mentioned just once in the three years of writing.

Support group I have had a flyer on my fridge for about a year now. It's for a Cancer Patient & Caregiver Support Group. Yesterday I finally went. It was very good for me and I should probably go regularly for awhile. I've never attended a "group."...All the caregivers there happened to be spouses. But still I took away something. The social worker was trying to catch me up on who was who and their type of cancer. Strange, the candidness in the room. "That's Harry, he's pancreatic." "This is Tom, he's head & neck." "Larry is lung." "Jim's another head & neck." And on it went till soon I knew way to much about everyone there and they came to know me in my vulnerable state (Isabelle, mother, 8/8/07).

Profoundly helpful in managing the stress of the illness and treatment was what the author referred to as "the village," as in the expression: "It takes a village to raise a child."

The village Good morning to Isabelle's village! It takes a village and then some. It seems appropriate today to say a giant Thank you to all of you who have read, posted, prayed, called, been there, cooked, listened, whatever it was. If you are reading, then a Thank you is in order. I can't tell you how much I have leaned on this carepage in times so dark for me and I have found messages that lifted me and allowed me to keep going. It's been two years today since Isabelle was diagnosed. Two years since we crossed the threshold into Unit 4800, two years since the word "cancer" was spoken in relation to our daughter. Two years that have felt like ten, and I have the grey to prove it! Well not really anymore, I had it colored yesterday. :) (Isabelle, mother, 12/22/07).

Bloggers also wrote of efforts made by the children to manage stress. In this example, medical play became a vehicle for expression.

[The child life therapist] gave her lots of port-a-cath paraphernalia the other day and Isabelle's been in hog heaven "accessing" all her babies and us of course. She's a pro! It's an incredible insight into her experience. She'll tell me more with her dolls than about herself. The other day she said about her doll, "she doesn't like the tape, it stings her." "Don't forget to count, she gets scared if you don't count." It's probably very therapeutic for her (Isabelle, mother, 1/11/08).

The next entry stood as a counter narrative to the now-debunked research claiming higher than average divorce rates in married parents of children with cancer. (Syse, Loge, & Lyngstad, 2010).

Relationships It also happens to be my wedding anniversary today! Yes, she was diagnosed on our wedding anniversary! Eight years married and a little over ten together. And let me say, that the fact we are together today after the stress of the last two years, means we'll be together forever (Isabelle, mother, 12/22/07)!

At times, blog entries expressed a hope for purpose in the sharing of so much information with readers.

This is the place I purge To only ask that "the force" be with us yesterday was a fatal flaw. This mommy needed way more than "the force" to get through that day. I feel as if I complain about the hospital/clinic days often. It's not my intention, but for those of you not on the front line and rather on the interior brigade, I hope it makes for good reading. I would feel great knowing that there is some value to the hell we endure. Additionally, as I've typed before, this is the place I purge. If I can purge the yuck in detail, then I can

release it. Besides, she needs to read this one day and know what a courageous child she was. Otherwise she may wonder how the heck she grew into the kind of woman she's yet to become (Isabelle, mother, 10/6/06).W

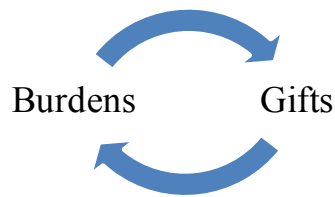
For some, writing became the means to process events and fight insomnia.

Fighting insomnia And there I lay, the words just dancing in my head. I suppose it's a curse, as I couldn't sleep without putting a few words at least, to the recent happenings. I tried to fight it and relax, but then I'd realize five minutes later I'm staring into darkness with open eyes. So I may as well get up, dump the words out and go try again. Maybe the sandman stands a chance then.

Earlier my mom was contemplating coming over today (yesterday now) or tomorrow to see Isabelle. I found myself suggesting today as, "she's not going to be home for long." She ended up coming today, as did [a friend] earlier too. I waffle between taking credit for "mommy intuition" and insisting this monster is unpredictable. Today the "MI" won and I'll find some morsel of invisible praise to bite, for tomorrow it will undoubtedly be the monster's return.

I'm truly not as crazy as I must sound. I just miss my daughter in a way I hope none of you ever know and I'm unfortunately wide awake at an obscene hour. Until tomorrow. . .

(Isabelle, mother, 1/31/07, 4:53 am)



Suffering

The burdens that accompany life during treatment for neuroblastoma are many and varied. The authors' narratives seemed to suggest that the suffering experienced fit into three broad categories: suffering related to the illness itself or its treatment; surplus suffering, first identified by Clarke and Fletcher (2004) in research on parents and childhood cancer; and shared suffering, or the additional burden of experiencing the disease as part of a larger family system.

Illness-related suffering. The themes in stories on illness-related suffering included a loss of control; taking on the role of 'nurse;' the feelings of isolation; and the lack of rest, both physical and psychic.

Loss of control After spending a week with many of friends going through this battle, I've had alot of time to discuss matters of the heart and soul with folks that are in the trenches with us. Once again, I see many themes that run true to several of the families in this fight....I've come to somewhat of an understanding as to WHY this disease is SO devastating to the family structure and lifestyle that everyone works for. Aside from the obvious ---- your child is sick and may die from this disease.....On a daily level, this illness can dictate when you laugh or cry, eat or go hungry, sleep or stay awake, work or stay home, watch tv or watch a monitor that is attached to your child, spend time with family or spend time with doctors and nurses, sleep in your bed or sleep at or near the hospital....when I

look back over the past 2.5 years, this disease has really dictated every move we've made. You try to retain control over your life and the lifestyle that you've provided for your family, but when sickness knocks on the door, you can't ignore it....it WILL NOT GO AWAY QUIETLY! Try to plan a night out with friends, maybe for just a few hours, and see if a fever doesn't pop up out of nowhere and have you driving to the hospital for four or five unexpected days. Try to plan a meal out to spare your wife another night of cooking, only to remember that your child's blood counts are too low to eat anywhere that doesn't have outside seating...and then try to convince a restaurant that you deserve one of those coveted tables. Try to plan some play time for your child with his friends, only to find out that one of them has been coughing lately, and you have to cancel, scaring his friends parents into thinking they should never risk bringing their child around yours. Try to plan even ONE or TWO weeks into the future for treatments or family gatherings or work, only to have everything put on hold because of surprise results, or new scares. Yes, we function. Yes, we dress ourselves in the morning, we drive, shop, eat, drink, sleep (sometimes) just like "normal" people. But...Now matter how hard you try, it finds a way to control every aspect of your life. You may think you have control, but you have no more control than the surfer that waits for the wave....he or she may have a great ride, but they have to WAIT for the right wave....they can't conjure one out of thin air, anymore than we can create a lull in the action to give ourselves a break (Danny, father, 10/19/02)!

Substitute nurse ...I think I'm finally starting to get more comfortable in my new role as her substitute nurse....What amazes me most is Leigh's complete

trust in me. I feel an incredible weight of responsibility because if I do something wrong, like neglect to disinfect a line sufficiently, the results could be very serious. I'm always aware that her health and life are in my hands when I sit down beside her and the two AIM infusion pumps, three BARD infusion pumps, syringes, tubing, blood sample tubes, needles, bags of TPN and lipids, vials and syringes of vitamins, dextrose flushes, saline flushes, and alcohol wipes. When I'm not doing my hands-on stuff I'm contemplating the new words in my life like acyclovir, fluconazole, neupogen, neutropenia, bilirubin, Hickman catheter, immunocompromised, monocytes, thrombocytopenia, veno-occlusive disease and Cysteine hydrochloride. I've always been a "word person" my whole life; in fact, Dave teases me because my leisure reading often consists of books like "Woe Is I" (a book on grammar) "The History of the English Language," "The Art and Craft of Songwriting," and "The Word Menu." Since I am a songwriter, I know that words are the tools of my trade; however none of my past reading and learning has even close to preparing me for this new world of medical terms, procedures and medications that I've entered....(Leigh, mother, 2/15/03)

Visible signs of loss 1 I asked the doctor about hair loss. She said it would start anytime. After she left I put on Jeremy's pjs and I noticed hair all over me. It is Jeremy's hair, it all of a sudden started falling out once we got here. I just broke down at the sight of it (I left the room of course). You are probably thinking, "it's just hair, it will grow back, you knew it was going to happen, why are you so upset?" I just have a hard time knowing that he will now officially "look sick." On days he is feeling well it is so easy to let my mind forget that he has cancer. He

looks like Jeremy, plays like Jeremy, smells like Jeremy... Now he won't look like Jeremy. I've seen cancer change people I love before and they don't look like themselves and it is a daily reminder of the illness inside of them. So that is why it hurts me so (Jeremy, mother, 2/24/09).

Visible signs of loss 2—small sorrows Although we are blessed right now with such good health, every once in a while I catch glimpses of some of the aftereffects of her treatment that make me sad. The other day she was taking her temperature because she didn't feel well. We were sitting with Dave down at the kitchen table and the thermometer started beeping rather loudly. Leigh continued to sit there, chatting away happily, completely oblivious to the fact that her chemo-damaged hearing would not even allow her to hear a rather noisy thermometer....sometimes things like that catch me off guard and I'm sad that what she hears and what other people hear will always be so different....I don't want to sound like I'm complaining: she IS alive, and that's the main thing. But there are still small sorrows along the way that remind me of all that's she's been through (Leigh, mother, 4/19/07).

God help me if she relapses ...I am going to be calling Memorial Sloan Kettering to get their opinion on the 3f8 for Ana. Dr. P. suggested I stick to the hard facts. Ask them how many children with initial disease have taken this and how many of them are alive and disease free today. She has no problem with me seeking this treatment out and will provide them with anything they need. She did say however that she still hasn't seen any proof that it is better than the current treatment that Ana is getting. So we'll see. I want to have no regrets about

decisions we made for her treatment. God help me if she relapses down the road and I didn't research or provide her with all the treatments that were available to her....(Ana Lynn, mother, 1/31/07).

It never gets easier While we were in between tests we met up with many wonderful neuroblastoma families from around the country and around the world. One woman we talked to said her son was diagnosed five years ago and has just relapsed for the second time. She said, "It never gets easier. You can never rest. Even if your child is declared N.E.D. (no evidence of disease) you don't relax." She very aptly summed up the other pressures of a family experiencing the disease--the financial strains, the marital strains and the pressures on the other children (Leigh, mother, 5/16/03).

In addition, parents wrote of the heavy burden of making life altering treatment decisions for their child. The responsibility was understood as the most serious element of parenting the child through cancer.

Treatment decision making Dave and I are finding ourselves in a state of sad numbness as we consider all these questions....I think I'll go crazy if I think about all this even one more minute. It's too much.

Dave and I know that if we decide to do aggressive treatment, some people may say, "Just let her live her life." If we don't do aggressive treatment, other people might say, "You're not doing all you could be doing to save your daughter's life." And although it doesn't matter what people say, it does matter that those are the very thoughts we're struggling with as her parents....Dave said last night that he can't stop planning Leigh's funeral—his brain just goes round and round and

round. When we look at her running around the house and smiling and giving hugs and singing it's almost too much to bear to think that she might not make it. And yet we can't cry all day over this burden because it's not good for us and it's not good for the kids. And so we get up and have breakfast, and go to the gym, and clean, and do office work, and work on music and take the kids to Taco Bell, and watch Sponge Bob, and try to pretend that a monster is not gobbling up our very lives....We're sharing all this hard stuff with you because we know you care and pray and because we can't make it by ourselves. We don't know what to do and unfortunately, no one can tell us what to do except ourselves. Treatment would totally disrupt our family for another year, and cause all sorts of pain and discomfort for Leigh....We could go through all that stuff and she could still die. If there was any sort of guarantee at all, even to the point of saying she would have a 30% chance of survival, we'd do it all without question. But her chance of relapse is so high, and the chance of surviving relapse so low that we just don't know how much to put her through (Leigh, mother, 7/8/03).

Double edged sword We had a conference call with Docs...and tossed around a few ideas with them. Funny thing is we, Henry & I, need to make the decision on what to do, what to give. I feel like we're holding the double edged sword. Tony's marrow is weak. It's not producing platelets and even his red production is questionable. So while we wait to see if he can recover the damn cancer is having a field day in there. Then when we decide we have to introduce some toxic treatments in order to fend off the cancer, we're knocking his bone marrow for a loop, too (Tony, mother, 8/2/08) .

The related burdens of deciding on untested clinical trials with uncertain outcomes, often involving randomization added even more weight.

Decision making and clinical trials Well, the computer spit Silas's name out as a "no" for the clinical trial of anti-body treatment. We were quite upset about it this morning but after mulling it over all day, we've come to accept that that's just the way it goes. Besides, it's not a miracle cure and it's still experimental and hasn't been made an approved treatment yet. If (knock wood) Silas would have a relapse in the future then he would get this treatment automatically after having chemo again. So now, we live with the computers decision and be happy that Silas is free and clear. Tomorrow he starts what's called maintenance therapy....(Silas, mother, 10/3/0/06).

Scan watching was also noted to add to the family burden. Parent bloggers did not explicitly identify this, but in analyzing across the cases, the theme became readily apparent. The definitive test for following neuroblastoma tumors is the MIBG nuclear medicine scan. Parents remain in the control room of the scan area to be near and provide vocal support to the child. The secondary effect of remaining there is that the parents can "look over the shoulder" of the technician. In so doing, it is often the parents and the technician that see disease progression together for the first time.

Scan watching—Tony Tony went in for his MIBG scan this morning and there were spots all over the place. Spots = neuroblastoma.

His scan started with his head where I saw a V shaped spot enhanced. Text to Henry: "spot on his head" send. Then we go down to his check/back area where I see the original spot looking pretty good. Lightly enhanced, maybe a little

smaller. Text that info to Henry. Move down to the abdomen/pelvic area. hmph, I've never noticed it being so enhanced in this area. Uh-oh, the tech is taking another picture of that area. Not good. Text info to Henry. Now we're at the legs and there's a vertical line on one thigh and a bright circular spot on one knee. Text to Henry. Response from Henry: F%*k F%*k F%*k. I concur.

So I'm sitting in the Nuc Med scan room, Tony is watching a Seuss movie while going through the scanner, I'm staring at the computer screens with all this crap on them, and I'm trying my damndest to keep it together while the tech, also named Melinda, is also trying not to lose it because she knows that I know what I'm seeing up there. She can't say anything as she's not a doctor - and not Tony's doctor. Tony is blissfully oblivious to the whole scene as Horton Hears a Who! is very entertaining.

After the scan Tony & I had to walk over the clinic to drop off a urine sample, me fighting back tears the whole walk and Tony pretending to be on a bear/deer/hare hunt with his new cap-rifle. All the nurses we see and know are in clinic and I just couldn't even tell them what I just saw because I knew I'd start crying and not be able to stop. So we hustled out of there and I took Tony back to school....We do not have the official results or reading from the radiologist yet. It will come sometime tomorrow. I think the shock of seeing the scans has worn off - a little - and I'm ready to hear what the plan will be to combat this invasion of Tony's little body (Tony, mother, 3/27/08).

Port-related stress: malfunction. Standard treatment for ALL requires central venous access, usually the surgical placement of an 'infus-a-port,' or 'port' as it is referred to in these

blogs. Parents of children with leukemia wrote volumes on the topic of stress related to the infuse-a-port used for chemotherapy administration and blood sampling. Each of the bloggers shared at least one story of port malfunction, some significant, others less so. This parent told the story of the infection of the child's port within days of placement.

2 week stay for port site infection within a week of insertion ...Courtney started to say her port sight was hurting and there was some drainage, so we called the PEDS on call doctors and they told us it sounded infected....They took a swab of Courtney's sight and sent it to the lab. We won't know anything until after 24 hours, to see if any bacteria are growing. Which is highly likely. Since she doesn't have any platelets really (17), she has to get a transfusion tonight. The stitches are where the infection looks like it started and traveled up her port. So to try and get it out they started her on two antibiotics right at the port sight. Since she cannot fight off any infections she will be on antibiotics every 8 hours. So that means more than likely we will be here for 2 weeks (Courtney, mother, 9/18/06).

Frustration with port access came with the intermittent inability to draw blood samples when needed, one of the beneficial features often named by healthcare providers at the time of insertion.

Blood refused to cooperate First off Kevin's port access went wonderful....not one tear!!! However, his blood refused to cooperate. You may wonder how blood refuses to cooperate? Those of you familiar with ports know exactly what I am talking about. Kevin's blood would not draw back into the syringe. Our nurse...tried everything from lying down, drinking water, standing up...nothing!! This went on for about 30 minutes. Dr. C ordered an injection into his port called TPA (it is an enzyme) it has to stay in the

line at least 2 hours if not over night. We opted to come back in 2 hours. By the way

Thank you to everyone who prayed for the injection to work. The TPA worked and his

ANC was 1638 and he recieved his chemo!!Yipeee (Kevin, mother, 7/8/08).

Attempts to correct the port malfunction meant only a temporary reprieve from problems. Later the same year, the port malfunctioned again, and again an attempt was made to correct the problem.

Repeated attempt They had to place TPA in his port and we are leaving it in over night.

TPA is an enzyme used to clear out any clots. The kicker...the cancer center is closed tomorrow. So mom gets to draw out the TPA, flush out the line, inject the heparin and deaccess his port. All in a mothers day. Lol. We have come to expect the unexpected in the world of cancer. As a mom you do what you have to do and then reflect on it later.

We have to be back at the cancer center Monday morning. They are going to do a scan of his central line (port). At that time and depending on the results, Kevin may have to go into surgery and have his old line removed and a new one installed! I know yuck!

Probably after the holidays. I am just praying GOD will provide the clear answers we need (Kevin, mother, 12/23/08).

Readers learned in subsequent entries that the child needed to have the port replaced, necessitating an unanticipated surgery.

Need for port replacement Kevin's port would not draw blood this morning. We have essentially done everything known to help clear his port. It seems that surgery is now our only option. We spent about 3 hours at the cancer center today with 3 kids....We also do not know if they will be able to do the surgery at [the preferred hospital]. Because of our insurance it may have to be at another hospital. I'm not so happy about this part. I am just

praying GOD will open the right doors so that we can be where Kevin will feel most comfortable. He loves every nurse at [the preferred hospital] (Kevin, mother, 1/5/09).

Steroids as a barrier to coping. Side effects of steroids that hindered coping came to be understood as a necessary evil in the experience. In one instance, the child's reaction to the drug was extreme, requiring a change to the medical plan.

Induced psychosis...Courtney was up until 4:30 this morning....She has some very bad obsessive compulsive disorder right now which is only making the emotions she has with the steroid use escalated. Her eyes seem very glazed over at times and she seems not to be in her own body/mind at times. It is very scary not knowing what she will do next. We went to the hospital today for shots and thank God that [the nurse] walked by our room and talked with us about how she is doing... we discussed with her what the last several days have been like and she went to Dr. L... and got him to come and see us. He tried to get her mad... he wanted to see how she reacted... they described it as an induced psychosis. We will be cutting Courtney's steroid med in half and giving her some benadryl and tylenol to go with it to take the edge off. Her body as she says can not relax and hopefully this will help her and all of us get through the next 16 days (Courtney, mother, 3/13/07).

Weeks during steroid administration meant isolation for some families. This mother wrote of the inability of others to understand.

Well Kevin had a melt down, but thank GOD it was in the car at Sonic....Steroids are not like your typical melt down...I'll explain. Kevin got upset with Bryce and it escalades...then he gets mad at me over onion rings. It is as if he has no control over his emotions, he does not understand...then the strong-willed personality comes into

play...Viola!!!Roid-rage!!! I dread this week like the plague. And before I get lots of messages...I try to have a positive attitude, but sometimes it just runs you over like a freight train...utter chaos!!...It is a cycle...a mean steroid cycle. It is hard to understand unless you have either been on steroids or have a child who has been on steroids....

Well sorry to vent...but this is my best time to just let it out!!! (Kevin, mother, 7/9/08)

Steroid influence on child's identity. All bloggers expressed frustration with their children's behavior on steroids. One mother differentiated between her daughter's personality on and off steroids.

Lucy took her last dose of steroids for this month this morning (thank goodness). I'm not sure how much more we could all take. That stuff is just downright evil. This time the food cravings have not been horrible, however the moodiness has been out of control. Jason and I have nicknamed her alter ego during steroid week "Steroid Girl" - she is so different from her normal self it doesn't seem right to call her Lucy. And "Steroid Girl" has been on the rampage. Generally it goes like this - 6 am - "Mommy, I'm hungry for McDonald's" "Ok, sweetie I will get up in one minute and we can go" "I SAID I'M HUNGRY NOW FOR MC DONALDS!!!! YOU HAVEN'T EVEN MOVED YET AND I'M STARVING!!!" "Ok, I'm up." "GOSH!!! EVERYONE IS SO MEAN TO ME!!! NO ONE EVER WANTS TO GET ME WHAT I WANT!!! ALL I WANT IS MCDONALDS" Burst into tears and lots of stomping Aghhhhhhhhh!!! This is just after 5 seconds of waking up. We haven't gone out much because seriously even in her sweetest moments she talks different and seems on edge, so we have decided it is best to just stay at home most of the time (Lucy, mother, 9/7/09).

Other side effects of treatment. Fatigue, alopecia, weight loss, infections, and nerve pain were some of the other reported side effects of ALL treatment. While the personality and behavior changes that accompanied steroid therapy were most prominent in the narratives, the other symptoms also interfered with the ability of the child and family to cope with the illness. One child experienced seventeen hospitalizations in the three years of treatment, including two intensive care unit stays.

Nerve pain resulted from administration of one of the chemotherapeutic drugs, Vincristine.

I love Dr. M... but we don't see him often. He spent a long time talking with us. We talked with him not only about the ankle but Lucy not being able to run and things. He wants to try some things to see if we can improve her leg function. So we are doubling the dose she is taking of Neurotin to see if that will help since he said a lot of the loss she is experiencing is from the nerves not communicating appropriately (Lucy, mother, 4/27/09).

Surplus suffering. In addition to understandably heavy burdens of the illness; its treatment; and side effects, parent bloggers of children with neuroblastoma wrote of the burden of additional burdens tangentially related to the illness experience: managing the details of the illness such as appointment making and financial planning; becoming the educators of staff members less familiar with such a rare disease; travel to distant hospitals to meet with and be cared for by neuroblastoma experts; dealing with systems frustrations; helping siblings cope with their own burden; and the confrontations with private insurance company representatives.

Costs of travel Now, on to our trip to New York. Just about everything is in place. We have signed consents and made arrangements to get some of her

treatment drugs provided here.... We officially begin our treatment on Wednesday here at home. We will then fly to New York on Sunday. We will be treated in New York for two weeks and then on the 30th we will return home. We are working out the details with the Ronald McDonald House (RMH) in New York for a place to stay. The cost per night at RMH is \$20.00 per night which is far more feasible than the \$200 per night we were charged for staying at the Helmsley Medical Tower. If it does not pan out we do have other options but all are well in excess of \$150.00 per night. But those options, when you consider the fact that we will be traveling to New York and staying there for two weeks each month for at least 4 more months (and maybe as many as 10), are not really options. Additionally, we hope to find out today if we qualify for any free or discounted flights for this trip. Just in case, we have already booked full fare (not fair) flights just to be on the safe side. The problem we run into is based on our income. Our annual income is too high to qualify for most aid which makes me mad because they do not seem to take into consideration the fact that we have had medical bills that more than offset our income (Cindy, father, 1/10/05).

Some stories included details of medical error, as in this narrative of a potential error avoided by the father's prior experience with scan misinformation.

Parents as staff educators ...So far, so good, right? WRONG! One of the office secretaries came back to the treatment room and informed us that they need an entire week for the MIBG scan....Danny has had this test done on three separate occasions, and it basically consists of a 2 minute injection on day #1, and a one-hour scan on day #2. That's all folks! After arguing about the timing issue for a

few minutes, the secretary walked away. The nurse that was caring for Danny had heard everything, and she said she would call nuclear medicine to confirm the details. Well, one phone call later we learn that our wonderful hospital is basing their scheduling on the wrong isotope. For those of you that don't remember, I had to enlighten our hospital and doctor's many, many months ago that they were using an outdated isotope when scanning for this disease. After arguing with me, they finally made some calls and got the situation fixed. But, they never bothered to find out that the newer isotope has a much faster absorption rate, so there is no need to scan after the second day. The bottom line here is that once again, I have to take a stance on an issue to enlighten people, so that my son can get the care he needs. I could roll over and play nice, but it would royally screw up Danny's schedule more than I care to imagine (Danny, father, 6/2/03).

Parents wrote often of the burden of guilt associated with perceived neglect of siblings during the affected child's illness.

3CS and SHC Finally, since Ric... wait, he's mentioned so little that maybe I should explain. In case you were wondering, Ric is our third child. He not only suffers from 3CS (3rd Child Syndrome meaning he can make his own toast at 2 1/2, watches way too much TV and way too much TV that is too violent for his 2 1/2 years but then what are you to do if you have a 6 and 8 year old and they want to watch Kim Possible and Battle 360 all the time?) but he also suffers from SHC (Sibling Has Cancer meaning his needs are frequently and consciously neglected in support of the greater good cause of taking care of Tony)....(Tony, father, 3/31/08).

Frustration with inefficient or overburdened health systems is expressed in this narrative by a mother from Canada.

System frustrations ...It's really been and up and down week.... When we arrived at the hospital there were no beds available in the oncology outpatient clinic so we were stuck in the very busy waiting room with Silas hooked up for hydration and trying to sleep in his wheelchair.

I know that the kids that are having their chemo early or having procedures done take priority but it hurts when it's your own child in discomfort. This may sound like a petty thing to **** about but I think the least we can expect for our sick children is a pillow and a bed when they have their treatments. It was only 3 hours and Silas had a bed by the time he was ready for his chemo but it brought back memories of when this happened 3 years ago and he was 3 DAYS delayed because of no beds. That should never happen.

I don't know what upset me more...the fact that it was MY child without a bed for 3 hours or that there are just too many kids with cancer filling up the hospital. It's just heartbreaking....(Silas, mother, 5/30/09).

Incompetence. After a stressful day in the outpatient clinic during which the child underwent lab tests and procedures, including a lumbar puncture, this blogger posted a cryptic but ominous entry.

I'm bitter And so another day of chemo comes to a close. Isabelle did wonderful and could teach us all a whole lot about tolerance; tolerance of pain, hunger, thirst, & incompetence. I'm bitter the last few days. I have just a few things to say. If someone you love is ever in the hospital for any reason, do not under any circumstances leave them

alone. Not that I did, but it's shocking what happens right under your nose let alone if you were gone (Isabelle, mother, 8/24/06).

Everything else you witness. After a day in the outpatient clinic, a mother shared a revelation about the stress of the experience.

Everything else you witness ...No chemo till a week from Monday. I'm exhausted, emotionally. [My friend] nailed it today at the hospital, she was saying it's not just stressful because of Isabelle, it's witnessing everything else you witness. Children from all walks of life, with all different conditions and different degrees of coping skills. I seldom walk through the children's hospital lobby without seeing at least one woman on her cell phone, crying. It's heavy. Heavy because of Isabelle, obviously, but heavy in general (Isabelle, mother, 10/27/06).

Insurance issues. As with the families of children in treatment for neuroblastoma, stories of concern over medical insurance were found in the blogs created by parents of children with leukemia. One parent briefly offered a Thank you to a friend who, from the early days of treatment, had taken on the responsibility to track, record and deal with insurance related concerns for the family. Most were not fortunate to have such help and lived with some degree of fear of routine insurance frustration or outright impending financial doom.

Uncertainty I want to ask you all to pray for us as we start to deal with our insurance company. We have received 2 huge statements from our insurance company saying they would be paying \$0. Pray everything they are responsible for will be paid for (Kevin, mother, 7/20/07).

Later help for this family came from a friend.

We are still having problems with our Insurance Company and it is so frustrating. We are only 7 weeks into this journey. We have a friend who lives in Florida, who happens to be an Insurance Attorney. She has offered to help us get through all the red tape, send letters and hopefully just get tough with them. Two words-Answered Prayer-Thanks [friend]!!!!... (Kevin, mother, 7/31/07).

The same family later faced a problem that occurs frequently in the American healthcare system: an announcement from the facility where they receive care that their insurance company will not cover care at that hospital; that the contractual relationship covering payment for services has ended. Often, this is a contract negotiation ploy to inspire calls of complaint to the agency by patients fearful of having to end the relationship with a trusted healthcare provider. Indeed, this seems to be the case in one of the blogs in this study.

Hospital-insurer contracts ... We received a letter from our insurance company on Friday that simply states: (our hospital) will no longer be a part of our insurance effective 5-31-08. OUR records indicate you have recently received healthcare from this provider (no...really!!!!) Sorry for the sarcasm!!!! IF you have an ongoing medical condition (duh???he has cancer!!!!) Sorry again I am so mad, I have cried and cried!!!! Sorry again...if you have an ongoing medical condition that requires a limited course of treatment or if you are otherwise concerned that this change may disrupt your care (that is an understatement!!!!!!!!!!!!!!!!!!!!!!) sorry, trying to let you know how upset I am!!!, you may be eligible for transition assistance to provide continuity of care.

They could care less that there is a little boy in [Texas] with a potentially life threatening disease. They could care less that it has taken a 4 year old little boy 10 1/2 months to become comfortable where he is!!! They could care less that we could potentially have to

receive medical care 6-12 hours from our home. I need prayer and I know I am going to receive lots of messages, that GOD will see us through this...I know that, I trust HIM, I am only human. Satan is doing what he thinks is a victory dance...but I will fight this every step of the way...kicking and screaming if I have to!!!!

My heart hurts so bad right now thinking that we may have to leave the hospital that we love...They have been by our sides this entire journey, from the minute they delivered the heart wrenching news our baby had cancer to the loss of hair, to everything!!!

As I sit here in tears, my heart hurts that insurance companies have so much control. Our situation is different, we can not say...fine we will get new insurance, we are stuck with this company until Kevin is 5-10 years cancer free. It makes no sense, it is a monopoly. I have to focus on GOD and know he will see us through this dadgum bump in the road....I am so sorry to vent and be angry and sad. I am going to [the hospital] first thing in the morning and I am prepared to go to the CEO if I need to. Please pray GOD will see us through this and help us continue this journey at [the hospital]. I am a mommy on a mission (Kevin, mother, 5/11/08) !!!

The saga ended with a temporary resolution for the family, but only after a prolonged period of uncertainty and fear.

No news about insurance. I do know that [the hospital] is working on renewing a contract with our insurance. I asked Dr. C if he had heard about our problem and he said no, so I explained and he simply stated...do not worry we will take care of everything. I know I trust GOD, I just need help with my unbelief at times (Kevin, mother, 5/13/08)!!!

Almost a year later, the mother reported the insurance company and hospital did indeed sever ties.

We are in the process of trying to get new insurance. PLEASE pray that we can get other coverage. [The preferred hospital] no longer accepts our insurance. We have an extension, but this will not last much longer. We are hoping and praying another insurance company will take us and not charge us as much as the new stimulus package. LOL I just know when they see Kevin's diagnosis, they will say sure we will take you...but it's going to cost you an arm and a leg!!! Please pray for us to find a resolution (Kevin, mother, 3/22/09).

The last entry on the topic:

We just received a quote from our insurance guy for possible new health insurance. Please pray GOD's continued hand in this issue. It has been so heavy on my heart. Please pray GOD will work out every last detail. As it is now, we are out of network with our current insurance. The new insurance would help us to be in network with all procedures and clinic visits (Kevin, mother, 4/2/09).

Parenting. Periodically parents included stories of the effect of the experience on the siblings of the affected child.

Siblings Ok, I need to tell my sweet story about my sweet baby Abbie. A lot of this is about Lucy but Abbie has definitely had her challenges over the past couple of months. Abbie is a pretty fun loving child who doesn't talk much about things. Well, her teacher Mrs. Martin came yesterday to tell my mom about Abbie's reaction to the counts being up. She said that after they found out Lucy's counts were up she went and told Abbie. They were out on the playground so Mrs. Martin went out and told Abbie she had some good news to tell her. Abbie said "Lucy's counts are up!" When Mrs. Martin told her "Yes!" she was so happy that she perked up the rest of the day. Mrs. Martin said that

Abbie had been happy all day but there was a noticable difference in her mood after she heard Lucy's counts were up. Isn't that just so sweet? I hate that it effects her so much but it shows what a deep thinker she is. Poor sweet baby (Lucy, mother, 2/21/09).

Parents identified conversations as stressful for their revelation of the child's thoughts about the illness and its consequences.

If I die... Today I realized yet again how deeply Lucy thinks about everything that is going on. She is a very deep thinker and obviously thinks about leukemia and all its possibilities way more than I wish she did....So sometimes I wonder what I should post on here, but I figure I haven't censored too much so far and I do want Lucy to have an accurate record of what happened during this time so here you go....So as she is sitting making this present she says "Mom, if I die of leukemia will you have another baby." Jaw on the ground "Ah, Um, Stutter stutter". I go on to tell her that she is going to be fine that she is doing well in treatment and her chances are great. Also, that we could never replace her. She then say "Yeah I know all that I was just curious if I did die, and you had another baby, and it was a girl would you name it Lucy". Ok, pick my jaw back up off the floor again! Two times in a row. "UM, no, you are the only Lucy and you aren't going anywhere". Then she sort of humpf and said, "But I thought maybe you would because it is a pretty name and you would want to remember me" Then I realize she is actually upset. AGHH you can't win....You know now that I think about it that conversation happened a couple hours after reading Abe Lincoln and he had a son die and then they had another child to help Mary get over him. Ah HA!!! Like I said deep thinker (Lucy, mother, 3/10/09).

Multiple small children. Decision making about symptoms in the affected child's siblings seemed to play a role in increasing stress among these bloggers. The impact of worrisome symptoms influenced the parent's thinking about whether or not it would be safe to bring the affected child home from the hospital to a house with a sick sibling.

How crazy a cancer mom's mind is To let you know how crazy a cancer mom's mind is this morning as I was getting ready to get Lucy, Abbie was coughing as I listened to her I had two opposing thoughts running through my head 1) Her cough isn't that bad it is left over from the flu and could last two weeks then I would think but are you only thinking that because you want Lucy home and Abbie can't be sick for her to be home 2) Abbie's cough sounds bad and way worse than typical flu then I would think but do you think it sounds bad just because you are scared Lucy will get sick. Needless to say I went in a vicious circle - "sounds fine - maybe that's because you just want Lucy home - sounds horrible - maybe you just are scared Lucy will get sick" - you get the picture. Finally I decided a trip to the pediatrician was needed to break the vicious cycle was in order. Luckily they didn't think I was crazy but thought it was a good idea to make sure (Lucy, mother, 3/5/09).

Shared suffering. The shared burdens of neuroblastoma were expressed by parent bloggers repeatedly over time. At first, the shared illness experience with other families living with the same illness was a comfort as they learned more about the illness, its treatment and its trajectory. Over time, themes related to sharing other families' burden were evident to a greater degree. While companionship, trust and reliance were evident in the stories, stronger and more numerous were the narratives of loss and grief, not the author's alone, but also the grief for other families similarly affected and for the heightened fear of their own child's death.

Family fraternity I've been following the website of a girl with NB who was declared cancer free SIX years ago. This year (when she was eleven) the cancer returned and she's back in heavy treatments....It's amazing how people we've never even met become a part of our hearts simply because our children share the same deadly disease. Even though it would be easier to ignore the stories of heartbreak concerning other children with NB, I feel so inextricably linked to them. Their burdens are my burdens, their pain is my pain. I know that when (if) the time comes when Leigh slides back into relapse, I will want to know we are being carried on the shoulders and on the prayers of ones who have been there before us (Leigh, mother, 11/9/06).

Reminder of what is important Lyle Saxon has earned his angel wings. I think everyone that knows Cindy certainly knows of Lyle and his family. They were a fixture in our lives from nearly the very moment of Cindy's diagnosis. In fact it was Merrill, Lyle's dad, who was the first person I had ever met that had a child with neuroblastoma. At the time, they were a huge source of hope for our family. It was Merrill that explained to me in those first few weeks after diagnosis that life would never be normal again but that our lives would take on a new normal. He told me that we would be okay. That we would make it through. It was that support and those words that gave me the strength to plug on and to care for my family....Lyle will live on in my heart. He will be a constant companion and a constant reminder of what is important in life. He will remind me to stay diligent so that we can help as many kids as we can. One day we will find a cure for this

disease and we will find it faster because of him. It is kids like this that remind us of what is important (Cindy, mother, 7/16/07).

Gifts

Narratives about gifts that could be cherished balanced the stories of burdens during treatment. The parent blogs were replete with narratives of thankfulness for gifts bestowed by the experience, both tangible and intangible: a renewed appreciation for even the simplest pleasures; admiration for the child as he or she copes with life during the illness; the help from family, friends, strangers (especially blog readers) and professional; the perquisites of charitable gifts from others; and the creation of lasting happy memories.

Answering 'why?' One of the questions that many people ask when faced with a crisis such as this is: "Why did this happen?". Now I don't know why, but I haven't asked myself this question and I guess it is time to face this demon. As it is, apparently, a "normal" stage of grief. I know Lesley has asked this question many times, but it has never occurred to me....The "Why" question has just never made any sense to me and I guess it might be because of the way that I look at life....It isn't that I don't believe in God. It isn't that I don't believe that there is someone in the heavens guiding our destiny. I just learned, early on from dad, that life wasn't going to be fair. I have accepted that mantra since I was just a young pup. I believe I learned to deal with life's little hurdles when my dad passed away....It became much easier to deal with crisis as I got older because I always knew that something positive would come from every experience. So, I spend my time looking for the good, looking for that special nugget of information that I should

learn. What can I gain from this experience? It just doesn't occur to me to look at life any other way....You know, I am lucky, this has already brought me a sense of compassion that I never realized I needed. I care more. I love more. And, most importantly, I appreciate what I have even more. We have a long road ahead and lots of learning to do. So for the time being, it really doesn't matter why this happened, but rather, what are we going to take from it (Cindy, father, 7/9/03).

Admiration He did really well on this round. It's awful to say, or strange or good or something, but I think he's getting used to the chemo drugs and handles it better each time. He didn't want to eat (besides the odd bag of chips) but he wasn't sick this time at all. I found out that the dark skin around his nails is a chemo side effect. It's changed the pigment of his skin from the top knuckle, up and around his nails to a dark brown. The poor kid. I'd been nagging him for the last couple of weeks to wash his hands all the time because I thought it was dirt. He's also started loosing his eyelashes and his eyebrows are thinning out as well. It doesn't bother him a bit though. He just shrugs and says "hey, it'll grow back". He really is an amazing kid. He rarely complains and he's so completely aware of everything he's going through. If I'm late with a medication he'll remind me and he even caught the nurse in a mistake she made in his chart when she mixed up his height & weight (Silas, mother, 5/22/06).

Perqs The Make A Wish Foundation has approved Silas's wish to go to Paradise Island in the Bahamas. We haven't set a date yet but sometime in the new year, we'll be off for a week of (much needed) fun in the sun. We wanted to wait until he has his Broviac removed so he can swim and we're hoping that will happen

before Christmas. He also wants hair before he goes on a holiday. It feels good to make plans for when his treatment is done (Silas, mother, 7/5/06).

Mario The highlight of Dman's day/week/month came today in the form of a guestbook entry. One of his chemo angels asked Dman who his favorite sports stars were, they try to arrange to have one of them send a message to the guestbook. Dman's number one choice was, Mario Lemieux.. and sure enough, he sent a message on Wednesday! If you read the guestbook, it's the second newest entry on Wednesday. I've already responded to the generous offer they made, and hopefully we'll be in town and be healthy enough to take advantage of it (Danny, father, 8/21/02).

Trip to Toronto We had such a great time in Toronto. The incredibly big hearts and generosity from PlayStation has been so overwhelming. I just can't find the right words to say how grateful we are for all the love and support we have received for Silas. I truly believe that all the good wishes and encouragement that he's been given from EVERYONE has nourished and helped him to recover so well. It will forever be felt by all of us.

Silas and Cassie were both spoiled rotten in Toronto. Not only was Silas presented with his PS3 (which he had hooked up, updated and was playing a game before I even got through the front door on Sat.) but also another big jaw-dropping surprise was the Flames jersey. Signed "To Silas, Thinking of you, your friends at the Flames" and all the players signatures. I think Brad almost fell off his chair when he saw it. And Cassie (who was feeling a little glum that morning)

was presented with her own silver PS2. Wow! Did that ever put the biggest smile on her face (Silas, mother, 11/20/06).

A memory to last forever This weekend we will be going on a trip to Washington D.C. Cindy has been invited to participate in the Easter Egg roll on the White House lawn. We are extremely excited about the opportunity and, to be honest, are just plain giddy at the thought of a vacation. We know it will be a memory to last forever (Cindy, father, 4/5/04).

Interestingly, a comment from a reader inspired a lengthy missive on the meaning and value of the special experiences afforded the sick children and their family members.

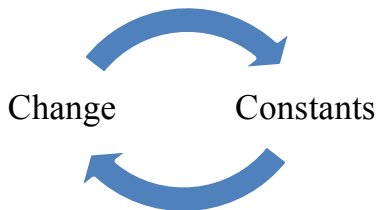
A few moments where we don't feel like the world is caving in on us Speaking of glitches, there is an area of this illness that doesn't seem to be discussed too often in the open. We've had the discussion with other families that have children with cancer, and it seems to be a theme that is quite common, so being the sarcastic mentally frayed individual that I am, I figure I can get away with writing about it on here.....so here goes. There are NO amount of camps, celebrity visits, trips, toys, parties, etc. that make having a child with cancer worth while!!!! Please don't misunderstand that sentence. We are extremely appreciative for all of the wonderful experiences that we've had, but, we'd gladly trade them in for a healthy child. This may seem like a very logical statement that should go without saying, but we have encountered people that exude a feeling of jealousy over some of the experiences that Dman has had. What some people forget, or never appreciate is, that every night when we go to sleep, we lay down with the knowledge that our child is fighting for more life. Every morning when we wake up, the first thought through our minds is about our child and that fight....so, when we are blessed

with a camp outing, or a football game, or a toy for Dman, we maybe get a few moments where we don't feel like the world is caving in on us....I believe that we are existing on a different level than we used to. Picture a piece of paper with a line dividing it in two, horizontally. Everything above the line is a positive experience (marriage, children, laughter, promotions, etc.) Everything below the line is a negative experience, (death of a relative, boss yells at you, pain, divorce, etc.) I think most people are able to stay on the line and live with the events that sometimes put them over and sometimes put them under. Now, picture another horizontal line that runs about three inches below the original line. THAT is where families like ours are surviving! The events that would normally put us over the top, only manage to bring us close to that "normal" line. The feeling is good, we really do enjoy the positive events, but you always know that you are there because of how sick your child is. And I think that it is important for everyone to understand this. THERE ARE NO AMOUNT OF SPECIAL EVENTS THAT WILL CURE OUR CHILD. But, they do make Danny feel great! They do give him moments where he doesn't feel like a human pin cushion, or a permanent resident of a hospital, so we gladly take advantage of them!...there are many families like us out there that have had to endure the same feeling that I have described above....(Danny, father, 9/23/02)!

ALL as ‘good cancer;’ ‘curable kind;’ ‘best type.’ For parents of children with leukemia, parents expressed relief when the child was recognized as having “low risk” ALL during classification of the child’s illness on the risk category spectrum.

More positive outcomes But, she said that the national lab that also does the tests showed that Lucy had a chromosome abnormality that is associated with more positive outcomes and thus instead of a standard risk patient she is now classified as a low risk

patient. YEAH!!!! This doesn't really change a ton. However, obviously it means that her chances of long term outcome are improved some. Also, it means that she is now placed on a different route of the study (Lucy, mother, 1/6/09).



Change

In the parent narratives, it was readily apparent that cancer brought profound change to family life. At the same time, some constants were described that the cancer experience could never change.

Time for some families was described as being divided into life “before” and “after” diagnosis. Everything was different, and sometimes this was welcome, as when parents wrote of renewed appreciation. At times, though, the frustration with the loss of control, the omnipresent uncertainty and the effects on the child and family were overwhelming and appeared frequently in the writing.

Before diagnosis/after diagnosis When she was home for three days...we took her and Martin to a kid's movie. I was amazed at how different everything felt-- Dave and I have discussed that life seems to be divided into "before diagnosis" and "after diagnosis." Before her diagnosis, I took her laughter for granted....But sitting beside her in the theater, after having gone through two weeks of pain and uncertainty and fear together, each smile and giggle was a beautiful treasure. Her smiles before diagnosis were worth about a penny, they were plentiful and

effortless. Her smiles after diagnosis are worth more than diamonds....(Leigh, mother, 6/4/02)

Metamorphosis I am continually amazed at this transformation that I have had as we have walked this road with Cindy. I continue to change on a daily basis. As I reread my diary and reflect on my fears they appear foreign to me. I think part of this metamorphosis is, not only the changes a parent of a child with cancer would normally go through but, also, the additional benefits of "Lunch for Life." [a cancer research fundraising effort] I no longer feel the powerlessness. I feel like I am contributing and I am making a difference. Combined with this I also have ever increasing hope. Hope is the most important feeling that a parent could have. It is the one thing that enables me to put my foot in front of the other everyday....What I am saying is that hope is the foundation and without it none of the other feelings and emotions would be able to exist....With all of the positive that is happening I no longer let my mind drift to the "what ifs." I simply do not have the time. I also feel comfort by helping others and that increases my sense of meaning. Right now, I am living in a whirl wind of positive emotions and it only can benefit me and my family....As I prepare for Cindy's transplant in the month of December I want to document all of these positives because I know there will be another time in which I am not so sure....(Cindy, father, 10/30/03).

Changes in life due to treatment for both neuroblastoma and leukemia were described by the bloggers in the context of pre-and post-diagnosis or as giving up an old and adopting a new normal.

Old normal/New normal NBL ... This week I read a quote from a woman whose child had also been treated for cancer. She said that when they got into the routine of blood draws, hospital visits, surgeries, procedures, etc. that became their “new normal.” She then went on to say that the hardest part of the whole experience was that when the “new normal” (the period of treatment) was gone, the “old normal” just didn’t seem normal any longer! That whole “old normal/new normal” dilemma is even more complicated in our situation because Leigh’s cancer and treatment have completely altered our lifestyle, our ministry, and our career. We aren’t planning to go back to the life we had before May 17, 2002; we’re going to sell our R.V. (which has been our home for almost eight years) and chart a new course. One of the main reasons for the change is that we don’t feel that traveling extensively around the country is something that someone with Leigh’s medical history needs to be doing....Speaking of the “old normal,” “yesterday, Dave and I sang together for the first time in eleven months....It felt good to step back into that role. But it still felt strange to me because the “old normal” was different. I had changed, Dave had changed, our lives had changed and our family had changed. I just felt adrift from my old life and not yet connected with a new life. It’s been a very strange season, indeed (Leigh, mother, 4/14/03).

New normal-ALL It is such a strange thing this new normalcy that we have. I realize most people would think it would be great and it is however it is also unsettling. I know that sounds weird but with each normal thing it just reminds you of how abnormal things have been. Also, it seems to put front and center how much things still aren't normal. I'm

not sure they will ever be completely normal - I guess this is the NEW normal you hear talked about around clinic and the doctors.

When things were just completely cancer you never thought to compare it to what it should be, you just knew it was all wrong. Well now we are trying to strike a balance between cancer and normal life. The problem is normal life doesn't include cancer.

I think one of the issues is trying to get back into normal life and normal problems. One thing cancer has taught us is that most things aren't that big of a deal in comparison to cancer. It definitely has put things in perspective, however normal life consists of a lot of little issues that we can't totally blow off. Trying to strike a balance is a challenge for us. Don't get me wrong I will take normal problems any day of the week over the issues that are dealt with at clinic. I'm sure we will find our way and really everything is going fine, but it is definitely an adjustment.... I just worry more. I guess that is the job of the mother. (Lucy, mother, 8/22/09)

From a sociologic perspective, it was interesting to find themes on parenting a child in the 21st century in general. A few of the parent bloggers expressed frustration with issues that have come to be understood as unique to millennials: the speed with which tasks get accomplished; the idea that attention to children can be portioned out in increments of time; and the effort to multitask so as to accomplish more in less time.

Cancer parenting in the 21 century ...Cindy is still competing for our time by acting out....It is somewhat unfair for her. Being the oldest we expect more from her. Elly is a newborn and requires frequent attention. Sam is fifteen months and requires constant supervision. So where does that leave Cindy? Well, it leaves her craving one on one attention and acting out to get it. As I said, Lesley and I are

struggling to find the balance. We try to spend at least thirty minutes of one on one time with each child everyday but right now, although it is better, does not seem to be getting the job done. It can be hard to see the trees for the forest. It let us see that our sweet baby girl was still in there and we just had to find a way to get her out again (Cindy, 5/7/05).

Families who experienced more than one change as a result of the illness were very expressive about the stress that this induced. Some families made changes in one or both parents' work, relocated temporarily or permanently to be nearer to care; remained in jobs that they were dissatisfied with to maintain insurance coverage; and changed schools to meet the child's unique learning needs.

Repeating second grade Since there's not a lot of medical stuff to report right now, I'll fill you in on what's going on with Leigh's schooling. A second grade teacher in our church did some extensive testing and confirmed that Leigh would have a difficult time going on to third grade considering that she missed more than half of her second grade year...I must say that I feel a sense of loss about not home schooling any longer; I am very much a teacher at heart and I have so enjoyed schooling my kids....The changes in our lives this year have been intense; although many of those changes have been incredibly difficult and wrenching, some of them have actually turned out to be good, like Leigh having her dream come true of going to "real school."... But things are changing again....So let the big orange bus whisk her away! Let her be in a classroom that doesn't teach about suffering and pain. Let her spend her days drinking in the riches and the joys of being a kid. Let her explore a new world that will thrill her

little heart. She's learned enough about real life to last a lifetime. Let the lessons of childhood begin (Leigh, mother, 6/21/03).

Here, the blogger expressed the unsettling feelings associated with identity changes that resulted from the experience.

I am the same person but I'm not. ...I've been pondering alot recently about life and how different mine is now. I am the same person but I'm not. There is something very different about me and it's not visible until I tell someone my daughter had cancer. The look on their faces changes instantly. It's strange. For me it's so matter of fact, that sometimes I think I overwhelm people with the way I talk about it like it's no big deal, rattling off about the tumors, bone involvement and marrow. Sometimes I leave people speechless and I don't mean to. Other times, people will ask about it and once they hear it all, I don't really hear from them again. I have some friends and family, but most of the time I feel so isolated....completely alone. The friends I do have I rarely talk to and I only talk to a couple people in my immediate family too. I am not great at making new friends. I have wonderful friends from all over the country that we have met through Sloan. They are the best friends because they "get it". Unfortunately I rarely get to see them. I'm at a complicated point now. I am closest to a "normal" life than I have been since Ana got sick. So where do I fit in.... I talk to people about regular every day things, but it feels awkward to me. I don't and never will look at things in life the same way again and unless you experience life having a child with cancer, you'll never get what I now feel. So many things that are every day worries or bothersome and aggravating to people, are petty to me....I think

that's why I am having such a hard time connecting with friends. So much has happened and I want very much and feel that it's time to get out there and make some new friends, but I don't know how. I think I am sabotaging my own efforts by internalizing and scaring people away by only talking about Ana. I don't know how to talk about anything else....But I have to. Then again, I don't think of it as a sad topic anymore, or at least I can see the good that comes out of it. I'm sure as time goes on I'll reconnect with old friends or make new ones, but I don't think I will ever lose that isolated feeling. I have a scar on my soul that has forever changed me. One that no one can see, but I feel every day.... (Ana Lynn, mother, 3/1/09).

Other parents in the blogs expressed the phenomenon of turning into “somebody new;” of becoming a blogger; of identifying with other parents living with neuroblastoma; that cancer became a way of life, but that it did not define them.

Turning into a cancer zealot? ... I think I have turned into somebody new. I am definitely no longer than man I once was. I am so more aware. I am so more feeling. It is an extremely wonderful gift to come from this tragedy but it also comes with many burdens....I am now on the inside looking out and I can't figure out why this was never important to me before Cindy was diagnosed with cancer. Why was I not affected? I think the reason is that I was not aware...and yet now, I feel it on a daily basis. I have thought about what it would be like if I lost Cindy to this monster. It is real. It is not one of those thoughts that just floats through my mind. I can feel it and taste it. Now, when I hear about the loss of another child it actually creates a physical change. My heart starts to race, my breathing becomes

shallow, and I can feel a lump in the back of my throat....I think part of my frustration also stems from all of the funding research that I am doing. I was looking through the National Cancer Institute's budget. This is the federal entity that doles out money and resources for all things cancer. Their federal budget was \$4.6 billion last year. Of that, pediatric cancer received \$154 million. All pediatric cancer. That is about 3%. 3 percent of the federal cancer research budget was spent on all childhood cancers. Is it just me? Is this shocking to you? To me it is but I no longer know if that would be shocking to me if I did not sit in this world....Look at the response that we had to the Trade Center bombing. In less than a week we raised more than the yearly budget for childhood cancer for the families of those that lost loved ones in the tragedy We lost close to 3000 lives in a few minutes. With childhood cancer we lose that every year. Why isn't it important? What is the difference and how do I fix it. What can I do right now to fix it? I certainly do not have the answers and I feel like I am turning into a childhood cancer zealot. Am I? My purpose is stronger than ever especially on scan day (Cindy, father, 8/16/04).

Identity as a blogger I was reading an article in the newspaper the other day and caught notice of the phenomenon know as a "blog." (Spell checker doesn't like that word...by the way.)

I have seen this word used before and never gave it much notice. Now of course I've come to find out that I am guilty (if there is any guilt in doing it) in participating in this practice. Here....all of this time I thought I was writing journal entries....when in fact I was BLOGGING!

I looked up "blog" on Google.....and it came back with 158,000,000 responses(Yes...you read that correctly 158 million.) If you don't believe me go type it in yourself. I didn't bother reading any of the links.....I figured.....well....I've somehow managed to fumble my way through this whole "blog" thing for a few years now....I guess I can handle it for awhile longer without reading up on how to do it (Danny, father, 9/3/05).

Identity change Who are we? That simple question is probably easy enough to answer for most people. Think about it, if a reporter walked up to you on the street and stuck a microphone in your face and said, "Who are you?" Most of you would be able to answer that without too much difficulty. One of the following statements might even escape your lips in an effort to summarize your identity: "I am a housewife." "I am a student." "I am a family man." "I am a police officer." "I am a doctor." "I am a volunteer."...I have recently come to the realization that Marcia, Danny and I may be facing a "hidden" challenge to our identities that we had never envisioned. On March 16, 2000, our identities were permanently affected by the diagnosis that we received that day....The trick in moving forward and carrying on with life is to not let moments like that DEFINE who you are or how others view you....So, why the philosophical discussion all of a sudden? Well, I am beginning to notice something inside of me that is quite foreign and somewhat intimidating. I am starting to feel like I am no longer the person who I thought I was....Danny has been battling cancer for 8 years. 8 years, and he is only 14 years old! That is close to 60% of his life. And when you factor in that it's the most RECENT 60 % that he doesn't have many memories from the first 40 %

you start to see where on most days he is DEFINED by his illness. In a perfect world, Danny would answer the "Who are you?" question like this: "I am a bowler." "I am a soccer player." "I am a son." "I am a student." "I am a giving person." "I am hopeful." "I am looking forward to the future."

Instead, he is more likely to respond: "I have cancer." "I am tired." "I am in pain." "I am angry." "I am frustrated." "I am worried about my future." "I am worried about my parents." "I don't want to die." "I miss the friends that have lost their battle with this disease."

As for Marcia, I have never asked her what her perfect world answers would look or sound like, but I can guess: "I am a mother." "I am a wife." "I have a healthy family." "I have a wonderful life." "I want for nothing."

Instead, I think that she is faced daily with thoughts like: "I have a son with cancer." "I have health issues that prevent me from fully enjoying life." "I am a mother who is worried that her son will predecease her." "I am depressed most days."

As for me, I guess my "perfect" world answers would sound like: "I am a husband." "I am a father." "I have a healthy family." "The future looks bright."

Instead, I feel mired in thoughts like: "I am a husband who cannot alleviate the pain of his wife." "I am a father who cannot find a cure for his son's cancer." "I am a person who can't remember what it is like to be without worries."

None of us are above life challenges or personal anguish. I am not suggesting that my problems are any worse than the problems that all of you face. I am merely turning the magnifying glass around and peering into the deepest parts of my head

in an attempt to see what it is that makes me tick. Like Danny, my memories of life before cancer are fading more and more every day. I have told friends on many occasions that because of how long we have been doing this, cancer has become a way of life for us. I guess the burning question in my gut is, WHO AM I? I thought that I knew who I was. I thought that I knew EXACTLY who I was. Now, I am not so sure. Maybe I DID know who I was, but somehow, I let that person become someone else. Maybe we all change over time and become a different person as we age and travel through the various stages of life....

Is there a difference between other people defining you a certain way and you defining yourself that same way? "There goes Brett & Marcia, their son has cancer." Vs "Hey, nice to meet you, my name is Brett, this is my wife Marcia, and that's our son Danny over there, the one with cancer." (We don't do that, but you get the idea.) What is our identity? Can we live in this cancer world that we find ourselves in and somehow define ourselves without it? Will Danny EVER get the chance again to be just 'Danny'? When does Marcia get to be defined without this hanging over her head?

I once heard that an economist can be compared to a person that stands on the back of a train, trying to determine where it is going, by watching where it has been. I'm guessing that what they were trying to say is that every once-in-a-while you should look out the FRONT of the train to see what is coming. I think that we are having trouble looking ahead, because we are so deeply entrenched in where we have been (Danny, father, 4/23/08).

Stories of personal change also included having learned to be more assertive and to live from day to day even though the parent had identified herself as “planner” before the child’s illness.

A change of thinking I can't say how difficult it is to live day by day like this.

The funny thing is, we all live like this, we just don't know it! I'm a HUGE planner...I have a calendar that sits on the counter at all times, I live by it!

Through this experience I have had to adjust to living just one day at a time. I don't know if I'll be home tomorrow, or in the hospital. I don't know if I'll be home next week, or in New York City. It is unnerving I guess...certainly a change of thinking for me. Aren't I glad I have my one constant...my hope and trust in God that is the same no matter what the day holds (Jeremy, mother, 3/2/09)!

Work. As family balance is regained with diminished intensity of the care being provided, some parents explored renewed attention to work life.

Today was a strange day. I actually helped interview two candidates for the position I resigned from. The interviews were held at the district office. I hadn't stepped foot in there since December 2005 and was so curious how I would feel returning, particularly under these circumstances. I have often considered whether I could go back, would want to go back, would have any interest, could make myself if I had to....I was hoping that after being there today I would be overwhelmed one way or another and unfortunately I was not. It did feel very comfortable being there. I suppose I was just left of ambivalent. Meaning, slightly more interested than perhaps I thought I may feel about ever returning. I went to my office and looked at my desk, which remained untouched. Literally untouched. There were even a few Christmas presents for me from 2005 left there too,

still wrapped. It was a sad commentary of a life turned upside down by misfortune.

There, tacked to my bulletin board remained a few to-do lists. It was like a little time capsule. Pictures of my kids littered the desk, all from a time when stress was of a different variety (Isabelle, mother, 3/21/07).

Later in the blog, the mother shared more on the topic of work.

The decision has been made, I have committed to working very part time this summer!

As many of you know, Special Education operates an extended school year (summer school) for their students. It's starting on Monday and runs through the end of July. I have agreed to work UP TO 15 hours a week for the extended school year only. At the end of this commitment I'll determine what, if at all, my schedule would look like. I obviously have very mixed feelings about the whole thing. I have of course worked in the flexibility of not being there should anything come up with Isabelle. So if necessary, I can not be there and on a good week I'll be there 15 hours. It should be a nice trial period. I'm also hoping to really focus on one or two projects and have requested to not be pulled in many directions as my psyche is fragile :) I anticipate them being pretty accommodating of MY many "special needs (Isabelle, mother, 6/11/07)."

When the demands of work life exceeded the mother's ability to cope with home life and vice versa, she wrote of the emotional toll.

Many of you have asked about my working. I have skirted around the topic for months because I wasn't sure what to say. It hasn't been black and white for me. Last summer I thought I was ready to give it a try. Isabelle was far enough into her maintenance regimen of chemo and things were pretty stable....The first week was super emotional. I was bumping into people I hadn't seen in almost two years and of course everyone's first

question was, "how's your daughter?" I was relieved once I had bumped into everyone. I hope that doesn't sound like I didn't want them to ask, in fact it would have been odd if they hadn't. I was just so still in the thick of it, it was tough. And while she was doing very well, Isabelle was still a baldy and very thin, so it wasn't like I could whip out a picture and say, "she's doing great, look at her." Anyhow, by the end of summer school, it was very apparent to me I was not yet ready. Since my work requires me to make decisions for children, it was weighing heavy on me. I couldn't be responsible for anyone else's child and couldn't in good conscience give it less than 100% I found myself crying when I would get in the car to go home about this child or that child (I work with special needs kiddos). I suppose it was too close to home. Soooo, I took some more time and planned on going back Dec. 1st. Well, then of course Isabelle had the pneumonia and we had to pull her out of school and Dec. turned into Jan. and just as I would put a day or two in, someone was sick. Anyhow, now I am back at work and on a good week I'm there 3 days. I have to say that aside from being an absolute freakish germaphobe (better now that flu season is behind us) I am enjoying being there. I wasn't sure I was going to ever be able to say that. Autism was my passion. Yet when Isabelle was so sick, I couldn't think of anything else but Leukemia. Friends or family would call and say, "there's something about autism on at 8" or whatever and I could not have cared less. It was unsettling to me that I didn't care. It was in fact foreign for me not to care. Well, I'm caring and quite relieved (Isabelle, mother, 4/10/08)!!!

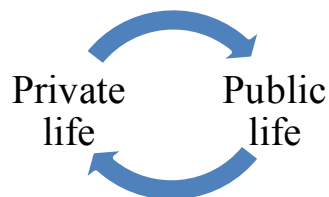
Constants

Parents identified those elements of life that remained constant in the face of the many changes that accompanied the illness experience: what defined the family; the ability to write

about the experience; the measure of success; and to maintain the ability to recognize when things were going right.

What defines our family We don't know how long these good days will last but we do know that our family is forever and the love we share will get us through whatever the future holds. Although cancer has left its mark of sorrow in our home, and although it may leave an even greater scar in the future, it is not what defines our family. We are defined by love, and by God's grace, and by the laughter in our walls. Cancer can never invade these halls of peace (Leigh, mother, 9/11/03).

Happiness as barometer of success Well, unfortunately I am still doing everything but what I want to be doing. Work is impossible. Although I love what I do, right now, I despise going into the office everyday. I can only remember once in life that I was this stressed out and to be honest I would spend everyday of my life in this state of stress than experience the stress related to Cindy's diagnosis and treatment. But, I still just want to get away. I am still spending quite a bit of time with my family even as I work myself to the bone but it never leaves my mind. I just never allow myself to take that relaxing breath. I would much rather be just enjoying our lives but instead I am walking around feeling as though a black cloud is looming over my head. I don't know when it will stop but something has to give soon....Cindy, Sam, and Elly all appear healthy and minus the usual angst associated with being a kiddo. I think they are happy which is my barometer of success....(Cindy, mother, 6/29/05).



Public

Parents seemed to struggle with the amount of self-editing that was required to maintain a balance between what to include and exclude from the blog. For nearly all the parents writing in this study, the blog became a forum for advocacy to some degree. Parents wrote of public speaking opportunities, fundraisers and media interviews as means to tell their child's story and to advance the research initiatives. Indeed, the blog became a medium for sharing the child's story.

Public speaking I was asked by the Quantum House to speak at their monthly board of directors meeting. All of their members have seen the house and been to functions here, but some have not heard from a family that has used this wonderful facility. I gave a brief history of Danny's illness and talked about staying here, and about our visits to the Ronald McDonald homes in Gainesville and NYC. Afterwards, I was pleasantly surprised that many of them had questions for me. They asked for more details regarding Danny's illness, and about how they might improve the Quantum House for families. I usually have a difficult time going through Danny's history, but I guess I'm getting more comfortable with relaying the story. This group was very caring and receptive to my comments.

After that, I dropped Marcia and Danny off at a local beach, where a few other families were meeting with Connor Moran Children's Cancer Foundation to video tape a commercial/promo video for that organization. They have done so much for us, we gladly participate whenever we're available. Marcia says that Danny was like a little movie star.....when Spielberg calls, I'll be ready (Danny, father, 10/12/02)!

Icons of NB Alex Scott passed away yesterday afternoon. She was the 8 year old founder of Alex's Lemonade Stand For Pediatric Cancer Research. Many knew her from appearances on the Today Show and Oprah. Over the last year she has raised nearly \$700,00.00 for pediatric cancer research with her lemonade stands. She was an inspiration for thousands upon thousands and for many families with neuroblastoma she was the torch bearing hope that this disease could be defeated. For me, she was pure and kind. She was the essence of what a child is and should be. She cared and she loved and she had such an incredibly happy perspective on life. I will miss her terribly and I feel so much for her parents. Alex often said "when life gives you lemons, make lemonade." I am struggling to make sense of how I can make lemonade from this. Tell me how this makes sense....(Cindy, father, 8/2/04).

A father expressly and proudly declared being willing to “use” his child’s story, his attractiveness, the sympathy engendered by the illness experience, etc, to aid research fundraising.

Fundraising—using Tony as a hook Melinda and I were invited to speak at [the local] Children's Hospital Auxiliary "Holiday on Broadway" fundraiser two weeks

ago. We thought it was a good idea for two reasons: One, the fundraiser was supporting pediatric cancer research at RCHSD. Secondly, we could tell Tony's story and hopefully by doing so, create more awareness about neuroblastoma and our personal efforts to fund promising research that can be used by Tony and his fellow NB buddies *soon*, if not *now*!

Our role was simple - to soften up the crowd with our (Tony's) story prior to an auction, the proceeds of which would benefit pediatric cancer research. So, all in all a worthy cause and one in which we didn't mind participating....As most of you know, we are not afraid to play the cancer card and above all are willing to use Tony as a hook to draw attention and funds as long as the people and the cause are something we personally trust and believe in. To that end, the night was a success and I believe they raised close to \$50K (Tony, father, 11/23/07).

During a time of particular stress for this mother, who frequently received comments complimenting her on her ability to "juggle so much," which can be interpreted as criticism for a too-busy life, the author takes an opportunity to remind readers of the reason for writing (Fey, 2011).

Blogging to tell the story, share faith I feel a little overwhelmed lately by the responsibility of sharing my family's life with everyone who reads our blog. Certainly we are in awe of the number of people who have read about Jeremy's story and we are humbled by how many are praying! I guess I just want everyone to know that in my imperfection I might not always write clearly, might not always explain things in the right way, and might not always do things the way other's think I should. I'm just a mom who is doing the absolute best she can right

now. I said this when I first started writing and I'll say it again, I'm blogging to tell the story of my precious son Jeremy who has cancer. I've since realized that by sharing the story of this difficult journey, I'm also sharing our faith. It is my prayer that I'm bringing glory to God through this blog, despite my imperfections (Jeremy, mother, 3/28/09).

Raising awareness I am at a loss for words. Yesterday was amazing, overwhelming, indescribable, touching, emotional, and fun!...I did my best to raise awareness to neuroblastoma and childhood cancer. I know that I could have done so much better...but did not expect people to just sit and listen as well as they did. I thought I would be kind of “background noise” and wanted to keep it brief. I think before I got my second sentence out the room was totally silent. I started to break down a few times, but knew I had to finish it. What I had to say and what I needed to share was too important to back out of. I was able to share with everyone a little background of childhood cancer and some information about neuroblastoma. I was also able to let people know a little about what Mimi did to show us that she was sick. I gave thanks to the many people who helped make the night possible, probably leaving out twice as many people as I thanked. As I left the stage I lost it. I was looking to walk straight back to the back of the room and find a place to just be alone to gather myself...and there were people everywhere!!! (which was a great thing!). I met my dad in the hallway and just lost it. Somehow my dad just has that effect on me, he can just stand there and be strong and let me fall apart – that’s what daddies are for I guess!! I feel terrible

because Chad had to come find me, I should have went straight to him. I just wanted to get away though (Mimi, mother, 4/30/07).

Solicitations to readers to become more active in politics as it pertained to childhood cancer were evident. One parent even made the decision to run for local office but withdrew from the race before the election.

Politics 1 Well, I am off. There is a ton to plan this week with all of the Lunch for Life events and it even looks like we may be able to get some families together to deliver lunch to the COG meeting this week. It is going to be a great opportunity to bring some much needed press to the Conquer Childhood Cancer Act of 2007 which is a very important piece of legislation for our children (Cindy, father, 4/16/07).

Politics 2 On Friday, I mentioned Proposition 15. Although this is a Texas "thang" its impact will certainly be felt throughout the world. For me, its passage is more important than any political election. This piece of legislation will save hundreds of thousands of lives and inject 3 billion dollars into cancer research. Although this is only a fraction of what is needed for cancer in general, it will surely speed the cure. It will save lives - PERIOD. Now, this is obviously not just for pediatrics. The bulk of the money will be used for adult cancer but I am all for the trickle down theory if will get more promising new agents into the pipeline. We need more options and this will provide it. (Cindy, father, 10/15/07)

Politics 3 PLEASE VISIT THIS SITE, SIGN THIS PETITON, FORWARD THIS INFORMATION, and GET THE WORD OUT THERE!!
WE NEED TO MAKE A DIFFERENCE NOW.....

Dear Friends and Families,

Children with cancer continue to be treated primarily with drugs that were developed 20-30 years ago. Scientifically, researchers have reached an era where new types of 'smart drug's can be developed to treat cancer at a genetic level....

As supporters of the development of new targeted therapies for children and adolescents with cancer, we petition Congress to support H.R. 1956, the "Patient Protection and Innovative Biologic Medicines Act of 2007;" legislation that creates a pathway for "follow-on" biologics but establishes an appropriate balance between reducing cost, ensuring safety and providing incentives for innovation.

Please forward to other friends, families, and colleagues and ask them to sign the petition as well (Mimi, mother, 6/4/07)!

For some, the blog was used as a place to make public the grievances some of the parents had about insurance companies. In addition, one parent publicized the class action lawsuit he and others had filed that centered on a potentially contaminated local water supply. The report of that narrative takes place over months, with updates by the parent from time to time.

Lawsuit 1 Well, here we are. Monday afternoon around 2pm and have I got news for you! Today in Federal Court, a lawsuit was filed on behalf of Danny against the company that operates the local nuclear power plant. There was a press conference that we attended where local papers and TV were given copies of the lawsuit and where our attorney gave a brief summary of what brought us to this point. I had prepared a statement that our attorney read to the press. Here is the rough draft of that statement: (Danny, father, 2/10/03)

Lawsuit 2 The NY Times broke the story last night about our law suit and some of the newer developments. By 4pm today there were over 100 news organizations around the world that had the story on their websites. Our local paper ran it front page! I don't want to turn this site into something it is NOT meant to be, so, if you are interested in reading about it.....just go to a search engine (Google) and under the 'News' heading, type in "Radioactive waste."
(Danny, father, 8/7/05)

Lawsuit 3 I have written very little about our lawsuit. I have tried to be patient and let the process run its course. We were 5 days away from the beginning of the trial when in a surprise move; the judge reversed his earlier opinions and gave FP&L a verdict in their favor....without a trial (Danny, father, 1/3/06).

By the end of January 2006, an appeal has been filed. No more mention of the lawsuit is found in the blog until more than two years later. Results were reported without much commentary.

Lawsuit 4 On a more somber note, the 11th circuit court of appeals has upheld the decision of the lower court and ruled against us in our longstanding case against the nuclear power company (Danny, father, 4/8/08).

Many of the bloggers received comments from readers encouraging them to create a book based on the blog writing.

Writing a book The good news is that about a week ago I started to write my book. I am probably about 20-25% done already! I was unable to sleep one night so I laid there in bed, organizing the chapters in my head, like Ive always done. When I got up in the morning, I sat down at the computer and put all of my

ideas into Word. When I sit down to write, my mind is about 5 10 pages ahead of my typing. I dont know if it will ever sell, but I am going to listen to all of you that have badgered me over the years to do it, and I WILL publish this book! It pretty much is a history of our experience, with advice and ideas on how deal with it from several perspectives. (Its happening to your family, your extended family, a friends family, or someone in your community.) As always, there will more than likely be more than a few sarcastic remarks and colorful words, but thats the way I write, so it will either work, or it wont (Danny, father, 3/18/08).

White House visit Friday was the White House tour and Capitol building tour. And in keeping with our long-running theme of living life in an exciting fashion, there was drama. Upon entering the White House, young Danny managed to set off the radiation alarm sensors. (Folks, I couldn't make this stuff up if I tried...Honestly, I know that I have pulled your chain in the past, but this really happened!) They were walking through the entrance, and from what Marcia tells me, you couldn't even see the detectors. When Danny walked through, the alarm sounded. The secret service immediately pulled him aside and allowed Marcia to walk through. She did NOT set off the alarm. The secret service asked if Danny was a medical patient, and he informed them that he has cancer. Another agent came out with a hand-held detection device that Marcia said looks like a golf club. They waived it over Danny and then asked that he and Marcia follow an agent into a special room. They entered a small room where there was only one chair. The agent had Danny sit in it, and apparently, the chair had some sort of special radiation sensors built into it. There was a large desk-like apparatus that

was displaying information about Danny's radiation to the agent. They asked Marcia the expected questions: "What hospital is he being treated at?" "What is his doctor's name?" "How long ago was he treated?" ... While asking questions, the agent spoke into a wrist microphone (just like in the movies) and within five minutes, they were able to tell Marcia that they had confirmed the type of radiation that young Danny was emitting and they were comfortable with the fact that it was NOT the "wrong" kind. They even asked if he was taking the SSKI drops to protect his thyroid. (He is.) The agent then escorted them back to their group and helped them through the second security checkpoint where Danny AGAIN set off the radiation alarm. (Marcia said that when the second one went off, several agents stood up to stop the group, but the escorting agent quickly informed them that Danny had been cleared.)

Drama.

Danny actually enjoyed the episode. He said the tour was pretty boring, except for the alarm excitement. What amazes me is that he is five weeks out from that treatment, and he still has enough radiation in him to set off sensors....(Danny, father, 6/7/08)

Private

Occasionally a parent mused in the writing about a sense of unease with what to include and exclude from the blog. This was by far the exception, as many entries included home addresses and phone numbers. Some self-editing was evident, as when the parent who had decided to run for local office withdrew.

What I should keep to myself I am not sure what to say today! I have so many emotions running, it is hard to tell what should be shared with others - and what I should keep to myself because they will pass in a few hours!!!

There are still a few hours out of every day that I find myself sitting, thinking "why is this happening". But I later find myself thinking that is so selfish when I know it could be so much worse. I know that pain and heartache are all relative to what you have had to go through...and yet everyone has had their heart broken at some point. What breaks my heart might not put a dent in someone else's...

Each night we give Mimi an injection of something to help her through her chemo. It seems a bit unreal when I look back on it...poking my 8 month old daughter. Not something I thought I would ever have to do!...I know I have said this to several of you already - but I am going to say it again. Being a mom of a baby who has cancer is probably one of the most challenging things I have had to do in my life...and I hope it is the biggest challenge I ever face. I feel like I have been given a life long membership to a club that I never wanted to join...but now that I am here I feel the need to educate as many people about it as I can. Before Mimi was diagnosed I didn't have a clue how many families were affected by childhood cancer...to be honest I didn't know anything about it...(Mimi, mother, 3/29/07)!

Performative Acts: Treatment phase

The six activities of narrative performance found in the diagnostic phase were evident in the treatment phase as well. Again, narratives with clear expressions of purpose were isolated and examined separately from thematic writing.

Reflection

Reflection expressed through writing was one of the main activities of the bloggers, especially during the treatment phase. Parents wrote on the themes of finding meaning in the illness experience, and the meaning of the healthcare providers, both the persons and the systems. Writing became a method for parents to explore and process the feelings they were having in the quest for balance between managing the illness and maintaining a satisfactory quality of family life. They used the blogs to imagine a future for their child and for themselves. They used the blogs to ask and answer questions of themselves and their readers. For some, the blog became an outlet for creativity when others were thwarted by circumstance and responsibility to remain at the child's side.

Rereading to remember As I do every morning, I reread my diary again today.

With life moving by so quickly I look at my words and read them as if they were not mine. Simply put, you forget. Things just happen so quickly. It feels like I have lived several lifetimes in the last few weeks. So I thought it a good opportunity to focus on Cindy's life today because I know there will be more bad days in the weeks, months and years to come and I need to remember that it gets better (Cindy, father, 7/4/03).

The phrase 'no evidence of disease' represented the Holy Grail for each family. Its meaning influenced daily life during treatment. Time waiting for its appearance was filled with longing; its presence, while welcome news, could also inspire ominous feelings, especially in the neuroblastoma group. NED remained a time for anxious watchfulness.

The meaning of NED 1 NED - what does this really mean to us?

#1 - it doesn't mean we can relax with Tony's treatment

#2 - it doesn't mean his cancer is "cured"

#3 - it doesn't mean his cancer will not come back

Too many times, in reading other families blogs, I read the cancer has suddenly, horribly, taken over their child's body. Out of nowhere... it just comes back full steam.

Don't get me wrong - I'm happy Tony is headed in the NED direction (he has a radiation set-up appointment on Tuesday to zap that bothersome spot on his spine) - but the nature of this disease is unforgiving, unrelenting. And so must we be in return (Tony, mother, 10/14/07)...

Even with good news... Even with all this good news there is always a lingering question. What does this mean? Well, this is a question I ask many times a day. Neuroblastoma is an extremely tricky cancer and it is impossible to "guestimate" the future. Sometimes kids respond throughout the treatments, some kids respond and then for some unknown reason just stop, and some kids never respond at all. Which begs the question - What will Cindy's story be? There is no answer but what we can do is hope and pray that the chemo continues to work, that she stays healthy, that her little body continues to weather the storm, and that progress continues. We can value every minute and every second that we spend with Cindy and we can let her know that she is truly loved.

When researching this disease I learned very quickly that there weren't any absolutes, that there aren't any typical responses overall. You see, to date, there

still isn't a cure for neuroblastoma. There are success stories, but long term (>10 years) survivors are few and far between. And that is the nature of the disease. For some reason it likes to come back and many times it comes back meaner than ever. So day by day, and week by week we hope that we continue to get the results that we have seen thus far. We continue to pray that the tumor shrinks and that her little body continues to fight. This will be the nightmare that we live with everyday. We will always be waiting for answers and assurances when none exist. It seems like a somewhat sad reality but I do remember. She is still real, she is still here. I can touch her, see her, and feel her and for that I am the luckiest man alive....(Cindy, father, 7/12/03).

The influence of the illness and its treatment was not lost on parents when reflecting on their child's growth and development.

Reflections on development Tonight I was just sitting in bed giving Ana her med through her IV when I thought about how very different she is from the average 2 year old. At this age most parents are dealing with the terrible twos. They are running after their toddlers and picking up their messes wherever they go. Vocabulary is a daily discovery....They tire their moms and dads out more than themselves by the end of the day.... Well, tonight as I was flushing her IV lines, she helped me as usual. My 2 year old can help flush her IV. She knows to hold up her leg for her blood pressure cuff. She holds her finger up for the pulse oximeter. She patiently waits while her temperature is taken. She turns her head from side to side for them to check her ears. She knows not to get too far ahead of her IV pole and she can even push it around by herself to get where she wants to

go. Although all of this makes it so much easier for her and the staff at the hospital, it makes me very sad that she has learned all of this medical stuff while other 2 year olds are learning how to share toys and play all day....I know the day will come that I can sit back and watch my little angel with a head full of curls, run and play and laugh in our backyard with her brother and sister without a care in the world. No tubes, no pain, no meds. That is what I look forward to. That is what gets me through (Ana Lynn, mother, 3/12/07).

Many parents described feelings of personal change, isolation, and feeling overwhelmed throughout the experience. Here, a mother expressed finding comfort in those who “get it.”

I am the same person but I'm not. ...I've been pondering alot recently about life and how different mine is now. I am the same person but I'm not. There is something very different about me and it's not visible until I tell someone my daughter had cancer. The look on their faces changes instantly. It's strange. For me it's so matter of fact, that sometimes I think I overwhelm people with the way I talk about it like it's no big deal, rattling off about the tumors, bone involvement and marrow. Sometimes I leave people speechless and I don't mean to. Other times, people will ask about it and once they hear it all, I don't really hear from them again. I have some friends and family, but most of the time I feel so isolated....completely alone. The friends I do have I rarely talk to and I only talk to a couple people in my immediate family too. I am not great at making new friends. I have wonderful friends from all over the country that we have met through Sloan. They are the best friends because they "get it". Unfortunately I

rarely get to see them. I'm at a complicated point now. I am closest to a "normal" life than I have been since Ana got sick. So where do I fit in.... I talk to people about regular every day things, but it feels awkward to me. I don't and never will look at things in life the same way again and unless you experience life having a child with cancer, you'll never get what I now feel. So many things that are every day worries or bothersome and aggravating to people, are petty to me.... I think that's why I am having such a hard time connecting with friends. So much has happened and I want very much and feel that it's time to get out there and make some new friends, but I don't know how. I think I am sabotaging my own efforts by internalizing and scaring people away by only talking about Ana. I don't know how to talk about anything else.... But I have to. Then again, I don't think of it as a sad topic anymore, or at least I can see the good that comes out of it. I'm sure as time goes on I'll reconnect with old friends or make new ones, but I don't think I will ever lose that isolated feeling. I have a scar on my soul that has forever changed me. One that no one can see, but I feel every day.... (Ana Lynn, mother, 3/1/09).

This poignant entry illustrated the types of loss experienced by neuroblastoma parents and the feelings associated with survivorship.

A survivor Ana Lynn is a cancer survivor.

I have had a difficult time with this sentence. I still catch my self telling people who ask about her that she has cancer and I have to stop and say, HAD cancer. I think it's hard because she is still in treatment and it took so long for her to get disease free. I sometimes wonder if it's more than that. Maybe I am scared to say

the words because they might be taken away with the next set of scans. I don't want to jinx it or something. I have watched so many many children die in the past 22 months and have attended 3 wakes for our local friends. The first was for.... I had missed [a child's wake] a few weeks before that and I saw his parents outside first. I of course gave my condolences, but they gave me encouragement back saying Ana will survive.....Ana will survive. I was there with [another child's] mom. Afterward we stood outside in tears knowing that we could each easily be in this position with our own child. We told each other our children will survive. A few months later, [her son] died. Again, I went to the wake and again saw...parents outside who once again said Ana will survive. I went inside and Trish now greiving and her parents as well all hugged me crying saying Ana will survive. I have watched many other kids die throughout this time that I met at Sloan or through their sites. When we knew [a child] had only days, [her mother] in her grief told me Ana would survive. A few short weeks later I find myself once again at a wake.... I see [another set of parents] whose daughter died a few months ago, then the [other parents] once again. They both, still feeling the loss of their children, tell me Ana will survive. I then see [yet another child's] parents. His mom...tells me Ana will survive. This time it hit me. Really hard. Here I am time after time going to wakes and seeing these parents grieving for their children and they are comforting me. They all are supporting me and remind me that Ana is a survivor. Ana is a survivor. Ana is a survivor! I realized that I haven't accepted that. She really is a survivor.

God has a plan here and I am patiently waiting to figure it out. In the mean time, I

am learning from it and watching others learn from it. This experience has changed my life. The reason Ana has survived and others haven't I don't know, but I am trying to accept it and draw strength from our friends, the parents who have lost. I am realizing that we need each other. Maybe I need them because they are living the fear in my heart and they are showing me that I could get through it if I ended up losing Ana. Maybe it's the hope that they fill me with every time I hear them say Ana is a survivor. I hope that they need me, to see a child survive and live. That not every child has to suffer and die. That their kids spirits can live on in some way through watching Ana survive.

Thanks for letting my deep thoughts spill out here and Thank you for all your prayers (Ana Lynn, mother, 7/11/08).

A father shared reflections on his perception of the 'perfect blend' of physician characteristics.

Meaning of physician I spoke with one of Danny's doctors yesterday and she is trying to get more information about the Fenretinide for us. She is pretty sure that we can get it on 24 hours notice, so we are working on the logistics of cost and insurance. We are very lucky to have this doctor. Danny has had two different primary doctors prior to this one. The one that runs the practice is very compassionate, but can be somewhat timid when it comes to pursuing new therapies. Danny's first doctor was very progressive and upfront. He pulled no punches and told it like it is....ALWAYS. He was not one to hold your hand; it was all about the numbers and medicine. This new doctor seems to be a perfect blend of the previous two. She listens well, hears what our concerns are, pursues

new ideas and therapies with vigor, doesn't bad talk our Protocol choices, and is supportive and compassionate (Danny, father, 4/10/04).

Here, the same father expressed gratitude for treatment successes mixed with the isolation of having one of the few children surviving past expectations.

Mixed emotions During a private moment between Marcia and the doctor, she actually thanked us for our participation in the study. She said that they do not have any other kids this far out with the disease, and that Danny is helping future kids by being a part of this study. Comments like that are always encouraging and scary at the same time. Encouraging because we recognize that he is doing well, in their eyes as well as ours. And scary because there really are NOT other children that we can look to for advice when it comes to having paved the way for our future (Danny, father, 1/11/08).

Parents often reflected on the uniqueness of their feelings about what constituted a 'big deal' as their experiences broadened.

Uniqueness—insertion of gastrostomy tube ...Driving from work over to the hospital, another NB dad called me and asked about Tony. I told him what I knew [about the gastrostomy tube insertion procedure] and he commented on how this is so unique to cancer parents. Something like this would probably be a HUGE ordeal in other households but its all part of the game - cost vs. benefit - of treating cancer. We know our kids are stronger and better for having this experience, tough as it is to imagine wishing this on anyone (which I don't) (Tony, father, 3/22/07).

For some, blogging was a way to process thoughts and information in search of answers about treatment decisions.

Reflections on decision making Wow! Tony's tenth round of chemo started this week. Hard to believe we have a five year old who's had ten rounds of strong chemo in only eight months and there's no end in sight. Yes, his cancer is stable... but how do we keep it there (or better) and not ruin his body with toxicity? We've had some good talks and emails with Tony's oncologist regarding the toxicity question and what we can do next. Henry brought up a good point about current therapies subjecting NB kids to really high dose chemo, hot antibodies, radioactive treatments (to name a few) and how none of it seems works in the long run (no remission). Sure it knocks the cancer for a loop for a little while - but it knocks the kids for a loop too. Can their little bodies recover faster than the cancer?

Currently, we're trying to keep the monster at bay without weakening Tony. After this course of chemo we're going to add a low-dose oral chemo that Tony would take everyday or every other day between IV chemos. This may require his IV doses to be lowered in order to keep his blood counts from dropping too much. The only way to tell is by doing it. The only way to see if it will help is by doing it (Tony, mother, 6/27/07).

On decisions made It is still mind boggling to think back over the past four years at all of the other treatment options that we turned down. Treatment options that friends of ours tried...and sadly found little success with. Why did the dice roll the right way for us? Why didn't we try one of the many protocols that NYC

offered us? How did we get lucky enough to find a treatment plan that would afford us such excellent quality of life? While I try not to allow these thoughts to consume my waking hours.....I will never be able to escape them. There have been too many brave souls that have traveled down this road before us.....so that we may enjoy this quality of life. WE ARE LUCKY (Danny, father, 11/10/06)!

The power of the healthcare institution for what it represented was also expressed.

What the hospital represents ...In some ways, I dread trips to Duke because it reminds me of Leigh's cancer; in other ways, though, I feel a sense of calm and peace when we walk in the door because the place represents the fight against my daughter's disease. I feel like we're in good hands when we go there and everyone there is doing all they can to help Leigh survive....(Leigh, mother, 11/16/06).

The profound and direct effect of the experience on the parent was explicitly described by most authors.

Furnace of affliction The quest for "greatness" has been a battle that I have ardently fought; I have long wanted to be a high profile minister (and I suspect that many a preacher has too) and have at times been quietly envious of those who "have it...." Church culture rewards "success" and encourages it in much the same way as the corporate world does, with perks, bucks and BMWs....There are some very small men/women in big places. There are some spiritual giants in small places....In the end, it's all about who we are when no one else is watching; who we are when God alone is the audience....In God's eyes, greatness is measured not so much by accomplishment, but by character and by how much we love Him

and how much we love people.... When I think of the furnace of affliction-Leigh's illness-that He wants to use to make me a "great man" I can't help but think-as a father who loves his little girl beyond what words can express-- that the price is too expensive. Maybe it doesn't sound spiritual but it's as honest as I know how to be. What I want is my daughter's health back and our lives put back together. Do I want to be great if God's brand of greatness can only be developed in me by my daughter's suffering? I honestly don't know (Leigh, father, 2/6/03).

Feelings of anticipatory grief and the struggle to live normally were juxtaposed in this striking entry.

Feelings creep in A couple days before that, I drove into Winston-Salem for an hour-long counseling session with the wonderfully wise, Christian therapist that Dave has been going to, on and off, since Leigh was diagnosed....Although I hesitated about going at first, it was definitely time well spent. [The therapist] helped me sift through my emotions and understood very well how difficult it is to get through each day knowing there is a 90 percent chance that our daughter could relapse. I told him that I just couldn't get beyond that statistic and that whenever I looked at her, or spent time with her, I was thinking, "This good phase isn't going to last. She's going to relapse. She's going to die." That gets to be a heavy burden to carry after a while!

Even though I've carried a great deal of personal sadness over all of this, I made a point of letting him know that I never communicate those feelings of grief and hopelessness to Leigh. When I talk to her I always say, "WHEN you get married. WHEN you grow up. WHEN you have children." He asked me why I tell her

those things and I said, "It's because I want to give her hope." He said, "You think it's okay to give hope to your daughter but keep it from yourself?" Well, I didn't have a very good answer to that.

Then he suggested that it might be time to decide which reality I was going to concentrate on. A 90 percent chance of relapse means that there is still a 10 percent chance that she won't relapse. He said, "What would be wrong with focusing on that reality instead?" I told him that if I talked myself into feeling positive about her chances of survival, that when (or if) she died, it would make her death even harder because I would have gotten my hopes up. He said that no matter what, her death would be hard. But he also added that if she dies, I would not want to have to grieve over her death while at the same time, deal with a lot of regret over all the joy and energy I lost to grief during the time she was with us....I left his office feeling like he had helped me process a lot of difficult emotions. Since that time, I feel like I'm doing better in that I'm looking at Leigh and thinking, "She's doing great, she's feeling well and where there's life, there's hope!" The only recent time I've struggled was when I was sorting through her stuff and taking out her summer clothes for storage. I pulled her frilly, fluffy, pink dresses from the closet and as I was folding them away, the thought hit me, "She might not be around to wear these again next summer." It's so amazing how those feelings unexpectedly creep in from nowhere (Leigh, mother, 10/11/03).

The complexity of answering even the simplest questions inspired authors' reflection.

'How is he?' I wish I had answers for everyone.....I wish I could transmit my thoughts into others, so that I wouldn't have to flip the mental coin every time that

someone asks me, "How is Danny doing?" And what exactly is the mental coin....you ask?(You didn't ask?...oh well..here is the answer.) The mental coin is flipped when I try to decide whether to say:

1). "He's doing great!" (This is both true...and misleading...at the same time.....relative to most other kids with his illness, he is doing "beyond" great. But, in comparison to kids that do NOT have cancer and do NOT need to take chemotherapy 10 days out of every 21, and do NOT need to do testing every time he gets a small pain or anomaly, and do NOT need to be constantly looking out for new therapies and treatments....well.....then I suppose he is NOT doing beyond" great.)

2). "(Insert long complicated explanation of his current treatment, multitude of doctors visits, hospital stays, testing, testing results, etc.)" Usually, when I take this approach, the person listening gets this glassy eyed look that conveys to me a sense of regret for having asked in the first place. I can almost hear them saying, "I didn't want to go to medical school today....I just wanted to hear you say 'He's fine.'.....I didn't REALLY want to know what was going on."

So there you have it.....at the end of the day, there is no good answer.....or question for that matter. There is no wrong or right.....we are not offended by questions....we welcome them.....but sometimes, if you ask a question.....be ready to get an answer. And if you don't want to risk getting an answer that you don't want to hear.....say something like; "I hope he is doing well....we think of him often." Or "We'll add him to our prayer list." Or something along those lines (Danny, father, 5/8/07).

Becoming close to other affected families instilled feelings of support, but also held potential for engendering tremendous loss

On loss There are so many different mental processes at play when going through the loss of a friend's child. I guess basic psychology would say that most people view loss on a personal level... "How does it affect me?" I'm sure that I am no different, but I do find myself "living" the loss on a personal level. I guess with Danny's prognosis, it is only natural to do this.....but this time it was different. During the slide show I actually "saw" his face on the screen a few times.....maybe it was the tears.....I don't know.....I was trying to stay focused on...THEIR loss.....but seeing all of the moms that had lost children weeping from wounded hearts that will never properly heal, it was very difficult to keep my mind in "support" mode....instead of "scared\$hitless" mode (Danny, father, 4/6/06).

Reflection on the idea of writing and its effect was also common.

On writing, to convey the news of another child's death Knowing where to start a journal entry is half of the battle. Usually I begin with the medical update and then I smoothly transition into the sillier stuff. I guess it never feels right to joke around and then try to be serious. Today's entry starts on a note that doesn't get anymore serious....(Danny, father, 4/8/04)

On writing avoidance A couple of days ago Marcia asked me if I was going to update the page and I dismissed the idea for some lame reason. That evening, I started to think about it and came up with a theory. I used to LOVE the updates and look forward to writing them in the evening. I would drive around during the

day mentally writing what I would later type into the journal, and it would give me great pleasure to convey our daily adventures. I'm starting to think that my avoidance of this duty may partially stem from not wanting to "think" about THIS anymore than I have to. "Out of sight, out of mind." (If I'm not having to put extra thought into our dilemma each day, then aren't we just some normal family with a normal healthy child, doing normal things?) Do regular families have to sit down each day and rethink about the magnitude of "non-curable" childhood cancer and how it affects their every-waking hour? Why should we? The answer is.....there is no answer. (At least no EASY answer.) This is the hand we've been dealt. Hiding from it won't make it go away. Avoiding it won't make it any less serious. We are lucky on many, many levels. We know this. Somewhere between staying true to who we are and trying to live like "normal" people is a balance in life that all families in this battle seek. (That last quote of mine might become famous someday....you should make a note of when you read it for the first time.....you know....so you can tell your grandchildren.) (Danny, father, 8/6/04)

Entries were full of detailed reflection, navel-gazing and even “no news is good news” entries in which parents expressed relief for having no disease or treatment information to share but write anyway to stay connected to readers.

On writing—no news/good news To keep in line with a longstanding tradition of themes that have run in these journal entries, there is good news and there is bad news. The good news is that everything is quiet and calm in our home. (Kaynahorah, ptuii, ptuii, ptuii. (multiplied by 999,999,999.)) The bad news is

that with everything being quiet and calm, I don't have anything exciting to write about (Danny, father, 2/5/08).

Milestones and missed milestones were the most common times for reflective entries. Anniversaries of diagnosis, transplant, adverse events, birthdays and deaths were cause for deep reflection on decisions made, feelings of pride, regret, gratitude and loss. Humor was used liberally as inspiration for reader reflection.

Milestones as time for reflection Yesterday marked another milestone in Cindy's life. Cindy was vaccinated. I was sitting there looking at her shot vaccination record. The last date on her card was from back in 2002. It is strange how things like this will set you off. I took a moment to look back and reflect on all that Cindy has been through....As I look back on our life I am still so thankful for many of the byproducts that have come from this roller coaster ride. After 3 years I still maintain that I am a better person because of the experience. I still hate the fact that Cindy got cancer. I hate that she had to suffer and I hate the fact that we still live in fear of this beast. However, I have a deeper more meaningful appreciation for my family and friends than I ever could have had before. I love more. I feel more. Yes, I am more of a man than I ever could have been had we never been slashed by this double edged sword. The big "C" gave me the gift of my family. I realized that my family was the reason I was here. They are my purpose.

However, they aren't my only purpose. Throughout this process I discovered that this whole disease was my purpose. Believe it or not, it empowered me. I discovered that I could do something about it....Searching for the cure not only

gives me the self satisfaction that I am doing something meaningful for my family but it also gives me the satisfaction of helping others. It feels like important work and I am empowered. Here I can make a real difference. One of my goals when I first started this diary was the hope that I could help others through this process, that I could make this journey somewhat gentler for those that followed in our footsteps and everyday I try to do that. I learn more everyday but I think I am having small successes. Others know they aren't alone. We are providing hope. It isn't just a gap in time. It is a purpose (Cindy, father, 8/31/06).

Humor was often used to diffuse tension or to give balance to more somber news reported in the same entry.

Humor “Top Ten Signs You’ve Been Fighting Neuroblastoma Too Long”

10. Every time your child gets a fever you hope it spikes to 101 or higher.
9. You’ve ceased to register the shocked faces at preschool when you off-handedly say, "Oh we can’t make it, we have chemo that day."
8. You’ve started inviting the nurses over to dinner
7. When you are at the ENT with your other child talking about removing his tonsils and the doctors says, "It’s surgery you know, it requires general anesthesia," you involuntarily go "Pfff."
6. When your child is diagnosed with pneumonia, you hope it’s the viral kind on the off chance pneumonia is an oncolytic virus that kills neuroblastoma cells
5. You can spell "pneumonia" and "oncolytic virus"
4. You don’t even flinch at throw up at a birthday party and help clean it up even when it’s somebody else’s child.

3. You can sleep through a stem cell transplant (stole that from [another family])
2. When your child says something hurts you hope he or she has broken a limb somehow.
1. You have a hard time drumming up sympathy for Elizabeth Edwards and get ticked at all the cheery articles on how great it is to live with cancer these days (Tony, father, 4/7/07).

Humor “I am not making this up” Tonight's update is brought to you by: Cigna

Healthcare - "Stressing out families and ruining lives, one patient at a time!"

Marcia was kind enough to forward to me the contents of a letter we received yesterday from the wonderful folks at Cigna. Here is the text from that letter:

"Dear Danny,

The American Cancer Society estimates that one in two men and one in three women will face cancer in their lifetime. Although these are scary statistics, CIGNA HealthCare wants you to know we're here to help. If you have been diagnosed with cancer you may be eligible for the CIGNA Cancer Support program.... As your Cancer Support Specialist, I'll work with you, your doctor and other healthcare providers to offer support and assistance....To learn more about the program and about these resources and other tools that are available to you, visit mycigna.com"

(I swear this is the real deal....I am not making this up.)

So, at the bottom of the letter was the name and contact phone number for our "specialist." I just called the number, you know, to introduce ourselves. I mean, we've only been fighting Danny's cancer for 8.5 years now, so I guess maybe we

NEED a specialist. I got right through to the specialist's extension and got this message:

"Hi, you have reached (insert name), I am on vacation and will be gone until next week. If you need further assistance, please call back and ask for another specialist."

(I didn't call back.) (Danny, father, 7/2/08)

Reporting

Parents often chronicled clinical details such as lab or scan results and the tasks associated with caring for the child at home, including the lengths to which they had to go to accomplish these. Many of these tasks were unexpected and required extensive instruction.

Busier than expected We're finding that being out of the hospital is great - but much busier than we even expected. Every day we flush the tubes on Tony's Hickman port (which is the catheter that was installed in his chest). Once per week we have to change the valves on his Hickman and the chest dressing. Mon-Tue-Wed he has to take a special medicine. For ten days following each chemo we (Henry & I) have to give Tony an actual injection (shot) in the leg (this is not fun for any of us as you can guess). Twice per week Tony visits the Clinic to get his blood counts and sometimes see the doctor. Thursday was our first clinic day. I figured we'd be out of there in 2-3 hours Maximum. Wrong. Tony's blood counts were really low and he needed a blood transfusion. We were there 8-1/2 hours. We were warned that this can happen! (be flexible) Tony got through it just fine. Gee... when our next visit only lasts 5 hours I'm going to be thrilled (Tony, mother, 11/13/04)!

Even with details regarding treatment settled, planning for travel to receive expert care was a common challenge expressed by parents of children with neuroblastoma.

Coordinating travel Of course worries about travel arrangements, time away from home, and organizing help with the kids comes to my mind. I have emailed a group called Corporate Angels who "donate" extra seats on corporate jets to cancer patients who need to fly to places for their treatment. They can only work on getting you seats a week or so in advance, so we have to make other arrangements with a commercial airline once we get an appointment. Then we contact them and see if there are seats available through their organization. Walt and I are thinking that we will both go down with Jeremy and stay until his surgery is complete. Then we will take turns flying home to be with the kids for as long as he needs to recover (Jeremy, mother, 3/9/09).

Significant ‘firsts’ inspired authors to write.

Walking into clinic for the first time We went to Omaha on Friday for round two Mimi’s expect eight treatments. Let me tell you that walking into the cancer clinic for the first time is something I will never forget. You walk into a room where suddenly everyone that surrounds you understands you, and knows what is ahead of you. Although we didn’t see any children Mimi’s age we did see them all ages – probably from age 3-16. These kids sit and play video games while they receive their treatments, play jinga while having their vitals taken, etc. It is just what they do. They are not going to let ‘this’ interrupt what they are doing! What a motto for life, huh?! (Mimi, mother, 4/16/07)

The use of complementary therapies was occasionally reported.

Complementary Therapy I picked up some Oil of Oregano yesterday. A few drops in juice or water a couple of times a days should really help with the Mucousitis. Silas is just starting to show signs of it so hopefully his symptoms won't be quite as bad as last time. A few other Mums have given it to their children and swear by it. Today will be a happy day. No bad drugs, only good ones (Silas, mother, 8/16/06).

Good sign It's gone, gone, gone! Silas had his central line removed on Wed. and recovered from the surgery with flying colours. For 287 days that tube dangled from his chest. That's over 40 dressing changes I did to keep it clean and about 70 saline flushes in both lines to keep it from clogging up. Not only are we all glad to have it gone but it's kind of a symbolic thing as well. It's a turning point that means he really and truly is in complete remission. His doctor would only agree to have it out if he really believed that Silas wouldn't need it in the near future. So that's a good sign (Silas, mother, 12/23/06).

Some authors provided advice on parenting and disciplining in general based on lessons learned from their own experience.

Discipline (“not an option”) We have learned a lot on this journey and one of the toughest parts about living in the hospital is disciplining a child with cancer. Early on we were so shocked about the diagnosis and we were so concerned about her welfare and her future that we spoiled her rotten. When you have a child in pain or a child who is sick it is very easy to let manners and politeness fly out the window in an effort to comfort. We got into the habit of giving her small gifts "happies" for just about everything that was even mildly traumatic. In the long

run, we created some problems every time we left the hospital. But, after months and months of practice we learned that we could still discipline her without an overwhelming feeling of guilt. We learned to balance discipline and hospital life. This really does help. It sounds rather harsh but dealing with even the smallest of discipline issues early makes her much more able to deal with her treatment....So, my advice, if you are new into this world, is to learn how to come to terms with dealing with your child's behavior in the hospital early on. In the long run it really does help everyone involved....(Cindy, mother, 12/23/04).

The overwhelming guilt associated with misreading fatigue for bad behavior was reported by several parents.

Misread behavior This brings us to the guilt story. Danny hates taking his chemo. (Who wouldn't?) Occasionally he will give us some grief about taking his medicines...but usually he is good about it. Well, the other night, Danny took his pre-meds at 8pm (normal) and went to watch TV in his room. It takes about an hour for those meds to prepare him for the chemo. Marcia and I were watching a program in our room and didn't think too much about what Danny was doing. Well, as it turns out...he was falling into a deep, deep, deep.....(did I mention deep?) sleep. So, at 9pm when Marcia went in to wake him.....she met some serious resistance. So, being the designated bad guy...I went into his room. I didn't have much more luck. Unfortunately for Danny, I had worked a long day, and had to get up early the next day.....so I didn't have as much patience as I should have. After several minutes of giving him a chance to get out of bed....I started to threaten to take things away.....his 'coma-like' response was, "GIVE

ME SOME TIME...I'LL GET UP IN A MINUTE." This went on for a few more minutes until I got VERY impatient. I gave him a last warning....which he defiantly ignored.....and then I did the unthinkable.....I unplugged his phone and told him I was taking it away.....he yelled at me to give him more time...so I started to unplug all of the controllers to his X-Box.....I took all of my new-found electronic goodies and hid them in my closet. He got up in a huff....took his medicine....and disappeared into his room for the night.

(Here comes the guilt part.) The next morning I was gone by 5:30am. When Danny woke up, he wandered into our room and asked Marcia, "What happened to my phone...it's not there this morning?" He didn't remember any of it....he was just too tired to function or think straight. So, I of course will have to live with the shame of yelling at and punishing my tired, sick, exhausted little boy (Danny, father, 4/29/05).

One parent reported on their decision to pursue legal assistance when the medical insurer's actions were perceived as overbearing and manipulative.

Going public Now back to insurance. We have tried everything within the insurance company. In fact, I am pretty sure we have tried everything 5 or 6 times to no avail. Time has always been limited to fight insurance matters....So, to make this huge story shorter we have finally pursued the matter legally. Neither Lesley nor I have the time to fight all the battles and sift through the mountains of paperwork that BCBS has created. About two weeks ago we contacted patientadvocacy.org which is a non profit organization dedicated to this exact type of insurance abuse. After sending them our mountain of paperwork they reviewed

it and said, basically, that we have done everything that could be reasonably expected and it was now time to deal with this using the courts....I still don't know where this will end up but, quite frankly, it is no where near over in my mind. At this point I am so angry that BCBS treats families in crisis in such a manner that there will be more that needs to be done. They need to learn that this behavior is not acceptable and it shouldn't be tolerated by the public. They are intentionally denying coverage and creating burdensome paperwork for those that they know do not have the time or expertise to stand up for their rights. They are hunting the wounded. The slap on the wrist and the agreement to pay for what they should have paid in the first place is not enough. They have caused us an incredible amount of stress and anguish. They have cost us the refinance on our house. They have created a financial crisis in our family. And, most importantly, they have taken time and energy away from our family which is where it is and was needed to the most. I don't know whether the answer is going public (probably is) but what they are doing is criminal and something else needs to happen (Cindy, mother, 8/16/05).

Another parent reported on advice received in response to the shock of exorbitant prices for medications.

Better off if you lost your insurance Back to the Zofran saga. Well, it seems that one of our kind visitors to this page emailed us with a possible solution to our dilemma. The mom had gone through a similar scenario and was able to work with an intermediary that is somewhere between the insurance companies and the drug manufacturers. This particular family had success in getting help with

obtaining Zofran at a reasonable price. I called the contact and was pleasantly surprised at how sincere she was about wanting to help. Unfortunately, she was not able to give us any assistance. She DID however make an interesting suggestion. She said, “You would be better off if you “lost” your insurance and went on public assistance. Then we could help you out. I’m not supposed to say that, but it is the sad truth.”

LADIES AND GENLEMEN, WELCOME TO "HOW TO BEAT THE SYSTEM IN 5 EASY LESSONS."

Give me a break please! Why is it that we are trying to work WITHIN the system, staying in the boundaries, not cheating, and we are being driven back to a place where stealth and deception are required? (Danny, father, 6/29/04).

As parents gained confidence in understanding the treatment plan and strong bonds developed in the reader-author relationship, more details were reported to readers. It is reasonable to consider the possibility that explaining things to readers served to reinforce personal lessons learned as treatment progressed. A few parents reported on help children received from mental healthcare providers throughout treatment.

Child mental health Danny has been seeing his psychiatrist and his psychologist a lot lately. There are hoards of unresolved issues floating around in that head of his that have been festering for quite some time. Between the life and death thoughts and the pain issues, he has a lot of confusion and uncertainty that are making it difficult for him to enjoy the mostly 'high' quality of life that we have. (Once again, I am comparing his quality of life to those that are constantly in-

patient, or worse, dead. I am NOT comparing his quality of life to children that have never had to face such a disease or illness.) (Danny, father, 12/24/07)

Altruism played a role in this parent's decision making process when research participation was considered.

Research participation ... We have decided to proceed with the study. We have decided that this will allow us to do everything we can for Lucy. We are also praying that God will make sure she is placed in the appropriate arm of the study.... We are also comforted some by the fact that participants of studies are followed very closely and that there will be more than just one or two set of eyes on her case. Lastly, we owe Lucy's life to the many kids and families that participated in past studies for Leukemia. This is a rare disease and without study participants they can't make advancements to hopefully reach a 100% cure rate or even something to prevent the disease. So we hope this study will help not only Lucy but the children years from now that are diagnosed with Leukemia (Lucy, mother, 1/2/09).

Study participation becomes a way of life during childhood cancer treatment. In this entry, the same parent discussed the child's assent and shared the child's perspective on research.

We officially enrolled Lucy in the study. It was interesting after Jason and I signed the huge consent form they also had a consent form for Lucy. She took very seriously her consent for the study and even signed in cursive which the doctor found impressive. We have discussed the study with her and though she says it is confusing she wants to help other kids too. She even was telling Abbie last night about how kids in the past use to die and that because of studies she won't die. Sad but very insightful. Nice bathtime conversation for a 5 and 7 year old huh (Lucy, mother, 1/7/09)??

This parent later described participating in two additional studies related to the effects of cancer treatment.

Then after she got her chemo today we participated in a study for the effects of the chemo on Lucy neurologically and her coping skills. It should be interesting to see the results of this. This is a smaller version of the testing she will do after she is done with treatment to determine any long term side effects on her processing/learning skills. The reason for this test is that the chemo they have found can cause some issues with learning. The main chemo that causes these problems are the spinal tap chemo.... While Lucy did her testing, I participated in a coping study for parents where they are trying to determine how parents cope to find ways to help future parents at the time of diagnosis. It was interesting and a bit of a downer to relive that time, but we are committed to trying to help others in the future. So, that was a good day at clinic (Lucy, mother, 9/2/09).

Expression

Every feeling was expressed in the blogs. Parents wrote of feeling frustrated, relieved, grateful, angry, astonished, desperate, happy, sad and proud. Blogging was named explicitly as serving a therapeutic purpose. For most, blogging was a platform for expression of emotions that were difficult to verbalize in person.

Wonderfully therapeutic to share our struggles and blessings On a more uplifting note: Have you checked out our blog tracker to the right? It is a map that tracks all of the "hits" we get on the blog. People from all over the world are reading about Jeremy!! I just keep asking myself, "How do these people know about us?" It is so amazing! If you click on the map it will show you a list of recent locations of the people viewing the site.

Today I read that someone in Rome Italy read about Jeremy! I guess I need to step up my

writing...talk about pressure!

I was really leery at first about starting this blog. Putting my thoughts out on the web for anyone to read was a little unsettling. But I can't tell you how wonderfully therapeutic it is to be able to share our struggles and blessings from day to day with all of you. We have been able to add so many prayer warriors to our team by using the internet! The comments of support that we read each day give us so much encouragement to keep going. I've been thinking a lot lately about awesome it will be to let Jeremy read this blog someday. I can't wait for that day...(Jeremy, mother, 2/13/09)

Astonished As the year ends this evening I think of how much we have been through this past year. I am astonished at how we have pulled through with strength I never knew we had. We are a stronger and closer family than ever. Our little angel has taught us alot these past months. To be so brave and have such courage not understanding everyhting going on around her. She has immense strength that amazes me every day. She has taught us what really matters in life is the miracle of life. To live in the moment and enjoy and treasure every second we have together. Priorities change. It's like we have the knowledge, the secret to what really is important...each other. We also cherish our families and friends, new and old. We have witnessed first hand God's goodness through all of you. I thank God every day for his blessings, for we have had so many (Ana Lynn, mother, 12/31/06).

Stupidest day ever Over the last week of April he'll have all the assessment scans done and then he'll be in to the long-term plan. The first 2 years will be check ups and tests once a month. Years 3 to 9 will be every 6 months and

starting 10 years from now he'll be right back where we started at once a year checkups. Silas will be 21 years old. It's all just too scary to think that far ahead. Day to day is much better and today is a good day. Silas has written in his school agenda under Mar. 8th, "Stupidest Day Ever". Yes, today marks one year since diagnoses. Way to go dude, you've beaten the odds (Silas, mother, 3/8/07).

Referenced by many authors, the roller coaster metaphor was scrutinized in the writing by two bloggers and deemed wholly illustrative of life with childhood cancer.

Part 1: the ride After that inauspicious start, we had a wonderfully relaxing day.

Well, I should say it was relaxing until Martin talked me into going on a roller coaster with him....Finally, we got strapped in and took off. And when I say took off, I mean, TOOOOOK OFFFF! After a brain tingling, spine snapping minute or two of frenetic action, the ride slowed down and I immediately started to pat my middle aged self on the back saying, "Hey, Ginny. You did it! You rode a scary coaster! You ROCK, girl!" And then all of a sudden, the dreadful thought occurred to me: The ride was not done. Indeed, the ride of terror had just begun. WHOOOOSH! we flew off down the track. WHAM! we turned sideways, back and forth, a hundred times. WHEEEE! we plummeted straight down toward some water. WHOOAAAAA! we ripped around several corners. It was bad but I was hanging on, screaming, yelling, hyperventilating, but still in pretty good shape. And then, to my everlasting horror, the ride REALLY took off.

For real.

Real fast.

And I lost it.

I closed my eyes as tight as they would go, grabbed on to my little shoulder harness (which I was convinced was going to let go of me at any second) opened my mouth and just WAILED. Yes, ladies and gentlemen, I actually CRIED on a roller coaster. Martin told me later that he looked over at me and was filled with a terrible horror that he was responsible for taking his mother on a ride that was making her cry!...A few seconds (or years) later, the cars finally careened into the station and there I sat in front of the whole waiting crowd, tears dribbling down my cheeks, nose running, terror oozing out of every pore....I am so embarrassed. Moment of silence please, while I just get over it (Leigh, mother, 8/17/06).

Part 2: the epiphany ...I feel compelled to re-address my “coaster confession” from my last post....I have given this whole “coaster trauma subject” a great deal of thought and since I’m being my own therapist today, I will tell you what I think happened on that infamous day. I think that I already had so much “real stress” (Leigh’s relapse) in my life that adding a dose of “pretend stress” (the roller coaster) stressed me out so much that the “real stress” level escalated exponentially because “pretend stress” created “real stress” and the “real stress” caused me to overload on the “pretend stress” which caused my “real stress” level to trigger real tears! Well, either that, or I’m just a true ‘fraidy cat! Take your pick! (Leigh, mother, 8/22/06).

In this entry, the roller coaster of a single day is expressed.

Roller coaster of one day Today was definitely a roller coaster of a day. We started the day with Rollie getting the ok from the doctor to go without his cast and get back to gym class and recess. (up, up, up) Then I got a hold of Dr. K. and

found out she was approved to go on the standard 3 f8 protocol, everything looks great! (UP, UP, UP) Now that we were approved, Ana would need to start shots TODAY! Dr. K. basically said, Good luck. Not very optimistic, but hopeful, he told me to call the nurse practitioners to get the med for the shots....(down, down, down) Adrenalin kicks in. I got on the phone and called to get a message for the nurse practitioner to call me. I called Tracy to get the fax number for the consent form to be faxed. I called Sloan to give them the fax number. I called the social worker to get our room reserved at the Ronald and our letter faxed for our ride.(UP) I called my mother in law and set up our ride. (UP) I called Anthem (our med supplier) to give them a heads up but she was out to lunch.(down) I tried reaching the nurse pract. again at Sloan. No luck.(down) I went to my brother's office to get the fax. After some problems with the fax machine I got the fax, signed the consent and faxed it back.(UP) I got back home to call Anthem and she has no idea what med I am referring to for her shots.(DOWN DOWN DOWN) We need this today and now it doesn't look possible. I get a hold of Sloan finally and talk to Linda the nurse pract. who informs me of the technical name of the shots and tells me she will call Anthem and I should call other pharmacies.(UP) I start calling every pharmacy I can think of. None of them have it.(down) I get a call from Anthem. She has the paperwork she needs, but they have to order it. Can't get it till tomorrow.(DOWN DOWN DOWN) WE NEED IT TODAY!!! I got back on with Linda at Sloan who tells me she will ask if Ana can start tomorrow but to try my oncologist up here to see if they have it. I get on the phone and after half an hour I finally get through. While I am on hold with my onc nurse Kelly

who is calling pharmacy to see if they have it at our hospital, I got a phone call on the other line. Anthem has it and can deliver it today!!!(SOARING UP and through a loop!) They have half the order and will deliver tonight with the rest coming tomorrow or Friday.(slowing down) I call Sloan and tell Linda we are all set. Ana will start the shot tonight! THERE!!!! See what a determined mother and alot of God's angels at work can do!!! (The ride comes to an end...or so I thought) Tonight we got the delivery then headed out for a family bike ride. We thought Ana would be thrilled to go for a ride. She was not thrilled at all. She cried and fought back against putting her in the bike seat.(down down down) After alot of cajolling and hugs, she finally was up for it. Within 2 minutes she was laughing.(UP UP UP) We had a nice long bike ride together. When we got home I got her med ready for her shot. I went to give it to her and when I put the needle in and started to inject the med, the needle tip popped off the syringe while in her leg!(DOWN DOWN DOWN) All the medicine was ON her leg, not IN her leg.(down) To make it worse, she was bleeding from the spot and not happy at all.(down down) So we tried again. This time I did things alot slower. She was good. Even though she screamed, she didn't move. I got it all done and you could barely see where it was done. No blood.(UP UP UP) Now my little bean has fallen asleep and the ride is finally over!! I am exhausted.

Thank you for all the prayers. They are indeed working, so keep them coming!!

Goodnight! Thanks for checking in (Ana Lynn, mother, 4/23/08)!

Narratives in the spectrum of emotions expressed follow. These included relief, gratitude, frustration, anger, despair, and feeling honored.

Relief.

Irony--Doing a happy dance about chemotherapy We were all making bets this morning before heading off to the hospital on whether Silas would be OK to start his 7th round of chemo or not. Actually we were all pretty confident and sure enough by about 10am the results were in and he was good to go. His AGC is up to 1242 (almost doubled from last Monday) and his platelets are in the normal range at 214. I never thought I'd do the happy dance over my child having chemo but after waiting an extra 2 weeks and knowing that he really needs it.....I can breathe again. I actually felt the tension flowing away today and even nodded off for awhile in my chair - which is really odd because I never sleep during the day (Silas, mother, 4/27/09).

Gratitude.

Thankfulness for friends ...Today, which is probably one of the hardest days I have had yet – I had four people do great things for me that were wonderful pick-me-ups! I had someone at the coffee shop give me a free smoothie, a friend send me flowers, another friend dropped off a card and several homemade headbands for Mimi and a handmade card from her son, and a friend send me a wonderfully nice email – just to say that she understands. Am I blessed or what. Kind of like God saying... “listen up Brenda...you have too much to be happy about to waste time being sad!”. I think it worked girls – so THANK YOU!! (Mimi, mother, 4/20/07)

A regular mommy It was super successful and now she's crazy in the water. I was having a "Mommy moment" while watching my little girl in the water with Helene,

following directions, oozing with pride. It was all too normal. (Except for the explanation of the port-a-cath, the huge bruise on her cheek and rubbing in the sunscreen on her head. But that's neither here nor there!) Today I felt like a regular mommy in so many ways and am utterly grateful for it (Isabelle, mother, 3/29/07).

Frustration.

Home care I walked in the door tonight and Marcia was on the phone, visibly upset. The call was from the home health nursing agency making arrangements for the nurse to come over to our house tomorrow to administer the Zofran to Danny. (Some of you read that last sentence and probably didn't notice a problem....others read it and are beginning to put two and two together to get five...just like the idiots at home health care did.) Zofran (for those of you that are unlucky enough to know) is one of the anti-nausea drugs that are used for chemo patients. So, the obvious question of the day is; "Why are they all set to administer Zofran, but they made no mention of chemo?"

Hmmmmmmmm....very curious indeed! After calming Marcia down enough to get some information, I called the gentleman (I'm using that term loosely) from the home health company and asked why we were NOT getting a nurse for chemo? His reply was interesting. "We don't have nurses that are chemo-certified." Oh no.....hell no.....no, no, no, no, no, no. There is NO way that you idiots have had this doctor's order for a whole week, and you're just NOW realizing that the funny long word at the bottom is a chemotherapy agent (Danny, father, 10/13/03).

While frustration with poor communication and delays in procedures or reporting of results is evident in all the blogs to some degree, strong expressions of outright anger are reserved for insurance companies' philosophy, policies, and representatives.

Anger.

POST and insurance I must be an eternal optimist. Somehow, I continue to allow myself to believe that things will work the way they're supposed to. However, I find myself repeatedly getting aggravated by the very companies that are supposed to be helping us....Tenet Health. This is the company that now owns St. Mary's Hospital. This is the hospital where Danny gets his chemotherapy. He has been getting treatments there for almost 3 years. (Way too long to be in this battle, but I DON'T like the alternative.) We are fortunate that St. Mary's has a Pediatric Oncology Support Team [POST]. These wonderful people have been there for us time and time again over the past 3 years. They help with bills, they have been very giving during the holiday season, and they have always been there for us mentally, with advice and help. Now, I don't fully understand Tenet's relationship financially with the POST team, or how exactly they get paid. But they are working and functioning in that hospital, helping families. So, the question of the day is, if Tenet is smart enough to have a POST team there to help the families, and if Tenet is smart enough to know that families going through this, NEED the assistance and certainly DON'T need to be harassed by bill collectors, then WHY oh WHY do they refer the bills to their OWN subsidiary for collection? They have the financial counselors in place, HELPING us, ADVISING us on what and who to pay. So why do they refer the bills that the

insurance company is dragging it's feet on, to collectors? I asked that very question to the collector that answered the phone today. (I received two collection notices totaling \$10,000.00 and change.) She informed me that Cigna is slow in paying, so they automatically send out letters to us, to get us to help THEM collect. I asked why they hadn't billed the secondary insurance yet, they would surely pay the bill. Her reply was, "We don't like to bother the secondary insurance company until we've finished completely with the primary." So, I asked, "Oh, you don't have a problem bothering and threatening me, but you don't want to bother the secondary insurance?" She didn't like the tone of that question, I think she actually blew a couple of veins in her head while I was asking it. I could hear the strangest popping sound. Anyways, the discussion ended politely enough with her telling me that she would try to have them stop sending letters, and me telling her to do unnatural acts to herself. All in all, I think it went well (Danny, father, 1/17/03).

Insurance coverage denial That brings up a whole other sore subject. Our all knowing insurance company has decided to deny us once again for the GM-CSF. They have decided that we really do not need it....There is a problem in our country's medical system when the insurance companies are dictating medicine and treatment instead of the doctors, yet that is exactly what is happening. I cannot choose what is in the best interest of my daughter and I am only allowed to follow the advice of specialists if my insurance company allows me to. I refuse to yield that power to them, regardless of how much it costs. Their decisions would have already cost Cindy her life and I know they have costs the lives of many

children and adults before them. Don't be mislead, health insurance companies do not operate in the patients best interest, they operate in the interest of their shareholders. The ethical dilemma is that their grip on the purse strings does cost life.

Can you tell I am a little pissed off? I owe a \$100,000.00 to various medical institutions. We have no Maximum lifetime cap on our medical insurance. We have a Maximum yearly out of pocket of \$3000.00. You do the math. We have always followed the advice of our oncologists. We have always had second opinions by the top specialists in the country that were in agreement with our medical decisions. We have only been treated by the largest children's cancer consortium in North America and the hospital that sees the most cases of neuroblastoma in the world. I have operated in my child's best interest and I have purpose. Stop screwing with me (Cindy, father, 4/19/06).

Despair.

Despair Someone told me a few days after Silas was diagnosed that it gets a little easier as time goes on. They lied. It's been 96 days and I still get the same gut wrenching, spinning out of control feeling that I had on day 1. It's bad enough watching your own child suffer but all the other little ones in this cancer unit.....it just gets to be too much. Our roommate is 6 and among other things he had a tumor and one kidney removed the other day. He's such a trouper and shows his stitches off to anyone that wants to see. He's hooked on Silas's PSP so his Dad is buying him one tomorrow. I guess I'm feeling sorry for myself right now but I just don't want to do this anymore. Could everyone just turn your

clocks back please, or maybe we could all blink at the same time and make it all go away....(Silas, mother, 6/12/06).

Honored and humbled.

Father's pride The next few days will determine when Tony can come home. Criteria basically are ability to manage pain on home meds. I'll leave my more emotional thoughts for later. Let me just say that being with Tony since yesterday afternoon has been both tremendously rewarding and extremely sad. I am so proud of him, his manner of acting and how he wants to be better. You should have seen him push himself to load his body onto the ambulance gurney. He gave perfect directions on where to place the equipment to ensure Maximum possibility of success. And yet I have to carry him into the bathroom as he can't walk more than a step or two. He is truly amazing and I am honored and humbled to be his dad (Tony, father, 5/3/08).

Parents' pride in the child's ability to cope was evident in each blog. This parent expressed this pride together with a sense of relief that cancer had not tainted the child's personal integrity.

Dignity, courage and cuteness Isabelle is amazing! First, her ANC was 800, just high enough to go through with treatment today. She went through so much and still made us laugh. I know parents always brag about their children, but if any of you could see what she goes through on a day like today and how she handles everything with dignity, courage, and cuteness, you would be in utter disbelief. She had 4 chemo medications put into her little body (three of them new today) and is playing on our bed with Cole and Jeff as I type. So far, she's lost her appetite, but not her cookies. The side effects are

horrendous and yet she remains the fiesty little girl I was raising two months ago
(Isabelle, mother, 2/3/06).

In addition to expressing emotions, bloggers used writing to highlight and clarify complicated situations for readers.

Difficult questions—how are you?

Inevitably, questions from readers and others came regarding how the family was doing. These proved difficult for bloggers to answer. One parent likened the answer to the ‘how are you’ question to the lab reports they were seeing. The results might be abnormal, yet the physician would describe them as great since they demonstrated improvement over the previous.

I know over the past month many people have asked us how we are doing or how we are holding up. Or they have asked Lucy how she is feeling. We are so trained by society to just say fine or good, but really it is a load of crap. Often as people have asked me this month I have answered fine or hanging in there, but underneath I have wanted to scream we are doing terrible. I mean nothing is really fine or good with your child is diagnosed with cancer and going through poisonous treatments that make them feel like crap. Or her hair falling out or her not feeling good enough to sit up and talk with her friends, but I guess like the blood results where the doctors say they look great and they really don't to any type of normal blood results this is our new normal. And we are doing fine in the new normal (Lucy, mother, 1/1/09).

Anniversaries

The scariest word So one year post diagnosis and we're still making our way. Last year the scariest word I could have heard, short of "dead" in reference to my children would have been "cancer." Today, it's "relapse." May I never ever have to hear that icky word.

Now the word "cancer" is commonplace. What a year can do (Isabelle, mother, 12/22/06)!

Mantras

Nearly every author in the study repeated a saying, motto, or sign-off that held special meaning; maintained a sense of identity in their writing; and indicated a sacred commitment. For example, "B positive" was not merely a child's blood type. It became the upbeat sign-off to every entry by one blogger. This story included a saying that helped a mother manage the flux between good days and bad.

I have tried to remind myself today not to get too excited that this doesn't change much. I'm really trying to apply what Dr. M... told us initially which is that "Nothing is ever as good as your best day, and Nothing is ever as bad as your worst day." Probably a good lesson in life but his point was to try and avoid the roller coaster. So, even though this is good news we still have a long road in front of us. While I'm excited I realize that there will be tough days ahead and I don't want to crash too hard when they come (Lucy, mother, 1/6/09).

This mantra was useful for the author during good times and bad as well.

We are all fine. Take that back, we are all great! Ellie included. My Dad always said to Sherry and I growing up, "When you're sick, I'm sick. When you're sad, I'm sad. When you're happy, I'm happy!" Well, Isabelle is great, so we're all great! "Maintenance" has been kind to us. I think it was our turn (Isabelle, mother, 6/23/07).

A father's reflections on feeling inadequate gave rise to the identification of his perceived purpose in life: his children, the affected child's illness and the search for a cure. Every subsequent entry included a sign-off related in some way to "his purpose."

Purpose Regardless, Cindy seems to be doing well....As far as I am concerned, I am frustrated. I have got to do something but I just don't know what it is. Since Cindy's diagnosis I think I have done a good job being a father and a husband....It just never seems to be enough. I look back over the last couple of months and wonder what more can I do. It seems to me that all I have done is simply exist. As I have discussed before, there is a lesson to learn from every experience I have in life....I want to make a difference, I just don't know what it is. I can't seem to find a direction....My mom always said that I could do anything in life that I wanted to as long as I wanted it bad enough. I believe it and I have never wanted anything more. But, what do I do? How do I do it? I am just going in too many directions. I study, and I study, and I study some more. Hoping beyond hope to find some piece of information that will lead to a cure. I know I am not an analyst, researcher, or doctor but I am capable of grasping the information and making sense of it. Is that my purpose? The frustration here is that I know it is wishful thinking. I know that there are those out there who are more prepared to find the answers. So maybe it isn't my calling. So, if I follow that philosophy, how do I make a difference? Do I help raise funds for neuroblastoma research? Do I increase political awareness?...Our story is no better or worse than any of the others out there. The kids of neuroblastoma are all normal children. They were all happy and carefree, surrounded by loving families, that because of a nasty cancer have all been thrown into the world in which I live. Some survive and some don't but all of them face this monster. They all have heart wrenching stories. They are all just like you and me. The only difference is the aura of pain, fear, hope and

sadness that surrounds them....I have to make a difference. This is my purpose in life, I just don't know what my path is (Cindy, father, 9/13/03).

The early days of treatment were revisited and reflected upon by many bloggers.

Therapeutic reading Speaking of the spring cleaning, I came across the notebook that sat bedside when she was first diagnosed. Reading it was heartbreaking. It had notes, questions, the doctors answers, lists of what to bring from home, more questions, more answers, and yet more questions. Some of which seem surprisingly odd. For instance, just 6 days after diagnosis, one of my questions was when will her hair grow back? The answer of course was during maintenance. It hadn't fallen out yet and still, that was a pressing question in my mind. Other info. in the notebook, I had forgotten. Like after only one week of chemo, the Flowsytometry results revealed that the leukemia in her marrow went from 90% to 35%. It was at 90% at diagnosis. Ugghh. No wonder she wasn't walking. Her first few steps two weeks later were accompanied by crying "Nana" and "BooBoo." Uh, that's enough. I sat there in our hallway on the floor reading it and whimpered. I suppose it was therapeutic (Isabelle, mother, 2/28/09).

Advocacy

During the treatment phase, advocating by parents in the blogs took the form of passionate writing full of conviction about the experience. Some entries described advocacy on the individual level, for the child within the healthcare system; some took the form of fundraising solicitations and activities at local and national levels.

I pled my case ANC is not back yet. Of course when you know it's too low to come home, results are back at 8am. When you are on the edge of your seat, they take forever. Murphy, whoever you are, you are on my list today! I pled my case this morning for her

to come home today regardless of her counts.

1. She's been home at zero before.
2. Nobody is sick at home.
3. Paula cleaned yesterday.
4. Isabelle's been fever free since admission.
5. Holding her own in terms of hydration.
6. SHE SHOULD BE HOME!!!!
7. I'm quite certain there are less germs in my house than on the 4th floor.
8. I could think of more, but I'm sure you all agree.

Nana, Cole & I are headed up soon. Dr. K., watch out, I can be compelling & persistent
(Isabelle, mother, 1/11/07).

One parent relayed news from a meeting (reported in another blog) between a neuroblastoma expert and family members.

On the verge of being part of something big I just posted a few minutes ago, but I just came from the Franca Family site. This young man, Nick is the first patient to be treated with a new antibody at Sloan called 8h9. His mother informed all of us last week that Dr. C., the leader of research and creator of the antibodies at Sloan was going to come and talk to the families at the Ronald McDonald house on Wednesday 6/20 (last night). I am in tears of joy to find out how very close we are to increasing our children's survival against this beast!!! We must find a way to make it happen!!! Please read his mother's entry regarding last night's meeting with Dr. C.. [report of meeting proceedings—update on research into 3f8, the mouse-derived antibody therapy and the improvement in

care that would come if human-derived therapy were possible]... The meeting was packed, no fewer than 30 people in a conference room. We were all trying to understand advanced chemistry, physics and medical jargon. WE were taking desperate notes. There were many of us who were just plain desperate for hope. Then, when the possibilities of the humanized 3f8 got some “legs” in the meeting, a dad very matter of factly asked.... How much to get the ball rolling with a drug company (Dr. C. already has one picked out). There was a collective preparation in all of our minds. We were ready to hear 50-100 million. WE HEARD 2 million to get started!!!! WE all were shocked. We looked around and said what would it take? Our kids don’t have decades, they have days, months, years for breakthroughs. We are only 2-5 million away from a therapy that would move Nick’s odds up considerably and be a treatment that all children everywhere could consider. What is wrong with this picture? How can we raise millions in a heartbeat for a political cause, or “the American cancer society” as a whole... and yet an orphan cancer like neuroblastoma scrapes to raise 50,000.00 in the public venue? So we all left the meeting feeling excited but desperately powerless. We have children in treatment. We have unreal lives already. How can WE take on fundraising to get the antibody humanized? Trust me it is the buzz of the house. So there are ideas, there are conversations happening, there are possibilities. We need famous people, we need funding for this, we need generosity, we need action. There were probably ten dads there. They seemed to have more of a” let’s get it done mentality. Moms were thinking more of how to juggle this with caretaking a sick child and most of the time a couple of others. It was a good

night. We are going to make this happen. I feel like I am on the verge of being a part of something big, that will help my son. When parents are on a roll, watch out!!!!" [from another parent's blog]

WE WILL CONQUER!!! (Ana Lynn, mother, 6/22/07)

Parents reported on neuroblastoma research conference proceedings.

Passion and conviction It certainly was a whirlwind weekend. I come away amazed every time I attend a function of the Children's Neuroblastoma Cancer Foundation....It comforts my soul to be part of a group that shares the same dreams and aspirations for these kids. It is personal. The foundation is absolutely bursting at the seams. We have so many things going on and just not enough hours in the day.... For me it is as if I have found a home. Being surrounded by the passion in this group goes beyond contagious. Somehow it alters your soul (Cindy, father, 1/30/06).

To represent our kids We're back in Vermont for the end of Tony's Nifurtimox trial....Yesterday, we attended a conference - Developments in Neuroblastoma - while the kids were babysat at RMH Burlington. It was a fabulous conference organized and hosted by the wonderful Dr. S. who cares so much about our NB kids. Besides some of the big names in NB research, Drs. M., M. and M., there were other UVM researchers presenting some fascinating work in the areas of cancer stem-cells, genetic origins of NB and more. While much of the presentations were so science-heavy Melinda and myself couldn't grasp the meaning of what was being presented, we still felt good being there, along with some of the other parents who attended, in order to represent our kids and the

ultimate reason everyone was there - to find a cure for this damned disease (Tony, father, 2/3/07).

One parent used his sons' story to increase the fundraising for neuroblastoma research.

Propoganda and advocacy On the propoganda and advocacy front, this week was busy...Yesterday, Tony was on San Diego radiothon supporting Children's Hospital....Melinda said he did great, was interviewed twice, and got a toy aircraft carrier out of the deal so everyone's happy. Next week, there will be a feature on the MagicWater Project in our local newspaper, The Carmel Valley News/Rancho Santa Fe Review/Del Mar Village Voice, which is a really good local newspaper combination. The MagicWater Project is also having discussions with Amy Marcus, WSJ reporter who is on leave working on a Robert Wood Johnson Foundation project focusing on orphan diseases. She's interested in our model, and of course our outcomes. Who knows what may come of these discussions, hopefully some good visibility and credibility for what we're doing. Like Dave Jobs' 2005 commencement speech at Stanford, hopefully this will all make sense at some point in the future (Tony, father, 3/7/08).

For some bloggers, photos were included to enhance readers' understanding of the burdens placed on the children. A photo of a blogger's child during radiation therapy is included here with the accompanying entry.



I'm sure this photo is disturbing. Exactly why I posted it (Tony, father, 5/17/08).

September possesses specially meaning since being named National Childhood Cancer Awareness month.

September Please do not forget that September is National Childhood cancer awareness month. The ribbon is gold. The ribbon for leukemia is orange. If you do not have a t-shirt, go to cafepress.com they have millions. I am in the process of making one in honor of Kevin (more to come) (Kevin, mother, 8/21/08).

Oprah Call me crazy, I've been called worse, but I just emailed the Oprah show with a story idea. RAISE AWARENESS FOR CHILDHOOD CANCER....More children die of cancer than of any other disease including asthma, diabetes, cystic fibrosis, congenital anomalies & AIDS, COMBINED!!! September is Childhood Cancer Awareness Month and so what better way to raise awareness than on Oprah. I'm sure her September shows are accounted for, but the timing of my email was appropriate. We shall see what happens. In keeping with the awareness theme for September, I have set up a group

number in Isabelle's name at the Community Blood Bank in Rancho Mirage. Please, I ask each of you who is able, to donate blood in honor of Isabelle (Isabelle, mother, 9/18/06). Nearly every family was asked or volunteered to speak to media about their child's cancer or an upcoming fundraising effort.

A newspaper interview Next week we are talking to the newspaper on Friday, September 5th and they are going to do an article on Courtney for the Leukemia and Lymphoma Society for the Light the Night walk that we are doing on Saturday, October 4th. When I booked the interview I wasn't really thinking of anything else just what would work best for our growing schedules- it happened that that is a day we will never forget. It will mark the two-year anniversary of when Courtney was diagnosed. It is amazing on how sometimes it seems like only yesterday we were told and rushed to...City. Then I look at pictures of my beautiful girls and I see how young and innocent they looked two years ago compared to today. [Her sister] was just two and Courtney was almost four. We have all grown so much- I believe all for the good (Courtney, mother, 9/1/08).

Public speaking was written about as a way to encourage donations to favorite organizations.

I am passionate I have been asked to speak at a luncheon for about 200 people at [the hospital] tomorrow. This is for Children's Miracle Network. I am nervous, but GOD always seems to fill my heart. We are so honored that they would continue to ask me to speak...honestly I am not good in front of people. However, I am passionate about the care and treatment my son has received.... We are so blessed to be a part of the CMN family. I can not say enough about this wonderful group of people. Please go vote for

CMN, at citybankonline.com. City Bank is giving \$10,000 to 5 local non-profit organizations. Anyone can vote (Kevin, mother, 11/10/08).

Parents also reported on commercials or photography sessions designed for fundraising.

A commercial Well we had a pretty good day today. Kevin was asked to take a picture with 2 other cancer survivors today for the Cattle Baron's Ball. Cattle Baron's raises money for ACS.

They will have his picture in the AJ on Sunday and he will be on a commercial. I will let you know times. They will be raffling off a Harley Davidson Motorcycle. The money stays in [our town] to help fight cancer. A portion of the money raised will be going to a breast cancer researcher in Chicago.

We were also contacted by Tony Jones who owns [a local] Pharmacy. He has asked us to do a commercial for them...more to come on that (Kevin, mother, 7/25/08)!!!

Archive

In addition to being a forum for reflection, reporting, expression, and advocacy, over time the blogs became a place for storage; a place to maintain a record of events and emotions. In a time of pervasive uncertainty, blogging served to document the events, decisions, progress, feelings, memories and photos.

Preserving memories On a side note - a cute story. We still have baby monitors in the kids rooms. I don't know why we still keep one for Cindy but we just never turned it off. The good thing about it is that we can keep Cindy from screaming to us from her bedroom and waking her brother. She has been trained, in that, she knows that if she needs something she can get up and go over to speak into the baby monitor for anything that she may need. It has been only recently that she

has decided to use it as a walkie-talkie. Several times throughout the day and night we will hear her voice come over the monitor. It usually starts with some rustling as we hear her fumbling to grasp the monitor to put it to her mouth. We then hear her speak with something like "Mommy, Daddy I love you. Please come here. I need a new milk cup because I drank mine. Mommy, Daddy please come. I love you, Thank you very much." and then we will here rustling as she sets the monitor back down. I wish I could play it for you. It is perhaps the funniest thing in the world to hear her words come over the monitor. There are certain memories that will stay with me forever. This is one of them (Cindy, father, 3/25/05).

Explanation

Parents felt strongly that readers understand what was happening, both clinically and to the family at large during the illness experience. It was important to the bloggers that readers learn about the times when parents disagreed and how they resolved differences.

A place to work things out I have really wanted to get back to the subject of neuroblastoma and what our future might hold....I really don't know if I am right but I do have some theories of where we are so I am going to use my diary as a place to work these issues out in my mind. At times it may seem like I am just writing a stream of consciousness and at others I might even make sense, but I think the journey of what goes through a parents mind is as important as the decision that is made....(Cindy, father, 1/30/06).

It was important to the authors that readers understood the motivation of the parents as they made decisions and contemplated living with the consequences. The explanations also became part of the record that would help them remember when things happened; why they made certain

decisions; and their day-to-day experience of the illness.

Decision making explained *** WE HAVE A PLAN *******

Everytime I type that, or say that, the doctors find a way to throw us for a loop....One other thing to keep in mind. Marcia and I are trying to remain focused on buying as much quality time for Danny, without sacrificing too much quality of life....We are definitely up to our ears in a very, very grey area of treatment. Alot of families that have found themselves in this situation, have stopped treatments and taken what time they could get. Other families, have traveled to the four corners (yes, I know the earth is round) of the earth trying every bizarre treatment they could find, only to lose their child thousands of miles away from home. We are somewhere in the middle. The doctors have made it very clear to us that: "WE ARE WORKING TO BUY TIME. THERE IS NO CURRENT THERAPY THAT CAN GIVE US A CURE." I know this may all seem confusing to alot of you. We speak of therapies, and treatments, levels of disease, and remission. What you have to keep in mind is, relapsed neuroblastoma patients have a very poor prognosis. Some of these children DO get several years of remission and quality time. This is what we're shooting for (Danny, father, 9/19/02)!

Need to do everything We spoke to the docs about the research treatment and we agreed to be part of it....Although it's tough putting her through more treatments that could cause her pain, we feel we need to do everything that's out there to prevent this nasty disease from coming back. We also feel we should help the next kid that comes along with this the way someone helped Carrie. So please continue to say your prayers not only for us but for the amazing people that work at [our hospital] and other childrens' hospitals.

That's all for now,B POSITIVE,Love Ellen,Bryce,Molly,Rocco and SUPER CARRIE
 xoxoxoxoxo.Hi kitties we love you and miss you (Carrie, mother, 4/3/07).

Stopping treatment Yesterday Danny and I had another one of those fun conversations that start off with him informing me that he is interested in stopping chemotherapy for a couple of months. I usually don't like to play along when he starts that game, but I decided to give him some extra rope to see just how far he would hang himself. Once he made the statement, I was forced to respond with the obvious question. "What happens if we stop the chemo and the Protocol is unable to stop the cancer?" His immediate response was, "I die of course." (The beauty of these conversations is you can usually lead a nine-year old down the road that YOU want to travel. It's like an attorney; you never ask a question that you don't already know the answer to.) My next question (which I knew he would answer incorrectly) was, "Well, if that happened, who do you think would be affected by your death?" He responded with, "No one. I can't think of anyone." (Bzzzzzzzzzzzzzzzzzzzz wrong answer.) This is what I said. "Danny, the decision that you are talking about making is an adult decision. Mommy and I have always tried to include you in these types of decisions. From now on, you will NOT be included." (This got me an immediate response.) "Why dad? Why not?" "Well", I said, "I asked you an easy question. You should be able to name hundreds of people that you KNOW care about you and would miss you if you died. But you chose to give me an answer that is NOT an adult answer, so you are showing me that you really DON'T want to have adult conversations." (He didn't like that. He said he was only kidding when he couldn't name anyone. But the bottom line was I got him to rethink his position.)

This is a dangerous game. You really don't want to instill a sense of guilt surrounding the whole death thing. Especially when that is the road that the doctors are promising you will eventually travel. On the other hand, you don't want to allow a child to disassociate themselves from loved ones and friends. That would only make it easier to give up. (I love walking the balance beam on these issues. It really makes life interesting when you get to have these discussions with your child.) NOT NOT NOT (Danny, father, 9/28/03).

Parents sometimes felt the need to state absolutely that while they were explaining a new treatment, comments with opinions on their decision were unwelcome.

Alternative treatment—I am not looking for approval ...I have spoken recently about how we don't know how much time this current chemotherapy will keep working to keep the cancer at bay. Several doctors have reported to us that when children like Danny get a benefit from this drug, it typically lasts between 7 and 12 months. There are no absolutes. Danny has been using this chemo for 6 months. We are waiting for urine results that should be in tomorrow. Danny's cancer could start progressing again now, or it could stay at bay for another 12 months....no one knows. There is NO crystal ball with this disease. So, we have worked diligently to find an alternative therapy that we could turn to once this one has run its course....If you don't have another therapy to turn to, you lose very valuable time, AND, you reduce the chances of future therapies from buying you quality time....Well, over the past three years, we have heard of many non-traditional therapies for cancer. One has you take your child to Mexico for some bizarre treatment. (That one was actually just in the newspaper...they were shut down by US, Canadian, & Mexican authorities.) Another is some silver treatment

in Canada. Our doctor told us that it would kill Danny if we tried it. There is yet another in Texas that costs \$30,000. This one is supposedly a hoax as well. The list goes on and on and on. There are many people out there that will prey on parents that are desperate to keep their child alive. One therapy that we had heard about several months ago intrigued us. We asked one of our doctors about it, and he felt that it would not help, or hurt Danny. In other words, if you want to try it, go for it. We were caught up in trying to get into the NYC program, so we put it aside. Recently we had the pleasure of meeting two families that have been using this supplement for over a year. Both families have a son with non-curable brain tumors that are fatal. The one family was given two weeks....that was 12 months ago. The other, they have been going for 16 months. So, why isn't everyone using this "miracle" cure? Well, it's a long story. It reads like a conspiracy theory novel, but we have personally met two families that are benefiting from it. It is a liquid that can be given while we are still doing the chemotherapy. It should not have any major side effects. Having come from a very scientific and logical background, I find myself treading in new and uncharted waters. As a father that has watched his son go through unspeakable treatments to fight a monster of a disease, I am praying that this IS a miracle cure that just somehow slipped through the cracks. As a man of logic and math and science, and all that is orderly and explainable in this world, I worry that I am setting my family up for disappointment. I have ordered the medicine. It is very affordable. The people making this stuff are not getting rich from it.

I am not looking for approval or criticism from anyone on this. I am only revealing this story because of how strongly I feel about having all of you join us in this journey. It would be impossible for me to write accurately about the coming weeks and months without having mentioned this new development. We do value your thoughts and prayers. One of the parents that has been using this medicine recently told me about how she had posted their story on a brain tumor web page. The other parents were very critical and borderline "militant" in their position against such treatments. She warned us that there would be those that are offended by the use of non-traditional treatments. I am in no way selling, promoting, or benefiting financially from any of you that may want to look into this medicine. I purchased enough to get us through about 4 or 5 months. We should know within 3 months or so if it is helping. I will gladly forward the web page to anyone that asks. You can do your own research....(Danny, father, 2/23/03).

Reports of parent disagreements were not common in the blog entries but the one parent who shared this phenomenon, expressed deep dismay.

When parents disagree What happens when two parents disagree about the treatment options that lie in front of their child? This is a situation that we have never run into before and one that is perhaps of value to all of the other parents that are out there. I do not want to over dramatize this but the simple fact remains: Lesley and I disagree about the future treatment options that lay before Cindy. The problem is that neither one of us is wrong. There is no right answer. There is no wrong answer. The problem is that Cindy will have to live with the decisions

we make. Lesley and I are getting along wonderfully. We are happily married and as always I am deeply in love with her. We are not at odds and our discussions do not produce anger and resentment. Yet, the problem remains. We disagree and we only have two short days to come to a decision that we can both live with.... We are equally competent to discuss any of the materials and we have the same reference of information.... The question: Should we have 14.18 monoclonal antibody therapy if randomized.....[protocol explanation]... Now you might think that there is an answer here. On paper, if you read the study rationale it shows a clear reasoning for success. It shows that it should work - theoretically. About the only thing we have a pretty good grasp on is that it should not reduce her chances of survival. So this begs lots of questions without even discussing quality of life, not only for Cindy, but our family. So what do we do?...(Cindy, father, 2/7/04).

It was important to report results and treatment related events to the readers to maintain a sense of connection and community of caring.

Stem cell rescue Henry and I were able to sit down with Tony's doctor for almost an hour while he was in the hospital. We had a lot of questions and she had a lot of answers. Most importantly, we learned that when Tony receives his 7th chemo treatment (March) the doses will be very high to kill, once and for all, most remaining traces of cancer in his body, including all the good things that are in his blood and all his bone marrow. He'll be on blood products (Thank you for your donations!) daily for 1-2-3 weeks depending on his blood counts. Three days after the chemo ends Tony will have his stemcells reintroduced and they will (magically) rebuild his marrow, which will rebuild his blood. Tony will be in an

isolation period in the hospital for 14-21 days - again, pending his blood counts.

At his point Tony will remain in a state of "isolation" for 60-100 days at home.

No birthday parties, school, movie theaters, stuff like that. Tony's doctor explained that following this big chemo and the stemcell introduction, Tony's body will basically be like a newborn baby. Any immunities he may have had - including all the immunizations he received and all the dirt we let him suck off his pacifier for three years - are gone. He starts over.

Also following the last chemo and stemcell treatment Tony will undergo several radiation treatments pinpointing any place in his body that shows traces of cancer (through bonescans, MRI, CTscans, etc.). The radiation will be like a very direct laser shot at each of these points. So... I think you're up-to-date (Tony, mother, 12/19/04)!

The sense of connectedness was maintained at precise moments as parents reported events as they occurred.

Transplant day Tony's stemcells are being infused as I write. Just a little bag of what looks like blood being dripped into him slowly over an hour. He was given some pre-meds (tylenol, bendryl) to counteract the preservative that is mixed with the cells to keep them from breaking down while they were frozen... so he's having a nice little nap during the whole uneventful procedure.

His blood counts are dropping rapidly now (platelets, red and white) which was the goal, and I expect that Tony will start receiving blood transfusions as early as tomorrow. He should also become less energetic until his stemcells engraft (as bone marrow) and start making blood on their own which takes around two

weeks. In the meantime, everything's going way better than imagined (Tony, mother, 4/19/05)!

It was important to bloggers that readers recognize the uniqueness of the illness; to describe the feelings of isolation and even visceral suffering.

On meeting a new family ...I have talked to hundreds of families before but never this close to diagnosis....I guess what I am trying to say is that I have also talked to many other families and although all cancer diagnosis affect me, my reaction is usually anger and sadness. To some extent, though, there is a protective shield around me. This time was different. This time it felt like Cindy's diagnosis all over again. I could taste it. I could feel all of those feelings that had been absent since the beginning....There is complete helplessness and emptiness. Shock is constant companion. I don't been "shock" as in it "shocked" me. I mean shock as in the medical condition. Your mind does not work properly. You can go for days with out remembering to eat or drink and I am pretty sure that if it was not an auto response you would not remember to breathe. You forget words spoken just seconds before. The body you walk in does not feel like your own. Sleep is characterized by sporadic moments of uncomfortable worry and fear punctuated by jolts of sheer terror that wake you. Your soul seems to be empty as if everything you have ever known about yourself comes into question. Beyond these terrible feelings are the normal ones. Body and mind are compromised by sleep deprivation. Most days you walk the halls of the oncology ward with that feeling that you have not slept, not in days, but weeks. Breathing seems shallow and you never feel like you will get another breath.

I make these distinctions because "profound sadness" is not descriptive enough. To say I feel their sorrow is not enough....I tell you all of this to help explain. This is as close as I have come to those feelings as I had since Cindy's diagnosis. It affected me so completely that at its conclusion I found myself alone, retching into a toilet in the bathroom. I had forgotten and yet I live it everyday (Cindy, father, 9/19/05).

It was important to the bloggers that readers know the 'worst part.' This changed over time and was different from author to author.

The worst part ...I'M AFRAID HE'S CAUGHT MY COLD SO WE'LL CONCENTRATE ON GETTING HIM BACK TO NORMAL AND GET ALL THESE GERMS OUT OF HERE BEFORE CARRIE COMES HOME....I'M SURE THAT A LOT OF THIS STUFF SEEMS LIKE IT BE WOULD BE TERRIBLY OVERWHELMING, BUT I GOTTA TELL YOU THAT THE WORST PART OF IT IS THE SEPARATION. ESPECIALLY OVER THE HOLIDAYS. WE ALL JUST CAN'T WAIT TO BE IN ONE PLACE....(Carrie, father, 1/2/07)

It was important for the reader to know the child's version of some events and of the experience from the child's view overall.

Why I hate cancer About a month ago when Danny missed three straight weeks of school, his class was given an assignment to write a story. They evidently worked on it over several days with guidance from the teacher....The following text is his story in its entirety. His words. His thoughts. Please keep in mind that he has "remembered" events in his own way. The timeline may not be accurate,

and some of the names and events have been "lost" in his recollection of the past four years. Here is his story.

WHY I HATE CANCER!

An original story by Danny

Hey, my name is Danny and I want to tell you my last four years fighting cancer.

It all started when I was playing t-ball and my back hurt. The doctors said I must of pulled a muscle and just to take pain medicine for the pain. But obviously that didn't work. After that I decided that I hate the doctors. Then we went to get an MRI. Then I started getting low fevers. After about two months of that they said "That's it! We know what's bothering Dan he has a tumor called neuroblastoma."

He also said that it is very rare and dangerous at this rate he may not make it.

After that scare they said that to take me to a hospital called _____. That was so bad. It was a "D".....which means dreadful! About five months later I had my first friend, Robert. He likes fishing and playing cards. A week after that I had my first painful bone marrow, since then I hate them. Especially when the nurses have to watch.....I'm surprised that they don't freak out. As always I hate bone marrows.....except the milk of amnesia, that stuff is so cooooooooooooooooooool!

After about a month we met a new kid named _____. He is cool. He plays every thing I play. Back then I was boring. When I first met Mitchell he had pneumonia and low counts. Plus fevers. And diarrhea. That mixed together makes him really sick. When I relapsed which means (the disease came back) I missed a lot of school. I also hated that. And they stuck me with so many needles in my port, my arm, my hand, and my legs. After weeks of nausea and vomiting I was

just about to hurt somebody. And also my hair was falling out. That stunk. My hair was falling out because of all of the chemo the nurses and doctors were giving me while I was staying at the hospital. The ride to the hospital was a long one and I almost always got sick in the car. Another bad thing about the hospital is the pillows are flat and the nurses don't let you sleep all night. My room was always cold and I never liked the food there. Since I was at the hospital so much, I had to leave my soccer team. They lost their best player.....ME! Not only did the chemo make my hair fall out but it gives me mouth sores. Mouth sores are VERY PAINFUL. They hurt when I eat and drink. When I get them the doctors give me magic mouthwash. It would numb the sores so that I could eat and drink. Sometimes it would not work and the doctors would give me morphine. The morphine would make me have bad dreams. It also made me grumpy. That would get me in trouble with my mom and dad every time. But when I was not being grumpy I was asleep. I would sleep during the day because of low blood counts. I sometimes sleep a lot during chemo. But what makes me angry about cancer is.....when I lose a friend or a family member. I have lost many people I know to cancer. I will name a few for you. _____, _____, _____, _____, _____, and grandpa. It is a mean disease. I wish cancer was not real. I don't think it is fair that kids get cancer and can die. I hope that I don't join them in heaven. I wrote this book to tell you why I hate cancer. This is about why I hate cancer!

About the Author: Danny...is a 10 year old cancer survivor that lives in...with his parents. Danny continues to fight his cancer to this day. To read more about Danny's adventures go to his web page at www.caringbridge.org/fl/....

The end.

I know there are run-on sentences and mistakes....but I can't imagine a story from him being any more "from the heart." There are many pictures in the book. The cover shows a needle with a big line through it....(like a no smoking sign.) The first picture inside shows him holding his back saying, "My back hurts still." The second drawing shows two boys kicking a ball back and forth. Underneath it says, "That is me on the left." The third picture is of the bed and pillow. It says, "Noooooooo. Not the bed!" The fourth drawing shows Marcia and me looking down at him and his arms are up in the air as if to say, "What did I do now?" The last drawing is of a tombstone that has "R.I.P." written on it.

Brett

P.S. Yes. I did buy shares of Kleenex before posting his story.

P.S.S. When he got his story back from his teacher, there was a post-it note attached that read: "You are the most amazing student I have ever met! 100 "

(Danny, father, 5/5/04)

One mother offered an explanation of the meaning and significance of the infus-a-port.

Like a good friend ... This afternoon I was showing Cassy the actual catheter that they took out. Pathology let me keep it. I was smiling while holding it in it's official hospital-grade ziplock and said, "it's like a good friend." "It was a life-line." "It did it's job and now it's retired." Isabelle was on my hip and she took the ziplock from me and hugged the bag and then gave it a kiss and said, "you're all done with your work now." I couldn't have said it better myself. I can't wait to see what she does with her life (Isabelle, mother, 12/4/08).

Another highlighted the improved quality of life after port removal.

Meaning of port removal I am also thankful it [the port] is out because I just took hers and [her sister's] temp because they have the coughing, sneezing, stuffy, and runny nose going on and it is 101.3. In our crazy "normal" 2 and a half year life that would mean...City here we come, but now in our new "normal" life we can just give tylenol and say goodnight! The things we use to have to do because of the common cold (Courtney, mother, 3/30/09).

Analysis revealed changes in tone as treatment ended. In the next chapter, findings from the analysis of parent narratives during the off-treatment phase are discussed.

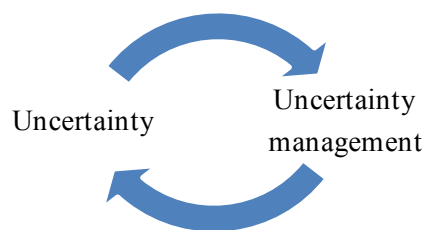
CHAPTER 7

Blog analysis: Off-treatment phase

For study purposes, off-treatment phases were defined as those periods in which the child was receiving no curative treatment for cancer. During the study, the five children with leukemia completed treatment as planned from the time of diagnosis and did not relapse. Two of the children with neuroblastoma had Stage III (“moderate risk”), meaning they had better odds of successful treatment, and did not experience disease recurrence. The remaining seven had Stage IV (“high risk”), which had, at the time of their diagnoses a 40-50% 5 year disease-free survival. Of those seven, three had died before study start; four were well. Of these four, three returned quarterly for surveillance scans and one was five years from her first remission, so was instructed to return only if symptoms occurred.

As life shifted into an off-treatment phase bloggers continued to write extensively. The same thematic categories were evident in this phase, but the shift in circumstances brought a shift in emphasis and more conscious and explicit attempts to regain balance in the new normal.

Thematic Categories



Uncertainty

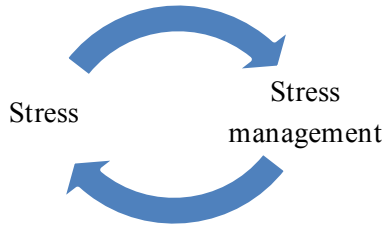
At this stage, the parents’ writing was dominated by stories of daily life events and the persistent burden of the uncertainty of living between that last scan and the next.

NBL limbo Well, there's nothing too exciting to write about this time around but did want to get something posted and let everyone know that things are going well....We're in kind of a weird sort of limbo right now because we're not really at a place where we can breathe a big sigh of relief at having completely clear scans and we're still having to go to regular clinic visits. I guess we're in an "inactive phase" of active treatment. (That made perfect sense, I know.)... Who knows what's ahead? Whether the medical news gets better or worse, it is out of our hands. I've been to so many websites lately where children are relapsing and children are dying and the issues that we're facing seem so trivial in comparison to what other families are facing. My baby girl is very much alive and happy, happy, happy!...(Leigh, mother, 2/13/05)!

Uncertainty management

While their child is off treatment, parents wrote of working at enjoying life to decrease the anxiety that accompanies the uncertainty. Many told stories of being almost "able to forget" until scan week when the fear of recurrence reappears in the entries.

"Luke"—giving a name to the fear of relapse If ever there were days where I "live in the now," they are happening now. "Luke" (my fear of her relapsing) has faded from the foreground to the background of my joy. I wasn't sure I would ever see the landscape of life without Luke the Elephant superimposed front and center in the frame. I think it's healthy in fact that Luke lingers on the horizon or fringe now. I know that for many years time will be referred to in my mind as BC (before cancer) and DC (during cancer) and AC (after cancer). I'm sure that sounds foreign to many and for those cancer moms out there reading, it likely resonates familiarly (Isabelle, mother, 4/16/09).



Stress

For the parents of children with neuroblastoma, life with their child off treatment still included scanxiety and the need to deal with the ever present fear of relapse. The message they relayed from the healthcare team is that with neuroblastoma, the question regarding relapse is not ‘if’ but ‘when.’ There are stories of unwelcome memories that occur unexpectedly similar in concept to those reported by individuals with symptoms of posttraumatic stress disorder.

Scanxiety—The unexpected is just as scary as the expected. Well, after a great weekend, I am here sitting at the computer getting ready to put the war paint on. This morning Cindy will begin her next round of scans starting with a check of her bone marrow aspirates and biopsies.....Neuroblastoma has never really struck our family when we were expecting it. It was always been the unexpected. So, for us, the unexpected is just as scary as the expected.

Even I have grown tired of the worry and fear of scan week. It is annoying. I am tired of writing about it and tired of thinking about. Shouldn't we be used to it by now? Every 3 months it is the same old thing. Can't we just stop the complaining and get on with our lives? In short, the answer is a resounding "No!" It does not matter how much time goes by. When your child's life and future depends on what feels like a flip of the coin, it is as real and as fresh as the first time. I don't

know that I will ever no longer fear this disease and, to be honest, I don't know that I want to. As long as I fear it I feel that we are somewhat protected. I know, I know. Asinine! It might be asinine but it is effective and it seems to work for me (Cindy, father, 11/13/06).

See the scan as its being done We still haven't actually talked to the doctor about Silas' scan results. We've been playing telephone tag all day and just haven't connected. But, from what I can tell, they are cleaner than previous scans. As those that have been through MIBG's know, you can actually see the scan as it's being done. I know assuming can be a bad thing but from what I've seen, they do look better (I think). The biggest "glow" is still below his left knee but the other areas (groin, shoulders and skull) seem to be fainter....I'll post again as soon as I have some definite answers (Silas, mother, 6/12/09).

For a child nearing the five-year mark from remission, a particular tension existed in the parents' writing.

Symptoms—inside I was going AAACCCKKK In other Smith Sibling news, Leigh scared me to death yesterday. She came into my office (on a special hall pass) and said, "Mom, I was in English class and all of a sudden the place in my side where my adrenal gland used to be started hurting so hard I could hardly breathe. And now I feel like the pain is in my back, too...." I remember the surgeon who removed the gland telling us, "Even though it looks like we got all the cancer, something can happen in surgery called 'seeding.' That is when microscopic cells drop off of whatever's being removed and remain in the body. They can remain dormant a long time before they start to grow again." Well, that's

what immediately came to mind when she told me what place on her body hurt.

She also seemed tired and looked very pale. I tried to stay matter-of-fact and calm when inside I was going, "AAACCCCKKKK!"

I just instructed her to tell me if the pain continued or got worse, hugged her and told her to get back to class. And then when she left, I sat in my chair a few minutes and said, "Oh please, God. Not now. Not ever!"

I kept a close eye on her last evening and today.... One more mention of it and I was going to be on the phone to Dr. D. at Duke. That is just too scary to hear those words.... (Leigh, mother, 4/29/08)

Like the date of diagnosis and other illness milestones, lasting effects of deeply stressful events during treatment were recalled on anniversary dates.

PTSD—2 year anniversary of a bad night ... This morning I colored my hair...no more grays, even though I earned every single one of them. Especially 2 years ago tonight in the early morning...

I woke up at 4:30 am to Ana's crying with the nurse in our room at Albany Med. Ana was there for round 11 getting high dose chemo. She had just finished her infusion of her monthly pentamidine when she woke with an odd cry. The nurse could not settle her. I got up and we both agreed something didn't seem right. Just then Ana stopped breathing, we immediately shook her and she started breathing again. The nurse ran out of the room to get a doctor to check on her. I turned the light on in the room because I thought her coloring looked off. When I got back to the crib Ana was gurgling and foaming at the mouth crying very odd and she was sort of bluish gray in color. She stopped breathing again. I shook her and she

started breathing again. I yelled for the nurse and then Ana stopped breathing again. This time shaking her didn't work and the nurse walked in as I yelled to her she wasn't breathing and a code blue was called. My immediate thought was that this was it, Ana was gone. Within seconds there must have been 10 doctors and nurses in the room surrounding the crib where Ana now lay lifeless. I became hysterical and all I could think of was to call John because I had to hear his voice if this was it for Ana. He answered and I sobbed telling him what was happening. I watched them scrambling to get Ana bagged and they were having trouble with it. I heard a doctor say there was no pulse. One of the nurses was about to do mouth to mouth when the bag was fixed and they put it on Ana. One compression and she was breathing again. During what seemed to last a lifetime, I had gotten off the phone with John and called Tracy for her to run to our house so John could come up here immediately then called John back in time to tell him she was breathing again. The doctor on call was there in record time, within 5 minutes of Ana breathing again. We rushed to CT to see if there were any indication of a seizure or anything. The CT was normal. John arrived just as the CT was done. We were brought up to the PICU where Ana remained stable. She had an EEG done later that day and nothing showed. We remained in PICU for one more night and then were released back to D7N for her to continue her chemo. This day will remain with me forever. It was the very worst experience of my life and I NEVER want to experience it again....(Ana Lynn, mother, 5/16/09)

Stress management

Parent narratives in the blogs about managing the stress of living between scans include focusing on the positive, seeking counseling, and organizing the fear so as to make it bearable.

Symptoms—better at being scared; stages of fear So, while I was in Chicago, Cindy apparently started having some leg pain. It wasn't crippling but she did limp at a few points during the day. When I saw her she was still having some issues but, to be honest, I did not pay too much attention to it. Over the years I have developed a balance. I have a tolerance for freaking out which has grown much larger over time. It takes something fairly significant to get the hairs on my neck to stand up. So, when I tell you that Cindy has leg pain it is something that I am acutely aware of but not something that makes me scream neuroblastoma. There is a process. There are steps and stages to terror. This was merely step number one.

Pain in the leg is significant. However, the cause can come from 1 million and 7 different things. There are lots of factors that we consider such as the location, appearance, and whether the pain changes with time. Frankly, using our eyes, hands, and a little thought we can usually find a cause that is probably not neuroblastoma related. But, when we have pain that is in a spot that is a known place for neuroblastoma related pain and we can't immediately rule it out, we begin to progress past step two.

Step three is the waiting game. In its most simple terms we are waiting for the pain to change. Ideally, we are hoping that it disappears. Thankfully, it usually

does. However, sometimes it gets worse. Sometimes she wakes up in the middle of the night with leg pain.

That was Sunday night.

That is the scariest of all signs and the one that makes me the most nervous.

However, you may also note that I am not running to the oncologist. I am not rattling off emails and I don't have phone calls in to 5 of the top neuroblastoma specialists on leg pain. We are waiting and watching.

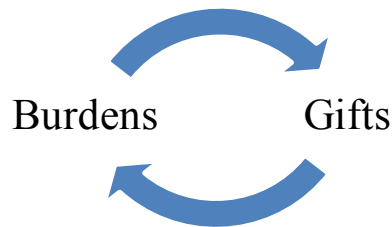
Scary stuff huh.

The pain is in the middle of the right thigh - known location. It is intense enough that she limps. It is also enough that she woke up in the middle of the night from the pain. This is stage 4 fear.

Now, the good news - the news that makes you not freak out and makes you stop wondering why we aren't sitting in an oncologists office right now - is that we gave her Tylenol and the pain went away. We also made her go to Tae Kwon Do yesterday afternoon. We wanted to see what stretching it out would do. I can tell you that she only flinched once and frankly I would have flinched as well....By the end, the pain was gone and she spent the rest of the evening without an ounce of pain. The big test now was making it through the night. She did. In fact, she just came down and told me that she slept beautifully. She does have pain. It is better. I can't tell you what the rest of the day will hold. Honestly, I can't even tell you that this is absolutely not neuroblastoma. I can't even tell you that we are feeling much better.

This was a jolt to our psyche and something that we will watch closely but

something I am so thankful was not worse. My purpose still scares me. I am just better at being scared (Cindy, father, 2/3/09).



Burdens

The isolation of living with neuroblastoma seemed to worsen during the off treatment phase. Parents told stories of feeling frustrated with a lack of connectedness with any one oncologist when two or more have been managing care. Their child may have started treatment at a more local institution, and then transferred care to a distant research center with neuroblastoma researchers. Once treatment was complete there, the second physician would not be responsible for day-to-day management of this illness that requires day-to-day attention. By default, parents became the care coordinator and articulated in the blogs the accompanying heavy burden of responsibility.

Care coordinator frustration 1 Walt and I are still trying to sort through what this next phase of Jeremy's care is going to look like. In all honesty, we feel WAY out in left field, all by ourselves, calling all the shots. By going to Sloan we in turn seemed to have almost cut ties with Strong. I know I have used this expression before, but Jeremy isn't on any one's "To Do" list. It is up to us to ask for blood work, urine analysis, scan dates, and I have to say I'm started to crack a little under this pressure. So we thought we had made a clear decision to just go to

Sloan for the scans. However, in just dealing with the scheduling process, I feel all the old familiar frustrations of being a little fish in a big pond. For example, we still don't have a doctor there who we deal with. We have very briefly met with 3 of their oncologists during our 3 trips there, all of whom learned about Jeremy upon walking into the office to meet with us. We don't have "a doctor" to call when we have a concern. For example, I had to call the surgeon's office to ask how to get scans scheduled. They gave me the number of the oncologist's office that I said I had liked the best. A different oncologist's office called me two days later with scan dates. If we do go there we will just have the scans done, then come home. We will have to initiate a meeting with "a doctor" if we want one, and if you remember there are no real appointments, you just kind of go and wait. So how does this play out if we are having to go down there every 3-6 months for the next 5 years? Who is our go-to person? When/where is Jeremy having his blood/urine tested? We are toiling over these questions and are frustrated that we have been sort of left in the dark to make these decisions. Please be praying that we will have a clear cut plan of action soon...My opinion is that we have enough to worry about just living with a child with cancer, we need a doctor to coordinate his care. We don't want that job anymore (Jeremy, mother, 7/9/09)!

Care coordinator frustration 2 I got a lot of answers today as to why things haven't been moving along with Jeremy's scans...

The answer???

My doctor never ordered them! I struggle with whether or not I should put some things on the blog related to our dissatisfaction with our experiences, but I think if

I am always honest, then perhaps our story will help someone else. I found all of this out by calling the MRI department for the 3rd day in a row. My wonderful nurse friend there and I have been playing phone tag. She finally got a hold of me and told me that they haven't been able to schedule Jeremy because they haven't received an order from the doctor. I emailed the doctor on July 16th, and she replied that she was putting in the order the next day. Thank goodness I saved all of the emails...

I was SO outraged by this, and so many other times that we have seemingly been forgotten, that I composed myself and called the oncology department. I told them what had happened, that I had emails documenting everything, and that this is not the first time our doctor has failed to communicate with us. I explained that I could no longer trust our doctor to do what she says she will, and that I am completely uncomfortable putting Jeremy's care in her hands. I then asked for a different doctor. I felt a little uneasy since I hadn't spoken to Walt about any of this, but I knew he would agree 100% (and they should be glad it wasn't him calling!!) A got a call back from a NP about 30 minutes later who wanted to know the whole story. I told her about this incident, about our doctor not remembering that she had met with us regarding Jeremy's post-op scans, and how no one called me back 3 weeks ago when I was concerned about his belly. She asked me to forward her the emails that I had, so I did.

An hour or so later, the secretary called me with a date of July 30th for scans, and an appointment August 5th with a new doctor. I'm sad that we are starting over with a new doctor (seems to be a trend in our lives lately). However, I will never,

ever apologize for expecting Jeremy's doctor to communicate with us and treat him as though he matters. So, one week from today we go to [the hospital] for MRIs of Jeremy spine and abdomen, as well as blood/urine tests. Then we have to wait until the next week to meet with the new doctor (who by the way we liked very much when we met him right after Jeremy's diagnosis). I also reiterated to the NP our requests regarding anesthesia. I'm not sure what will happen on that, I have a feeling we will be hashing it out with the anesthesiologists that day (Jeremy, mother, 7/23/09).

Other burdens parents wrote about were the “small sorrows” of late effects of treatment; the need to maintain a sense of urgency regarding symptom monitoring; and the waiting, between scans, and for reports of scan results.

A burden I am willing to carry Tomorrow we are going back to the clinic to have our final treatment checkup and begin the process of preparing her little body for next weeks scans. They really could not come at a better time. We are in need of our quarterly reassurance. Although the grueling schedule and treatments are over with, the fear still remains....It should be happy carefree times but I still find myself in a constant state of fear of the monster. It isn't incapacitating but it is fear, none the less. I don't know if I will ever overcome this hurdle but life is certainly livable and it is a burden I am willing to carry as long as it never comes back. My purpose is stronger than my fear (Cindy, father, 8/12/04).

Side effects of treatment were juxtaposed against the saved life of the child.

Bad news relativity ...The bad news is twofold. The doctor said that in her opinion, there is a pretty good chance that Leigh may never grow any taller than

her present height. (She's only 4'11") She also that she noticed some moles on Leigh's back that are suspicious and need to be carefully watched. That kind of threw me for a loop. I've gotten so used to to positive check ups... I realize that in the scheme of things, having a short, ALIVE daughter is a huge blessing compared to not having a daughter at all. But I had always pictured her tall (like me) and willowy (NOT like me) and it seems strange to re-picture her as a small person. When I said to Dave on the phone, "She won't even be tall enough to drive a car" he chuckled and said, "Honey, she's taller than her doctor!" I said, "Oh." (smile) (Leigh, mother, 11/3/07)

The losses she's experienced THE NEUROPSYCHE REPORT IS IN!...So here are the main points which I'm just going to list in random order....Leigh's overall cognitive functioning is generally comparable to that of her same aged peers. Leigh is a motivated and conscientious student despite processing speed difficulties. We recommend academic accommodations that allow Leigh to continue learning the same material as her peers, but focus on mastery rather than quantity and also provide compensation for Leigh's slow processing and writing speed.

So there you have it. I told Dave, "It just worries me that everytime she goes to be tested, that they will keep on saying, 'Well, in this area, she decreased some more.' When will it ever end? When she has NO memory? When her function speed has decreased to NOTHING?"

Big Sigh.

Despite all her difficulties, however, I find it interesting that she brought home a

report card last week containing with 1 C, 2 B's, and 5 A's! I guess no one has told HER she's supposed to be having problems! Although cancer has definitely taken some of her memory, her IQ, and her processing skills, it has also taught her to stick with things during tough times and never give up. (She spends TWICE as much time on her homework as her classmates do.) Her report card, and her zest for life reflect a wonderful, admirable attitude! That's the attitude that encourages me when I'm tempted toward sadness concerning the losses she's experienced (Leigh, mother, 11/11/07).

Yet another foreign object ... So today we went to [the hospital] to have her ears cleaned and that doc recommends that she get hearing aids so she has every advantage we can give her when it comes to school and learning. We are a little hesitant because it hurts to see her wearing yet another foreign object on her little body, but we will do whatever for our sweet baby (Carrie, mother, 9/25/07).

For those families in the disease surveillance stage, "the worst" was the waiting for results.

Waiting is the worst Good morning! Well, if you are waiting for some results you are much like me - still waiting. This is always such an issue. The waiting is the worst. And, universally, it becomes much, much worse when you have been told you would hear something and you still have not. It is at that point in time when the paranoia starts to set in and the incessant questioning begins. "Why have they not called? They said they would. Did they find some thing? They must have." From that point the line of mental questioning and the possibilities of what could be wrong grow exponentially. This is a lesson for all of you future (or

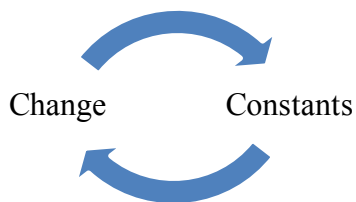
current) oncologists....In fact, I would always put it in this perspective - "If it were your child, would you want to know?" I think you will find that you would almost never, ever want to wait. This is, of course, my opinion, but I know that it is one that is certainly shared by most if not all of the parents I know....(Cindy, father, 11/11/08).

Gifts

Even parents whose child had died identified many positive experiences. The flip side of the experience of symptoms of post traumatic stress is the expression of growth when living through difficult times (Barakat, Alderfer, & Kazak, 2006). There was evidence in support of this theory in the stories of personal growth in the parent blogs.

Cancer as helpful in work as pastors Another reason I've been looking back at Leigh's cancer experience lately is because I have been so amazed at how much her illness has helped us in our work as pastors....The fact that we have been down that road, we have walked the halls of the hospitals, we have sat in Intensive Care, we have spent time in surgical waiting rooms, we have read blood count charts, we have had serious conversations with doctors—all of those things give us immediate entry into the lives of hurting people....We speak that language. They can talk about feeding tubes and IV's and bed pans and they know that we're on the same page with them. While we were going through Leigh's treatment I couldn't imagine anything good coming out of it but looking back at it, as a pastor's wife, I am so thankful for the experience. Our hearts have been broken by illness and fear and the shadow of death and I think that hearts that have been broken relate well to other broken hearts. And so I find one more thing

to be thankful for—our daughter’s suffering has paved a road into the lives of those who suffer. It was an expensive price to pay but the end result is valuable and precious (Leigh, mother, 5/8/06).



Changes

Many stories of change were found in the blogs during the off-treatment phase. Children had grown physically, developmentally and emotionally over the years. Parent stories highlighted the positives and negatives of the changes the children experienced. Parents reflected on never being normal again, that the “new normal” was grounded in hypervigilance and straining to appreciate the fact that the child is surviving even as ‘survivor’ for some is a taboo word. The most stressful time for some was when news of relapse invaded the off-treatment phase.

Relapse I had just barely managed to choke out the word, “relapse” before he gathered me into his arms while the most incredibly gut wrenching sobs took over my body. Thankfully, the school was out for the summer and the office staff was gone; it was just my husband and me in the empty church, weeping in each other’s arms over the news that our baby girl’s body was once again being victimized by a violent and hideous predator.... We called a few people, put some things in order for the Sunday service and then finally, about 5 pm, hooked up with Dr. D. on a phone where the three of us could talk and hear at the same time.

Although we discussed several different treatment options with him, we are still a long way from making a decision on anything. He said that this time around, Leigh is old enough to have some say in the decision process; if she's not willing to fight, if she doesn't have ownership in the treatment plan, then she won't do as well (Leigh, mother, 7/2/06).

Shock of relapse The worst has happened. I am so, so sorry for this shocking news I need to post, but Silas has relapsed after 17 months of remission from Neuroblastoma. He turned 13 at the end of July. On Sept 29th Silas woke up to very bad lower back pain. We all tried to figure out what he may of done but over the weekend it didn't get any better....[workup report]... Yes, our lives have changed.....again. But we've done it all before and we're stronger for it, so we'll fight again and just do whatever we need to do to get our boy back on track....and try and have as much fun as we can in between. I will post regularly and now that Silas has his own laptop, I will try and get him to write as well (Silas, mother, 10/15/08).

Identity changes were expressed as negative in this mother's story of discovery.

I have changed I've recently discovered that I have changed. I use to be the person to do nice things for my friends and family out of complete randomness and selflessness. Now, I barely make time for my friends. I want the old me back, and this is a step I have taken to move my life back in that direction!

My second change comes in my newest and most important TO-DO list! My goal is to have a list of things to complete this month, and hopefully each month, to help others...and to give back to others. Please feel free to make suggestions to

add to my list, and ultimately the richness of my life.

If I want greatness to come into my life, I need to start putting greatness out. This is something I am determined to do...(Mimi, mother, 12/4/07)

Effects of treatment were described by a mother as having changed the child in physical ways.

Late effects ...Ever since her cancer treatment (remember, it was a cancer of the nervous system so I guess this makes sense) she has a very difficult time handling loud noise; it's like her nerves just can't take it. She also wilts very quickly in heat of any sort and isn't able to be out in the hot sun for more than a short while....(Leigh, mother, 4/19/08)!

The father who wrote daily about “purpose” expressed a sense of fulfillment and a feeling of longing for others to share it.

Evolution of ‘purpose’ For the first time in quite a while my plate feels complete with meaningful work. Last week brought forth a sequence of events which has completely reinvigorated me. Although I have been focused on neuroblastoma full time for quite a while now finding my place and my purpose has been a bit of a challenge. Previously much of time was absorbed in Lunch for Life and now as my time begins to free up I find myself going in 1000 directions. For me the difficulty has been trying to identify where I can be most effective - where I can be of the most help....At the beginning of March I will be speaking to the NANT [New Approaches to Neuroblastoma Therapy] on behalf of the neuroblastoma community of families. I am searching for the words and the theories that hold the most weight. This will be the opportunity to bridge the gap.

We need to put the focus where it belongs. We need more hope and options.

We need to share the same purpose (Cindy, father, 1/8/07).

The “normal” expressed in earlier phases evolved once again to include a state of heightened awareness of any symptoms that may hold implications for disease recurrence.

Another ‘new normal’ I thought it was about time I posted some news about our boy. Silas is now almost 5 months in remission and doing GREAT!!!!...He’s at once a month checkups until next April with a CT and bone scan every 3 months....Every ache, pain and snuffle is recorded (and worried about) but I guess it will just always be that way. We’re thankful every day for having him with us....Keep it up my boy, you’re a winner (Silas, mother, 9/30/07).

For many parents, the consistent care provided by the primary oncologist was a significant factor, with implications for the off treatment phase.

Isabelle's next scheduled clinic is Sept. 30th. It will sadly be our very last clinic with Dr. F.. She told me last night that she's leaving [the hospital] in early October. I can't tell you how unwelcome that news is. I was holding back tears for her sake and Isabelle's....I know it will be a wonderful move for her. I am grateful that she saw Isabelle through treatment and a bit beyond. Many of you will not understand, but her voice alone is of comfort to me. I will miss her tremendously. I asked that Isabelle be turned over to Dr. K.'s care when she leaves. I'm sure I'll cry like a baby on Sept. 30th when I have to say goodbye to the person most instrumental in saving my daughter's life (Isabelle, mother, 8/25/08).

In fact, this mother rearranged care coordination to occur at the facility the physician moved to in order to maintain consistency through the disease surveillance period, even though this meant travelling for follow up visits.

...As always, Thank you for still checking in on us. Oh, we've made the decision to see Dr. F. at Cedar Sinai in Los Angeles for Isabelle's follow up care from here on. Now that she's an every 3 monther, it's do-able. That's hot off the press, so I've got to work on the switch. Luckily I've got a few months! :) (Isabelle, mother, 4/25/09)

Constants

For authors whose child died, the quest to memorialize and honor the life was a central theme. In addition, stories were found that relayed the difficulty parents experienced in accepting the permanence of the loss.

Permanence Well, we're overdue for a post. Neither of us has felt like posting lately. For me (Henry), the reasons are quite simple. What can I say that hasn't already been said, or that isn't painfully obvious? The pain of missing Tony grows more and more every day - I clearly didn't feel this way in the weeks after his death. Now, the shock and the sharp pain is gone, replaced by a dull, aching kind of pain. The pain that comes with the realization that what I'm dealing with is permanent (yes, logically I knew that when he died, but emotionally I didn't comprehend *forever*).

We continue to live, we might even thrive someday. But we will never be the same (Tony, father, 2/9/09).

For the parents with a child surviving the illness, stories of 'constants' seemed similar to those shared during the treatment phase

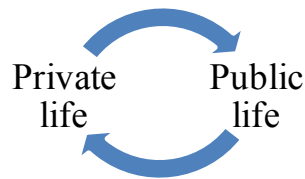
Life is never truly normal in a NB family I guess the subject of doctors offices got her wheels turning because she suddenly got quiet and said, "Will I ever need to have more scans done?"

I said, "Well, Dr. D. basically told us that unless something unusual happens, you're all done with scans."

She thought about that for a minute and said, "Something unusual. Like if I have those weird symptoms that mean my cancer has come back?"

There was a silence in the office for a moment after she said those words. We looked at each other and both realized that the subject was never too far out of reach....I hate that those words are even in her thoughts, even in her vocabulary. I hate that while other girls in her class are caught up with cell phones and homework and new shoes she has to deal with niggling worries that her cancer could come back. (And if statistics hold true, it's not a matter of if, but when.)

And so even though I make jokes about how I have nothing "important" to write about because life is wonderfully normal, life is really never truly normal in a NB family because the shadow hangs over our hearts as we look into next month and next year and wonder what might lie ahead (Leigh, mother, 4/15/08).



Public

For the families with children who are surviving, room in family life permitted more activism and engagement with the public.

Blogging contest On a lighter note...I've entered a blogging contest. The grandprize is a laptop computer (woo-hoo!) and some free blog publicity. It's an exciting opportunity to share Jeremy's story, our faith, and raise awareness about NB. Entering is kind of tricky, but I only need 10 nominations to take part (the more the better though). I need the nominations by Sunday night (Jeremy, mother, 4/16/09)!

Media A reporter from the Daily News is coming to do a story on Jeremy in an article about the Festival of Hope. I'm praying that the photographer will use a great shot of JUST Jeremy. I plan on making his as adorable as possible to help my cause, perhaps I'll just stay in my pjs! I'm so proud of my little man (Jeremy, mother, 6/1/09)!

Private

Some stories relayed the fear pervading some of the darkest thoughts parents have had over time.

Thoughts that never made their way into the diary ...Through this experience I have relived so many of my early thoughts of diagnosis. I had even forgotten

some of the darker more fearful thoughts that never even made their way to my diary. Things that even I, with all of this experience, fear to write about to this day. It is a terrifying time that only another parent of a child with cancer would understand. I hope that in some way I have helped and comforted them. I pray that I am making this easier for their family (Cindy, father, 6/30/08).

Performative acts: Off-treatment phase

The six activities of performance in bloggers' writing remained consistent through the off-treatment phase. Purposes for writing were often found to be explicitly stated as in the earlier phases. As balance is restored for some, the new normal becomes more comfortable. For those families living with alternating periods of NED and disease recurrences, the quest for balance continued in a status of of disquiet.

Reflection

The stories that demonstrate the authors' reflection during the off treatment phase are varied and rich with recollections of events, feelings, predictions and conclusions. Anniversaries are cause for deep reflection as they were during the prolonged treatment phase, and now for some, there are more narratives of PTSD experiences and regret.

Developmental relativity ...He [another patient receiving treatment in the clinic] was a tall, lanky teen but instead of sitting in a classroom studying algebra and gearing up for the afternoon's soccer game, he was sitting in a cancer clinic, a baseball ball cap covering his bald head, and a mask of weariness and fear covering his face. I was immediately reminded of my tall, strong son at home and was so thankful for his good health. It was hard enough for Leigh to go through cancer treatment; I can't imagine how much more complicated it would be for a

fifteen-year old young man. The teen years aren't easy anyway, and to compound their complexity with cancer treatment would be incredibly hard. I looked at that boy through a mother's eyes, and I had such compassion for him that I couldn't help but cry over what he is facing. I cried over how much of his normal teen life will be snatched away from him, and I cried over all the lovely fall days that will fade away outside his hospital window while he lays in a bed watching poison drip into his body and faces a future that is scary and uncertain (Leigh, mother, 10/7/04).

Old entries were copied and pasted into current entries to remind readers of the trying times and to reinforce lessons learned.

Looking back In honor of Mimi's upcoming birthday I thought it would be fun to see what I was writing about one year ago.... wow...I remember typing that!! I had to laugh when I read "I am amazed how much life can change in a year..." I had NO idea what our life would bring this year. After this past year I can't help but be scared to see what next year brings - but excited all the same!!! After all, after this year - next year can only be better!!!!!! (Mimi, mother, 7/23/07)

3 year anniversary—PTSD Three years ago today Danny was diagnosed with cancer. I was driving in our work truck in Ft. Lauderdale, and Marcia got the call from the physician that had ordered the MRI. "Your son has tumors on his spine. Go directly to St. Mary's Hospital in West Palm Beach, they are waiting for you." I got the call from Marcia, and proceeded to cry all the way to West Palm Beach while I tried to figure out what "tumors" meant. Having been raised in a family with a strong medical background, I guess I should have known. Maybe it was the

shock, I don't know. I remember getting to the oncologist's office before Marcia, Danny and my father showed up. I was given a clipboard with the various paperwork to fill out. I took it into the hallway, because my tears were interfering with my ability to answer the questions. The waiting room had several bald children. My world had just collapsed on me....Danny has neuroblastoma. It is in stage IV which means that has progressed quite far....I don't remember how many boxes of tissues I went through that morning, but I do remember at one point venturing to the back area of their offices to find more.

When Danny arrived, they were shocked to see him walk in without any help. The scans had shown them a very, very sick child. They expected him to arrive in a wheelchair.

I don't have many regrets from how we've handled things over the past three years. You can't. They will haunt your thoughts and dreams and torture you if you let them. I do regret not being stronger for Danny that first day. I can vividly remember the look on his face as he watched me crying....He did great with the needles and poking, and prodding, but he was clearly nervous because of my reaction to what was happening. If there was one thing that I could take back, it would my inability to remain strong for him that first day.

I see those first hours at the doctor's office when I close my eyes. I see them while I drive around in the quiet of my car and truck. I see them when I get ready to go to sleep, almost finding a place in my mind where I can believe that it is all just a nightmare....Three years ago today, our world changed.

Cancer sucks! (Danny, father, 3/16/03)

Reporting

Parents wrote about the effects of some of the decisions made during treatment; provided information about new studies; plans for the writing now that the topic of illness is diminishing as life becomes balanced differently; and the sense of loss they experience at milestones missed by the child due to treatment.

Why was I bald? The night before last she was looking at a picture of herself from two years ago. In it she was lying in my arms as we napped on the couch. It was just after her last two rounds of chemotherapy and she was bald. Cindy said "Hey, look at me, no hair. Why was I bald?" Lesley explained to her that she was sick and she had some medicine that made her hair go away....The point is that Cindy really has very little recollection that any of this happened. After all that chemotherapy, all of those surgeries, weeks of radiation and years of painful immunotherapy she really has no recollection other than some vague memory of and strange attraction to the people that cared for her.....To many this may not mean a whole lot. But to someone just stepping into this world and worried about what their child's future may hold, I am happy to report that, even after all of this, it seems to be happiness....(Cindy, father, 11/21/07).

No news/good news And speaking of writing these updates, I'm trying to make up my mind about what to do with this website. I really don't want to impose on you all's patience by just blathering on with endless Smith Stories which is really all I have to write right now since (thankfully) Leigh does not have any medical crises to report on. However, since she still does have a few ongoing medical situations remaining, I think I can feel "justified" in keeping the site going for a

while. Since my time has become much more limited since going to work at the church, and since the medical news is much more sparse, I am probably going to move to a schedule of only updating once or twice a month. Of course, if something out of the ordinary happened, I would write an update immediately and fill you all in (Leigh, mother, 4/16/05).

One of our best decisions Then we headed over to onco clinic and they continue to tell me how pleased they are with Carrie's progress. She will be finished with her suppertube [nasogastric feeding tube] in less than 2 weeks! They feel she has enough meat on her bones to be done with it and that's fine with us. We feel that having that tube was one of our best decisions, it really kept the weight on her and guaranteed her nutrition. We can't wait to see BOTH of those chubby cheeks (Carrie, mother, 10/30/07)!

Many parents reported major life changes that were directly connected to the illness experience.

LPN program ...[after treatment completion] I want to go to school for a 1 year LPN program. I feel at home in the hospital now, I can't think of a better job for me. I also have a hell of alot of experience under my belt thanks to miss bean. My sister in law... is going to go too. We can help each other out. She is in the same boat as me (Ana Lynn, mother, 8/2/08).

For parents who lost their child, the entry informing readers of the death is especially poignant but also very matter of fact regarding the plans for the memorial. There were specific suggestions about what attendees might wear ("purple!"); what they should bring; and that they should be prepared to write in a memory book.

Tony is dying I was trying to be creative in titling and writing this post like so many other parents have been when it has been time to convey the information that I will in this post, but creativity escapes me now.

Tony is dying. He has been dying for some time, of course. Since 2004, he has been battling a cancer that had a terrible cure rate to start with, then he relapsed in 2006, then progressed this summer. Now, the neuroblastoma seems to be spreading rapidly to soft-tissue areas of his abdomen (liver, kidneys), despite continual treatment.

So, we are making plans for when Tony leaves us and becomes pain free forever. Melinda and I knew that this time might come, but harbored hope that it never would, that we would be "the lucky ones." We still have a smidgen of hope, perhaps that's our downfall and will cause us much pain in the near future as we find it hard to let go of him, but without hope, what is there?

Let me give a quick update and then that will be it for this post.

- Pain: Tony is on a morphine PCA pump. Last Thursday we had a horrific night - Tony in so much abdominal pain that he was going practically crazy. Due to some transition issues with our hospice provider, we were caught off-guard and Tony had to spend several hours writhing and screaming in pain, without anything we could do but try to comfort him with words (note: it doesn't work - try it - cut off your finger and see if kind words help soothe the pain). I fear we've done more damage to Tony's psyche with that episode than shows. Remembering this night makes me so mad... sad...

- CT: we are having a CT done today to determine the spread of Tony's disease.

Last Thursday we had an emergency CT to determine what was causing Tony's abdominal pain. It was there that we saw the disease in his liver and kidneys.

Curiously, the pathology report from Tony's brochoscopy procedure two weeks ago showed no disease.

- Radiation: we are starting palliative radiation to Tony's liver today. We hope this relieves some of the pressure on his abdominal area so that he is more comfortable. Right now, he only wants to wear pajama pants.

I want to close with a picture of Tony. So many pictures have been posted lately showing unhappy Tony. There are moments of lucidity and happiness on his face, though they are fleeting. Those moments are treasures and Melinda and I are doing our best to make sure that as we capture them for the future, we also enjoy them in realtime (Tony, father, 8/26/08).

Tony passed away at 8:45pm Sunday, August 31, 2008 By Henry (Tony's dad)

This will be an evolving post:

Update - 9/1 5:55am.Missing Tony terribly already. Two moments of magic Sunday morning captured on video. This was the real Tony. **Update - 9/1 2:00pm** Henry & I are planning Tony's Celebration service. *Tentatively*, we are shooting for Saturday late morning, September 6, 2008...

Update - 9/1 6:55pm For anyone wanting to contact us for any reason, Melinda's sister, Randee, is going to serve as our go-between. Her contact info is: ____ We would like to make a request at this time that instead of flowers or gifts in memory of Tony, please make a donation to the MagicWater Project. More than ever this is where our our efforts will be... to help prevent other families from

having to suffer the loss of a beloved child like our Tony. Thank you (Tony, mother and father, 8/31/08).

Two weeks later, the mother shared a sense of inadequacy with finding words to express her feelings and offered advice to readers sharing this experience.

What to say A note from Melinda...A very nice mom friend of mine came up to me this weekend and expressed her sorrow for our family and apologized for not talking to me sooner - but she simply didn't know what to say. I know this is troubling everyone - even me. I don't know what to say either. Please know that a seemingly simple "I'm sorry" and a hug is huge. Really. I'll see you this week (Tony, mother, 9/15/08).

In the same blog there is a particularly touching story sent to and shared by the parent about the ways in which classmates grieve the lost child.

Schoolmates' grief Email sent today from Tony's teacher, Lisa:

"The kids are really missing Tony. They don't like his empty chair, too much of a reminder I think, so they've taken to putting Larry the stuffed alligator in it. But they call it Tony and make sure he has the right folder out, etc when we're working. Interesting how kids grieve... They've also been rereading some of the grief books we've read. Your sweet boy is sorely missed!" I'm sure Tony is very happy with his classmate's selection of his proxy (Tony, father, 9/15/08).

One entry from the mother whose child had died was interesting for her endeavor to reflect on the anticipatory grief she experienced a year before the child's death.

Retro-anticipatory grief Hi everyone, well we made it to and from the beach with just a few minor bumps and bruises:)We had a wonderful week and the

weather couldn't have been nicer. I know Molly and Rocco had an excellent time. They were boogie-boarding like pros. I was amazed at how perfect the ocean was and thoroughly enjoyed it too. It was so nice to be together and just have fun. We did have our moments though. It's hard not to think of how much Carrie would have loved going with us. She would have had a blast. I watched other little girls playing in the sand and water and just wished she was there too. I remember thinking last year as I watched Molly and Rocco in the ocean, how weird it will be when I'm watching just 2 kids and it is, extremely weird and heartbreaking. She had so much fun on the boardwalk rides last year. We rode this submarine ride over and over again, she loved it and the ride operator just let us stay on as long as we wanted. It's so difficult moving ahead without Carrie and there we were on vacation without her. I started a new job about 6 weeks ago and Bryce is starting a new job tomorrow. Again, we're moving ahead and making changes without our girl. I know it has to happen, it just really sucks that it's happening at all (Carrie, mother, 7/7/09).

Expression

For parents with a surviving child, narratives at this time expressed feelings of pride; fear of disease recurrence; and an expression of conflicted feelings about the future.

Veteran of war I swiped at my eyes once more, and then headed back up the hallway with Dave, away from my funny, brave, whimsical, battle-scarred little second grader who has taught me so much about life. They may not realize it yet, but what they're getting in that classroom today is a child who has the body of a

second-grader but the soul of a veteran of war. Last year at this time, while her classmates were learning their addition and subtraction facts, she was having her bone marrow and immune system destroyed by chemo; while they were having recess, she was having her spirit bruised by isolation and pain—she's a veteran, indeed.

So even though it was a tough morning, I am thankful that Leigh is still alive and is healthy and strong enough to attend school! So many neuroblastoma kids have died this year and an even greater number have relapsed and are re-entering the second stage of the fight for their lives. The fact that Leigh is doing so well is an incredible blessing (Leigh, mother, 1/504).

A longing for meaningful connection with the healthcare team as they monitor for signs of relapse expressed by some authors.

Survivorship; a new oncologist; and a reputation We just got back from our appointment with the new oncologist and I wanted to quickly type an update. Everything from the scans looks great! We covered a lot of things during the appointment. The new doctor feels it is important to scan every three months for the first year, and then every 6 months for the next 4 years. Jeremy's first surgery, the laminectomy, puts him at high risk for spinal instability (outward curving of the spine--think hump back!) Obviously this is a huge concern and we want to establish a baseline and have this monitored closely as he grows.

We both felt very good about the new doctor. He obviously knew why we were there and that we had been with another doctor whom he works closely with. I appreciated that he asked us what he could do to meet our needs. I'm sure we have

a reputation now, but at least now we feel like someone is on top of Jeremy's care.

He already has submitted the requisition for October's scans. I love that type of efficiency (Jeremy, 8/6/09)!

Surprising questions from the child and seemingly mundane events like shopping elicited feelings of pride and purposefulness.

Do you think I'll ever understand? I just never quite know what conversational track that child will lead me down. Yesterday we were driving to the local garden center when she piped up from the back seat, "I still don't understand why God let me get cancer. Do you think I'll ever understand?..." As Leigh continued to talk, she seemed very fragile emotionally and I could hear tears in her voice as she wrestled with a subject she hadn't brought up in a long time. "Mom, what is the purpose of my cancer? What good has come out of it?..." The first thing that happened to come to mind was to remind her of how many parents have told us that reading her story on her web page has helped them to be better parents, and has helped them to be more patient and loving toward their children.

I was about to go on when she said, "Wait a minute. Hold it right there. That's good enough for me. I hate it when parents aren't nice to their children and if my being sick has helped a parent treat their child nicer, than that makes me happy."

And that was that. She'd found her purpose again; she remembered that she hadn't been sick for no reason....(Leigh, mother, 4/24/04).

Becoming a survivor We realized this afternoon that her swimming suit had disappeared (this seems to be the trip for things breaking and being lost) so she and I ran out to shop for another suit. I never thought we'd have a cancer

conversation in the dressing room but it turns out that we did. I had brought a couple of tank-ini suits back for her to try on in addition to the one-piece suits. She fell in love with one of the tank-inis (which covered all but a couple inches of her torso) but she was initially troubled by the fact that the suit showed her scar. I sat down beside her on the dressing room bench and said, “Leigh honey, this decision is entirely up to you. How do you feel about people seeing your scar? Will it bother you to have to explain it to people?”

She was quiet for a few minutes and then she lifted her sweet, serious face to mine and said, “Mom, I think my scar is beautiful because it saved my life. I’m going to get this suit and show off my scar.” I was so touched by her attitude and her words and her earnest, grown-up face as she made the decision to take yet another step beyond being a cancer victim to becoming a cancer survivor....(Leigh, mother, 8/18/05).

The last of treatment was cause for particularly expressive writing.

Letting go of the bike She’s finished! It hasn’t quite sunk in completely. Monday I couldn’t sleep a wink and last night I fell asleep at 9:45!!! Thank you all for the congratulatory messages and hugs. I haven’t posted because frankly, what do I say at this point. We are just beginning a new chapter (or as Jeff put it, “hopefully a new book!”) and it’s strangely bitter sweet. I am beyond ecstatic, elated, overjoyed, grateful, so full of hope....and yet, I am scared to death. The safety net of chemo is gone and I’ve done all I can do. It’s like teaching your child to ride a bike. First you start with training wheels and eventually you lose the training wheels and are running behind your child desperately holding the back of the seat. Your hold loosens and is really just cursory, so you let go

and off they go wobbling and teetering, but riding independently. And there you stand, with your hands up to your face, smiling, but scared to death they're going to crash and yet simultaneously excited at their accomplishment! With the last dose of chemo, I let go of her bike. She's riding on her own and all I can do is watch. Here's to Isabelle..., my brave little girl with so much spunk and spirit to spare (Isabelle, mother, 5/1/08).

The irony of discovery of positive feelings at a funeral inspired this father to write. Interestingly, the use of the phrase "saddest funeral I have ever been to" reminds the reader of just how common an occurrence that activity has become for these parents.

A great weekend included a funeral Saturday marked the funeral for _____. You might think it strange for me to say that I had such an incredible weekend when I attended such a sad event. I think so to. However, let me explain. This funeral was perhaps the saddest I have ever been to. Unfortunately, I now have experience to compare. While I take something special from every funeral I attend this one truly inspired my faith. First, [her mother] did an incredible job of reliving [her] life through words. I felt so close to her and I felt like I knew her better than I ever had before. Perhaps, [the mother's] incredible story telling and the realization that she was gone was why it was so unbelievably sad. Regardless, I truly felt like the child] was at peace and I could picture her in Heaven in my mind....The thought of [her] complete unearthly joy in Heaven bathed me in comfort for the rest of the weekend (Cindy, father, 6/30/08).

Sometimes seemingly inconsequential statements were shared to heighten meaning when they had been reflected on within the context of a child's unexpected longevity.

Sobering One thing that was a bit sobering at the hospital last week was an off-the-cuff comment that Dr. D. made. We were talking about hearing loss in kids who have been through transplant and he said that data has shown that some kids continue to experience hearing loss even two and three years past transplant. I said, “How about after 4-5 years past transplant?” He got kind of quiet and said, “There isn’t much data that far out.” The unspoken message in the room was that there were precious few Neuroblastoma kids left to study at that point. It’s moments like that, moments that crop up out of the blue that sober me up and keep me treasuring each day that passes with this beautiful angel in our lives. My prayer is that she will be one of the rare ones that will reach the 5-year mark and they can use her in some of their studies to help the ones that come behind her (Leigh, mother, 9/14/05).

Just scars When the [camp] nurse asked Leigh [during screening] if she had a central line or a port-a-cath Leigh just looked her square in the face and said quietly, “All I have are scars. Just scars.” The nurse looked at me and I looked at her and we shared a moment of quiet understanding. We were once again reminded by Leigh’s words of just how important it is to have a place like Victory Junction, a place set aside for the kids with the scars--the precious kids who carry marks on their body and marks in their spirit, kids who just need to laugh and be silly and throw Jell-O at their counselors (Leigh, mother, 6/12/06).

Parents whose child had died, referred to as angel parents, expressed a strong desire to memorialize the life lost; to give back; and to attend to the lives of the siblings.

Grieving Well, we're overdue for a post. Neither of us has felt like posting lately.

For me (Henry), the reasons are quite simple. What can I say that hasn't already been said, or that isn't painfully obvious? The pain of missing Tony grows more and more every day - I clearly didn't feel this way in the weeks after his death.

Now, the shock and the sharp pain is gone, replaced by a dull, aching kind of pain.... To be honest, some may think that we are simply grieving by continuing to fight for a cure.... that this is therapeutic for us. I wish it were that simple.

Believe me, sometimes it is, and sometimes it isn't. There are only 24 hours in a day. Most all angel parents are still parents to other kids that need time, attention, love, and a roof over their head. This work takes away from hobbies, vacations, and families. It is not without reward, but it is not without costs either. To these angel parents, I say simply, "Thank you."... So many of our days feel strange because Tony is not with us. No matter what we're doing - whether we're having fun (we do), or feeling melancholy (we do) - the feeling is there....Rebeccah starts 5th grade today at a new school (5-6 only), and we will be dropping her off together as a family. She is somewhat nervous but mostly about homework. Tony would have been starting 3rd grade. So many "I wonders" around this missed milestone: I wonder who his teacher would have been; I wonder which kids would have been in his class; I wonder how he'd be doing in math, and what he would be writing about. It will feel strange not to show up at Solana Highlands on this first day of school (Tony, father, 8/31/09)

6-month anniversary Hi everyone, it has been 6 months since our sweet Carrie left us and went to Heaven. That is still very hard for me to believe. I feel as if it

were yesterday when we drove Carrie to [the hospital] for what would turn out to be the last time. It was the last time she saw her house. I replay that last day and night over and over again in my head. It is just as heartbreaking then as it is now, everyday. I'm never going to feel right in my heart or my head again. I am so grateful that she left us peacefully. We were glad that she was able to be at [the hospital], where we knew her friends there would make sure she was completely comfortable and in no pain. That last day she was in a deep sleep but she knew Mommy and Daddy were there with her. We told her how much we loved her and how proud of her we were. No one could ask for a stronger or more beautiful child. We read her psalms from a childrens book that Sister Alice gave her. We told her we would miss her more than words could ever say but it was okay to stop fighting and to go with God. As she took her last breath, she opened her eyes ,as if to show us those big beautiful blue eyes one more time. I am thankful to have that memory. I am so thankful that Molly and Rocco were able to come and say goodbye the day before. I thought it was very sweet how staff from all over [the hospital] came to say goodbye to her. They are good people. That's why they work there. Bryce and I have been dreading February even coming for a couple of weeks now. This time last year, we were eagerly anticipating Carrie's Make-a-Wish trip to Disney for her 4th birthday.... We also took Carrie to the Padre Pio memorial which is about 15 minutes from our house. It was extremely emotional for us and Carrie didn't understand why we were there. I told her we wanted to pray to a special man, to make her healthy again. The lady there let Carrie touch the Padre's gloves and we put a purple bracelet on his statue. We felt so desperate

and helpless. Carrie looked so good that the lady thought we were there to pray for Bryce because he was still in his neck brace. I thought the day Carrie was diagnosed was the worst day of my life, but we still had hope, a lot of hope and B POSITIVE vibes. Then when she relapsed, she was feeling and looking good so we thought lets pray and pray some more, she will still beat this monster. But when Bryce and I had to say goodbye and make that drive home without Carrie, that is truly the worst day of my life.

I hope and pray that you are happy where you are little girl-running and playing and free.

Never to have cancer or pain again.

Love Mommy (Carrie, mother, 2/5/09).

I don't want her to be forgotten We are headed to [the hospital] on Monday with a van full of all kinds of goodies. Thank you to everyone who is helping us with our mission. This is really so important to Bryce and I. Speaking for myself, I don't want Carrie to ever be forgotten. I don't want her memory to ever fade away. I was watching videos the other day and boy do I miss that voice and face and well everything. I am trying to post them directly on to the update but don't know how. I want to share these videos with you all, they are so Carrie! So if anyone out there in carepage world can help me please let me know. That's all for now, please pray for a cure, please! E-mail politicians and businesses and tell them about childhood cancer. Tell them how much this sucks for us and too many other families. There are so many sick babies, too many. B POSITIVE and love

Ellen,Bryce,Super Molly,Super Rocco and always Super Carrie xoxoxoxoxo

(Carrie, mother, 6/19/09)

Advocacy

Parents used the story of their child's experience to teach; to advise; to raise money for research; and to inspire readers to political action at any level.

Alex/Pay it forward Since Jeremy's diagnosis Walt and I knew that for the rest of our lives we would support the cause of curing pediatric cancer. It's hard to do that when you are in the midst of the battle...but we were always talking about ways to "pay it forward" and make a difference in the world of family's affected by pediatric cancer. Now that we have had a few weeks to take a deep breath, we are ready to start helping!

We are pleased to announce that our family will be organizing an Alex's Lemonade Stand this year at the...Labor Daze Festival (our local summertime festival).

Who is Alex? Why are we selling lemonade? Before I explain any further, please take a minute to watch this video that will introduce you to Miss Alexandra Scott and her dream of helping to cure pediatric cancer, one cup at a time. Turn on your volume and [CLICK HERE](#). In her short 8 years, Alex lived a BIG life. She courageously fought Neuroblastoma while raising 1 million dollars for pediatric cancer research (Jeremy, mother, 6/17/09)!

A father wrote to remind readers, especially other affected parents, to direct and attention at those individuals in a position to set policy and to make change.

Politics I have learned many things since we first began our journey through the neuroblastoma world. However, one of the biggest veils to be lifted from my eyes has been the politics behind so many decisions in the research world. This is not to point fingers. Much of it is due to what they call the "scientific process" I call it haggling....Parents often blame researchers for being the reason that it takes so long to move new drugs and trials forward. After all, it is generally the researchers names who are on the protocols. Who else are you going to blame? What I have come to find out is that the answer is - not them but nearly everyone else. The researcher is hardly ever the problem. To this date, I am yet to see research slow due to the researcher. I have seen it due to pharmaceutical companies, the FDA, the NCI, an IRB or a myriad of other factors....We often hear that a trial was opened or that something got funded. We rarely get insight to all of the work and effort that it took to get there. That is my favorite part. That is how you speed things up. That is how you make things happen. You may not be aware but the National Institutes of Health (NIH, the parent company, if you will, of the National Cancer Institute, NCI) quietly received an increase in their budget of 34% due to the stimulus package....In this case, much of the story was captured in the New York Times. To my surprise, a very savvy Arlen Specter, got the job done....It is amazing to me how solutions often come down to the quiet actions of those with purpose, drive, and focused energy....(Cindy, father, 2/20/09).

A few months later, the same father admonished parents to be vigilant, intelligent and assertive in pursuing research-based treatments.

This entry will make plenty of people mad I am sure this entry will make plenty of people pretty mad but, to be fair, it is a subject that drives me absolutely crazy.

There are several parents out there in the neuroblastoma world that are touting new drug combinations for relapsed and refractory children. I am bothered by this because so many of these combinations have little support for efficacy in kids with neuroblastoma....They claim fantastic responses but I am yet to see one who has had a response that would be considered "real" in the medical world. I am yet to see a response that is any better than standard relapse chemotherapy. Families are choosing these unproven combinations over therapies which we know have produced good results and in many cases have put kids back into remission. For example, I can't tell you how many kids I have seen achieve a second (or first) remission with MIBG therapy and / or antibodies - but, there have been many. These are all relapsed and refractory kiddos - the worst of the worst. Furthermore, I have also seen kids maintain years of remission after refractory or relapsed disease with all different kinds of low dose agents that are available and have proven track records. Most importantly, these are all drugs with a response history in kids with neuroblastoma.

Maximize your options!

Choose therapies and options with the highest response rates before jumping into the unknown.

Be conscious of the toxicities - known and unknown.

Consider the impact and recovery of the marrow from every regimen. Sometimes a high dose therapy can be appropriate if it provides the possibility of sparing the marrow in the future.

Be critical of everything you hear. Verify responses. Make sure they are real.

Find the successes. They are out there.

I have no intention of telling you what to do but, as another parent, I ask you to look at these things logically. When you talk to other parents consider the successes that they had. Go to the source. Talk to the successes....When you look at combinations of drugs (even known ones like topotecan and cytoxan) that are adding other experimental drugs make sure their response rates are at least as good as the combination alone and not worse than the same combination with another drug.

Ask questions. Look everywhere.

Do it with purpose (Cindy, father, 5/6/09).

Archive

As was evident in earlier phases, during the off treatment phase parents wrote of the value of the blog as a record of events and decisions made. In addition, photos that illustrated the feelings experienced on the journey were included in increasing proportion to earlier entries.

Scar photo I wanted to add this picture I took of Jeremy's back tonight. The darker scar running down his spine is from his January surgery. On the right side you can see his incision from his recent surgery. The other marks are scars from various drainage tubes. His chest tube scar isn't visible in the picture, it is under his right arm. I have to say that tonight was the first good look that I got of his

back since this last surgery. I gasped and just teared up at the sight of my poor baby. This is just another reminder of how amazingly brave Jeremy is!



(Jeremy, mother, 4/23/09)

The idea of the blog as a place to preserve thoughts and a record of events took on significance over time.

A diary to look back on—reviewing recent events Since this blog is a little bit of a diary for us to look back on, I wanted to expand on Henry's latest post and review what has happened since July 2006. Tony went in for his regular three month check-up the week of July 17 (MRI & bonescan). Both scans showed that a spot had appeared on his spine somewhere around T11 (if you know what that is). His oncologist ordered a biopsy on the site. Tony underwent a *CTscan guided needle biopsy* of the site, however, pathology came back negative for cancer. In this case, *negative means inconclusive*, because if it's not cancer then what is it that's showing up on the scans?

The best course of action for now was to schedule Tony for an MRI every month to watch the spot and see if it goes away (hooray), or grows (bad)....So, Tony went in for his three month check up on October 20. The original spot was still on

his spine, unchanged. And now we have a new spot on a rib. Great. We're now waiting for a CTscan to be taken for Tony's surgeon to get a better look at the rib so she can do the biopsy. We should be going in for all of this Halloween week. As you can imagine Henry & I are pretty stressed out, but doing our best to keep it normal around the house for the kids. Tony is feeling well, going to school, and having fun in general....(Tony, mother, 10/27/06).

The next two entries exemplify the significance of recording thoughts on anniversaries to parents regardless of diagnosis.

Anniversary significance NBL Three years ago today, our lives changed forever. Three years ago, at 10 am, I brought Ana to the pediatrician and he recommended blood work and an ultrasound. Today at 10 am Ana went to her new school and met her pre-k teacher and her classmates in her new classroom. Three years ago at lunchtime I got on the phone with the doctor who told me there was a tumor in Ana's tummy. Today at lunchtime, Ana walked into the kitchen demanding a turkey and cheese sandwich. Three years ago this afternoon, John and I put Ana in the car and drove to [the hospital] where I held Ana screaming as she got her first IV and was later admitted. Today, this afternoon, Ana Lynn is playing around the house, jumping on the bed and being an energetic preschooler....Thank you GOD for healing our baby girl and allowing all of us to be a part of this journey. We have learned so very much. Thank you to all of you for following this journey with us and for always supporting us and praying for us. We couldn't have gotten through this without all of you (Ana Lynn, mother, 8/28/09).

Anniversary significance ALL So three years ago tonight my sister, Jeff, Isabelle and I crossed the threshold of [the hospital] not knowing anything more than Isabelle likely had Leukemia. What lay ahead remained a mystery, thank God. When the glass sliding doors opened into the lobby, “Joy to the World” rang out from a group of carolers. It was startling, yet comforting all together. We made our way to the registration line and I remember the lady helping us was cold and likely bitter to be working late so close to Christmas. She asked where our pediatrician had referred us and I had to say “Children’s Oncology.” I know I didn’t hesitate in saying it, I know because I was desperate for help. Yet in that half a second before those two words were spoken, time stood still. I remember thinking, “If I say it, it will be true, but I have to say it.” I expected her to look up from her computer, say “I’m sorry,” look at me with pity, but there was none of that. Just “sign here,” and “take this to the fourth floor.” When we made our way to the fourth floor, we were ushered in through the double doors and followed Isabelle’s very first nurse to room 16.

That walk seemed like forever. On the way we passed the “Cub Den” or little library area they have on the unit. For some reason it was there, that another wave of my new reality slapped me. Jeff and I have talked about it so many times. Strangely it was there that it hit him too, right by the Cub Den. The patient rooms were within view. I couldn’t help but look in. The institutional cribs that looked more like giant birdcages would catch anyone’s eye. I remember later that night, after Isabelle had a PIC line placed, Tylenol and antibiotics on board, and some stranger’s blood being transfused, more carolers came by. We had the window bed, so I could see them approaching. I sat in the blue vinyl chair, holding my Isabelle and they stood in the hall just outside her room. The slider was

open and there I sat listening bravely, their tiny audience. Some volunteers followed behind with a big cart full of wrapped gifts. A lady handed me one labeled, "Girl 0-2" while I tried to reconcile how it was that I ended up there (Isabelle, mother, 12/22/08). Plans for the child's funeral were placed on the blog to allow readers to participate in whatever capacity possible.

To honor his life Please send stories and pictures, anything that to you, epitomizes Tony (email or just comment here). And any pictures or videos from Tony's celebration of life - especially of the fly-by! We have our memories, but would like to know yours as well. We are having some videos created of Tony's life. One is going to be especially for Ric. We already watch clips of Tony with Ric and Rebeccah, but this we envision as more a movie, if not feature-length. Our good friend Leo is creating this for us with his kids helping out. Tony, it turns out, was the topic of conversation around Leo's dinner table with his kids for the better part of four years during Tony's battle. We know there is no one else in the world who can tell Tony's story better than Leo.

We have also found an artist that is going to create a permanent resting place for Tony's ashes. Because his death caught us quite by surprise - really, we were totally unprepared and unfocused on it happening *then* - we rushed into a decision for an urn at the funeral home. But really, would an urn from a catalog - something that others had also purchased for their loved ones - do for Tony? Not for us. So we decided that what Tony came home in from the crematorium was only a temporary home, and that we would create, or have created, something that with one look, would say, no *scream*, Tony.

Thanks to the wonders of Google, 30 minutes of online research turned up Funeria, an artists representative that specializes in "personal memorial art". We found an artist - Chris Rizzo - that connected with Tony's story and are signing the commissioning paperwork today....Everyday we strive to behave and make decisions that honor his life (Tony, father, 10/18/08).

Explanation

Parents of children with neuroblastoma explained to readers the meaning of being off treatment; that “cure” likely would not become part of their lexicon even as their child was surviving; that scanxiety and hypervigilance would persist; that overreaction to symptoms that in other families would seem minor was part of the “new normal.”

The meaning of ‘off-treatment’ We spent several hours with Dr. E. yesterday morning. It was our final therapy wrap up session, a retrospective look at where we have been, where we are, and where we are going. We discussed every aspect of Cindy's treatment and what it means for her future. Cindy is officially off treatment and today marks another day 0 on her calendar. Much of her progress will be measured from today as well as the day that she received her stem cell transplant. Cindy is considered in a complete remission. You notice that I do not use the term cured....So, what does it mean? It means that they can no longer detect any levels of cancer in Cindy's body. Unfortunately, there is no guarantee that there isn't any there....What does it mean about her chances of overall survival? Cindy sits in about as good of place as one can sit. She hit all of her milestones. With that being said Dr. E. estimated that Cindy's chance of overall survival was somewhere above 40% to 45%. There is no absolute number

because, unfortunately ,there just weren't a lot of Neuroblastoma survivors in history to come up with a solid number....(Cindy, father, 8/26/04).

It was apparent in several blogs that authors wanted readers to be aware of the heightened levels of anxiety that were possible when the child experienced unexplained symptoms.

It is important that people know Let me just share a little story with everyone, that only about three people know about...A month ago we decided to finally take Mimi to the eye doctor because of some excessive blinking she has been doing. I assumed it was allergies, but we started to worry that it could mean a problem with her vision. We took her in, and sure enough she needed glasses...she is near-sighted with astigmatism....After a concerned email from a loved one we looked a little further into the excessive blinking and Neuroblastoma...it was devastating. Many times excessive blinking can be a sign of relapse in the brain, often misdiagnosed as something minor....I cannot even begin to explain how it made me feel - completely nauseous, panicky, and overwhelmed to the point I couldn't hold a complete thought in my head!

We called her oncologist in Omaha and because she is scheduled to return for scans in a few weeks they said they were comfortable assessing her at that time. I was told that it was very good that we kept a close eye on all of her neurological development and anything that seemed out of the ordinary....I have found calmness in knowing that she is okay and it is just a fluke...not a relapse. But it made me think.

If Mimi were to relapse - - - I can't even let my mind go there. Not only is it too painful, but it is too overwhelming.

I share this story because it is important that people know what “our” life is like now. When I say “our” I don’t mean Chad, Mimi, Harper, and I...I mean any parent of a cancer survivor and warrior....(Mimi, mother, 9/12/09).

Hair loss was portrayed as significant more for its representation of the illness’ meaning than for any aesthetic quality. Its return heralded progress, hence the effect of the following narrative.

Loss Now, brace yourselves for the devastating news of the week. Today Isabelle cut her own hair! Yes, it’s true. I called home on my way home from work to check in and while I was chatting with Cole I could hear Isabelle, “Mommy, Mommy!” So she got on the phone and said, “Mommy, I cut my hair and it looks beautiful!” I have to be honest, I was devastated. Call me superficial, call me vain, but I was upset. I couldn’t get home fast enough to see the damage and yet when I got in the garage I found myself stalling....Finally I went in and Isabelle was on her bed with her head buried under her pillow, so first I saw the four inch chunk of hair on her bathroom counter. My stomach was sick. I just held it and thought, “the price she’s paid for this hair.” Finally I was able to see her and it’s cut from front and center. The irony is just too much for me to digest....I am still in shock and denial and already feel petty for caring as much as I do. Yes, I understand that I’m not the first parent to find their child with a hunk of hair gone. And yes, I realize that it could be much worse. I know better than most that it could be worse, but I’m sad. To me, her hair growing back has been symbolic of all her accomplishments. So it happens to sting in a different kind of way. Yet, I can see the humor in the whole thing too. Like I said, the irony is over the top. So just let me wallow in my disappointment of the short lived pretty hair. I’ll get over it fast enough....(Isabelle, mother, 5/1/08).

Transition to end of therapy

Parents of children with leukemia narrated the end of therapy differently than the parents of children with neuroblastoma. This mother imagines the straightening of the curve in the road that was leukemia.

Today, I took the kids to lunch...[My son] didn't order any [fries] and was eating from her plate which had a big blob of ketchup. He says, "I can't double dip, right?" I agreed and then I told him if he put some on his own plate he could. Then [my daughter] says, "But I can double dip in his if he doesn't because he's not allergic to my germs." I said, "Well, in general it's bad manners to double dip, even though that's true that it's a bigger deal for you to get anyone else's germs than it is. . ." Then she says, "But when my chemo's all over, I can double dip and eat your germs...!" They both smiled and single dipped and I sat there thinking how very strange my life has been. The curve in my road, so to speak, should straighten out soon (Isabelle, 3/31/08).

In contrast, parents at the end of therapy for neuroblastoma were plotting the next therapy in preparation for the inevitable recurrence of the disease. Relapse was described not in terms of 'if' but 'when.'

CHAPTER 8

Analysis of reader comments

Co-creation and Ballast

Work on the conceptual analysis of illness blogs led to the last research question, i.e. “What is the influence of author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer? One of the defining attributes of the illness blog is author-reader interactivity. Blogs would be more comparable to diary writing without the inherent connectedness between the author and the audience unique to the medium. This chapter will report on the analysis of the influence of reader comments on the bloggers’ writing and on the illness experience.

Two thematic categories were identified in the analysis: co-creation and ballast. Co-creation is meant to be understood not merely as the act of two parties contributing to a body of work, but also to be understood as representative of the process through which both blogger and reader influenced each other personally in the creation of an experience larger than the individual. Blogging and the ability to comment on entries enhanced communication; permitted broadcasting of information; inspired understanding, emotions and action; and created opportunities for readers to contribute in word and deed. The comment feature is the *raison d’être*, the justification for blogging rather than other forms of communication during illness.

Ballast was the term applied to the second thematic category. After the third reading of the comments; after the crucial role of “balance” in the analysis of the authors’ blogging was apparent, the effort exerted by commenters to support; to express solidarity through affirmation and identification; to contribute, in word or deed, seemed an embodiment of a vestibular effect on the authors’ experience.

Thematic categories and performative acts found in reading the comments by readers were isolated using the same method noted in the analysis of narrative themes of the blog posts. It was essential to examine these separately to gain understanding of these comments as stand-alone narratives toward an understanding of how they then became the foundation for author-reader interactivity. Identifying the small, frequently expressed thematic categories ultimately provided insight into the author-reader relationship that developed as the illness progressed. The most commonly expressed themes were solidarity and support; and expression of gifts received through reading the blog, such as inspiration, gratitude and awareness of others' suffering. In addition, some comments could be considered as standalone narratives, telling powerful stories independent of but influential both in the creation of the blog and of the families' experience with the illness.

The thematic categories found in the narratives, co-creation and ballast, will be discussed within the temporal frames of the illness and treatment. Examples of comments received that contributed to the creation of the blogs and of the illness experience during the diagnostic phase centered on the blogs' purposes and effects; inspiration received; inspiration offered; expression; and the icons and legends that influence perception.

Diagnostic phase: Co-creation

In the diagnostic phase of the illness, readers shaped the parent narratives and experiences by reinforcing the significance of the writing, by relaying their impressions and by inspiring them through encouragement and storytelling.

Blog purpose. The ability to comment allowed readers to place messages that served many purposes. Even as readers expressed gratitude at receiving reports during the uncertainty of the diagnostic phase, they began to create a narrative larger than the author's alone. For

family members who wished to provide support but were unable to be physically present, the blog and the ability to leave comments permitted at least a facsimile of presence and engendered feelings of solidarity.

I have read through your blog and I must say how very proud I am of you. What an enormous task God has set before you, but He continues to be your source of strength. You are a fantastic mom to all of your children. How sweet it was to see you be able to hold [your son] again after his surgery. I can't imagine all of the emotions you feel, but know at the end of the day there is a great multitude of people praying for you and your family. Remember that God will use every opportunity in your life to bring glory back to Him. Know that we love you so much and will be praying for all of you....Thanks for sharing in this blog. It means a great deal to those of us who can't be right there physically for you. May God continue to give you strength, peace, hope and rest (Jeremy, 1/28/09)

For readers, the blogs also represented ready access to people experiencing similar events and feelings. Family members of children with neuroblastoma are repeatedly reminded of the rarity of the illness; yet everyday through the blogs they can connect online with people with whom they have much in common across the world.

- (1) That is why the NB blogs are so very powerful! For me, I started reading Tony's then linked over to Martin's, Carter's, James's, and Will's. My response has been emotional (!) but it has also spurred me to action. The blogs provide the story and a picture of a child to go with the terrible statistics. It does make

it real and tangible. You feel you know these kids so you want to do something! (Tony, 9/24/07)

(2) Hello, Lucy. I read your mom's *blog*...is that what it is called?... I'm kind of old, probably older than your Nana....Anyway, I would like to promise that I will always respond to your mom's messages for as long as she keeps writing about your family.... We are here but we are with you in spirit....Love and hugs for you from all of us in NY. (Lucy, 12/14/08)

Blog effect. The expression of the effect of the author's writing became an element of the co-creation.

(1) ...I cried when I read your mom's entry today. I cried for you because at 7 years old you are becoming schooled in subjects most people never have to think about. I cried for your mother because I know how much she wants to take this pain and dreadful experience away from you and she just can't do anything about it. I cried for your grandparents because I know how much they love and adore you and your mother and Father, and I know how much they want to take all of this away from all of you. Lucy, I cried because I'm a grandma. Benjamin is 7 and Nicholas is 6. When this first happened to you, I remembered how quickly life can change on us, and I thought I couldn't handle it if this had happened to one of my boys. You know what? You have been teaching us all, that, yes, we CAN handle it. You have become a bright and shining example of courage and hope. I am very humbled by your bravery. This journal is bringing together complete strangers in prayer and compassion. Every single day someone is praying for you. Special prayers for strength, and hope and

healing. So, remember, every single day that someone writes to you in this journal, you are NOT ALONE. (Lucy, 12/14/08)

- (2)All of you wonderful people that I have met through caringbridge site have become like a family to me. You understand my pain and my joy. As much as I have not been through half as much with Neuroblastoma as most of the people I have met online, I feel a special place in my heart for each and every family that has been touched by cancer. I always think of how lucky we were...being there for other families who aren't as lucky as us has been my quest. My husband doesn't understand when I stumble into the living room with tears in my eyes to tell him of yet another child who has lost their fight or a family who has received news of a relapse but these sad moments are what being part of the neuroblastoma family is all about. I have found that through everything I have been through including the recent loss of my daughter that it has been my online friends that have been there for me even more than my family and offline friends. I think of you and your family daily and pray for a complete healing....I have seen miracles...on a number of occasions so I know they can happen. (Leigh, 12/12/03)

Some readers expressed a change in their professional path that resulted from reading the blogs.

- (1) ...Although I don't know your family personally,[your child's] story has inspired me to do my postdoctoral research in cancer after my PhD. I've only just started my PhD so there's still a long way to go, but this is my goal for the future! The stories of all these brave kids...touched me deep down in my

- heart. I just want to let you know that your family is a true inspiration to people all over the world. Hong Kong, China (Leigh, 10/22/04)
- (2) I stumbled on [your child's] site while doing research last year and have been following it ever since. I am at university now and would like to become a pediatric oncologist. [Your child] is a real inspiration and never fails to make me laugh! Toronto, ON Canada (Leigh, 11/19/04)
- (3) ...I know that I'm just another stranger to you....I live in England (right next to the seaside) & I work as a clinical psychologist helping to look after kids who get sick with cancer and other horrible things. I've been reading your mom's diary for a while now & have learned so much from you all - especially from you....I've been really sick too sometimes - I had leukaemia 5 times between the ages of 12 & 25 so I kind of know how it might be for you & even though you seem to be really positive, I know it hurts sometimes....I wanted you to know that you have the love of God, your family & friends (on both sides of the atlantic) all through these times & we're all hoping that the news is good for you. I know the words of a stranger aren't that important at times like this but you are in my thoughts & prayers....You've been inspirational to me in my professional and private life & I think you've taught so many other people so much too - you go girl! Feel free to contact me if ever you'd like to. North East, England (Leigh, 1/14/07)
- (4) ...I would love to brighten your day by signing your guestbook. Your daughter, and entire family, are such an inspiration....To share a bit about myself....I am...from NJ. I graduated from Rutgers University in 2005 and

went onto law school. However, God had a different plan for me. He used [your child]..., and a girl from my hometown...to show me my calling. I have returned to Rutgers and I am just now finishing my first semester of accelerated Nursing school. I am on my way to becoming a pediatric oncology nurse, and I have never been so happy. New Brunswick, NJ USA (Leigh, 8/10/07)

Inspiration: Received. Frequently, readers expressed appreciation for the inspiration received from reading about the experiences.

- (1) I look for your messages, Larissa, and, though I expect we will never meet, I have to say I appreciate all the shared words that carry such human suffering and stamina. You are inspiring. I pray never to have a loved one go through what Lucy faces moment by moment but, should something happen, please know you will be helping us bear it. You and she and your whole family are a blessing to the rest of us. May 2009 be so much better than we expect it to be... for all of you. Nancy (Lucy, 1/2/09)
- (2) Your story is so inspirational. My son is 5 and was diagnosed with neuroblastoma in March. It is refreshing to hear of an "older" child doing so well with the disease. I will pray for your family and appreciate you sharing your story. scottsdale, az usa (Leigh, 6/6/05).
- (3) ...I stumbled onto your site thru the internet, I haven't read the whole thing yet, I can't wait to....You have touched my life in many ways this past week. We were faced with a decision on which road of treatment to take for our daughter, who has stage IV, n-myc amplified neuroblastoma and no other treatments have taken her to NED; I opened your site on Monday when faced

with the decision, and one treatment was the accutane. I felt like God led me to your site on that day, we are going with the accutane; which starts on Monday. She was diagnosed at 11 weeks old and is now 13 months old. She is a total gift from God, every day is! Thank you for inspiring me, and helping me without even knowing it! [Your child] is an inspiration to many. I thank God for having our paths cross! God Bless your family in the wonderful ministry you do! Lakewood, WA USA (Leigh, 7/6/07)

Inspiration: Offered. Readers often commented to inspire bloggers: to remain strong in the face of adversity; to maintain hope; to take support from others; to continue writing; among many others.

(1) Hello again....Just wanted you to know how IMPORTANT it is that you keep your web page updated....[My family was] so worried about [your child's] MRI that [my relative] called me to see if you happened to have put an update on your web page, (they don't have a computer). Well, thankfully you had and I had read the update hours before [he] called me. I was able to give him the good news both about the MRI and [your child's] increase in...growth. Just wanted you to know how important this web page is, you may not realize it, but it is the link between her health and me updating everyone at church about her health. Grove City, PA USA (Leigh, 5/22/05)

(2) i read somewhere of a village in Africa, where the medicine man was many miles from the village. Whenever someone got ill, they were laid on a stretcher, and the first set of six stretcher-bearers would pick up the stretcher and start walking. The terrain was rough, and the bearers would get tired

quickly. But, behind them was a group of faithful followers, and as soon as the tired bearers would set the stretcher down for a rest, a new group would appear to pick it up and keep carrying it. On they went, each group taking their turn, until they finally reached the help the sick person needed. And so it is with Christian brothers and sisters.. each of us finds it an honor to take our turn bearing your stretcher of need. We carry you along in prayer until the next group picks up the load, and we will get you to where you need to be.

Why? 1 Cor. 13:13...(Leigh, 7/30/06)

Readers employed humor as a means to inspire as well.

I was volunteering in my youngest daughter's classroom today. You sent your oldest off to college and I sent my youngest to kindergarten....It reminded me of when my son...was 2 1/2 yrs old, only months into chemo. He, his older sister and I were making construction paper turkeys with craft store feathers. He colored his turkeys but kept refusing the feathers his sister offered him. Finally he told her "Mom said if I get fea/v/ers I have to go to the hospital." I almost cried! My poor boy had bald turkeys because he was afraid feathers would send him to the hospital! Thought a word loving family like yours would enjoy that....(Cindy, 9/20/07)

Expression. Some readers shared their stories of illness in detail, often from a position of expressed solidarity.

(1) ...my daughter started to get sick when she was about 6 months old and later we didn't find out till she was almost 2 that she has this very rare genetic disorder that can cause tons of things to go wrong. thankfully we think she got

a mild form of this disorder and she is disabled from it for now and has a very rare form of seizures that causes her to stop breathing and her heart rate to drop....if you need someone to talk to that has a sick child and also is in and out of hospital a lot. please feel free to email me. (Leigh, 7/9/03)

(2) I do speak from experience. I have a very special daughter, who just turned 16 yrs old. She got sick when she was 15 mths old. She is completely dependent. But she is the happiest person you could ever meet. Only God could give someone that kind of peace and joy to be able to smile in such circumstances. From a parents standpoint take one day at a time. I used to try and plan for the years to come, but the possibilities are too hard to comprehend. For me that was where satan would try to pull me down the hardest. Treasure every minute with your whole family. Know that even in those scary, lonely times, you are not alone (Leigh, 7/9/03)

One reader wrote to express gratitude for media exposure of one blogger-family's illness experience that enabled a link to help.

I NEVER pick up newspapers, but [a familiar] face jumped out at me and after reading the first few sentences I quickly purchased yesterday's WSJ. WE have a 7 year old son with stage 4, high risk neuroblastoma. We've just finished the standard 6 rounds of chemo, and had the tumor removed Nov. 28, 2007. Now we wait (for isotopes to be produced again) for pathology results and MIBG scan to determine if radiation will be necessary, then the stem cell transplant. But what comes next? We are realistic - it's stage 4, high risk . . . how long before it comes back. MY husband and I both feel like we are not being proactive enough, yet we don't know who to ask, where to turn for help. Our

oncologist can't advise us. This article has opened up a whole new doorway for us. Thank you, Thank you and we will add [the children featured in the story] to our "hope" list.

BC Canada. (Tony, 12/15/07)

Readers shared ideas that might expand understanding of life with neuroblastoma.

A comment that begins with support for the blogger's child discipline conundrum expands into an expression of her own philosophy of parenting a seriously ill child.

...you and your wife are the greatest parents. When my [child] was first dx we too threw the rule book out the window... Boy, was that a fatal mistake.... To make a long story short... She was 14 and suppose to be in at 9:00 when out on her bike with friends. She showed up at the house at 11:00 like she was allowed to hang out that late with the biggest smile on her face thinking discipline was not going to happen because she had cancer....We punished her and I was the one that went to my room bawling.... Now when we were told she had a couple months to live... I brought her everything she ever wanted, took her anywhere she wanted to go, allowed her to do anything she wanted to do...

ALMOST... To the point of filing bankruptcy after we lost her but I still till this day do not care because those memories of the smile on her face and the happiness we brought her in those last 4 months are memories that will last me a life time. Those memories have over taken the bad soooo many times....(Danny, 6/8/06)

Icons and legends. Comments from readers often referenced public figures influential in the cancer experience. Lance Armstrong, a testicular cancer survivor, has become a widely accepted icon of cancer research advocacy. The cancer iconography has widened to include others such as CBS Evening News anchor Katie Couric, whose husband died of colon cancer and Susan G. Komen in whose name a foundation was created for breast cancer research. Alex

Scott, of the Alex's Lemonade Stand Foundation for childhood cancer research, has become the public face of neuroblastoma.

I've been following your journey for almost 2 years now, though most closely the last year when I find myself checking every other day for updates. It all started from hearing about Alex's story on Oprah, visiting her website, and finding a whole world of children battling NB, including beautiful Leigh. I have to say I really do enjoy your writing, although I wish different circumstances could have surrounded the journal (Leigh, 12/4/07).

The influence of institutions specializing in this rare cancer loomed large within the online neuroblastoma community. Although the number is growing, only a handful of centers across the US were fully capable of treating the children in the blogs analyzed. In order, Memorial Sloan-Kettering Cancer Center in New York, Vermont Children's Hospital and the Children's Hospital of Philadelphia were the most frequently mentioned in these blogs. The physicians at Sloan are mentioned by name in many comments, often to refer the author or fellow readers to the center. One surgeon was referred to repeatedly by name as particularly skilled at performing the complex surgery required to excise the tumors associated with neuroblastoma. A legend about this surgeon was copied and pasted in more in more than one blog. One mother posted it the night before his scheduled surgery.

...I have told some of you this story about him, but for the others out there, it is quite beautiful. It was Christmas Eve 2007 - a week since [my child's] diagnosis- and I couldn't sleep. I met another insomniac mom...in the hospital pantry in the wee hours of the morning, we exchanged stories, and she was able to tell me where the closest Catholic

Church was so I could attend services. She also told me that she came to Sloan all the way from Texas with her 1-year-old child because of [Doctor], the chief pediatric surgeon....She told me that she often went to pray and saw [the surgeon] there early one morning with the priest after mass. She questioned the priest afterwards and he confirmed that it was indeed [the surgeon] and that he came each morning to get his hands blessed before going to work to perform surgery on the children. I caught my breath at the thought - how beautiful... [soon after this, my child] suddenly needed emergency surgery. It didn't even dawn on me at the time that the man explaining all the risks...was the same doctor. It wasn't until after everything was over and we were thanking him profusely, that he raised his hands up and said 'Hey, it's not me' and looked up to the heavens. Suddenly, the pieces connected and I exclaimed, 'You're the doctor that gets his hands blessed every morning, aren't you?' He just looked at me and one of the nurses said to him, 'They're on to you! They heard about you.' Since then, I have heard time and time again about families who come specifically to Sloan so that [this surgeon] can be the surgeon who operates on their child. I was told of a family from Costa Rica (I think....) who didn't speak much English, but could communicate that they were in NY for 'God's Surgeon'. Talk about pressure. But we can't think of anyone else that we would want operating on [our child], can you?!?" (Jeremy, 3/30/09)

Comments immediately following that entry expressed the influence of the story on other readers.

- (1) ...the story about [the surgeon] actually gave me chills! That is so powerful! I will continue to pray for Jeremy and that [the surgeon's] hands be blessed as they operate on your sweet boy! (Jeremy, 3/30/09)

(2) Wow that is so awesome! I can only imagine how much all those prayers from LU have moved the hand of God! I am so glad God worked all this out so that you could meet with this special doctor. After 3 failed IVFs, we switched doctors and I remember seeing the new guy bow his head and pray right before he transferred 3 little embryos in me. And now those 3 are 15 months old today so I know prayer works and how important it is to find a doctor who shares your faith! (Jeremy, 3/31/09)

Ballast

Future orientation, a sense of solidarity and affirmation for parents' feelings were identified as fundamental to the thematic category of ballast during the diagnostic phase. Ballast is the term being applied to the stabilizing force readers seemed to exhibit in the author-reader relationship. Examples highlight the influence of emphasizing an orientation toward the future and affirming the feelings of the blogger.

Future orientation. Hope for the future was offered in these comments affirming that the child had an identity uniquely suited for survival.

(1) ...You were a fighter from the time you started growing in your mama's belly. You keep it up girl!...Your mama and baba have arranged things so someone is always with you. You have someone to hold you when you cry, when you laugh and especially when you feel icky from the yucky medicine that is getting you better. My sweet girl you are on your way so keep bossing everyone around. Your very nature makes you a survivor. I love you and I can't wait to see you again....(Isabelle, 1/18/06)

- (2) My godson went through what you're going through when he was seven. Now, 11 years later, he's waiting to find out if he gets into MIT, Columbia or UPenn. Now, I'm not saying that you'll have to settle for schools like that, but that once you get better, you'll get to make many exciting decisions, just like him. (Isabelle, 1/18/06)

Solidarity. Readers often expressed a sense of solidarity with the blogger in the diagnostic phase by sharing similar feelings, thoughts and experiences.

- (1) Hello....I also have a daughter that was diagnosed with neuroblastoma in September, so I know how it feels to have this nasty disease turn your life upside down. I just thought I would let you know that we will be praying for your entire family. I pray that God would send some very good moments your way. I have found that I have to hold on to every good moment to get through the tough ones. (Ana Lynn, 11/29/06)
- (2) Although I don't know you and your family I am also a Triplet Mom with the [online] group. Please know that I am praying for your dear and sweet son...and your entire family. (Jeremy, 1/22/09)

Messages of hope and suggestions for expanding the search for optimal care accompanied these expressions of solidarity, especially in relation having their children treated by familiar practitioners.

...My son...has neuroblastoma just like you. We found that out in October 2005. It was a really bad day just like the day your family found out, but we have had lots of good days since then and you will too. I know lots of great doctors at [your hospital] so you are in good hands and you were really lucky to meet up with [your doctor] who I believe has some extra training in Hematology. If you do not

already know this one of the best neuroblastoma surgeons in the world...is just a few hours away at Sloan Kettering in New York City and their neuroblastoma team has a lot to offer too. Hang in there and don't forget to have fun....(Ana Lynn, 12/5/06)

Affirmation. Readers frequently acknowledged and sympathized with the experience of surplus suffering described in Chapter 7.

...I am sorry to hear about all the miscommunication or "lack of" communication occurring at the hospital. This is so frustrating as you are trying to plan your days and want to know what is next for treatment, etc... I do understand and being a nurse, it frustrates me to think that this happens in healthcare but unfortunately it does (not that it is right)....(Jeremy, 1/31/09)

Readers attempted to reassure bloggers through affirmation of the unsettled feelings that accompany uncertain futures.

...I am so glad you are all home under one roof as a family...cherish these days and try your best not to worry about the days ahead. Although there are so many "unknowns" right now...the one constant and sure thing is the love of your family and friends. Several friends have worked with Sloan to treat their NB kids if you want/need support from people who "know" and understand some of what you are going through. Continue to be brave and strong and lean on others for support--- God (and your children) will give you both strength to get through this!...(Jeremy, 1/24/09)

In addition, readers attempted to reassure bloggers by commenting on the comfort that comes from the certainty of having a plan in place.

It's must make you feel a bit better now that the dates for surgery etc have been made. A plan always adds a bit of security and comfort. Everything here is going along great....Our prayers are with you...and sending you lots of BRIGHT white healing light. lots of loving sending out your way....(Silas, 6/15/06)

Treatment phase

More influence from readers in blog and illness experience co-creation; and as ballast for bloggers was evident in the analysis of comments posted during the treatment phase of the illness. Elements of co-creation included expressions of the blogs' purpose and effect; the pattern of reading and commenting; inspiration; the idea that a book should result from the writing; personal strength; expression of emotions; the use of imagery; the immediacy of call-and-response communication; and the understanding between authors and readers of a code of conduct. As readership grew, the volume and depth of comments expanded.

Co-creation

Co-creation of the narrative and the experience reached greater depths as relationships expanded and deepened through the writing, reading and commenting.

Blog purpose/meaning. Readers expressed gratitude for the ability to share in the experience.

You are going through so much, but you're strong, and we know you can do it. This, too, shall pass. Before we know it, you'll be back home taking more and more steps. You are in my thoughts every day, and, by the way, tell your Mama I just love this web page!

What a great way for everyone who cares about you (and there are soo many of us) to be able to follow your progress without bothering your Mama and Baba with phone calls....(Isabelle, 1/28/06)

Blog effect. They also reported on the effect of the blog and its meaning to them in vivid detail.

I want you to know how much your family has truly affected the life of mine. We found out recently that [our son] is legally blind in his left eye....My heart is breaking for him and there are days I feel like I can't take it anymore and then I think of you...and the life of your family and you inspire me with your strength and courage and if you can handle what your sweet [child] is going thru than I can handle this. I know I speak for others when I say that you are an amazing mother, your strength is unbelievable and you are a true example of faith!...Thank you for being such an example to me and helping me get thru this difficult time!!! (Isabelle, 2/17/07)

Reader patterns. The pattern of reading and commenting varied greatly from blogs to blog, from reader to reader, and over time.

(1) We are always so Happy to read your Mommy's updates and to see all of the pictures.

I am sorry I haven't written to you before now but I didn't want to bother anyone....We get on the computer every day, sometimes twice a day, to look at the new pictures and up-dates....(Courtney, 9/25/06)

(2) ...Following each CP is DEVASTATING--until I consider that I have three grown--

26,27 and 32-yr old children. That is a blessing that so many families will NEVER have! Following the stories of your family and so many others grounds me and reminds me of my many blessings every day! Thank you for the difference you have made in my life!

(Kevin, 12/18/08)

(3) ...I have followed you for years. I've watched [your child] grow up before my eyes, as you have blessed us with allowing us to follow her journey. I know you have received a lot of bad news lately, and it awes me how you stay so strong and have so much faith. I wanted you to know that although I am losing my life, you...have touched my life like no other. You have taught me what true bravery is. [Your child] is my little hero, and whenever I am in pain, I think of what she has gone through and how far she has come. Thinking that helps me get through the painful times....I admire your bravery too as you face the obstacle ahead. But you and your family have such an impact on how I look at things. I am slowly finding my way back to God after finding out my prognosis for this year is poor. And I wanted you to know that I come to this site, look at the pictures, and just read for inspiration. You have given me so much of that. I know that if I get to Heaven, it will be because you took part in helping me grab His hand again....(Leigh, 1/28/08).

Some blogs included messages from the people the child and family members saw every day. This factor calls into question the notion that blogs are created solely to maintain connections across distances or through separations. In fact, the following entries support the idea of blog commentary as expansion on the journaling and memoir concept.

I was so blessed to be able to go with you and mama to [the hospital] on monday. I got to see a little bit, firsthand of what you go thru each week. You are a real trooper. I do understand why it takes so many people to go with you and mama. Thank you for allowing me to be part of your life....(Isabelle, 3/30/06)

Here, the commenter who frequently accompanied the child and mother to clinic spoke first to the child in praise and awe, then to the “village,” the core group of family supporters both near and far. The commenter, positioned as insider, offered a first-person observational stance that illustrated broader themes.

Ellie Girl, you were Mama and Baba's brave, amazing girl today, going NPO until 1 pm when you had your treatment. I loved watching you get feisty and controlling when it came to your body and how it should be treated. You rock girl!!! Village: Unless you have been there...you can't fathom the resilience and maturity of this little one. I think she is here to teach us all a lesson. Of course, Mama and Baba and brother Cole are her wonderful 100 + support group...beyond all they should be, lucky Isabelle. There is a wonderful future for you our little Isabelle, thanx for letting me be part of it. Love you, Bob (Isabelle, 2/5/07)

Inspiration: Received. Frequently during treatment, authors received comments from readers about the inspiration they and their children provided.

You've been given so many gifts of character already...your strength, tolerance, and ability to rise above this patch in your life amaze and inspire me on a daily basis. I commit to things I may not be able to do, only because you inspire me to "do the thing I cannot do." If you can be so sweet and perfect daily, I have no room to say, "I can't". (Isabelle, 2/24/06)

Inspiration: Offered. A message from a blogger reveals the inspiration flows in both directions.

I find such comfort in reading your messages. It is truly therapy for my soul. When I read all of your messages, I know you guys are lifting Kevin up. I check the messages several times a day. If there have been no messages, I will admit I feel discouraged. Even if it is a

short message, I find such strength. Someday I will print off this entire carepage for Kevin to read and enjoy. I know when we look back at this we will be so amazed at GOD's children and how you have all been a inspiration to our family!!! You guys are daily devotional for me as well!! Love, Mary (Kevin, 8/3/07)

Book idea. Exchanges such as the following between the commenter and blogger were found in several blogs.

...[we] read about your progress on these Care Pages. Your Mommy writes some very interesting stories about you. Maybe someday, after you are better, she can write a book because she is a very good writer. I thought that I would share a story with you about your friend...He is my grandson. His father...called me tonight because they took [him] to the hospital tonight. Guess what happened?? [He] swallowed a magnetic marble (from a K-NEX set). They took x-rays of his tummy. [He] got to see the xray of his bones, his tummy, and the little marble inside of him. The doctor says that the marble will eventually come out. The doctor told him not to put anything into his mouth that he is not planning on eating. It's a good rule!! Just thought you might enjoy hearing this story....(Courtney, 10/24/06)

[Mother's reply] Mary Beth thanks for the great laugh!!! I will tell Courtney this story in the morning I think she will really enjoy it. As you were writing your message I was thinking I could turn this into a book- how weird is that?? Thanks for all your continued support we really appreciate it....(Courtney, 10/24/06)

Personal strength. More evidence of the power of the comments to inspire reflection came in the following reader-blogger exchange. This comment was quickly countered in the mother's reply.

It was so good to see [your child] this week at school.....as a mom, I am totally amazed at your strength. I look at [your child] and think how unfair this all is for a little girl to go through. I know as a parent you do what you have to do for your children. I just don't know how you have managed to stay so strong....Thank you for sharing her with me, she brings me happiness and reminds me often of what is really important in life. (Courtney, 9/29/06)

[Mother's reply] You are so wonderful and make me thankful to have people like you in [my child's] life and my own. Believe me I have my moments of strength and weakness- in front of [my child] always strength and sometimes when she is not looking I give in. The first phrase out of my mouth at the hospital was "This is not fair!" But then I think who is it fair for? [We] are great parents and are there for [our child] in anything she needs. At the hospital I saw plenty of children who did not have their parents and my heart broke for them. So in my time of sorrow and pain I still thought we are better off than others and I just have to continue to think that. I am so grateful that she has a wonderful and caring person like you to look after her in moments when I can not be there. I am forever thankful for you (Courtney, 9/29/06)

Expression. This comment highlights feelings of gratitude and admiration experienced by many for the ability of bloggers to speak for others.

You were able to put into words what I've been feeling myself but would never be able to say as beautifully as you did. This whole "new normal" thing is hard to get my head around. Having a child with cancer is such a life changing experience. We will never be the same again. It's bittersweet - I try to embrace all the good that has come since [my child's] DX (Yes, there has been a lot of good). But then I'm quickly thrown into the

"What could've/should've been" mentality. My head spins as I think about what this has done and is doing to my son - to our entire family. Just as quickly I remember how lucky we are and how easy we've had it comparatively. I'm trying to learn...and just go with the flow, enjoying every minute of every day. I never understood what that truly meant until our cancer journey began...(Lucy, 8/22/09)

Readers shared ideas that might expand research on the understanding of life with neuroblastoma.

(1) ...By the way...has Magic Water [a nonprofit childhood cancer research organization (Magic Water, 2010)] thought about funding a 1/4 million dollar study to monitor the sleep patterns of 100 relapsed NB kids? This might go a long way towards increasing our further understanding of how a lifetime of chemotherapy impacts the sleep patterns of incurable children. Where can I sign my son up? I hope it is soon so that we can enroll before disease progression takes his life...(Tony, 4/3/08)

(2) I think [the previous commenter] is on to something...but perhaps Magic Water could instead spend the quarter mil on the sleep patterns of the NB warriors' parents. Geesh; they only sleep 4-5 hours a night (if that) for years as they fight this monster yet they still function. Perhaps it's a genetic difference (the NB warrior parent chromosome) or maybe how much florescent light they receive as they pace the hallways of hospitals....(Tony, 4/3/08)

This commenter affirmed a blogger's frustration with inconsistencies in management of side effects of treatment.

Our clinics should all get on the same page -- especially since they claim to be following the same COG [Children's Oncology Group] protocol! I was told that our drs are shooting for [our daughter's] ANC to be between 1000 - 1500, and was told in no uncertain terms last week that if it's below 1000, that means weekly clinic visits....I've heard that some clinics don't care at all as long as it's between 500 and 1500, and even heard that another clinic wanted it between 1500 and 1700....Wouldn't it be great if there would be some consistency? But I guess there's consistency in the drugs being given and the timing, and that's what's most important. Aside from that, I guess it's a matter of how conservative/liberal the oncs are at each hospital. (Gosh, I've even recently learned that some hospitals admit leukemia patients for an automatic 48 hours for fever EVEN if the ANC is higher than 500 -- so glad we're not in that boat!). (Lucy, 8/19/09)

Expressions of joy after reading of good news in the blogger's life were common.

We just wanted to tell you how happy we were to read that you guys are expecting! What a blessing. When our [son] was born in the midst of [our other son's] treatment, it was such a wonderful distraction and brought us all so much joy.... We wish you all the best as Courtney finishes her treatment and you prepare for your new addition. (Courtney, 9/13/08)

Humor was employed frequently by readers to bring cheer to the blogger and to fellow readers.

(1) ...Just to bring ya'll laughs on a day when family should be together....my husband...takes my son on a five mile hike Wednesday while I am working. Nicholas has just turned three so of course Daddy carried him part way...that was the whole story- I thought. Friday I pick him up from pre-school and the teachers run to me...we have such a great story for you. I'm thinking what has [my son] done now?

Well, he told his whole class of 3 and 4 year olds, "My daddy took me on a hike and he shot the Easter bunny!!!!" Oh, the horror!!! So I immediately I go to the husband and he explains, "Yeah, we had the two dogs and I had a rifle because of cougars. We saw a bunny and I shot it!!!" OH..... MY GOODNESS!!!!!!!!!!!!!! There are so many parts of that story that are wrong and horrify a mother. So, MOMMY took Nicholas to the park to see that the Easter bunny is alive and kicking. For all you California folks this is so alarming but i live in a place that simply could be thought of as the Old West in 2006.... (Isabelle, 4/16/06)

- (2) ...We had a similar incident only it involved Q-Tips. Zoe had a friend over and they were playing doctor ever so quietly, I walked in her room just as she was ready to swab her friend for VRE (Butt&Nose) the Hospital here does the swab on every admittance. We stopped the process and explained but hope that the other parents understand, in this case the Mom was able to laugh. Glad things are going well we all need a laugh sometimes....(Kevin, 4/14/09)

Reflection. As reported in earlier chapters, the bloggers wrote in reflection on the past to make meaning of current events; so too did readers.

...I find myself looking back on the past two years and am blown away. What a fighter you are little Ellie! I am thinking about the first time you were admitted to [the hospital]...I remember driving up on Christmas Day...your Mommy and Daddy were meeting with the doctors. I was holding you near your "room" and we had a very special moment together. Magical really! You were so tired and spent. However, you were able to lift up your weak head and look at me...we spoke without saying words. Then you put your little arms around me and gave me the softest squeeze, yet it said so much. It was

then I knew -- everything was going to be ok. You told me! I have held onto that ever since. Just wanted you to know how proud I am....(Isabelle, 4/4/08)

Imagery. Readers used metaphors and other literary devices to illustrate their writing.

(1) ...I don't know if it will help you, but when I would feel some of the effects of the chemo, I would picture it like little soldiers fighting the bad cells. Those strong soldiers need lots of energy to fight, so I knew they were borrowing it from me. I didn't mind because I knew they were doing a good job and I would feel better after. It always seemed to help me feel better....(Courtney, 9/20/06)

(2) ...You've had your beautiful family life torn apart by a beast. Worse yet, a beast that attacks children. Everyone who reads your posts knows none of you are "fine", but we are all blessed because as you wrestle this monster to the ground, you and your husband and children, especially [your child], are teaching each of us how to fight, how to tolerate more than we thought was possible and how to share the burden. If you are having a bad day, hand your sword to your Mom or Dad or another trusted warrior, and just go ahead and scream!!! Screaming might even scare the snoot out of that nasty bugger~ When you're finished, get your sword back and come out swinging!!!!...(Lucy, 1/2/09)

Here, a grandmother portrays the child's story as a performance.

The lights go dim as the movie begins... you hear only silence, then the excited announcers voice comes over the microphone...."High Five to the [family]~ [hospital] Team as they win stage one of "Kickin' the Purple Booooooty" Go Team!!!!" The crowd roars as they jump to their feet... Confetti flies through the air, and the Anti-Purple Banners, printed with "The...Team" are raised by the loyal fans who chant [the child's

name]!!!!!" The beautiful [child] stands and with an angelic smile, bows to her fans. Then she regally turns and invites her loyal family to stand beside her. Her sister...smiles and approaches her. Her beautiful mother...with [the child's] handsome father...join them. Together they bow and the crowd goes wild!!!! [The] entire family is there, to celebrate. Her [grandfather] grins and [grandmother] wipes her tears of joy from her eyes. It is a wondrous scene to witness.

You can still hear the fans cheering as the scene fades and the credits begin to scroll....

Act I is completed. As a critic, all I have to say about this is Wow.... That was awesome!!! I know Act II will be even better. I heard [the child] gets a Makeover in the next Act. Her fan base is growing daily.... (Lucy, 1/3/09)

Call and Response. Occasionally the blogger left requests for readers for more comments. These back-and-forth entries highlighted the meaning of the messages to the author. This interactive writing is one of the central features of blogs that distinguishes the medium from other online communication, even from CMC such as listservs where communications depends on readers' give and take in commenting. The sought-after reader comments belie the apparent emphasis on first person narrative, making clear that while a primary focus is on author expression, an equal benefit is the feedback received in response to these thoughts.

[Call]

[mother] Okay, so no news means no messages for me, eh? Don't you realize that this carepage is my lifeline. No pressure or anything, but do know that I check this thing more than you think. :) (Isabelle, 3/1/06)

[Responses]

- (1) We hope you have a positive day tomorrow....sorry we havent been sending you any messages. You are always in everyone thoughts. Good luck and we love you. (Isabelle, 3/1/06)
- (2) So sorry about the lack of text support! You and your family are in my thoughts nearly every waking moment. I am glad to hear that your days lately have been uneventful. I hope you have many more with only good news to report....(Isabelle, 3/1/06)
- (3) Shame on me for not writing in a couple of days!...I walked into your house this morning and as always you were a breath of fresh air. I watched you in awe as you patiently handled [your child's] demands, while dealing with the pool man and finding [your other child] pictures of the Whales in Hawaii, all without ever missing a beat! You are my inspiration!... (Isabelle, 3/1/06)

[Mother's response]

Well that worked like a charm!!!! Thank you. We're off to sleep in hopes of a long day. A short day will mean her ANC isn't high enough to go ahead and so we'll wait another week. So as hard as it is, a long day is a good thing. My mom and Karin will be joining me. Katie may even make another appearance. That was fun last week....(Isabelle, 3/2/06)

Codes of conduct. The issue of privacy was not often explicitly discussed in the blogs or comments. Unwritten codes of conduct were either understood by all, or when questions were raised by readers, authors replied to add clarity. One episode of privacy violation perceived as egregious by both blogger and readers was understood by all as a betrayal of trust. To appreciate

the context within which comments were posted, here is the blog entry by a father that sets the scene, with typesetting intact:

We have a spy among us. It is true. There is no denying this. The question remains....is the spy or spies lurking out there.....watching out for us.....and trying to act in our best interests.....or is there another agenda? I have been thinking about this for several days....since I learned of the traitor....I apologize.....I am sorry for the traitor comment. The person or persons that are lurking out there...reading every word that I type....and then reporting back to the institutions that I write about.....have NOT been shown to be acting in a malicious manner.....it is entirely possible that they have our best interests at heart. It is also possible that they merely wanted to help ‘repair’ or ‘fix’ the situations that I was writing about.....and that, instead of contacting us and offering assistance, they felt that by tattling on us, they could bring light to our dilemma’s and make things better....So....that is that.....and I leave it up to you to decide.....do we have a spy that is working against us, or do we have a wanna-be guardian angel? I truly don’t know the answer to that question. All I know is this.....I received a phone call from the unnamed department that I wrote about the other day.....and they asked about this web page....and why I was writing “bad” things about them.....How’s THAT for drama? And how did I respond to that totally inappropriate and outlandish, yet true, accusation?.....I owned up completely to writing about anything that I DAMN well want to write about.....I calmly explained that this is a PRIVATE web page designed for us to inform friends, vent about our frustrations, or do whatever the hell else we DECIDE to do here. I further explained that I quite often VENT on this site....and that I use it as a means of therapy. The person that I was

speaking with very coolly avoided outright asking me to change my tune on here.....they said, "I just wanted to make sure that we were doing everything that we could to help you and that there were not any other unresolved issues." I thanked them for their help....but I also made it clear that we have lost our faith over the years in their institution. I explained that this did NOT happen over night.....that there were a multitude of issues that led us to that mindset. And that is where we left it.....What I didn't say....but was sort of thinking....was this.....we are ten days away from the fifth year anniversary of writing journal updates on here. In those five years, just under 500,000 visitors have graced our page with their presence, (480,440 as of this writing). I have written about many, many of our adventures....I have exposed a lot of inadequacies and errors over the years.....but.....as I sit here....writing this entry.....let me assure you of this.....without moving anything other than my head.....I can look off to the right side of the room and see a closet.....a closet FULL of skeletons. However many times that I have written about frustrating situations, there are a dozen more UNTOLD stories.....however many injustices that I have exposed....there are hundreds more that I have kept in the closet. So.....what have we learned here today? Well.....we have learned that there is a person or persons that decided to take it upon themselves to lurk amongst us...and then report back what I am writing about.....what we have NOT learned....is whether or not they did this with the intent of helping us.....or just spying on us. I guess it doesn't really matter.....what matters is how we move forward. I need to be able to vent on here...and to write about whatever comes to my tiny little vindictive mind.....without worrying about retributions.....if I can't write in that style.....then you all are going to be reading journal entries that will

sound something like this: "Everything is fine. [My son] is fine. [My wife] is fine. I am fine. All of the doctors, and all of the nurses, and all of the hospitals, and all of the testing institutions, and all of the labs, and all of the administrators, and everyone else is, fine. Stay tuned for another update tomorrow....but don't worry....I'm guessing that everything will be just.....fine." P.S. Feel free to post your observations or feelings about this update.....don't be shy. (Danny, 5/17/07)

Here are a few of the dozens of comments posted in reply. Readers alternately address the blogger and the perpetrator of the offence:

(1) I'm a lurker that has followed [the child's] story for many years, but I just had to respond today. I'm appalled that a "professional" medical facility would stoop to this type of intimidation to keep you from telling what truly goes on. That's exactly what it is: INTIMIDATION. I hope you document this and any further interaction with this group, making note of the date, time, person you talked to, and how contact was initiated. That way you have a complete record of harassment, should it continue. As far as the traitor goes, they should be ashamed! It's this kind of person that causes caringbridge pages to go private. I hope that never happens here....I would hate to be cut off from what's going on with him....(Danny, 5/17/07)

(2) I check in on [your child] all the time, but don't sign too often.. sorry about that. First, please don't stop the journal entries as you write them - the whole unvarnished truth. It is helpful to others going thru similar things .. even if it's just to know that you're not alone! I really really hope that it was 1)someone who worked in this facility and was trying to help them see the error of their

ways in a constructive way or 2) just someone who wanted to help. If you don't truly care about the Caringbridge families you check on, why would you spend your time checking on them? I have a good friend with a little one newly diagnosed with neuroblastoma, and have found invaluable information in your journal. I tell her, she asks her doctor.. it just gives her more information and options. Any and all information is helpful, in my opinion. Please don't change the way you write your journals....(Danny, 5/17/07)

- (3) Hey guys! It's been a long time that I've been touch with you. Like a lot of people, I check your updates almost daily, but rarely post. I couldn't resist this one. We've also had our share of problems with doctors and hospitals. The doctor at our hospital threatened to refuse treatment if we didn't stop complaining about things going on at the hospital. He's also the same doctor that would never give us a straight answer about anything, just that it was very serious. He's also the same doctor that will never look me straight in the eye almost 6 yrs later, he only looks past me. They have no sense of urgency. They have become hardened to these children and the situations. It's just like everything else, no one cares about what you're going through, it's not their problem. I'm sorry that you are still going through all this and still fighting this horrible disease, even if the quality of life is there....Keep venting. That's the only thing that makes you feel better. Who cares what other people think or do. You NEED to vent....Time is of the essence and unfortunately we're the ones that have to be proactive to make sure that these people are doing the jobs that they are being paid for...(Danny, 5/18/07)

- (4) Sorry to hear someone's been showing your journal to people who work at the hosp etc, I update a friends caringbridge page when she in hospital (long term admissions rather than short ones) but her doctor made a couple of remarks hinting about reading about her on a website etc so we ended up locking it so we could update rather than do the option you mentioned "the world is fine"!
Take care, from the UK (Danny, 5/22/07)

Ballast

Bloggers found families to identify with in the comments. During treatment, ballast took the form of connection; helping parents imagine a positive future; sharing information; providing comfort, a sense of solidarity and support. In addition, readers' comments served to normalize elements of the experience for bloggers. Comments also established and served to maintain relationships across distance. Other elements within the thematic category of ballast included the recommendation to avoid regret; sustain faith; empathy for the myriad surplus suffering; and the reminder of figurative gifts being received.

Connection. Parents received messages from readers in similar situations hoping to make connections from far away and not so far away, as in these two examples.

- (1) You don't know me but I have just read all the journal and it could have been me writing it! My daughter...was diagnosed with Tcell ALL December 18th 2008 - not long after [your child]....We have been through very much the same as you guys but [my child] did manage to get through DI relatively trouble free....We live in the Channel Islands, a group of islands south of England and near the west coast of France. [My child] is 9 and will be 10 in December. It has been such a rollercoaster of a year. After getting over the initial shock, numbness, anger, frustration and utter

devastation we have managed some normalcy in life....When she feels well, we feel good. When she feels bad we feel bad. We just make the most of the times when she is well and try and do the normal things any family would do. We also have a younger daughter...who will be 3 in August. That has been so hard to deal with because we often have to leave her with my Mum and Dad or my sister (thank God we have them) when we have to be at hospital. What is also difficult for us is that alot of the treatment cannot be administered here in [our town] and we have to fly off island (around a 30 minute trip then 15 minute cab drive) to [a town in southern England] where our consultant it based and where there is a dedicated oncology ward. Dont like flying and having to go through busy airports with a sick and neutropenic child but we have no other option....I would love to chat more with you - the only other leukaemia patients we have met are all boys or very young children and with [you child] at a similar age to [mine] we are going through similar emotions I should think. I worry daily, I pray daily, I cry daily but on the whole her father and I are dealing with it fairly well I think. We do still laugh, argue and go about our normal daily lives (although I have had to give up work to care for [my child]) and I even find myself shouting at her sometimes ! Especially when on the dreaded steroids. I am worried about Swine Flu which is becoming more and more prevalent in the UK now and there have been quite a few cases in [our town] (population 60K 9 miles x 3 miles). IF you have time I would love to hear from you, but if not , know I am thinking of you and will read your journal daily and am with you all the way. Reading about the poor children you know who have lost their lives as a result of

chemo rather than the leukaemia itself worries me so much. My email is... (Lucy, 7/15/09)

- (2) My son Thomas was diagnosed with T-cell ALL on 12/11/08, just shortly after you were diagnosed. He is 15 years old, and he too is being treated at [the same hospital]. We just started a CaringBridge website about a month ago because Thomas wasn't quite ready to "go there" until recently, and one of the biggest blessings we have discovered since joining, is that it has allowed us the privilege of learning about, and following the journeys of other brave, beautiful children such as you!...I look forward to our paths crossing one of these days at clinic, but in the meantime, please know that you and your family are in our prayers each and every day! (Lucy, 5/28/09)

Future orientation. In stark contrast to the blogs created by parents of children with neuroblastoma, blogs by parents of children with leukemia contained many comments from survivors or family members of survivors offering messages of hope and strong sense of future orientation.

- (1) ...I live in Louisiana. I am a friend of...I wanted to meet you and to tell you that I am praying for you and also tell you about my daughter. [She] was five years old when we learned that she had ALL. We took her to St. Jude's Children's Research Hospital in Memphis. She took treatment there for 2 1/2 years (we were able to take some at home but went to Memphis once a month.)...After those 2 1/2 years, [she] had to go back to St. Jude's every three months for a year, then twice a year, then once a year until she was 18 years old for checkups. She is now 27 years old (WOW, I know that seems old to you). She has her Masters Degree in Psychology (she works with kids). She is married and has a beautiful two year son....He is lots of fun. (Lucy, 12/24/08)

(2) ...I stumbled upon your website by "accident". But I don't really think it was an accident, I think I was supposed to find it. When my little boy was 5 years old, he too was diagnosed with A.L.L. I sure don't have to tell you how rough it is, and we really went through allot. Today my little boy is 25 years old! He is handsome, happy and most important healthy. He recently got married...After all he'd been through, I was so proud to see him marry. Anyway, I know sweetheart how awful it can be, and I'm so sorry for all of us who've gone through it. But you and your family will come through it. This is not forever this cancer, you will soon be better and then actually forget so much of it! Hard to believe I know, but it happens. My son was treated for about 3 years, and he honestly can't remember the bone marrows and spinal taps at all. He does however, remember and keep in touch with the many, many friends we made at the hospital and at Camp... Life long friends....I love your website, and it's clear you have much loving support from your wonderful family. That my friend, is half the battle! Stay positive and know that people who don't even know you are praying for you and your family. (Lucy, 7/16/09)

Information sharing. Readers occasionally offered suggestions for augmenting treatment.

(1) In the little spare time that exists in your world, you might want to look into the healing properties of mangosteen for fighting leukemia. i take it every day as a body tonic and love it. <http://www.cancertutor.com/Cancer/Mangosteen.html> Not to repeat myself, but you are truly and exceptional human being with tremendous tenacity and strength. (Isabelle, 2/1/07)

- (2) I have looked into banking our new little ones cord blood too. I have been in contact with Cord Blood Registry. I told them about having a child with Leukemia, and they told me about this program they have: As a public service, Cord Blood Registry provides the Designated Transplant Program (DTP) to families wishing to store their newborn's umbilical cord blood stem cells for a family member diagnosed with a life-threatening disease which may be treated by stem cells. To enroll in the program you have to have her doctor fill out some paperwork, and then they determine if you can qualify for the program....(Courtney, 12/26/08)
- (3) I was reading something and instantly thought of your family. There is a program called "SuberSibs" It is a program for siblings of children with cancer. The goal is to reach out to brothers and sisters (ages 4-18) whose siblings have been diagnosed. I thought you might want to check this out for [your child]. [Your child] is such a brave little girl and [her younger sibling] has been a wonderful little sister with her support! Just food for thought, I know you have a lot on your plate, but I wanted to pass the information along. Website is www.supersibs.org. Your all in our prayers. (Courtney, 5/24/07)

In addition to sympathy for the stress resulting from health insurer communications, readers suggested practical help.

Mary and Carl, be persistent with your insurance. You all know how awful they can be. We had a nurse in O.K. City who offered to fight on our behalf, so ask your doctor's office if they have someone like her who will represent the patient. She liked the refusal to pay anything as it was easier in her opinion than when they partially pay a bill. (Kevin, 7/22/07)

Solidarity. Several of the blogs were created only after the treatment phase of the illness began. As families moved into this stage, comments affirming a sense of solidarity were frequent, especially from new readers. These messages often included background information on how the blog was found, words of empathy, personal experiences with neuroblastoma or other cancers, and promises to maintain the online relationship.

I just wanted to leave a quick note to say that we are with you. My name is _____ and my son was diagnosed with Neuroblastoma, Stage IV on June 29th, 2007. We left _____ (VERY difficult decision) to pursue treatment in NYC at Sloan Kettering and it was absolutely the best decision we could have made. God was truly watching over us in that decision. [Our son] has done 9 rounds of the 3F8 antibody treatment and has been disease free since the second round (not all kids have the same result). We have been able to avoid the very risky stem cell transplant and feel that some of the best minds in Neuroblastoma research are at Sloan. The Ronald McDonald House in NYC holds 83 families and 80% of those are Neuroblastoma. We have become VERY close to many of these families and share our experiences and learn from each other about the different treatment options available (Sloan has many options and they aren't suck on following a protocol, they will change it if it's not working for your child.) Anyway, I just wanted to throw an intro out there and tell you that you are MORE than welcome to e-mail me with any questions you might have about Sloan. It is very tough at first to be exposed to this world of pediatric cancer and have to make big decisions, but God will be there with you every step of the way.

In Him, (Jeremy, 1/31/09)

The theme of many comments made to bloggers during the early part of treatment is ‘you are not alone.’

...I recently learned of your story through [a friend]....I have been reading your blogs with tears in my eyes, I can completely relate since my son Andrew also has neuroblastoma. We were originally diagnosed in August 2008. His 2nd birthday was just a couple weeks before. He was (or seemed) completely healthy since birth. We were at the beach the day before. Then he had blood in his diaper. What a shock!!! They thought he had a Wilms tumor first (kidney tumor with much better prognosis) and actually did surgery. The surgeon came out and told us it wasn't Wilms and most likely neuroblastoma. THAT was the worst night of my life. Another shock! We were treated in Buffalo (where we are from) for 3 weeks before transferring to Sloan. We lived in the RMH for 5 months during chemo, radiation, surgery, and 3F8 antibodies. Now, we travel back and forth for scans every 3 months and 3F8s. I just wanted to say hello, and let you know you're not alone in your fight against neuroblastoma....(Jeremy, 4/15/09)

Comments also overcame the effects of geographic distance.

...I'm sending you a big GDAY all the way from...Australia! [Your child's] story is one that is very close to my heart. My family is best friends with a family whose middle child...was diagnosed with Stage 4 NB in June 2003, and was 10 years old at the time - as you very well know, that is ancient for an NB child. [The child] went through the same treatments as [your child]- ...she was living up the off treatment life. In October last year our lives were shattered when her cancer had relapsed and the doctors told us there was nothing they could do for her. They said to send her home and keep her comfortable because she would only have 5

months at the most. Here we are 8 months later and to look at, you wouldn't even know anything was wrong....Just thought I would sign in because I don't think I have before even though I've followed [your child] for a while, and let you know that we are on the same page even though I am on the other side of the world....(Leigh, 6/11/07)

Readers frequently commented during periods of bloggers' 'scanxiety,' familiar to them from their own experiences.

...I have been following your website for quite some time. My daughter was also diagnosed with neuroblastoma and is currently ned. I know the horror of every bone ache and stomach ache and walking in for those scans, looking at the techs and trying to read their every move....(Leigh, 7/18/06)

Support. This comment was posted in support of a blogger who had written of feeling angry when people looked in horror or judgment at the child's bald head.

...in one of the [Bible] studies she talked about how in Biblical times (and today in many cultures) women wore black for up to a year to show that they were in mourning. This was an outward sign to people to take special care of these women because they were going through a tough time. Perhaps baldness brought on by chemo is God's outward sign to the world that [your child] needs prayer and TLC. Every time I see anyone sporting a chemo "do," my heart automatically goes out to them, and I say a quick prayer. Maybe you could tattoo "Quit Staring and Start Praying" on his precious little head! (Kevin, 7/25/07)

Gratitude for material help was expressed frequently in the blogs. In one, the comment section was used by the readers to organize the meal preparation effort.

(1) We will plan to start up again this Mon. Jan. 8th. I will send you a schedule with names and phone numbers. Please let me know if we can help in any other way. I hope everything goes well today. (Courtney, 1/6/07)

(2) Hi I'm so happy to hear [your child] is doing well and was able to go to school. Are you ready for meals to start back up? Did you like the Mon. Fri. meal days? Is there anything you would like to be done that isn't or differently? Let me know and we could start up next week. We think of you often and you all continue to be in our prayers. (Courtney, 1/24/07)

During times of acute stress during treatment, readers, especially relatives, expressed feeling one with and in the presence of the affected family members, regardless of distance.

There is nothing nobody wouldn't do for those wonderful girls, and anything you EVER need we will all be here. Love comes from everywhere, and today that was shown. (Courtney, 10/15/06)

Support most often came in messages on the topic of prayer.

I have put you on our church prayer chain. I also submitted a request to the World Prayer Center in colorado springs where [a friend] lives. This is a center that is interfaced all over the world by computers and your request will be shown by computers as it is shown at the center to those who are there right now praying. People from many countries including the U.S. will be praying for you today!! God Bless and give you peace. (Courtney, 4/26/07)

A common refrain was that 'God never gives more than one handle.'

Venting sometimes is the best therapy. I personally have no way of knowing the frustration and hurt you must feel every single day... but I still hurt for you, and each and

every family going through this horrible nightmare! Maybe one day we can all know the "whys"! But in the meantime.. when you aren't feeling very strong.. let your friends and family be your strength... and always remember, God never puts on us more than we can handle... You are a wonderful mom, and VERY VERY special, because God chose you to care for [your child], because he knew that "YOU" were exactly the "mommy that she needed!!!! (Courtney, 11/7/07)

Also frequently expressed in comments aimed at support was the suggestion that the blogger look on the experience within the context of its perceived positive meaning.

(1) ...We know the mountains ahead seem high, but we are all behind your family pushing you up those mountains. I think you get the sense through this care page and many acts of kindness for your family that there is "no way can you fall". And, for those of us who have been through this, we rise up and become especially strong and determined to help in any way we are able. Praise be to God for you. He has allowed us to get even closer to him and strengthen our relationship with Him through [your child's] illness. So you have blessed us all without even knowing us. All things work to the good for those who Love the Lord....(Kevin, 7/11/07)

(2) ...I am tremendously moved by the powerful message that you wrote for today's journal. I believe that God is going to use you in very unusual and dramatic ways to spread the word across the nation about leukemia and the need for funding. It is amazing to me to see the truth of the Biblical promise that God can bring good even out of the very worst things that can happen to us become reality in your life. Lucy's leukemia is a horrible thing, but God is using it to fire you up to be a change agent in the world....(Lucy, 1/8/09)

A comment from another affected family both welcomes the blogger into the clinic 'family' and stands in juxtaposition to narratives of surplus suffering.

...you will LOVE clinic....[nurse] was [my son's] favorite, but followed very closely by [three other nurses]. [nurse] is a DOLL...and then there is our [favorite nurse]. If you meet any of these ladies, please tell them that I said that they are to give [your child] an EXTRA portion of love and care...except that they do that without asking! Sometimes clinic is hectic, but you will adjust and [your child] will feel comfortable soon...most of the time the kids feel that they are totally in charge! It is the BEST of places to be sick in...if that makes any sense. (Lucy, 12/23/08)

Comments from schoolmates offered the promise of solidarity and continuity when the ill child was away from school.

I can't wait to see you on Thursday at school! I hope you feel good and can come. I think you should pretend you have hair and ignore anybody that might be mean. I have never seen anybody be mean to you - but if I do I'm going to tell them to stop and you are my friend. Then I'll tell [the teacher]. Even though your hair is very short, God still knows how many hairs are on your head and you are special. See you thursday....(Lucy, 8/11/09)

I am in Mr. B's class in 5th grade. Today everybody in 2nd grade and up went to the gym and heard this man...talk about bullying. [A teacher] recorded it so you can see it and [the speaker] sent you a surprise so you will probably get something with your school work....He was really funny so it might make you laugh! I hope you get better soon. A lot of my friends have been talking about you and we feel bad for you. I'm sorry for you. We have been praying for you....(Lucy, 12/10/08)

This message expressed solidarity with an idea that appeared in several blogs: that families dealing with cancer deserve a privileged status when it comes to routine life annoyances.

I am so glad that your family had a nice weekend out. What a special treat and sooo well deserved. What is so sad is that you had to deal with a ticket and court appearance on a scheduled treatment date. Did the officer not see [your child's] beautiful face, and no doubt your, tired one? What us Leukemia families need is a special license plate. (After all disabled people get them). I wish I had the energy to think of a catchy phrase for it, but it should read something like, "Our family is struggling with the most stressful, heart wrenching, energy consuming, money depleting challenge of our lives. If you make our lives worse, you are truly a mean person." Maybe someone with more creativity and energy can come up with better. (Lucy, 4/6/09)

Solidarity also came in the form of empathy for the pervasive uncertainty that persisted throughout treatment.

I know how you're feeling with the future being so uncertain. It is a difficult aspect of having a child with cancer to deal with, one which never gets any better with time. You guys have had a tough road so far, with [your child] having such a difficult time with chemo, infections, appetite, weight, on and on and on. Hopefully with maintenance just ahead things will begin to get easier and easier for you and her. I think once you are over this very difficult part of treatment, your outlook on this day to day life you've been living (what's tomorrow going to hold?) will get much better. (Courtney, 5/10/07)

Fundraising was another means found for readers to express solidarity. Raising funds for research and for the immediate needs of the bloggers' families was a frequent topic for comments.

(1) ...The pictures of [your child] are adorable. She certainly is a "Little Princess".

Things are coming along well for the Bake Sale that we (Applebee's) are having in the...Applebee's parking lot August 12th and 13th. All proceeds benefit [the child] and my friend...who is also battling with Chemo. There will also be a car wash during the bake sale and all those proceeds go to benefit Alex's Lemonade stand. If anyone would like to help out and bake anything just get with [the child's father] and he has my number....(Carrie, 7/25/06)

(2) Hey they Carepage watchers! We will have purple B positive lollipops for sale at the Hope Church Craft and Flea Market tomorrow 5/12 from 8:30AM to noon.... also will be selling PURPLE hope filled helium balloons and Hope stones (purple of course). There is a pix on the carepage for all to see, so check them out! We will be there to celebrate the strength and courage of [the whole family]...Come out and show your support and have a sweet Lollipop to celebrate!!...(Carrie, 5/10/07)

Over time it was routine to see expressions of sadness, empathy and joy that mirrored the emotions expressed by the bloggers. Interestingly, occasional unsolicited enthusiastic expressions of anger or resentment expressed in defense of the bloggers were found. In the following example, a reader stood in solidarity with the blogger by appealing directly to other readers on the topic of "little pink ribbons."

With a risk of also being diatribe (and offending breast cancer patients and survivors who might be reading this), I will say I get a little bit annoyed when I see pink labeled merchandises displayed at groceries, departments stores, and catalogs. Yeah, sure, women are the purchasing power. Get on board, put on a little pink ribbon, donate

certain percentage to the Foundation and you got yourself another brand line. It is getting too much these days....(Tony, 4/3/08).

Readers noticed when a comment was removed by the administrator (the blogger). This is usually done when a reader has posted an inappropriate or insensitive comment. These two comments among many that expressed solidarity in defense of the blogger after an apparently upsetting comment had been posted and then removed.

(1) I don't know who you are "anonymous" that keeps posting about what they will or will not use for transportation for their son...BUT...I just want to say you are so out of line. You obviously have no business reading this blog or really any care or concern for this family except to publicly judge their choices. You "anonymous" should be ashamed of yourself. Stop coming here, and stop posting. There is no room on this blog for your insensitive comments and evil that looms with you. With that said...[to the blogger] you are FABULOUS parents and everyone knows you hold all of your children's safety close to your heart. NO ONE IS JUDGING YOU!!...(Jeremy, 3/28/09)

(2) Oh Honey, it saddens my heart to see that you've had to remove a couple of comments. Whatever they said, please just put it out of your mind! They aren't worth one single negative thought that they may cause you. I'm sending many many prayers for [your child's] health, the trip, the people watching over [your other children] as well as all of the littles too. Remember that you all are in God's hand right now. Everything will work out...(Jeremy, 3/27/09).

The next day, the blogger's entry expressed her thoughts and feelings about the incident.

Not an awful lot to report today....I feel a little overwhelmed lately by the responsibility of sharing my family's life with everyone who reads our blog. Certainly we are in awe of the number of people who have read about [our child's] story and we are humbled by how many are praying! I guess I just want everyone to know that in my imperfection I might not always write clearly, might not always explain things in the right way, and might not always do things the way other's think I should. I'm just a mom who is doing the absolute best she can right now. I said this when I first started writing and I'll say it again, I'm blogging to tell the story of my precious son...who has cancer. I've since realized that by sharing the story of this difficult journey, I'm also sharing our faith. It is my prayer that I'm bringing glory to God through this blog, despite my imperfections. I appreciate more than words can say those of you who are willing to continue to stand by us, pray for us, and support us with encouragement as we travel this road. [Our child] is worth it all...(Jeremy, 3/28/09).

That entry inspired more comments of support and in her defense.

- (1) Thank you for sharing your story with all of us. I also have a blog where I write a lot about my son who has been really sick. It is wonderful to get so much support but some days I find myself worried about what and how and when to say this or that. But in the end...all we want to do is pray for your sweet little boy and your family. I hope you can feel the support (Jeremy 3/28/09).
- (2) ...We are not here to judge you through your blog. We are here to share and support you as you pour out your deepest feelings; whether happy or sad. There is no right or wrong. I so appreciate your candidness and know that you have helped others to strengthen their faith in Jesus...(Jeremy, 3/29/09).

(3) This is [your child's] journey, your journey! Write what you need to!! Each situation is unique, each child is different, everyone has their own "way" of doing or saying things. That is what makes this crazy world so great!! That we can all be a bit different and learn from one another!! I for one would not or could never judge you for what you write, what decisions you make...I have never walked a step in your shoes and have no idea what you must be facing!! Your words are powerful, and what you are dealing with is powerful! Keep doing what you are doing!!...(Jeremy, 3/29/09)

Comments affirming bloggers' feelings also served to signify a sense of solidarity. This reader seldom commented, but felt compelled to write on the topic of the effect of the illness on siblings.

...but today is the second day that I felt like my life experiences as person with a disability might provide a unique perspective for you. You probably don't know this about me, but I have a younger brother named David. He is almost 5 years younger and most of his early childhood was spent waiting in doctor's offices and hospital lobbies. David's life was frequently interrupted with my breaking an arm or leg unexpectedly and being rushed off to the hospital...As adults, we have often talked about how his life has been impacted by having a sister with a disability, and now that he has children, he talk about how my niece and nephew's lives are different than they would have been if their aunt wasn't in a wheelchair. Yes...[your child] having a sister who has had a major illness early in her life has changed his life and will leave a "lasting footprint"...but that's not necessarily a negative thing! My brother is a very unique individual and an incredibly sensitive, intuitive and caring husband and father...perhaps he would have been

anyway...but I know that I am a very different person than I would have been if I didn't have a disability and I suspect that he is a very different person because of his experiences of having a sister with a disability as well....After all...look how good my brother and I turned out and believe me...my parents didn't have any education, training, family or support network to help them 45 years ago! You're doing a great job Molly!
(Isabelle, 1/22/08)

Another notable element that appeared to provide ballast was affirmation from readers that the family was being perceived as living in the present and maintaining a positive outlook

...One of the blessings we feel from our experiences was that we learned "the hard way" to cherish every moment... even the times when [our child] lost his hair....While it was upsetting at first we turned it into a new hair cut..which is very close to what his identical brother still keeps... and his daddy doesn't have much either.. We embrace each moment... when we get to see that smile after a treatment and you know they don't feel good but they still muster the energy to give you a smile. Or how about when they eat... how many people do you know embrace "eating" besides those who just like food alot.. [He] went through many months where the only thing he would eat was cheetos... What a joy I get now every time I see a bag of cheetos b/c I remember the orange stained lips, fingers and occasionally my clothes. While the times of trial will always be with us one of our many choices is to find the good in it and to share it, and from the sound of your daily messages y'all embrace all those moments. We continue to pray for your family and if there is anything you need please let us know. (Kevin, 7/25/07)

Sometimes comments came from survivors wishing to affirm bloggers' feelings.

I have never commented before, but there is a first time for everything.

I get what you are saying about a different identity after having cancer being put into your life. I feel like my life will always be split in two times: BC (before cancer) and AD (after diagnosis).

I am and forever will be the teenager who had cancer, never got to go to prom, and when I should have been going to parties with my friends, driving, dating, and being a teenage-pain-in-the-butt...I was going to doctor's appointments, taking numerous pills a day, being careful with having no immune system, and dealing with things that no kid, teenager, or adult should ever have to go through.

But that is the life of a cancer survivor and their family. Always having a part of our life affected by cancer, if not all of it....Valrico, Fl (Danny, 4/25/08)

In addition, readers acknowledged a blogger's sense of alienation and addressed her sense of overreaction to unexpected events.

[Blogger's entry:] I read on another mom's blog today about her daughter who was complaining of a stomach ache. And she said something that rings true for me. When your child is a cancer survivor or warrior nothing goes unnoticed.

Without sounding negative, I see the weird looks a lot of people give me when I express my concern about Mimi being sick or acting "funny". I can feel the "you are over reacting" vibes you send me! However, the pit is always in our stomachs that it is more than meets the eye. And, as this mom said...unless you are a parent of a child who is fighting or has fought cancer you will never understand the pain that any "off" movement gives (Mimi, 1/4/08)]

[Reader's comments:]

- (1) I don't think you are overprotective at all. B/C of your experience I am MUCH more in tune to Calla's health (more so then I would have been before)...I want to be able to notice if she is acting different and be able to know what is normal for her! (Mimi, 1/4/08)
- (2) I am GLAD you posted everything you said!!! I KNOW people give you comments (that they shouldn't) and looks (that they shouldn't)! You and Chad are WONDERFUL parents and I want you to ALWAYS remember that!!!! (Mimi 1/4/08).

Some of the strongest statements of affirmation for parents were the comments left in support for their decision making. As parents expressed in detail in the blog posts, the greatest challenge facing them after the possibility of the child's death is the burden of making treatment decision on their behalf.

- (1) ...You as parents are making the best decision you can make as parents based on the expertise of your doctor! You also must believe that God has his hands in this process and has led you to the decision you made yesterday! As parents we all have tough decisions to make and I think that you have made a very tough decision and have made a great decision. I support you 100%!!! You need nothing but support right now and as you continue on this journey as a family. Only you know what was discussed in that room and you are the ones that have to make the decision. I hope that no one chooses to be critical of your decision. Remember, God works in mysterious ways and he is guiding every decision you make with the doctor!!!...(Mimi, 6/23/07)
- (2) ...There are no words to express how proud I am of you both. This is a decision that no parents should ever have to make, but you are handling it with a remarkable

strength and grace. I hope that you save all these journals for [your child] to read when she is older. She really still has no idea that she's been blessed with the world's best parents! What a lucky girl:)

As for your decision, I was literally cheering (and crying) when I got to the end of your entry and read what option you had chosen. I truly believe in my heart that it is the best one. You have let the medical world work their magic on the cancer, and the result has been tremendous. Now it is time to let God do the rest. I know that He will carry your family through this, and I have faith that you will look back on your decision as the "right" one....(Mimi, 6/13/07)

Normal. Recognizing the significance of reading about more normal family activities, while acknowledging the permanent change that resulted from the experience, added meaning to the co-creation.

I'm glad Kevin enjoyed the horse therapy - that sounds really neat. And so good to hear that he's enjoying school and getting to do some "normal" things. I bet that 3 months seems like a lifetime. I think it is partly because you can look at that specific date as the day your life changed forever. One day you will be through with all the treatments, but you will never be the same people you were before cancer. Some of the changes are good, like how you appreciate all the small things, and some are not so good, like how every time one of your kids has a fever or ailment of any kind, you think, "It may be cancer." At least I do, and I was never like that before. I'm glad you are able to settle into a routine - in talking to other families with leukemia kids, it does get easier - those first few months are horrible, but then you settle into a routine and this becomes your new normal. I guess that's kind of sad, but good too....(Kevin, 9/14/07)

Relationships. Maintenance of relationships with family and friends is one of the daunting challenges of neuroblastoma treatment. Comments provided evidence that an online presence can be an adequate substitute to physically being together.

...We are glad that you are feeling better. We miss you all. We would like to visit you but with all our germs it is better that we visit through the computer right now. Keep those ingenious ideas coming....Band-aids always make things feel better too.....ask your nurses for some, I am positive they have them there....(Carrie, 7/24/06)

With almost daily connection to bloggers' thoughts and emotions, online relationships develop over time with people the authors have never met.

(1) ...You all are in our thoughts, you are all I talk about....There is not a day that one of my clients ask me how are those cute triplets doing?...I know you don't know me but I feel like I know you and the babies. I don't even have pictures of my own kids on my mirror....You and [your husband] are so strong, together you will get through this. I admire your strength and your faith. Thank you for this blog I'm sure it has to be hard to find the time....(Jeremy, 2/5/09)

(2) ... Hi! I just wanted to stop by and tell you that you have become one of my dearest friends. I know that I've never met you, but I feel so close to you that you could be my sister. You truly have the light of Jesus in your heart and believe me~I can see it from West Virginia! Leigh, you have touched so many lives by letting Jesus work throughout your life. I pray that each and every day you will continue to follow God's amazing plan and continue his mission: to preach the gospel~you go girl! Have a great week at school, sweetie!...(Leigh, 10/9/04)

Regret. The theme of regret was found in many comments, particularly when associated with discussions of treatment decision making.

- (1) ...We've conversed on the phone about protocol [a complementary therapy] and the rigors of NB. I lost my daughter in July, last year, and I must tell you that because of you. Your strength, ability to get things done, I have no regrets. I know, without a doubt, that we did all we could for our beautiful daughter. Without your example, your refusal to accept below par care, I might not have had the strength and validation to fight the fights that I had to fight. Since I did fight for the best care, since I did have courage to ask the hard questions and demand the best answers, I don't have to add regret to my days. Mourning a child is enough. Thank you very much for all you have left yourself open for. More than anyone, you helped me get through treatment and helped me do it with as much knowledge and power as possible....(Danny, 6/20/05)
- (2) ...I just want to chime in as a parent of a child who had antibodies and relapsed and died despite the antibodies. I believe that at the very least, antibodies gave us an extra year or more with Martin. Even if it wasn't the antibodies that kept him from relapsing sooner, or kept him from relapsing in his bone marrow for a few years, it gave me an option, to do everything I could do to keep neuroblastoma from killing my child. The peace of mind, that I did what I could as his parent to keep him alive, is priceless now that he is gone. There were difficult times during antibodies and also fabulous times in the big city with my son that I treasure. No regrets. (Cindy, 12/31/08)

Faith. Frequent references to the faith life of readers were found. Affected families were identified by readers as representatives of the evidence of God in daily life. Readers attempted to make meaning of the illness by connecting God's power and intentions to both positive and negative events.

- (1) ...Your blog is a testament to God. He gave you [your child] for a reason and the world is able to read about it. Your faith, strength, happy times, trials and real emotions keep us in touch with you and praying ALL THE TIME for [your child] and everyone. We are behind you! Rely on God and your parental instincts with these important decisions, you know your child! Prayers and Love (Jeremy, 2/25/09)
- (2) ...I ask myself many similar questions all the time. The simple truth is that God loves us because He loves us. We can't do anything to deserve it - but we can show our love and gratitude in response. I am confident that God's plan is being worked out through this entire experience and that He has a very special plan of [your child]. Just like the trees need to be pruned to be healthy and blossom, sometimes we need to go through difficulties to become stronger and more fruitful in the end. Please remember that you all are loved by many people and that we will do whatever we can to support you and show that love. (Carrie, 4/19/07)

Even readers who did not pray participated in the faith experience by proxy.

I don't really pray so my sister is going to say a Novena for [your child's] pain to go away. Not sure what it is but I am sure it is some great catholic thing!!! Whatever works right?!...(Tony, 5/1/08).

At times of illness crisis, usually with recurrence of the child's disease, a few readers called on Satan, portrayed as having the power to interfere.

...Then, we read your update and our first reaction tends to be one of discouragement. But then we say.....Get behind us Satan, for we are all marching hand in hand through this battle and we are gaining in numbers and becoming stronger. We WILL NOT surrender and will not even consider it because the victory is already HIS... and thus ours.... Satan knows that [this child] is hemmed in on all sides by our Almighty Father and that our tight net of prayer is never going to let him fall. It does appear, Satan is shaking in his boots and is now pulling out all of the stops. So, Courageous [child] put on your Armor of God each day and just run right over him. And if you don't get him the army marching right behind you will. Does Satan or cancer think they can defeat a four-year-old who is a Soldier of God? Phooie....(Kevin, 11/12/07)

Specificity of both prayer content and timing was achieved by readers as the blog was updated.

(1) Thanks for taking time to do this blog. It helps us pray more specifically for [your child's] needs and those of the rest of your family. We have contacted the faithful prayer warriors that we know and they've have joined in, too. Know that you're always in our thoughts and prayers. (Jeremy, 1/26/09)

(2) ...Could you please tell me what time your biopsies are scheduled for on Wednesday? I want to make sure that I am praying at the exact time. I hope you are ok. I think about you several times a day. (Leigh, 2/4/08)

References to 'prayer warriors' and 'prayer bears' were found in some of the comments and signatures. A Google search of the term 'prayer warriors' returned 413,000 results. The second result linked to a website that permitted readers to make requests for prayers and to request information on becoming volunteers who pray for others around the world (Prayer Warriors of the World, 2010). Similarly, the Prayer Bear Ministry was found in a Google search. The group,

based in Texas, connects those wishing to pray for others and those in need of prayer together online

(1) What a joy you must be to your family! That was so awesome the way you prayed for [your friend]. I know she was not nearly as afraid after the two of you talked, and you prayed such a POWERFUL prayer! I am a member of the Prayer Bear support group, whose goal is to visit children on the various Caring Bridge sites, leaving notes of love and encouragement for our children and their families to read and hopefully draw sustenance from. We have about 150 children that we pray for on a daily basis, and since it would be virtually impossible for one person to visit every single child, we have an "adoption" list, where each individual is adopted by one of the Prayer Bears. At last count, I had 16 names on my prayer list. Each member is expected to visit "their" children each day, leaving messages of encouragement when needed, and updating the Prayer Bear list when new developments are posted.

I have adopted you...and I will be dropping in here every day or so to check things out and see what is going on with you. If you don't mind, can you write me and give me your birthday? The Prayer Bears keep a birthday list so that we can ensure that each of these special children do not go un-noticed on their special day....(Leigh, 4/19/05)

Padre Pio was noted to serve as particular inspiration for families in need of a miracle.

Canonized by the Roman Catholic Church in 2002, St. Pio of Pietrelcina is believed to posses healing gifts (Padre Pio Devotions, 2010).

I've been a lurker for years - only because I do not have a child with cancer. Although I have a son [your son's] age and can so relate to the antics he gets up to. Would never

dream of trying to imagine what you all go through, hence my lurking status. However, I have been a silent prayer warrior for [your son] and your family. I guess my tears of joy for all of you are overwhelming me so I de-lurk myself. I can't say who "put you over" on the prayer chain but believe me, through the intercession of Padre Pio - he has worked so many miracles. I am no way saying this is the "one" but if anyone wants to see the amazing testimonials (as my family has first hand) go to St. Pio's website. I'm sure I am not the only reader who prays for [your son] through him. I'm also pretty sure it was a group effort.

There is a Centre for Padre Pio in Barto, PA - not that far from [the hospital]. You might want to venture a trip the next time you are up North. Please don't see this as preaching.

Just since we are on the subject of miracles....(Danny, 11/5/08)

Some readers' comments took the form of evangelism, even on blogs created by Jewish parents. In one comment this practice was addressed by someone who appeared to know the family.

(1) I pray...that you will know that the God of the Bible is real. I pray that your parents will know that God is real. He desires your soul to be saved by Jesus and His sacrifice for you, so that if you call on the name of the Lord you shall be saved, and have everlasting life. The thief next to Jesus on the Cross at Calvary believed and he was forgiven instantly and went to heaven that very day. Wouldn't it be comforting to your parents and friends who will believe (or maybe come to believe someday) that they will see you again, and in a very wonderful new place and healthy body. Please pray to Jesus and ask to have all your sins forgiven and ask Him to save you and He will and you will know it is real for the HOLY SPIRIT will enter your heart and the

fear of death will lose it's sting. Hope you trust in Jesus, hope to see you in HEAVEN....(Danny, 12/8/08)

(2) [a comment from another reader in rebuttal]

Continued prayers for peace...[to the previous commenter:] do you realize that the [family is] Jewish. I am sure they appreciate all of your prayers but asking them to do it in Jesus's name is not appropriate....(Danny, 12/8/08)

Surplus suffering. In addition to caring for the ill child, siblings, spouse and self, maintaining a household, working, etcetera, the role of advocate is added to the list of tasks for parents to undertake when a child is seriously ill. Readers described experiences of mishap to commiserate, comfort and educate. Here, a reader identified problems with administering blood products at “odd hours.”

...How terrifying! Yet another reason these transfusions should be done during "normal" hours. When they give the meds overnight or very early morning it is hard to watch for reactions! And this one being a very scary one. I was always arguing with them about doing things at odd hours because if [my child] got into trouble the normal docs weren't there at that time, or if we were sleeping etc. I am soooo happy that she is ok, hopefully you will be back in peds, the PICU is not as comfortable, and the nurses aren't as nice either....(Ana Lynn, 5/17/07)

Here, a medication error involving mail order prescription with the associated consequences was described:

...[our child] is experiencing her very first unplanned inpatient stay since diagnoses (14 mos ago) and as with any other parent in this situation, I am a wreck. Come to find out, after investigating her recent prescriptions, she has, for four weeks, been taking a TON

more Methotrexate than what was supposedly prescribed (READ: lets totally sue the prescription mail order drug idiots for not reading a prescription properly!) And she is NONE to happy being a resident of the "Big House"....(Danny, 7/3/07)

A delay in reporting of test results was a frequent subject of readers' comments. Parents and family members expressed increased anxiety and frustration with these delays.

I have a friend in the U.K. who waits 2 weeks to get MRI results for her son. At our local hospital here...people wait a week. Seems like cruel and unusual punishment to me. [One hospital] will read the MRI's immediately if the parent is anxious, otherwise it's the next day at the latest. Personally I don't think they should give you the report without having someone go over it with you. We kind of get to learn the language, but not really. I think if they used simple language we could all understand, people would start thinking that the doctors aren't all that smart after all....(Danny, 10/10/05)

Specific strategies to combat perceived illogical or inefficient aspects of care employed by readers were shared in the comments.

When our grandson was getting his chemo we at first were giving the Neupogen and it must be refrigerated. One mother forgot to put it in the refrigerator and 10 vials were ruined. I looked on the little box these vials came in and you will never guess by the price what it said it was derived from....e-coli. After they came out with the Neulasta we no longer had to have anything here for him...he got his shot at the hospital. Also if you have trouble with insurance paying for injected medicine you can have him admitted as an outpatient....get the shot and then they release him....now it is covered under medical. At the price of medicine you do what you have to do for these kids (Danny, 5/11/08)

Readers from outside the United States (US) expressed bewilderment about, and offered suggestions for outwitting the US health insurance system.

- (1) I have read for a while and never commented, but this hassle with insurance companies I just find incomprehensibly awful. My eldest sister was treated for acute myeloid leukaemia for over three years (1984-7) and because I am in the UK my parents never had to pay a penny (except of course for travel costs, loss of income and so on). Her treatment costs - she was saved in the end by an experimental drug regimen and bone marrow transplant (very rare at the time) and is still alive and well - must have run into the millions. Even so, her long illness and hospitalisation was a huge financial strain. One of my close friends sadly lost his little brother two years ago from a brain tumour - which is how I know this site - and not only was all his treatment free, including respite care in a children's hospice in [a city outside London] that he loved, he also had child-centred occupational therapy appropriate to him (such as woodwork) offered without charge. We complain a lot over here about the NHS, waiting to see a doctor, doctors being rushed and too busy and so on - but when it comes to the gravest diseases we are I think incomparably lucky.... Danny, 5/7/08)
- (2) ...Short of packing your bags and moving up here to Canada where all of [your son's] meds would be paid for by The Man, I have a suggestion that might somewhat mitigate the Zophran costs. Have you looked into out-of-country internet pharmacies? There are quite a few companies making a KILLING off of filling prescription orders from American customers at considerably lower prices. It's cheaper to have those pills mailed to you from where I live than it is for you to pick them up at your local drug store...how messed up is that? The meds are the same, made by the same companies.

Just less gouging. If I recall correctly, the state government of Minnesota posted a list of recommended non-American internet pharmacies for Minnesotans to consider getting their meds from in an effort to force American drug companies to stop gouging. Something to consider if you can't come to some sort of reasonable resolution with the insurance vultures in a timely manner....(Danny, 6/30/04)

Gifts. Readers often named gifts that came, in addition to affirming the suffering experienced.

...It would be so great if you all could come down over the summer so we could have the chance to visit with you guys. Although I wouldn't wish this situation on any family, it does bring about unity and connections in families, a bright spot amongst the difficulty :) (Carrie 2/12/07)

Off-treatment phase

Comments during the off-treatment phase were fewer with the presumed return to normal. Bloggers sometimes had to remind readers to leave comments, but faithful readers continued to check in frequently with narrative acts of co-creation and provision of emotional ballast.

Co-creation

Comments with messages of inspiration, expressions of the effect of the blog on readers' lives; points of debate on treatment research; and expressions of joy and triumph were all elements of the thematic category of co-creation found during the off-treatment phase. Interestingly, during this time many readers announced themselves by "delurking" or writing for the first time though they had read the blog for a long time. Readers let the authors know that

they understood the blogs were ‘not just a story,’ but that the events and people were very real to them.

Inspiration. Bloggers were often credited with ‘giving voice’ to others’ experiences. Readers persistently encouraged authors to use the blog as the foundation for a book.

...what you wrote in your hospital journal goes beyond any of your writings, exceptional as they are. Your ability to express rational thinking amidst an irrational situation...your enlightened observations, both physical and spiritual, amidst the darkness...the strands of faith and hope that are woven amidst the fear of the unknown outcome and the all too real possibility...the strength and courage that you found in the knowledge of [your child’s] heart....I’ve always encouraged you to keep writing. But, now, I am encouraging you to write a book, a manual of processing hope, truth, and love in the middle of fear, doubt, and isolation. Nothing seems normal to the parent of a child with cancer. How can it be normal when normal so clearly is health and the promise of a future. By sharing your words, your thoughts, you give voice to the "normalcy" of thinking and feeling during such an abnormal time. And you give peace and clarity in the purest writing I have ever seen you share. (Leigh, 10/25/08)

The hope found in reading provided inspiration to “get through” remaining treatment.

Hello...I have not introduced myself yet but I stumbled upon your CarePage recently. My 3 year old daughter was diagnosed with ALL on Oct 30, 2007. Next Friday she will start Maintenance. I am so excited about our next phase. You all must be completely overjoyed to be done!!! Reading your page will be an inspiration to me that we WILL get through these next 2 years, too! And look at that beautiful head of hair that has grown back!...(Amelia 4/19/08)

A reader found inspiration in the blogger's writing to inform the work of childhood cancer advocacy.

...I work for a children's cancer advocacy group in DC (the Children's Cause for Cancer Advocacy - www.childrenscause.org) and I've been reading your blog for several months after stumbling upon it. I just wanted to say that - while I always appreciate reading about what you're up to in the advocacy community (and what your kids are up to in their latest trouble-making exploits!) - I really thought your comments about the messaging issues with childhood cancer were very insightful and well-written. I've passed this along to our staff, as it's especially timely for us since our winter print newsletter has a feature article on neuroblastoma and we're finishing it up right now - this blog post will hopefully help our staff focus some of our thoughts a bit as we edit that piece, to make sure we're hitting the right message....(Cindy, 12/12/08)

A reader from South Africa expressed gratitude to a blogger for the inspiration to remain vigilant in advocacy efforts.

...thanks to you to for all the awareness you are bringing to the world on NB - wish we could raise more awareness and funding in South Africa as no research is done here - but you can be sure that we spread the word each and every day and as you say one day it might even reach Bill Gates or Oprah - we shall continue to fight this battle head on and our children will be victorious!.. (Mimi, 9/18/07).

After a death, readers expressed in great number their appreciation for been inspired by the child's and family's stories.

Its amazing what the internet is capable of doing. When you add that with a beautiful little boy and his amazing family, it changes you forever. I learned to live life to the Max,

I can't help but admire you and all your family, in the middle of all the cause that you where living and live you still find and found ways to touch us all. Feel Hugged and I am sorry, and wished I knew what else to type. Love from Brasil! (Tony, 9/15/08)

A nurse from the United Kingdom (UK) wrote to express gratitude for the lessons learned by reading.

I'm a children's community nurse. I have been reading your journal entries for over a year. I admire your ability to articulate your thoughts and feelings. I admire the way you navigate the medical nightmare. The decisions you have had to make can never be easy but you have made them and for that I admire you. I hope that because of reading your journal I will be better placed to help support the children and families on my case load and for that I Thank you....England (Danny, 1/3/09)

Delurking. Delurking, or emerging to post a comment for the first time after reading for a long time, occurred most often during times of high stress and high emotion. As children transitioned to end-of-life care, many more comments were posted. Many contained personal stories that had prevented from writing earlier.

(1) My heart is breaking for you reading this post. I've never posted before, I'm not sure why, maybe because I never knew what to say. But I am so moved today. I am so sorry that you and [and your family] have to face a day without your precious [child]. Thank you for sharing all of those beautiful, and sometimes heartbreaking moments you shared with [your child]. She is also waiting for the day where you all will be together again. Please know that I am surrounding all of you with love, warmth, and peace. (Carrie, 2/6/09)

(2) I have never commented before, but I have had your site bookmarked for a long, long time. I grieved with you when [your child] passed, and I now keep you and your family in my thoughts, and hope for the best for you. I still check in every other day or so for an update, and I probably will forever - out of habit, there are a list of families who I check in on on a regular basis... and although I always hope for an update, I think it's completely understandable that you would feel the need to update less and less often. I will continue to keep you guys in my thoughts...(Danny, 7/22/09)

(3) I am nobody who has followed [your child's] journey for a long time. I am so sad for you, for the words that no parent should say never in regards to her/his kid. As you say, my only comfort is that [your child] will be pain-free soon. I have another comfort, I will see [your child] in Heaven, healthy, running, smiling....being a kid again. That would be fantastic! The only thing I can do is pray for you, for your pain, and for [your child's] care in these difficult days. In His Love (Caracas-Venezuela) (Tony, 8/26/08)

After reading of one child's his death, readers posted 149 comments in one day. The average contribution on the site before that was 4-5 per day.

...I've been meaning to comment for a long time. I've been reading your blog from the start. [Your son] and my son were in the same 3 year old class [in school]....anyway...I had a brother that died of cancer when I was 8...he was 5. I clearly remember the time my parents choose to take him off treatment and bring him home. We had a great 3 weeks with him before he died. Me and my sisters almost felt relief that he would be in a "better" place, call it naive thinking, but we don't feel much guilt or remorse for our

thoughts, although this same period of time was torture for our parents. Call it "faith vs fear" mentality. We truly had faith that he was in a better place. I'm wishing you the best with [your child]. Enjoy your time. Thoughts and prayers are with you. (Tony, 8/2/08)

Expression. Expressions of emotions of all kinds were found in the comments. Many readers reported feeling enriched for having read the child's story.

I feel truly blessed that you shared your precious angel with us and i feel that i am a better person from knowing the struggle you have all gone through. I never actually met [your child] but have come to love her like my own. May you all be at peace knowing that [your child] is in a wonderful place. I believe she will always be with you and I will always have a special place...in my heart. I feel as though I have been given a gift in knowing [your child's] strength, courage, and that amazing little (or should I say HUGE) personality. You will all be in my prayers. (Carrie, 8/8/08)

Friends of the children sometimes contributed comments.

...My mommy just told me you went to heaven, and I hope you will have fun in heaven. I feel like a thunderstorm inside my heart so I had to cry. And I really missed you. I thought you were coming to school tomorrow, but you are in heaven now. And you will be my best friend forever. I will always talk to you if I have time because I know you can hear me. (Tony, 8/31/08)

Expression of criticism of the bloggers' writing was rare and usually considerate. The blogger had posted an entry expressing sadness on the need to use white boards and other adaptive devices for hearing loss for its signal of another loss related to the child's illness

...I've been a faithful reader of [your blog] for quite a long time. I know you didn't mean it in a negative way, but I wanted to reply to your feelings toward the white board... You

see, I am a deaf individual and very proud of it. When I first met my boyfriend who is hearing, we wrote notes back and forth to each other to communicate until he learned enough sign language to do without notes....It WAS romantic because it showed me how important to him that he must be able to communicate with me and that he was devoted....I know this situation is different than yours but for a lot of deaf people, they can't talk well using their voice so all they can do to communicate with hearing individuals is write back and forth on pen/paper, a whiteboard, etc. At least they're trying to communicate, and at least there's something to communicate with, rather than saying nothing/doing nothing. By the way, [your child] is one of my heroes. she is such an inspiration to all! happy valentine's day! (Leigh, 2/13/09)

Readers who had experienced the death of a child provided support and reassurance to grieving parents.

I am so sorry for your pain, a pain without a cure. In my experience with family and social events, I stated before hand, if I feel like I can attend, it may only be for a short time, I may leave without warning or good byes. I let my friends know that chances are I may not show up, however even if I do show, I may leave at any time. No one ever questioned or said anything when I would quietly say good bye and leave, in some cases I slipped out the door without my good byes. Slowly, very slowly the time I spent at each event increased to where in most cases I now can attend a whole family event. I don't think this is retreating I think of it as a means of protecting our fragile hearts. (Danny, 4/28/09)

A reader expressed understandable outrage in this story of an experience shared by many parents who have lost a child.

...Just something with regards to 'the things people say'.....when [my child] had his relapse in 2004 I will never forget what one woman said to me....she asked how many children I had and I told her three (including [the child who relapsed]) to that she just said, 'well, at least you have two other kids'....WHAT?! I knew she did not mean malice...she just didn't know what to say and THAT came out...to which I replied...how many kids do you have??? '5' she said...and I said, okay, pick which one you want to die....I know, very harsh, but she was shocked and I quickly told her that I knew she meant no harm, but that's what it sounded like.... I cannot imagine what you two are going through....I can't. My thoughts and prayers continue to be with you both. (Danny, 3/27/09)

A mother who had recently lost a child to neuroblastoma wrote to express an altered perception of what she understood about her son's end of life.

I read your updates and my heart goes out to each of you in the deepest of ways. It is particularly hard for me as I feel that [your child] is conveying the physical pain to you that [my child] could not to me. In a way, I am gaining more insight into [my child's] end and it pains me even more. However, I am so proud of [your child] and the both of you for every step you have taken in this journey....Much love (Danny, 1/6/09)

Grief over missed experiences was often the subject of comments after the death of a child.

I think of yall every day. Yesterday, I took my son to take his road test portion of his driver's exam. Out of the blue, standing there among dozens of other parents, I started bawling, and wound up with my mascara running down my face. (I looked like an

antique version of a rock star by the time I got things under control. NOT a pretty sight.)

But I got to thinking about [your child], and the fact that yall wouldn't get that experience, and I just lost it. Our daughter died in 1990, and we have missed out on everything that so many parents takes for granted. (Danny, 4/9/09)

After the death of one child, many readers wrote to express feeling overwhelmed at how many lives were touched by the child through the blog.

(1) I have been following [your child's] life story for just a year now, but he has touched my heart so deeply. He became a regular part of my day and a person who was always on my mind and in my prayers. I never had the wonderful opportunity to meet [your child], but my heart feels so broken. I found myself in tears throughout the day yesterday after finding out that his wonderful spirit had moved on. While there are no words that can take away your pain, I hope it does help knowing that your amazing little man touched hearts and lives all over the world, and he will live on through so many people. Furthermore, it was so apparent how VERY loved and cherished he was....Thank you so much for sharing his journey. I am forever changed. (Tony, 9/1/08)

(2) I am yet another who does not know you but has been drawn to your amazing son by several unrelated sources. I know there is a reason. Your family and your remarkable son have touched my soul and affected who I am. I wanted to grieve today when I found out about his death...but all I was allowed was to rejoice in his life and be happy that his pain was gone. I wanted to wallow...that wasn't allowed because his life and spirit pervade wallowing. He and his life are to be celebrated. You are to be admired for setting the example. WE ought not give up on the fight to keep these

souls around us as long as possible. Bless you and please know Tony has influenced, so positively, so many many, many of us. (Tony, 9/2/08)

(3) I teach junior high English, but I'm going to find a way to work these two beautiful children's stories into an upcoming lesson plan. I hope to teach my students to "Live life to the Max!" God bless your precious family, and may He hold you firmly in his arms. (Tony, 9/7/08)

Readers shared narratives about signs of the child's presence after death.

I'm sorry for your loss. [Your child] was the sweetest little girl I've ever known. She is in a better place now, free from pain and free of this horrible disease. If you need anything, please let me know. She will be missed. She is still with us and looking over us, I was out with the baby today and as we were in line to buy tickets I turned around to see a butterfly that landed on his stroller, then after we got the tickets and moved into the park, the same butterfly landed on his stroller again. I truly believe this was her telling me that she is happy and running around Heaven free of everything and I know she wanted me to tell you about this so I wanted to share this with you and your family. God Bless....(Carrie, 8/8/08)

Research debate. Though much of the blog content remained grounded in the expression of and support for psychosocial issues related to the illness experience, several debates on the merits of recently reported clinical research occurred.

[from a commenter:]...Just wondering where you found "4 complete responses out of 15 patients in a phase 1 trial." According to the ASCO abstract, the trial accrued 32 patients, 30 of whom were evaluable for response. That would make the response rate ~13%, not ~26%

[the blogger's response:]...The statement is from the conclusion of the trial. "4-

HPR/LXS oral powder was well tolerated, obtained 2 - 5 fold higher 4HPR plasma levels than fenretinide capsules on the same dose and schedule ($P < 0.01$), and showed anti-tumor activity (complete responses in 4/15 patients at DL4-8)."

I think the miscommunication is regarding which patients they were evaluating. They were looking at the 15 patients in dose levels 4 - 8. Regardless, this is an excellent response rate for such a non toxic agent. In fact, I cannot think of any other agent that has produced such results in neuroblastoma with as little toxicity. (Cindy, 6/16/09)

Joy. Readers rejoiced with the bloggers upon hearing good news at the end of treatment. This comment revealed as much about the reader's perception of the illness experience itself as about the shared joy.

...So happy to hear you have finally come to this day. Boy do I remember the day [my child] got her port out. We felt like we had been released from prison. No more worries have hospitalizations looming over our heads!!! Yes, I will pray she stays well & there are no delays. It sounds like God had kept her well & I will trust that he will continue!! Blessings to all of you! (Courtney, 2/19/09)

Triumph. While some expressed joy, other parents painted a picture of the ALL survival experience as a triumph over challenge. Here, the port catheter, saved as memento, represents broader meanings of survivorship.

OMG! I am so glad you kept her catheter! Now you can look at it and admire it, thank it and remember the good times and hard times. I sure it evokes weird mixed feelings of love and survival. I always think of the hospital as my alma mater. You can look at the

cath as a diploma or even a good citizen certificate. What's better than to be a graduate of life? :) (Isabelle, 12/5/08)

In this related comment, the blogger received support for the idea of saving the catheter for all it represented.

Excellent! Now just think about what you'll be forgetting in 3 months time! I have not read *The Secret*, but can also respect the idea of not putting negative thoughts into the universe. However, to completely forget your cancer experience would be a dis-service to all. You should not and cannot forget your journey nor the lessons learned nor the strength gained. Don't deny the battle. Keep your mementos, your badges of honor. Refer to as needed. Until then, it looks like this storm is just about over, sister...simply enjoy the gently rocking of your boat...I see some calm seas ahead... (Isabelle, 4/16/09)

Not just a story. Readers sometimes expressed the need to remind themselves of the reality of the situation.

Oh my goodness...seeing [your child's] sweet pictures really makes it all more real. I read your blog everyday and have to remind myself that this is not just a story, your family is in this fight right at this moment. Thanks for sharing. Thoughts and Prayers are with you. (Jeremy, 4/7/09)

Some expressed understanding over time that the ultimate subject was the family experience, and not the cancer or its treatment.

And, of course, today I was reminded that it never really was a story about cancer to begin with! It is a journal of love, laughter, faith, promise, God, hope, inspiration, courage, and so much more. (Leigh, 5/12/09)

A reader expressed grief over the death of a child by using sarcasm to complain about the ending.

What the F...Cancer Sucks and I have had enough already....I have followed your blog for a very long time and I am pissed off at the ending. Its not fair. Just once I was hoping that the good guys would defeat this flippin beast....I am truly sorry. I wish you nothing but happy memories and I pray for a salvation after passing that is truly amazing, beyond anything that we could ever humanly describe with mere words. [Your child] deserves this and much much more. I know I sound like a nutball, but I won't apologize either.

Cancer Sucks and I am tired of it!!!! (Danny, 12/23/08)

Ballast

Narratives in the readers' comments provided ballast for parents in several ways. Reiteration of a sense of solidarity reassured the bloggers that support would continue. Many examples of comments offering advice and debating the research were found. Especially influential in the parent experience, as evidenced by subsequent blog entries, was the encouragement from readers to consider regret as a core mitigating factor in off-treatment decision making. Ballast was also revealed in a continued emphasis on faith life; deepening of the blogger-reader relationships; empathy with the experiences of surplus suffering; and in comments posted in defense of the bloggers when negatively-perceived criticism was received.

Solidarity. For some bloggers, the end of treatment meant the end of the child's life. During this time, readers continued to post messages of solidarity in response to bloggers' entries. A unique approach to the traditional 'laying on of hands' prayer over a loved one was completed by a Pastor's online comment.

One of our members who loves you dearly...has asked for our congregation's prayers and we have repeatedly lifted our hearts to the Lord for [this child]....Let me imagine [the child] here and let me share the words I use for young and old alike: "I lay my hands upon you in the name of our Lord and Savior Jesus Christ, beseeching him to uphold you and fill you with grace that you may know the healing power of his love." I pray that for you all, even as I trust our Lord for healing and hope in my life too. Trusting in the relentlessly faithful love of God for each of us, God's Spirit works to bring comfort in our fears and to sustain us in our hopes. (Carrie, 6/26/08)

Even during a child's last days, remaining present despite geographic distance was possible online. A relative who is a nurse commented:

Sending all the kisses to you my little lovey! I need to get to 200 kisses before I leave for Africa, OK?!...When I look at the moon from Ghana, I will think about all my babies back here....My stethoscope and I will take care of all the little African babies that need a doctor and then I will be right back, I promise. Just remember how much I love you and be strong,...my love. (Carrie, 7/24/08)

Angel imagery was ever present, both in blog entries and in comments.

as a mother to an angel, i wish you peace at knowing that you truly did all you could to try and stop this beast. the only peace that comes is knowing "no more pokes, no more medicine, no more pain" [your child] will always know that you loved him, and vice versa. im not a very religious person, but i do believe that some people and children were meant to come into our lives for a little while, and no doubt leave the most lasting imprint. i lost my daughter at just 3 1/2 years of age, she fought it for just a year and a

day. but i can truly say that every day we lived life to the fullest especially knowing that she had a life threatening illness. (Tony, 8/26/08)

Empathetic messages were posted to comfort...

I wish I could say "welcome" to the World of Surreality...but, welcome is not exactly the sort of word one says to a mother and father in your position. The dual existence continues as well,...only in a different way. Every moment of every day that you are living here with us, you will feel your heart and mind screaming for a different place, another existence...yet, as each sun sets and each sun rises, you will realize that you have managed to live another day without your sweet son...and he will be proud of his amazing parents for continuing on without him...(Danny, 1/18/09)

...and to commiserate.

(1) ...I wish I had the courage or the strength to comfort you and tell you that everything will be okay but the truth of the matter is that i dont know if it ever will be okay. It used to disturb me, no it used to anger me when people would tell me that it would be okay, that something good would come from my sons passing but nothing good ever came from it, not a damn thing. I miss him terribly and I know you will miss [your child] every day. I have missed you guys terribly but have been too much of a coward in dealing with my own sadness to try and help you guys...over these past few years. I have been thinking of you two constantly and ask [my wife] about you every time i know she visits or talks with you. I know my kids enjoyed seeing and talking with [your child] the last few weeks and they have a lasting memory of how a young man gracefully dealt with knowing his last days were upon him. Your son showed

tremendous courage. I love you guys and hope you find peace in the coming days.

(Danny, 1/18/09)

(2) As a parent who has "been there"...(and it is never the same for any 2 parents) I held [my child] in my arms as he took his last breath as I did when he took his first one.....I thought I would never survive this. People always said "it will get easier with time"...NOT. It gets more tolerable. It will never be easy with out our kids but take it one moment at a time. It gets more tolerable. [My child] said to me about 2 weeks before he died as we were standing talking to nurse [____]"mommy, you are the best mommy in the whole world". Those are the words that kept me going. I did not want to let him down...We kept fighting when he was with us and we keep going today. Don't get me wrong we have our really really tough times,,oh dear god how do we go on times...but we do.I am going to send you a book that someone gave that I found helpful, by no means made anything better but helpful. I also feel the best place for [my child] is here with us but I know he is now in a place free of pain...(Danny, 1/22/09)

Six months after her daughter's death, the blogger received comments of solidarity after expressing her relentless grief online. Evidence was found for the pervasiveness of the use of the phrase 'one day at a time,' though its context has changed.

...It brings tears to my eyes when I read your post because I can relate to the feelings. I do remember your [child] because the nurses would get confused because [our children] looked like twins with their bald heads and mask on. I hope one day we can learn to cope from losing our precious babies. I do not think I will ever heal but I do think I will learn to live with the pain. I guess it is one day at a time. (Carrie, 2/6/09)

For many parents, the end of treatment meant significant changes in thinking and behavior.

Comments from readers expressed solidarity with the bloggers' experience.

(1)although our kids are on different ends of the cancer spectrum, I totally agree with you about the ending of active treatment. I was terrified. The port is still in, they say we can do bloodwork every 4-8 weeks, I make sure its every 4; its hard to suddenly drop what has become normal. And more so when people look at you like you should be relieved that the active treatment is over. I felt like it went on for 3 years and I was supposed to suddenly think positive and become normal again overnight.... its scary. And then I did a number on my head, thinking okay is this normal fear I am having, or is it a premonition of something bad to come and thats why i cant let go.. I have decided ignorance really IS bliss!!! (Leigh, 12/27/03)

(2) ...I just wanted to tell you all that I commend your decision to let go and live, live, live ...I can totally relate to your situation. My husband and I have decided on no more treatment as well for our son....He also has stage IV neuroblastoma and we are in the same boat. He recently had a small tumor removed that the doctors believe is neuroganglioma. Our home hospital says one thing, Duke says another, and Sloan says to do nothing further! It can be SO crazy, I know! Anyway, on our end here we are going to focus on BELIEVING that those cells in [your child's] marrow were ganglioneuroma. Let's belief in life for a change and know [your child] is on the road to wellness!....(Leigh, 7/1/03)

Advice. Advice flowed in and out of the blogs. Topics included managing life after treatment, child discipline, late effects, and education, among many others. Here, a commenter encouraged a blogger to advocate for the child regarding special educational services.

I haven't finished reading today's update yet, but I wanted to comment before I totally forget. Whether [your child] is home schooled, private schooled, or public schooled, you pay taxes to your school district. By law, they are required to provide special education care to any student that is determined to be special needs. They will fight and scream to NOT declare her special ed because then they will have to be responsible for and IEP (Individual Education Plan) for the student until the child is 21 (depending on type of need). You may need to acquire a special ed advocate, but unless federal laws have changed since I was on the Board of Education, these are the rules. We had many students who attended Catholic school but who came to us and our teachers for speech and hearing therapy as well as other special ed needs. (Leigh, 6/14/09)

Advice for parents of a child dying from neuroblastoma was usually pointed and addressed specific issues such as the following on the topic of comfort at the end of life.

My heart aches for you and your family. I have been following your journey and its as if I was telling my story. My son battled cancer for over 8 years and lost the battle at age 15. I have been wanting to express my feelings for awhile on yes cancer does suck. I finally thought I should write and ask if you have heard of PROPOFOL? My son was administered this sedation drug at home under nurses care on his last week of life and if administered correctly it makes them more peaceful during the last part of the journey. I believe he was the first to receive this at home and it took alot of red tape for his doctor to allow this procedure at home. He was in alot of pain the last few days and this helped tremendously with that because at this point morphine no longer helped, the only drawback is they are not coherent and cannot talk or in other words they are pretty

sedated but at that point being the pain verses communicating we thought this was the best thing. My prayers are with you and your family. (Danny, 1/15/09)

Another suggestion from a reader met with criticism from fellow readers for the reader's insensitivity on the topic of 'just letting go.'

We've been in your shoes and are so sorry you're there. We've fallen in love with your sweet son and all of you and have followed your story for years as ours with our kiddo ended a few years ago. Our advice to you is to stop the blood transfusions and let him go. Let him be pain free. There is no need to continue to watch him suffer. We still cannot shake those terrible images. You want your mind filled with good ones. We wish we would have followed others' advise and not kept ours going on for a couple more weeks when the suffering was like [your son's]. By stopping the red blood transfusions he'll have a peaceful death. He should go to sleep and then you can honestly talk with him as you're struggling to do before he goes to the next place. Our hearts and thoughts are with you and I hope you're not upset by our honest advice but we have travelled your road and would change things if we could. (Danny, 12/28/08)

This prompted enthusiastic and empathic responses from readers:

(1) Like you, I would hope that the suggestions from everyone who reads here come straight from the heart. I would also hope that all of us who offer advice want nothing more than to find something -- anything -- that might help you and your family. I agree with the commenter who says the right decisions are the ones that are right for your family. Even when we sometimes say things that are unintentionally hurtful (who, us? the internet?) I'm glad you can keep your eyes and heart on what is important --[your child]. Many, many blessings to your family. (Danny, 12/29/08)

(2) ...well said about the entry from the parent of a child that cancer took from them.

Through the pain of burying their child, they have earned the right to have their opinion and their perspective on the steps to take near the end. Everyone has different opinions and not all circumstances are the same; if [your child] wants to keep fighting and he has good quality time with friends and family. How can you and [your wife] deny that? As difficult as these decisions are, I have no doubt you all will make the right decisions based on the day, as you have for the past 9 years. (Danny, 12/29/08).

(3) ...I am sorry that [your child] is in his current state. As the physician that diagnosed him with Neuroblastoma in March 2000, and as a practicing pediatric oncologist and pediatric hospice specialist, I find nothing wrong with transfusions for terminally ill pediatric oncology patients. I presently am taking care of a 14 year old patient with refractory neuroblastoma who is nearing the end of life. He is transfusion-dependent and would die within a month without transfusions. With transfusions, he is able to maintain some quality activity. Those moments allowed by this transfusion treatment are very important to the patient, family, and friends. I am confident that you will do the right thing for [your child]. You have been doing it for his entire life. (Danny, 1/1/09)

Nearly a year after a child's death, a reader solicited advice on one of the Phase I clinical trials the blogger's child had participated in more than a year before. The comment also highlights the thin veil of privacy that exists in illness blogs.

...I found your website by actually searching in google. I must have typed in Univ. of Vermont and somehow it brought me to you. A quick background: My little sister...is battling recurrent medulloblastoma we are looking into the Nifurtimox trial phase II. It

looks as though you all think very highly of Dr. [____]. We live in Ohio but are willing to go wherever we can to help [her]. We think [she] might be the first medullo. patient to enroll. If you have a few spare minutes could you email me about anything you know about Univ. of Vermont and Nifurtimox? I am so very sorry for your loss. [Your child] is an inspiration to all. My email address is...(Tony 5/12/09).

An emotionally charged comment requesting encouragement was posted to the blogger (of a neuroblastoma survivor) who became a lay neuroblastoma researcher-advocate.

...I am giving my friend...your information because I don't know what else to do. Her baby...is 2 months old and was just diagnosed with Neuroblastoma. We live in Virginia and because [the child] is on Medicaid they will not pay for her to go to New York for treatment. [The child] has her first MIBG scan tomorrow...they have already placed a central line - they are frantic, scared, feeling hopeless. Here is the information to their CB site...The doctor found this mass at her 2 month visit and said it is the size of a baseball and all scans show it wrapped around the aorta. Thank you for any encouragement you can provide them...(Cindy, 10/1/08).

Debate. Months later, the same child becomes the subject of much debate about the risks and challenges of offering advice, even when it is solicited. In one entry, the blogger highlights both pro and con comments received in the debate. On the 'con' side:

...Don't do it. Don't give in to the dark side and provide "advice." Stick to what is known. I say this with your best interest at heart. I know you have good intentions, but the last thing you want to take on is the responsibility of giving parents advice on what they "should" do and then having to face them if things go terribly wrong. Let them make the

decision that is best for them, their children, and their families with their doctors. Don't give them someone else to blame if the outcome is not what they expect. Just thought you might want another perspective. (Cindy, 2/5/09)

On the 'pro' side:

...I am so thankful NOT to be in the position personally to need advice on this disease, but as someone who has talked to you personally about [this child] I can tell you that after what you have been through and the research you have done and the conferences you have attended and been a part of, I would trust your opinion on this as much as any doctor. I understand how you would not want to be responsible for making a decision for another family, but there are doctors out there (and I watched [the child's mother] deal with them) who don't have a quarter of the information that you have. Please do not stop talking to these families, sharing what worked for you and giving out the newest information. If the situation is anything like what [the child's mother] went through...the local hospital had no clue how to deal with Neuroblastoma and wanted to do procedures...that were completely unnecessary and very risky. You may not have MD after your name, but you know this disease better than a lot of people who do. (Cindy, 2/5/09)

After the next post by the blogger, in which he very carefully reviews choices without recommending any one particular plan of action, the following comments were posted:

(1) 2 thumbs up! I like your style. Keep on sharing information. It's helpful to everyone.

(Cindy, 2/6/09)

(2) Good, important information presented in a way that is not giving specific advice.

Keep it up! (Cindy, 2/6/09)

(3) I think it was brilliant! I also think your unwritten rules needs to be put in to book form.

Keep them coming!!! (Cindy, 2/6/09)

(4) Couldn't help commenting. It is a funny coincidence of your entry, as we came out of surgery two days ago, hopefully with a complete resection. This has been the highest point for us so far. And you are absolutely right about having second opinions, looking for the best of the best. And may I add, still questioning and researching. You have been a wonderful source of information for us, I surely check what you have on internet before and around any decision that we have to make about our daughter's treatment. So, yes, keep up sharing information! (Cindy, 2/6/09)

In a subsequent comment, a reader offered support for the blogger's writing and included a narrative of personal experience:

When it's your child and every decision seems extraordinary, I concur that the biggest is the surgeon. After 6 rounds of chemo we were introduced to the surgeon. World class expert in pediatric heart lung transplants. He emphasized how difficult the operation was going to be. We asked how many neuroblastoma resections he had done and the answer was five. After some more research we concluded that there are some surgeon who do that many in a week. We signed up for an extra round of chemo, arranged travel to NYC and prepared for an extended stay at the Ronald's house in Manhattan. MSKCC welcomed us, and there is great comfort when a surgeon that has performed thousands of surgeries specific to this condition says "I removed all of the tumor I could see and feel"... (Cindy, 2/11/09)

A month later, in response to the same entry, a reader asks for help in obtaining a second opinion.

hi i need a second opinion on my sons surgery,he was due to have his op on 26th of this month it was booked 2 months ago and the surgeon agreed to do it.Tody however they have cancelled my sons appointment and sed surgery is too risky for him,surely its more risky to leave the tumour in.He has stage 4 high risk nb and responded well to rapid cojec his tumour shrunk by 70% so i cant actually see how much more they evpected please e mail me a list of surgeon to contact im takin ur advice im running for that second opinion (Cindy, 3/13/09)

Regret. Even from the early days of treatment decision making, regret loomed large for these families. At every phase, whether considering survivorship or end-of-life care, parents weighed risks and benefits with care, then shared the process with the bloggers and fellow readers. Some readers commented that the potential for regret ultimately determined the plan of action.

(1) What a beautiful daughter you have! I would like to comment on your question on Neuroblastoma List Serv....[My child] actually took accutane 8 months because he had headaches and we gave him less but longer and that may make a difference. [My child] relapsed in April of 2005 and we've done chemo every three weeks since. He is considered NED and has been since tumor was removed in 2005. [My child] was 3 1/2 when diagnosed we were given less than a 20% of survival because of stage 4. When he relapsed we were given like less than 2% and are going to try to go to New York after we finish 3 more rounds of Irrenotecan/oral temador....My husband and I want no regrets. We will see if our insurance will pay for 3f8's. I don't want to do nothing since he relapsed. (Leigh, 11/22/07)

(2) ...Lean on Hospice they are the most wonderful people in the world! I would not have made it through my loss without them, family and friends. Spoil him rotten, hold him tight, give lots of kisses and have Christmas early this year. I did not because my 16 year old only child...refused to give up and knew she would be here for Christmas. I lost her on the 15th of December with the Christmas presents under the tree unopened. That is my only regret that rips my heart out till this day since losing her 7 years ago. Live these last days, months or year with [your child] as each one is his last. From a Mom that has been through this they will make wonderful memories when the pain does begin to ease. My love to all of you at this time...(Danny, 12/5/08)

(3) Keep fighting for his right to enjoy his life the way he wants.

I regret I didn't fight harder for my [child]. I begged the doctors to do something for her, they didn't, and she died too soon, and without any quality of life for the last weeks...(Danny, 12/30/08).

Faith. At the end of life, readers encourage family members to continue to believe in miracles, in God's goodness, and in a purpose in life.

(1) We were disappointed to hear the news about [your child's] current condition. We still have not given up hope for her. We truly believe God can give us a miracle at anytime. He has a purpose for all of our lives, and even though we may not always figure it out on our own, he knows. [Your child] is a beautiful blessing that has been sent into all of our lives, and she is touching all of our lives in so many different ways. She is an inspiration to so many people. She is brave and courageous, and most importantly she is a fighter. Don't give up on her ability to fight or God's. We still

have faith in both of them. We will continue to pray for her, and ask our church to pray for her as well.(Carrie, 6/1/08).

(2) ...Something I held onto each day when [my child] was sick -giving me hope and peace while in the storm, was that I knew that God was still good and still in the business of doing miracles. I pray that GOD continues to be your source of comfort and strength....(Carrie, 6/3/08)

One reader commiserated with a blogger who wrote of her faith challenges since her daughter's death.

...As for church.. sister, I can IDENTIFY! Of course, the church we "belonged to" at the time we lost [our child] had just built a new sanctuary. We'd never been in the new one.. until the night of the wake and the day of the funeral. We tried to go back but just couldn't. The LORD worked it out so that some other friends were just "in-between churches" at the same time we were. We started meeting in their house and realized that it was indeed Biblical. When we learned that we weren't sinning by doing church in homes we never looked back. Our friends knew the songs that broke our hearts so we avoided them. Our two families grew to three, then four.. and now we're up to almost 30 on any given meeting. It's been AMAZING! We base how our church is patterned by 1 Corinthians 14.. "let every man have a word". This way EVERYONE is studying the same topic and each of the men can bring something to the study....(Tony, 3/31/09)

Relationships. The relationships formed or maintained online during the illness grew more intense as treatment ended. Near the end of life, one reader expressed gratitude for being included in the journey.

...We have come to love you though we hardly know you. We Thank you for being so open and letting us share this journey with you. We pray that you would sense God's presence and love at this time. Heaven is a beautiful place where [your child] can be free from pain and sorrow and she can run and play and someday your family can all be there together. This is our hope and what holds us together at a time like this...(Carrie 8/3/08).

Another reader described the relationship between blogger and readers as an internet family.

...I've been here through the time that you have had the site - sometimes posting in the guestbook - a lot of time just reading. I find myself tonight (as some previous ones lately) blubbering like an idiot. I CANNOT imagine what you are going through. I pray that [your child] has a peaceful end to a long tortuous journey. I pray that it is fast and peaceful and that the [family] find a way to live through this awful nightmare. I pray that God grants you the peace of the good memories and the grace of forgetting the hard ones. I pray that you have numerous friends, family, and internet friends to be by your sides as this journey ends. Please know that we as an internet family are out here thinking of you during all this. May [your child] sleep the sleep of peace and know that he has been much loved in his short lifetime and that he has changed so many of our lives. (Danny, 1/14/09)

Despite never meeting in person, readers expressed closeness at the end of life and after the child's death.

(1) I can't think what to say, except he mattered to people who had not even met him who know him only through reading his blog. My heart hurts for you. What a precious boy. (Tony, 8/31/08)

(2) ...I wish I really knew you because I would go up and say "I'm sorry" and give you a hug. As a member of your cybercommunity that doesn't really know your family, I want you to know that I still check the site regularly because I miss [your child] and think about your family all of the time. (Tony 9/15/08)

Surplus suffering. Hospice was generally commented on as helpful, but inconsistent and inadequate when it came to the needs of children at the end of life.

I didn't realize how incredibly lucky we were (HA!) that our local VNA comes out to our house to draw...labs. It saves countless hours, countless trips, and certainly helps lessen the fighting and anxiety that come with hospital trips. It has been a remarkable thing for us and I hope that it goes just as well for [your child]. I just assumed this was standard procedure everywhere but was saddened (and selfishly happy) to discover it is exceedingly rare. We'll never mover out of their coverage zone....(Tony, 7/31/08)

Once treatment was over, screening scans for survivors were typically done every three-six months. Parents, and by association the readers, explicitly described an awareness of the likelihood of recurrence, so anxiety on the bog was always heightened in the days preceding and following scans. Communication of results was a frequent target of criticism.

Thanks...for all the entertaining, informative updates you provide us. We do appreciate this peek into your life, even if we don't always leave comments. I have to say, though, that from your updates I've been unimpressed and vicariously frustrated with [the hospital's] seeming lack of timely communication with you. It seems that every time you've been there, you've had to wait and even fight to get your results by the promised

time. A little girl's life hangs in the balance here - how could they ever be "too busy" to deal with that? Perhaps I'm missing something....(Leigh, 8/2/08)

One reader wrote that dealing with insurers was high on the list of sources of suffering, after the loss of her child.

...We continue to follow and support you and your family especially these very tough days well they are all tough but these are made tougher with little medical assistance and of course the call from your "case manager".... funny isn't it when you try to get ahold of them you never can then all of a sudden they are calling you with what....nothing....other then losing our [child] dealing with the insurance was the worst nightmare...(Danny, 12/14/08)

One family, who found a new mission after the death of their daughter, received comments of support for their new cause and gratitude from those who were now benefitting from their work.

(1) ... My granddaughter is being treated at [the hospital] with stage 4 NB....When we were there last week, we were told that you were there, we must have just missed you! We have read your about your heartfelt journey with your little [child] and my thoughts are with you always. Thank you very much for the chicken soup and bread, you are so very thoughtful to continue to support and reach out to the patients and families on the 3rd floor. I hope and pray that you and your family receive the strength you need to get through each and every day. (Carrie, 2/5/09)

Dozens of comments were posted after a father posted a question on the blog from his preadolescent son who had recently experienced a recurrence of his disease. The question posed by the son to the readers was whether he should pursue any further treatment. The response from readers was overwhelming and full of emotion. A small sample follows.

(1) Danny, when I read your dad's entry last night, once again, I cried. My heart goes out to you more than you can even begin to imagine. And once again, I was awake a majority of the night, thinking about your question, and praying about it. Being the mother of three boys, one of which is a teenager, (they're 16, 6, and 3), I was afraid of even tackling this question, but I know in my heart that I owe you a response.

First off, let me tell you how I came across your site. My little friend... had Stage 4 Neuroblastoma, and he was declining quickly, so I went to Google (I love that site!), and typed in the keywords, and I was just amazed at the amount of sites that I came across. Too many sites, which means that Neuroblastoma, which I had read up on, and oddly enough I had just read that it was a rare type of childhood cancer. I found that to be very untrue. So I spent many countless hours sitting here reading on each child's progress, and their treatments, to see if there was anything out there that maybe [the child's] doctors didn't know about yet, or hadn't tried. When I came to your site, and saw your family picture, I just fell in love with your family, but, to be honest, your dad was intimidating to me for some reason, (and I honestly cannot even remember why), so I didn't sign your guest book for a long time. I really don't even remember my first signing, but I can tell you this, you touched my heart, and I was so excited to see your age, and immediately, I began to thank God for giving you the precious time that He had given to you since being diagnosed. And I was so excited for you, and I just knew in my heart that I was looking at a picture of a SURVIVOR. And I've been praying for you, and checking up on you ever since then....I don't want to see you give up the fight, because I know in my heart that you are already a winner. And I truly believe that a cure for this monster is out there, and I pray that it

is right there waiting on you, and that you will reach out and grasp it with all that you have, and be a part of the discovery of that cure. No one deserves that more than you do. You and your parents have become a daily part of my life via this site, and I have learned that you can actually love someone that you've never met in person before. And I worry about you just like I do my own boys, even though I know that you are in very good hands with your parents. It must be a mother thing. Please pray about your decision, and don't wait too long. (I sure don't want to see it get worse!) And remember, you are already a winner, a survivor, and someone I truly respect and admire. (Danny, 4/11/08)

(2) ...I am a lurker and have been following your fight for a while now. I want to answer your question this way: Today is my b-day, and it is also my daughter's b-day, she is 13. I have decided recently to change my career, I will be going back to college, to get another degree, and my goal is to work in the pediatric cancer field. Following your fight and the fight of other kids has inspired me. And the way for me to pay it forward is to help in this fight. I pray you find the strength to keep fighting, I know it is not easy, but please do not give up you have so much more to offer then you can possibly imagine. Thank you for inspiring me to help kids like yourself. (Danny, 4/11/08)

(3) I know this is hard as you are a teenager & want a normal life like the rest of your friends. If you can just for the moment step out of the box & put yourself as the "parent" instead of the "child", would you want your "child" to fight or give up? Would you do all you could for your child physically & emotionally to keep your child positive & fighting? All I can say is so many love you...& like others have said

there are so many new things being found as we speak. FIGHT..., "Never give up"!

A "winner" never quits & a "quitter" never wins! (Danny, 4/12/08)

When this child's neuroblastoma progressed during subsequent treatment, readers posted comments with affirmation of the decision not to pursue treatment.

I've been reading your journal for a couple of weeks now. I came by your caringbridge site through [another] site. So many times I've tried to sign the guestbook, but the words just didn't come. So I read your stories...laughed at your jokes...and cried for you and your family. I know exactly what you're going through. My husband's son...lost his battle with leukemia in February of 2007. [He] was 9, and if my math serves me correctly, that's how old [your child] was when he was diagnosed....don't for a minute doubt that you are doing the right thing for [your child]. We had a long hard struggle with [our child's] cancer and there were times that people told us how we should handle his treatment, and we didn't agree. We trudged on OUR way, and you know what? Our way gave us 16 more months with [our child] that we might not have had if we had done it THEIR way. (Danny, 1/6/09)

Defending the blogger. Readers were especially eager to defend bloggers who had been writing for years. One father made a tradition of writing a fake entry on April Fool's Day every year. Each year, readers unfamiliar with his practice reacted by commenting in confusion or outright anger. The first April Fool's Day entry after his son's death inspired dozens. Here, one pointed comment on the father's attempt at a humorous post:

I have a good sense of humor but nothing about this is funny. (Danny, 4/1/09)

Here is a sampling of the outcry that followed:

(1) I was hoping you wouldn't see that comment. I'll tell you the truth..when I read about the tatoo being a prank, first I laughed and then I cried. It was so good to see a little of your old spirit shine through, and [your child] would have loved your prank. I thought maybe the comment came from someone who was also hurting over [your son] and in that case thought it may be forgivable..but still hoped that you wouldn't see it. Sorry that you did. Keep on letting the sun shine in, whenever/however you can. However "twisted" anyone on the outside might see it, it's nobody's business but your own how you cope (Danny, 4/6/09)

(2) [to the critical commenter]...I have something to say to you ...nothing you wrote is funny how DARE you try and take [the child's father's] april fools joke away from him and tell him its not funny Let me give you the low down.[The father] is a mighty funny man and he pranks us all the time and we all fall for it all the time I look forward to [his] pranks Fast Forward to today I haven't been here since the day you wrote your thought (witch SUCKS)when I got here this morning I was furious with you how Dare you [The parents] just lost their son to cancer and you want to sit on a thrown and cast your disapproval for the way that [the father] did his april fools trick ..I got one word for you your shameful and full of strife [to the father:]I want you to know you not only had my chain in your hand but [my husband] was believing it as well your good my friend ...keep it up when your able I hope it did help it did put a smile on your face...!!! [My husband] and I support you in all things ..I had to write this over 20 times to make it G rated (Danny, 4/7/09)

Patterns and rhythms

In addition to consideration of the fit of comment themes into logical categories of understanding, patterns and rhythms of the comments became obvious within each temporal phase. In early comments on the blogs, during the diagnostic phase of the child's illness, readers were primarily family members and friends attempting to find information about the extent of the illness, the needs of the families and to express solidarity and offer prayers and material help. Comments were addressed to the blogger, the spouse, the ill child, and occasionally a sibling by name or not.

As time elapsed for each of the families, the readership grew to include family members of children in similar straits; so-called "prayer warriors;" random blog readers; and occasionally hospital staff members offering solidarity and support. In addition to family and friends, authors received early support from established internet compatriots. For example, as the mother of a triplet, one blogger had an established connection to an online group of mothers of multiples.

Similar patterns and rhythm of commenting were noted among the blogs, with fewer comments noted during times of lesser stress. For example, between two and five comments per day were found following each entry in one blog during calmer periods of treatment activity. On her birthday and at the time of her baptism about 20 comments were found; at her first relapse, 22; at the second relapse a year later, 32. When her parents posted the message announcing the persistence of her disease and the end of curative therapy, 44 comments were found. Similar high numbers of comments were noted at the first anniversary of her death. After the post announcing her death, 64 people commented within about twenty four hours, with many more in the early weeks, ultimately dropping off to 3-6 in about 2 weeks time.

Two of the bloggers made periodic attempts to increase readership by engaging in question and answer, call and response post patterns. These tactics were employed during periods of diminishing comments when readers were ‘lurking’ more than commenting, i.e. reading without posting comments. Readers acknowledged regret when ‘delurking,’ i.e. posting a comment after an extended period of reading the blog without contributing (A Dictionary of the Internet, 2009). The following comments are just a sample from 135 placed on Leigh’s blog in one day, in response to her mother’s suggestion in her post that she may not continue writing.

(1) First guilt. Then manipulation. Did you happen to train under my mother because she was the queen...only it doesn't seem to bother me coming from you! Okay, so here is your post as required through threat of silence. I check your site every day...that would be EVERY DAY...to see if there are any new entries from you. I look forward to the comments, observations, shared facts and photos. Surely the site has a counter that tells you each time one of us views it. So you must know how many of us check regularly (did I mention I check every day?). If you don't, well, let me clarify it for you: Lots of us check your site every day, some check it a few times a day. Those people who probably lead a more active and less compulsive life probably check in a few times a week. Okay, now you know. Do you feel better?...you must toughen up a bit (is toughen a word?) because when you write that book I keep telling you is in you and you sell thousands of copies of it...you won't get much in the way of feedback (short of calling everyone who purchased a copy). You will just have to trust that your work is read, appreciated, enjoyed, and often shared. Just keep writing!!!! You know, I'm beginning to think you don't really need the feedback. I think you just miss

us when we are silent. Okay, [fellow readers]...let's get real noisy out there. (Leigh, 11/30/07)

(2) By the way, I avoid signing the guestbook for the same reason that someone else mentioned below. I feel "silly" signing because I've never met you in "real life" so I feel like I'm intruding or something. But maybe that feeling itself is silly, since writing and journaling are arts in their own right and folks have been connecting through writing for many centuries...(Leigh, 11/30/07)

One blogger actively sought information about her audience by posting questions. She asked how many men were regular readers (Leigh, 11/16/07). Three men commented in reply, among dozens of regular commenters. She asked how long people had been reading. Some replied they read from the beginning; some had arrived to the site the day before. Bloggers often expressed interest in learning more about the audience of readers. To that end, bloggers occasionally posted entries asking about readers' favorite things or requesting readers write ten things about themselves. One blogger, mentioned earlier, made a practice of posting a joke entry on April Fools' Day each year, including the April after his son had died.

The nature of communication between blogger and readers is unlike other internet communication. Bloggers posted whether anyone was reading or not, though undoubtedly the presence of an audience was found to enhance future writing.

CHAPTER 9

Discussion and Conclusions

Research purpose

The purpose of the research was to explore, describe, and analyze the online narratives in the hope that knowledge generated would amplify the voices of families living with childhood cancer. The research aimed to identify thematic categories of narrative and experiential elements. The influence of the social interaction with blog readers and the reasons expressed by parents in the blogs for writing and publishing online were of additional research interest. The study employed narrative analysis of parent blogs about living with childhood cancer to answer the following three research questions: (1) What life stories are evident in blogs created by parents of children with cancer? (2) What themes are evident in the illness narratives contained in these blogs? and (3) What is the influence of author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer?

A sequential application of three narrative analytic approaches was used to analyze the illness blogs from different but concomitant perspectives: life story, thematic analysis and text-in-interaction narrative analysis (Polkinghorne, 1995; Georgakopoulou, 2006; Riessman, 2008). A new, more exact understanding of the meaning of the narrative in large, small and shared thematic categories resulted from the iterative employment of the three approaches.

A year passed between the last consent received and the completion of the three analyses of the illness blogs. Deep attention to the reading and the sequential interpretation of the blogs required multilayered iterative exploration of the data. After identifying a set of thematic categories, the review of the list inspired further organization until a moment of epiphany

resulted in an even more concentrated iteration. This occurred in both the thematic analysis of the blogs and in the narrative-in-interaction analysis of the comments.

Research findings

Research question 1: the life stories

The application of three narrative approaches in sequence revealed separate layers of meaning of the blogs to authors, to readers, and ultimately to healthcare professionals. The life story analysis made it possible to view two blogs as complete stories of the illness. After reading all of the blogs included in the study, it was possible to answer the research question, “What stories are evident in blogs created by parents of children with cancer?” All of the illness blogs contained “small stories,” of everyday events related to the illness, its treatment, and of the daily life of the family. When examined as a whole, however, the blogs told a larger narrative about the authors and the narrative elements that heralded important plot points and themes. Some told only the story of the illness diagnosis and treatment, keeping personal and family details to a minimum. This was the exception, however. The two blogs selected for life story analysis in this study were rich in detail, illustrating both the everyday and the totality of the experience from a deeply personal perspective. Summaries of these narratives as the researcher’s creation allowed viewing the data as possessing a larger scope of childhood cancer beyond the accumulation of the everyday (Polkinghorne, 1995).

Aligned next to each other, similarities and differences were evident between the two blogs chosen for life story analysis. Both highlighted the pressures exerted on personal and family life by the uncertainty and stresses related to the illnesses and treatment. The pattern and intensity of the uncertainty and stress were found to be different in the two life stories. For the mother of the child with leukemia, the profound uncertainty and stress in the early phases gave

way ultimately as she adapted to the off-treatment phase that, while still rife with potential for disease recurrence, permitted a realistic vision of a future in which the child would live disease-free. For the mother of the child with neuroblastoma, even a child surviving many years past expectations, the struggle to fight the plague of uncertainty that might incapacitate with recurrence of the illness remained long after treatment end.

Research question 2: the mes identified in the blogs

Reflection on the thematic categories identified in the second phase of analysis of the illness blogs led to organization into counterbalancing concepts. Tamboukou's (2008) notion of 'technologies of the self' played a crucial role. Technologies of the self are the ways in which small details within a large narrative are synthesized toward an understanding of a narrator's identity construction and attempts at deriving meaning from experience. Like Tamboukou's attention to the small things or 'insignificant details' she found in the genealogical approach to women teachers' diaries, this analysis found significant information by examining each blog entry as a particular entity.

Iterative reading of the blogs, each time highlighting more expansive thematic elements in the narratives, led to clarity. It was during this phase of reading and rereading, pulling blog entries out of the context of the larger narrative but within the temporal time frame of the treatment phases that the longing for balance became apparent. Each of the "small stories" selected as significant were held together by the common thematic drive by the bloggers toward balance of negative forces with positive. Narratives of uncertainty were balanced with stories of working to manage the uncertainty with specific tactics. The other thematic categories identified, i.e. stress/stress management, change/constants, burdens/gifts, and the conflict between public and private personae will be discussed in relation to previous research.

Uncertainty/uncertainty management

From the time parents learn of the diagnosis, the blogs included narratives of the frustration and anxiety that accompanied the many levels of uncertainty related to the illness, its treatment and the changes that occurred as a result. For many parents, it was this uncertainty that became the filter through which they viewed every day events and processed the experience in the attempt at meaning-making. Uncertainty was described as torture. Metaphors helped to illustrate feelings of powerlessness, chaos and distress. The illness trajectory was compared to a roller coaster. The disease was a monster, a beast, the “thing under the bed.” Parents and children engaged in a “battle” with uncertain outcomes. Bad news came out of the blue. Good news was suspect, greeted with alternating doses of thankfulness, skepticism and wariness of its short half-life. Mishel (1988) found uncertainty to be considered a danger or an opportunity (e.g. hope in a period of uncertainty) by parents of children with serious illness. DeGraves and Aranda (2008) found that parents considered uncertainty a danger *and* an opportunity. Bloggers in this study seemed to view uncertainty as what Mishel referred to as danger. No evidence of uncertainty as an opportunity for hope was found in any of the writing. The assertion by Stewart and Mishel (2000) that uncertainty management was a principal preoccupation of parents living with serious childhood illness was supported in this work. Interestingly, efforts toward uncertainty management such as keeping records of events, information-seeking, and an active faith life, among many others, were found throughout all phases of treatment.

The findings support the idea that information sharing and family education to enhance information-seeking skills can decrease uncertainty, especially in the diagnostic and early treatment phase. This supports the findings of a longitudinal, prospective, grounded theory study of thirty-two members of seven families who had a child recently diagnosed with cancer (Clarke-

Steffen, 1993). The core process in which families in the study were found to engage involved six main strategies: (1) managing the flow of information; (2) evaluating priorities; (3) shifting priorities; (4) changing future orientation; (5) assigning meaning to the illness; and (6) managing the therapeutic regimen. These elements were found across all phases of treatment in the blogs, in writing by both the authors and the readers.

Expressions of stress and anxiety in blog entries during periods of uncertainty were noted. This is consistent with findings of research in which reliance on emotion-focused coping strategies and perceived illness uncertainty were associated with PTSS and general symptom severity in eighteen parents of children with brain tumors (Fuemmeler, Mullins & Marx (2001). In the blogs, parents expressed a feeling of being in control over emotions and experienced help with coping through the act of writing. The coping strategy of blogging seemed to assist in the management of overwhelming uncertainty.

Support was also found for the unique and potentially isolating uncertainty experienced by parents during childhood cancer treatment between hope for cure and contemplation of the child's death, especially at times of disease relapse. This supports the ethnographic research of DeGraves & Aranda (2008), who found the fluctuation between hope for life and fear of death to be a type of coping mechanism in the attempt to manage the uncertainty inherent in relapse. The narratives in this study highlighted uncertainty as changing in quality and intensity through the three phases of life with childhood cancer. In addition, differences were noted in the narratives of uncertainty between the two types of cancer blogs included, which seem to follow the illness trajectories.

Exploration of two types of childhood cancer was thought to hold promise for the potential to highlight differences in the experiences. In the end, far more similarities were found

than differences. The differences appear to center on degree rather than uniqueness. Of course, the degrees of negative forces are mitigated by the anticipated outcome—the differences in statistical survival rates. For the parents of children with leukemia, there were many unknowns in the first four to six weeks, but the intensity and duration of periods of uncertainty and illness-related stress for the authors seemed less extreme than for the parents of children with neuroblastoma. The growth of an online community beyond family and friends was much more pronounced in the neuroblastoma blogs, presumably due to two factors: the isolation imposed by the small number of families affected; and the interminable length of the illness state due to exacerbations and remissions of the illness.

Blog entries frequently included references to or quotations from the Bible and other texts. These seemed to play a role in uncertainty management and to mitigate the sense of powerlessness when parents felt unable to provide concrete expressions of help to the child. Prayers and requests for prayers represented action. Written expressions of faith were particularly common at times of critical decision making. One blogger used Biblical quotations as a framework for each and every entry, seemingly to inspire and to guide her writing and her perceptions of the events of the day.

Stress/ Stress management

Support was found for the relationship between blogging and the management of stress. Authors repeatedly described the blogs as a place for the expression of emotions such as feeling overwhelmed, powerless, frustrated and sad. Indeed, evidence was found in entries for blogs as the one place to express some negative emotions and attitudes that authors described as too painful, too complex or too isolating to relay in person even to close relatives and friends. Narratives of being troubled by unwelcome thoughts and flashbacks of stressful events and

nightmares support the findings of a study done on the experience of PTSD in parents of childhood cancer survivors. Two-hundred forty-nine parents of survivors completed questionnaires on PTSD symptoms 1-10 years post-treatment. Thirty percent of mothers met diagnostic criteria for PTSD since the time of diagnosis and 13.7 % met criteria at the time of data collection (Kazak, et al., 2004). Findings are also consistent with research by Pöder, Ljungman and von Essen (2008), who found parent reports of symptoms of acute stress disorder within one week of diagnosis of childhood cancer and reports of symptoms of posttraumatic stress at two months and four months after diagnosis.

Alternatively, even in a single blog entry, writing often shifted from a report or assessment of stressful encounters to a narrative of personal growth resulting from the perceived trauma of the illness and its treatment. This finding of personal growth is consistent with work done by Barakat, Alderfer and Kazak (2006) on the phenomenon of posttraumatic growth. The researchers found that the stress associated with the experience of childhood cancer can coexist with positive emotional outcomes. Positive changes that result from negative life events are being measured with new instruments developed to attend to parents' and children's resilience and so-called 'benefit finding' behaviors (Phipps, Long, & Ogden, 2005; Phipps, 2007).

Change/Constants

Each blog contained references to a changed life "after cancer" and descriptions of a new normal. In fact, several phases of change representing several new normals were noted. Upon reflection, life during the diagnosis phase was considered by some to be the period of highest stress and uncertainty, when the first new normal began, i.e., the end of life "before cancer." These findings support research with mothers of children with ALL interviewed at three time points (3-4 months post diagnosis, 15 and 27 months) who at first reported feeling optimistic that

normal life was possible, but later described how difficult it was to achieve (Earle, Clarke, Eiser, & Sheppard, 2006).

The second new normal seemed to emerge when treatment was underway. Work and school obligations were met, albeit with interruptions for hospital and clinic visits. Knowledge about the illness accumulated and confidence in the ability to meet the child's emotional, medical, and physical needs grew. During this time, parents expressed unhappiness and fear related to the illness experience and the associated uncertainty, but this was also a time bloggers wrote of an awareness that some of the constants that sustained the family "before cancer" remained: abiding love, financial stability, the comfort of daily routines, faith, and family traditions.

Some reference to the positive effect of living through the experience was found in each blog. This was especially true during the off-treatment phase or after a child had died. Parents expressed some mix of surprise and pride in having learned that despite the obstacle that childhood cancer represented to the entire family and to each of them personally, the identity change that resulted was interpreted as positive. The individual and family identity changed but bloggers learned lessons they otherwise might not have. Personal strength and an appreciation for life were frequently mentioned enrichments to life after cancer.

A third new normal occurred as families entered the off treatment phase. The resumption of normal family functioning was discussed in the writing as in delicate balance with the fear of illness recurrence and hypervigilant observation for symptoms and late effects of therapy.

A fourth new normal occurred after the loss of a child. Identities shifted anew. Questions such as "How many children do you have?" were often difficult to answer. In a reply

to a brief summary of the findings emailed to parents and discussed later in this chapter, one blogger expressed the new normal after the loss of his child in terms of suffering:

I often look at things with the perspective of "how it was," and "how it is now." "How it was" was much better (Carrie, father, personal communication, 2/17/11).

Burdens/Gifts

The principal burden reported by authors, the burden expressed as the most difficult to bear was a sense of loss. Evidence was found in support of the idea that parents experienced the loss of a life in which cancer was an unknown and the acquired burden of having cancer as a permanent part of life (Woodgate, 2006). Parents expressed feelings of sadness at the loss of normal life, separation, everything from hair to missed celebrations to the loss experienced with a death of the child and of children with similar illnesses.

Examples of surplus suffering, i.e., the imposition of discomfort, pain, or stress in addition to the predictable burden the illness and its treatment represented, were found in every blog. This supports the findings of Clarke and Fletcher, (2004), who were the first to use the term, "surplus suffering, to describe significant burdens identified by parents layered on top of those associated with the illness or its treatment, such as financial or work-related stresses. Nearly every blog contained writing on the burdens of expense and separation associated with the travel required to receive care at distant centers where experts in these rare illnesses could be found. This is consistent with findings of additional expenses and parental feelings of isolation during travel for treatment in previous research with parents of children with cancer (Scott-Findlay & Chalmers, 2001). Parents also expressed feeling burdened with having to take on the role of educator when staff members were unfamiliar with equipment or procedures. During hospital stays, witnessing perceived incompetence and the suffering of other children and

families living with cancer were also referred to as intensely difficult to bear. For one father, the aggravation of communication with health insurers rivaled the burden he experienced in his child's death. For the rest of the bloggers, communicating with insurers was expressed in the writing as taking time and energy away from life with the child at a time of great need.

After reading the study summary, a father replied by email about the meaning of surplus suffering, stating "surplus suffering comes in many shapes and sizes and continues long after the death of the patient" (Carrie, father, personal communication).

Gifts expressed in the writing support the notion that writing in general and blogging in particular engender a sense of communal support between authors and readers. Authors also noted the acquisition of gifts of personal growth; an awareness of strength; and an appreciation for life, for family and for what's 'really important' during the treatment and off-treatment phases. These ideas are consistent with the findings of Orgad (2005) in her study of women with breast cancer using computer-mediated (listserv) communication, in which storytelling was found to be a means to maintain the capacity to have plans and desires; and to hold on to a sense of themselves with control over their lives.

Private lives/Public lives

Parents' identities as private persons and public entities oscillated as time passed. The community of readers grew from family members and close friends to a broader audience interested in events, in the narrative and in providing support by writing and by taking action. Prayer, companionship, raising both funds and awareness were found to be acts of support and expression demonstrated by readers. At times, parents wrote of feeling conflicted about how much information to share and when. Ultimately, the benefits of taking on something of a public

persona appeared to outweigh side effects such as reader misinterpretation, negative feedback, and reader suggestions perceived by bloggers as unhelpful, even hurtful.

Two blogs were registered in the public domain. The remainder possessed what is now being referred to in websites as ‘light’ password protection, i.e. membership on the website (here, CarePages and CaringBridge) requires only a self-created username and password to access all the blogs on the domain. Evidence was found that parents understood the degree to which their privacy was protected. While no violations of privacy were found, parents wrote of feelings of violation of trust at times, particularly once when information from the blog was referred to by a hospital executive in the context of managing family dissatisfaction with systems issues. In another example, a parent struggled with private/public identity when a comment came from a reader critical of the parents’ decision making during the last days of the child’s life. The reader (a parent whose child also died) suggested the parents stop the administration of blood transfusions and “let him go.” This advice was perceived by the blogger and subsequent readers to be inappropriate and hurtful. Comments in support of continuing transfusions came from many, including the physician who had diagnosed the child years before. While the line between public and private; acceptable and unacceptable behaviors online remains unclear in every blogging discipline from politics to journalism to religion to these illness blogs, bloggers and regular readers, i.e. members of the immediate community of influence seem to develop and maintain a code of acceptable behavior (Heilferty, 2011; Sievers, 2006)

A finding in this study, yet not discussed in current research literature, was the influence of physician and nurse comments on the blogs. Further research would help to identify the effect on the experience and on patient-healthcare professional relationships as these pertain to blogging and to Internet use in general. The comments from professionals in this study were all

found to be supportive and collaborative in nature. No evidence of patient privacy or confidentiality was found out of context with what had been already shared by the parents themselves.

Research question 3: Author-reader interaction

The return to the blogs to answer the third research question, “What is the influence of the author-reader interactivity expressed in illness blogs about the experience of parenting a child through cancer?” permitted exploration of yet another layer of blog purpose and effect. A defining feature of illness blogs, interactivity was found to be the intersection at which author and reader connected in the search for the equilibrium longed for by parents. Co-creation of a broader narrative of childhood cancer was the result of this interactivity. Together, bloggers and readers shaped not just the dialogue but the experience itself as well as its perception, one of the core meanings of what Serfaty (2004) referred to as coproduction in an early study of blogging.

Evidence was found in the analysis of comments that supports conclusions drawn about meaning making in research on communication in breast cancer listservs (Orgad, 2005). In the study of computer-mediated communication by breast cancer patients who used a listserv, meaning making was found to be one of the main effects of the action of storytelling. Clearly, one of the effects of readers on bloggers in this study was the enhancement of bloggers’ ability to make meaning of the illness experience and to cope with stress and uncertainty—providing ballast for parents feeling off-balance.

The lasting effects of the interactivity were most apparent in the treatment phase, where readers had the greatest influence on the authors’ subsequent writing. During the diagnostic phase, reporting details and events predominated. During the off-treatment phase, parents were either deep in the isolation surrounding the loss of the child; or they were better skilled at

maintaining the balance inherent in survivorship. During the treatment phase, comments could lift spirits, affirm feelings, and provide useful information.

As expected, comments from readers were found to influence the bloggers' writing, but the degree to which the comments influenced the illness experience was surprising. Bloggers expressed the need to hear from readers regularly, even in times of stability. The blogs truly became works of co-creation, influencing the bloggers' perception of the negative forces and inspiring emphasis on positive thinking. Ballast, in the form of expressions of solidarity, helped bloggers regain balance.

The phenomenon of blogging

Though small and selective, this sample of illness bloggers supports the notion that demographics for this group are far different than those of the general population of bloggers, found to be primarily young men (Pew Internet and American Life Project, 2006). Of the 14 blogs in this study, 11 of the main authors were women and all authors were over 30 years old, consistent with recent reports on demographics of cancer bloggers (Kim & Chung, 2007).

Trustworthiness and Rigor

No consensus exists within the narrative research community on the subject of rigor. Critics cite the emphasis on researcher interpretation as a flaw that can lead to misrepresentation, though this is a common criticism of qualitative methods in general (Atkinson, 1997). The most comprehensive answer to critics of narrative methods was written by Riessman (2008) who outlined a set of criteria to be met in the attempt to assure research trustworthiness. Rather than verifying the "truth" of events, it is the interpretive work with the text that is to be evaluated. The first facet named by Riessman related to trustworthiness is the coherence of participants' narratives. "Do episodes of a life story hang together? Are sections of a theoretical argument

linked and consistent? Are there major gaps and inconsistencies? Is the interpreter's analytic account persuasive?" (Riessman, 2008, p. 189). This research is based on the interpretation of one researcher. Others might have identified other thematic categories or used other narratives for examples when analyzing the blogs of parents with cancer.

It was important in the thematic analysis to battle the assumption "that everyone in a thematic cluster means the same thing by what they say [or write]" (Riessman, 2008, p. 76). In addition, it was essential to account for the researcher's role in narrative construction and analysis when reporting on interpretive decisions. To enhance credibility, a detailed audit trail that included study design decisions, rationale for the proposed research questions and support for the methodological approach were included in the proposal. From proposal defense forward, a journal was maintained of decisions made; reflections on the research process; and emotional reactions to the work.

Riessman claimed good narrative research persuades readers through presentation of data in ways that demonstrate genuineness, plausibility of interpretation, and reasoned and convincing discussion of data. Positions taken in the reporting of study findings were supported by examples from participants' accounts, with negative cases included and alternative interpretation considered. Lastly, to ward against mere excellent writing being used to convince readers, Riessman suggests that findings by the researcher must be presented to an academically critical audience that is expected to attend to details about the rigor of the study design, study execution and the conclusions drawn based on the findings (Riessman, 2008). The mechanism to achieve academic persuasion and ensure the coherence of the narratives and themes reported was to rely on the counsel of members of my immediate academic community, i.e., the doctoral committee and university representatives enlisted to review the study design and execution. Regular

meetings of the researcher and committee members were scheduled to review study decisions, procedures results and reflections. Notes from these meetings were included in the researcher's journal.

The incorporation of participant comments on the conclusions drawn can serve to affirm findings in narrative research (Riessman, 2008). At the completion of dissertation writing, a brief summary of study results was emailed to the bloggers (Appendix B). Email responses from seven parents were received. Parents expressed appreciation for both the research effort and for receiving the results. There were three requests to send the complete dissertation, even after the parents were informed of the length. Parents also provided some affirmation of the findings:

1. I thought your findings were most insightful and accurate. I would only add that "surplus suffering" comes in many shapes and sizes and continues long after the death of the patient. There is the parent's guilt associated with not being able to protect one's child from anything. The disappointment in the faces of her siblings, and the impending sense of mistrust whether perceived or real are very painful and nearly insurmountable in the family dynamic. Also the pain of seeing others you love in pain is quite difficult. Cancer takes everything and gives very little in return. It robs a father of his potential and drive. It snatches away a little boy's chance of being a big brother. It takes a baby from her mother.

I often look at things with the perspective of "how it was," and "how it is now."

"How it was" was much better.
2. It sounds very interesting. I really started the blog/carepage to keep family and friends informed but it quickly became a way for me to get my feelings out. I still go

back and read it often and marvel at all that we endured. Thank you for your interest in this subject.

3. Thanks for the info. I'm glad reading our journey may help make a difference. We have a week left in treatment now. What a roller coaster.

A reply of mine to a blogger's emailed request for the dissertation subsequently was posted on her blog (she informed me):

Very recently a friend in the nursing field wrote to me, "I know each new developmental phase will have Elle revisiting her experience in a new and sometimes unexpected way and this will bring challenges to you as her mom as she makes sense of it." Her timing was serendipitous and insight remarkable. In fact, I had written to her the day before about just this and before sending, had deleted what I wrote. I had minimized my experience. She unwittingly validated me. The truth is, this dependable but never predictable revisiting of Elle's journey is what inspires me to keep writing. This part of her story is as important as the rest.

Limitations of the research

From the outset, several limitations were inherent in the study design. The small sample size and the process for selection of the narratives make generalization of findings impossible. Gender differences (i.e., between mothers and fathers) in the expression of the experience of parenting a child through cancer cannot be accounted for in a broad way through this study. It was also understood from the outset that limiting the sampled blogs to those created by English-speaking Internet users and to parents of children with leukemia and neuroblastoma will result in a narrow expression of the significance of blogging in the illness experience.

The inability to verify the identity of the bloggers and the truthfulness of the blog content must be considered another study limitation. This limitation is inherent in Internet research in general. Truthfulness in narrative research is often impossible to assess. The consistency of the application of the method, the trail of evidence and its critical evaluation established the trustworthiness of the work (Riessman, 2008)

Two factors contributed to an “elite bias.” These vividly descriptive, emotionally charged and particularly well-crafted stories must be placed into proper perspective within the population of parents in general for whom personal expression is limited in some way. There exists the possibility that parents were blogging because they are writers by vocation, surely limiting the applicability of the results (Sandelowski, 1986). The second factor is the discrepancy in access to and utilization of the Internet by parents of different cultures, lifestyles and socioeconomic settings. A recent study by the Pew Internet and American Life Project (2010) reported those with higher incomes engage in most online activities more frequently than others.

No conceptual definition of balance in relation to illness was found in a literature search of CINAHL and Google using the dates 1950-2010 as limiters. Search results led to papers on resilience, a concept closely associated with balance perhaps, but expressive of a clinical interpretation of attitudes, skills and behaviors, not descriptive of personal experience.

The recognition of the significance of “balance,” a word overlooked a thousand times in the blog reading ultimately illuminated the meaning of blog creation and maintenance. Over and over again in the blogs, it is equilibrium that families said they seek in the childhood cancer experience. Blogging, for these families, played a role in that search for balance. The use of positive attitudes or behaviors to manage negative events over the course of the illness through

the performative acts of blogging seemed to move the authors toward equilibrium. What of the readers? Readers brought ballast to the blogs and ultimately to the bloggers' lives, through support and an overwhelming dedication to solidarity; to 'standing with' parents.

Recommendations for future research and for nursing practice

This study adds new knowledge that can inform an understanding of the impact of parents' use of the Internet as a means of communication during illness (IOM, 2007).

Assessment of the efficacy of online community interaction in decreasing uncertainty, stress and suffering could be the foundation for interventions aimed at enhancing parent-provider relationships; promoting personal and familial growth; and improving care quality. Information on the effect of blogging for parents of ill children might be gained by comparing measures of uncertainty, stress or caregiver burden between members of groups of bloggers and non-bloggers.

The performative acts noted in the analysis represent one of the areas of greatest potential influence on nursing practice. Parents reported psychosocial, physical, spiritual, developmental and financial stresses and management strategies. Parents' writing included evidence of treatment efficacy and adverse effects; barriers to compliance with therapy; and their understanding of the illness, its treatment, the healthcare system and the education they received about all three. They advocated for change; suggested areas for improvement to the healthcare system; and lobbied for expansion of treatment research initiatives both locally and nationally.

The analysis suggests that incorporation of parent writing may improve family-healthcare professional communication; enhance the family-healthcare professional relationship; enhance safety by preventing medical errors; improve reporting of clinical trial data such as adverse events; and improve satisfaction. The capture of parent suggestions and parent-reported clinical

data might be accomplished through direct solicitation of parent reports that could be transmitted into the medical record online from home. Participatory medicine, gaining popularity as a new model for healthcare, might include expansion of the electronic health record to include space for parents to report symptoms, problems or questions (Society for Participatory Medicine, 2011). Initiatives underway in healthcare toward establishing and maintaining electronic health records (EHR), especially “openEHRs” in which professionals contribute to the EHR regardless of geography, are changing the documentation of health care (Kohl, Garde & Knaup, 2008). In fact, some institutions are now referring to the documentation as the PHR or personal health record. Some healthcare systems already use these PHRs to email patients, allow self-scheduling of appointments by patients online and to report results of laboratory test. Research is demonstrating improvements in safety and expansion of access through the realignment of healthcare relationships toward equal participation and accountability (Society for Participatory Medicine, 2011).

The significance of the research to parents rested in the attention paid to their longing for authenticity, ownership and control over the story of the child’s cancer experience. The desire to seek and find meaning in the events surrounding the illness and in its telling; acknowledgement that their suffering matters; and the quest for a unique relationship between author and reader are all important elements of the inherent lesson in researching this genre (Bochner, 2001). A deeper level of understanding of the value and meaning for parents of creating and maintaining blogs in the context of the lived experiences of childhood cancer resulted.

A principal finding in the analysis of the blogs was the overwhelming volume and complexity of parent suffering endured while caring for the ill child. A new and deeper level of understanding, directly from the parents’ perspective, that expands current knowledge of the

childhood cancer experience for health care professionals resulted. These findings can be used to increase health care providers' awareness and understanding of the parents' day to day experiences resulting in greater empathy and support for these families. Further study might include a trial of interventions directed toward decreasing the number and intensity of caregiver burdens. One example might be to identify potential relationships between caregiver burden, parental uncertainty, parental anxiety and the use of an online parent support group in which parents can seek and receive help with problem-solving, coping and emotional support, led by expert pediatric oncology nurses.

A separate investigation into the surplus suffering experienced by parents of children with cancer is warranted based on the research findings. The underestimated influence of financial, work-related and health system-related stressors needs to be assessed. Interventions geared toward assisting families to manage these burdens should be evaluated for efficacy. For example, many institutions have employed financial counselors to assist family members with health insurance and other illness-related financial concerns. Comparison of measures of caregiver burden, parental uncertainty and parental anxiety in parents served by institutions with and without this support might yield useful information about the efficacy of this type of support. In addition, research into the relationship between direct contributions from parents to the medical record (e.g. via the EHR, online from home) and parent satisfaction, child symptom measures and the frequency or type of adverse events might result from pre- and post-measures of these phenomena before and after creating the mechanism in the EHR for parents to do so.

One of the most frequently mentioned sources of stress expressed in the blogs was related to the periods of uncertainty during which parents waited for laboratory or scan results. The writing during these times was dominated by the frustration that accompanied passive waiting

for information with life-altering consequences. Many parents in this study expressed a desire for greater control over the flow of information in general, and about result reporting in particular. Study of parent and physician expectations in this regard, as well as assessment of the mechanisms currently in place for communication of test results in pediatric oncology centers may suggest a need for creation of new, more efficient means of reporting and discussing the meaning of these results.

Support can be found in the findings for augmentation to the new role of nurse as “navigator” of care. These nurses help patients and family members collect, organize and understand information; streamline communication; promote wellness; and solve problems in complex health systems. Expansion of the EHR to permit inclusion of patient and family documentation in the plan of care could achieve the same goals online. In the same way nurses now triage care by phone, the definition of care can be further broadened to include Internet nursing. The role of ‘phone nurse’ has shown evidence of enhanced communication and improved safety (Wheeler, 2010). Why not a ‘web nurse’ or online nurse navigator? This nurse navigator could be responsible for education regarding the parent use of the Internet as a treatment and system improvement tool, for example. The nurse in this role might also be responsible for online treatment education and integration of parent reports of symptoms, side effects and other problems into the plan of care for the child. The online nurse navigator could also enhance communication among all members of the health care team, including the parents, to improve care for the child. This shift of the organization of the health team toward a more fully collaborative partnership would position the parent as being as integral to the child’s treatment as any other member of the health care team.

A need for new ways to assess parent coping during childhood cancer care was suggested in the parent narratives. The high degree of specificity and vivid descriptions of effective and ineffective coping behaviors found in the blogs highlighted the inadequacy of the current system for collecting this information in the context of the inpatient/outpatient approach to care. Analysis of online parent narratives, in blogs or another means of computer-mediated communication, specifically for coping behaviors might inspire ideas for the creation of new tools for assessment of parent coping.

Clarity regarding what parents mean by “balance” is needed. Is it balance in emotional states or balance in life experiences parents seek, or both? Is there another meaning? The relationship between blogging and some measure of “balance,” however parents define it, could be explored. The inability to find an adequate analysis of the concept of balance in relation to illness in the current literature is significant given the implications of this analysis.

Positive changes that result from negative life events are being measured with new instruments developed to attend to parents’ and children’s resilience and so-called ‘benefit finding’ behaviors (Phipps, Long, & Ogden, 2005; Phipps, 2007). Future research might examine the effect of blogging on measures of benefit finding in negative events. Another area in need of investigation is the extent to which families with children with other serious illnesses utilize blogging and other modes of online communication, such as Twitter, Facebook, listservs, etc., during the illness experience. In addition, questions regarding the expansion of accessibility to blog creation technology to underserved populations should be investigated. Information about new clinical trials was found in these blogs. By connecting with readers and other bloggers, it is conceivable that expansion of blog use to underserved populations could connect children to advanced care sooner. The unique characteristics of the phenomenon call for a

systematic effort to understand and describe this new tool for managing illness and maintaining quality of life.

Findings of the study can enhance nursing education by bringing the voice of the families directly into the classroom. The new knowledge gained about the family experience of daily life with childhood cancer and the ways in which that experience is mitigated by online communication can illustrate for students at all levels the challenges and rewards families experience.

Conclusions

Future research can lead to the development of a middle range descriptive theory of online communication in illness. Parent narratives from these blogs will guide new research as nurses seek to discover new interventions that improve the quality and safety of care, especially in regard to the meaning of balance and the influence of Internet use on the illness experience. Benefits of the research included the acknowledgement of the importance of the blogs to parents and clinicians; the validation of the suffering that accompanies life-threatening illness; the expansion of bloggers' audience; the potential to design more personalized and effective psychosocial interventions for parents of children with cancer in the future; and the potential for parents' voices to be heard in new ways.

Analysis of parent blogs has yielded new information about and insight into the parental experience of living with childhood cancer by examining the parents' acts of writing online. Analysis of illness narratives has contributed to a broader understanding of the ways in which parents are living with childhood cancer (IOM, 2007). Ultimately, it is hoped the results will inform nurses and other caregivers about the complex nature of parents' quest for balance when living with childhood cancer.

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APPENDIX A

Consent to participate in research

You are invited to participate in a research study conducted by Catherine M. Heilferty MSN RN, from Villanova University. I hope to learn more about what parents are writing in blogs about the experience of childhood cancer and why they state they are writing. The results will contribute to the completion of my research project, *Illness Blogs: Attending to Parent Narratives of Childhood Cancer in the 21st Century*. You were selected as a possible participant in this study because your blog was found in an online search.

If you decide to participate, your blog will be analyzed as a narrative, or story, of parenting a child through the phases of childhood cancer treatment. In addition, some of the exchanges between you and those who comment on your blog will be analyzed for information about the effects of these interactions on your writing.

Blogs will be analyzed from the beginning to the date when you agree to participate. In this way, it is hoped that influence on your current writing will be minimized. The intent of narrative research is to gain understanding of experiences using full-text descriptions. Text from the blog will be copied and pasted onto blank documents for analysis.

There is no cost to participate. There are no risks associated with participation. Potential benefits may be (1) the acknowledgement of the importance of your blogging in the advancement of professionals' understanding of the daily life of a parent with a child who has cancer and (2) the sharing of the negative and positive aspects of life with a child who has cancer with the child, parent, professional and public communities.

Identities of those named in the blog will be changed to fictitious names.

Your participation is voluntary. This study is in no way connected to your child's treatment or the medical team. Your decision whether or not to participate will not affect your relationship with your medical team. If you decide to participate, you are free to withdraw your consent and discontinue

participation at any time without penalty. If you withdraw consent, no information from your blog will be included in the research report.

If you have any questions, please feel free to contact Catherine M. Heilferty MSN RN at Catherine.Heilferty@villanova.edu or by phone at . If you have questions regarding your rights as a research subject, contact Suzanne Smeltzer EdD RN, Institutional Review Board Chair, Office of Research and Sponsored Projects, Villanova University at 215-519-6828. This Office oversees the review of the research done at Villanova University in order to protect your rights and is not involved with this study.

Your signature indicates that you have read and understand the information provided above, that you willingly agree to participate, that you may withdraw your consent at any time and discontinue participation without penalty, that you have received a copy of this form, and that you are not waiving any legal claims, rights or remedies.

Print Name _____

Signature _____

Date _____

APPENDIX B

Brief study summary for parents

February 11, 2011

Dear _____,

At long last, I am happy to share the findings of the nursing study of your blog about your child's cancer. I began reading your writing in the Fall of 2009 and completed the analysis in December 2010. The research was meant to explore your blog and others for important elements of the cancer care your child received and to attend in a meaningful way to your written expression of the experience.

Allow me to tell you how I accomplished the research. I first read each of nine blogs from beginning to end (the end being the date before you consented to include your blog in 2009). I read 9 blogs created by parents of children with neuroblastoma and 5 blogs created by parents of children with acute lymphoblastic leukemia. I first transferred the text from the website to Microsoft Word documents to maintain the integrity of the writing and to ensure the privacy and security of the data (your stories).

I read each blog once without taking notes to get to know you and your story. After the first reading, I returned to the beginning, read the stories a second time and took notes on what I found to be significant to nurses and other healthcare providers. I then returned to the beginning to organize these notes into groups of themes and to name some of the purposes for blogging that you expressed. The last analysis I performed was on the comments you received in response to your entries. I read through these, then took notes and organized ideas in the same way I had with your writing.

I learned a great deal from reading your work and the comments you received. Since life changed so much over the course of your child's cancer treatment, I marked time in three segments: the diagnosis, treatment and off-treatment phases. In each phase, I noticed these themes as common to many of the stories I read. Here are the elements of your stories I found most important.

- Uncertainty/uncertainty management
- Stress/stress management
- Burdens/Gifts
- Change/constants
- Public/private lives

For example, the uncertainty that came during the time when your child was being diagnosed had very different qualities than later, during treatment, when you may have felt a little more under control yet still lived every day with the uncertainty of the cancer's return. Stories about managing the uncertainty and about managing stress were very instructive.

I found one common denominator in all the blogs that represented the stories of alternating negative and positive experiences. This became the title of the dissertation: "The balance we seek." As I read and reread the blogs, this seemed to be the object of greatest desire. The effort toward balance between the five themes listed and their counterparts was one of the elements that jumped off the pages. For example, during some of the burdens experienced, gifts were seemed to be found. Many bloggers described learning of an inner strength they didn't know existed until their child faced not just the illness but the discomforts and annoyances that came with its treatment. The good balanced the bad again and again.

One of the most significant burdens expressed by each blogger was what has been referred to by nurse researchers as “surplus suffering.” It has not been researched extensively, but I believe it needs further study and a plan of action. Surplus suffering, to me, is the suffering experienced in addition to that which comes with the illness and its treatment. Surplus suffering can be caused by family, friends, providers and the healthcare system. Even the bloggers seemingly satisfied with the treatment shared stories of friends or family who said unhelpful, even detrimental things; staff that treated family members impolitely or worse; and a healthcare system seemingly designed to confuse, aggravate and add injury to families already experiencing pain. Insurance company treatment is a category of surplus suffering that stood far above all else and should be researched in depth.

The purposes for writing were clear whether the blogger stated them outright or not. For some, the blog was a place to express things that were difficult or impossible to say in person. Writing seemed to be a way to reflect on events, feelings and changes over time. All the blogs seemed to have started as a means to keep family members and friends informed of events when telephone calling was ineffective for reaching large numbers of people. Writers used the blog to advocate for care for their child by reaching out to others in similar circumstances and to advocate for improvements in and funding for cancer research. Many used the blog to preserve memories, as an archive of the events, the changes in family life, and the feelings experienced. Another purpose for blogging was to explain to readers more about the decisions made on behalf of the child or about procedures and treatment events.

The comments from readers followed similar patterns of the themes and purposes listed above. It was easy to see how important readers were to the bloggers, especially in the entries by bloggers who made direct requests for more responses. Readers seemed to offer comfort,

support, affirmation of feelings and a sense of community when families were feeling particularly isolated. In my report, I describe the contribution of readers as ballast, or a steadying effect, when bloggers' feelings or events were off-balance.

I intend to share the findings of this research with healthcare providers, especially nurses, in professional settings. This may be in the form of research journal articles or in presentations at professional nursing conferences. Be assured that all the names in your writing were changed in the dissertation (the report of my research) and would never be used in any publication or presentation.

I am grateful for your willingness to share your stories with me. Reading them has changed me. It made me more determined than ever to improve care for children with cancer. May you continue to inspire, to be inspired and to be blessed with love.

Sincerely,

Catherine Heilferty MSN RN

Villanova University

Villanova PA