SELF-TRANSCESSION: A PHENOMENOGICAL PERSPECTIVE
OF THE MOTHER’S EXPERIENCE
OF HAVING A CHILD WITH A DISABILITY

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By
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DEDICATION

To my husband, Bill, for your love, continual patience and support for my education

To Billy, may you always be happy and enjoy life

To Colin, may your recent triumphs make you reach for the stars

To Conor, may your love of life never waiver

My dearest sister Janet, and brother Russ, with love and affection

To my parents, may their memory continue to warm my heart and guide my way

To all of the mothers in this study,

your unconditional love and dedication to your children is extraordinary
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ABSTRACT
Joyce Ann Wright

Self-Transcendence: A Feminist Phenomenological Perspective of the Mother’s Experience of Having a Child with a Disability

Having a child with a disability is experienced as the loss of the illusion or “perfect” child and has a powerful and continued impact upon the mother. This interpretative phenomenological research guided by Patricia Benner’s (1994) methodology, and a philosophical perspective of feminism, explored the world of mothers caring for children with disabilities. The research question was “What is the nature of having a child with a disability for the mother?” Participant mothers were accessed approximately 2-years post disability diagnosis from a New Jersey early intervention program. Two interviews were performed several weeks apart in the mother’s home environment; a third contact by telephone confirmed the emergent themes and the true representation of the phenomenon.

Manual coding, evaluation and interpretation were carried out for data analysis. The following themes emerged from the interpretive data analysis of the mother’s experience: (1) consuming blame while searching for an explanation for the child’s disability; (2) overwhelming cloud of not knowing in the search for answers; (3) striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability; (4) experiencing complex and changing motherhood roles; (5) destiny preparing mothers to care for their children; (6) spirituality giving a deep inner dimension; (7) experiencing appreciation of the greatest magnitude for a better life, and (8) becoming, a profound personal growth. The overarching theme to represent this phenomenon was self-transcendence.
This research has contributed to the overall body of research on the nature of the mother’s perspective of having a child with a disability. High-risk infants are now surviving with complex and intricate health care needs and multiple disabilities. Nurses must be knowledgeable to care for this vulnerable population, the mother and family unit. By heightening awareness and creating dialog, this phenomenological research will lead to a greater depth of understanding and meaning of the mother’s perception, and through that insight may lead to improvement in practice and further nursing’s knowledge base.
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CHAPTER I

Introduction to the Study

Having a child with a disability is experienced as a loss of an illusion or the "perfect" child, (Eakes, Burke & Hainsworth, 1998) and has a powerful lifelong impact upon the mother and family. The disability diagnosis is almost always unanticipated; therefore, most families are unprepared to cope with the event (Heaman, 1995). The aim of this research which used an interpretative phenomenological perspective (Benner, 1994), was to understand, from the mother's perspective, what is the meaning of having a child with a mental or mental and physical disability.

Life, for the mother of a child with a disability, is filled with challenges of an intensity far greater, more constant and prolonged, making life a continuous roller coaster of events with emotional highs and extremely frustrating lows (Marsh, 1995). The mother may feel the essence of unfulfilled and lost dreams. The chronic nature of this state-of-being requires continuous adaptation, adjustment and compromise on the part of the mother.

"A child with a disability seeps into every crack of the mother's life, the professionals try to compartmentalize it: they don't realize that it filters into everything" (Marsh, 1995, p.97). Understanding the magnitude of the child's disability will reduce the isolation and vulnerability of this unrecognized and exhausting mother's work (Marji & Upshur, 1989; Read, 1991). The reality of caring for the disabled child has impact upon every common day-to-day occurrence that families with children unaffected by disabilities take for granted. Nothing is simple anymore.
Successful coping strategies are absolutely essential to dealing with the daily challenges that the mother of a child with a disability faces. The mother not only encounters the lifetime commitment to a child with a disability, but copes with the attitudes and behaviors of other family members, acquaintances, school officials and a myriad of other people (Marsh, 1995). Nurses are in a foremost position to make the difference, to facilitate healing as an ongoing process of development, as well as to move the process of healing forward.

Unfortunately, nurses may not fully recognize the extensive problem of the mother's experience of having a child with a disability. They may not understand the deep pain, anguish, the grieving process, and loss the mother experiences immediately following the diagnosis of a disability, and for months and years thereafter. The uncertainty of the diagnosis, the chronicity and future health of the child contributes greatly to a terrifying and lonely experience. Many childhood disabilities are not diagnosed at birth. The diagnosis may not be evident until the later developmental months or years. However, today's nursing care is in a crucial and opportune position to assess the efficiency of the mother's coping mechanisms regardless of the timing of the disability diagnosis. This nursing assessment may prevent the mother from becoming isolated in silence, to intervene with this mother, to help her cope with her initial feelings of loss and sorrow. Nurses have the chance to compassionately appraise a mother's position in the grief process and allow her to feel understood, enhancing a positive experience and ability to cope. She would benefit from a health care team that has a
sensitive understanding of the complexity and long-term effects of this phenomenon, to assist the mother in any way possible.

The nurse can employ attentive and compassionate listening skills, the gift of the profession. The mother can only benefit from this therapeutic communication, and enable her to express concerns and feelings of grief after the child's diagnosed disability. Such feelings of loss and sorrow are normally experienced, expressed by and are common to most mothers of children with disabilities (Damrosch & Perry, 1989; Eakes, Burke & Hainsworth, 1998; Gath, 1985; Gowen, Johnson-Martin, Goldman, & Applebaum, 1989; Kearny & Griffin, 2001; Read, 1991). It is crucial for nursing to impart this commonality of feelings to the mother of a newly diagnosed infant or child. The mother's realization that her feelings of loss and loneliness are shared can only enhance her ability to cope.

A feminist framework (Harding, 1987) was used to thoroughly explore and interpret socially influenced gender roles and how they relate and influence the experience of a mother with a child with a disability (Feminist Ethics, 1998). With the current practice of non-institutionalization of children with disabilities within the United States, the major burden of care has shifted to the mother (Harris & McHale, 1989; Marji & Upshur, 1989; Read, 1991). Therefore, only the mother was interviewed.

Interpretation through the lens of a feminist perspective may further expose the significance of gender-biased role expectations, moral issues and values of this population of mothers. The intersection between societal role expectations and the intense personal experience of having a disabled child was the interpretative element for this dissertation.
The societal and medical practice of not institutionalizing children with disabilities has been evident only during the past 30 to 40 years (S. Levine, personal communication, April 2, 2002). Prior to this time interval, an entire team at the institution cared for the child, the care that a single mother now is responsible for and accomplishes.

Having a child with a disability is an area of immense concern and great passion that has been further explored by this researcher, having experienced the phenomena first-hand. The research process for this study, was a personal effort to validate a phenomenon that has been a personal transition, forcing this mother to question the deepest beliefs and rewriting life's rules (Beck, 1996). Gaining a deeper understanding of the nature or meaning of an everyday experience, and the view of this experiential situation, this research provides insight and interpretation into the lifeworld of this phenomenon. This research produced compelling and insightful descriptions for the reader, so that one may partake and briefly come to know this unique and extraordinary phenomenon.

Research Question

The research question for this study is “What is the nature of having a child with a disability for the mother?” The research question promotes a description of the life experience from a qualitative, phenomenological perspective (Benner, 1994).

Perceived Justification of the Study

It is most important for nurses to understand the phenomenon of a mother’s experience of having a child with a disability. Justification for study of the phenomenon comes in part from personal observation that despite many empirical, descriptive studies
and research into the phenomenon of mothers with disabled children, (Lauterbach, 1993; Read, 1991; Van Riper, Pridham, & Ryff, 1992; Van Riper & Selder, 1989) mothers continue to experience nursing care that is often inappropriate and in some cases non-existent as discussed in further chapters. Nurses are in a strategic position, given their frequent interactions with the mother, to facilitate the coping process of this often-anticipated event. The nursing profession is known to facilitate a genuine, honest and caring atmosphere with patients, leading to a trusting and communicative environment. In addition, 94% of nurses are female (Hawke, 2000), further enhancing the avenue for potential communication and a trustworthy environment. This particular mother may more readily communicate with another female nurse. This association is cited in the feminist literature (Reinharz, 1992) as women-to-women talk. It is a correct assumption, that mothers feel more comfortable and conversed more freely with a female nurse rather than attempt to establish communication with a male physician.

The mother returning home an infant newly diagnosed as disabled now has a two-fold and complex emotional situation to confront. The transition into motherhood is complicated enough without the overwhelming news of the child’s disability. Simply put, the responsibilities of motherhood of a disabled child are magnified, more perplexing and complicated, when compared with the mother of a child free from disability. Communication will enhance appropriate future social supports for the mother and child. Nursing has an obligation to be cognizant of this loss phenomenon, to enhance therapeutic, empathetic communication and further understand the lifeworld of the mother. This lifeworld may consist of the loss of a dream, loss of unfulfilled dreams, loss
of many missed opportunities (Lauterbach, 1993). Mothers returning home with a newly
diagnosed infant with a disability may pull back from society, or isolate themselves, thus
creating a unique opportunity for visiting nurses to reach out. The subsequent
abandonment of the mother by the larger social world actually assists the mother to create
a boundary for herself within which she privately grieves in the manner she chooses
(Lauterbach, 1993).

Through an interpretative methodology, the concealed meanings of this
phenomenon are illustrated. This interpretative account illuminates the world of the
participants, articulating taken-for-granted meanings, practices, habits, skills and
concerns (Benner, 1994). This study explored and clarified the meaning and
understanding of this loss phenomenon, which may also transcend other life events, such
as the loss of a loved one, or the loss of a body part.

Its relevance to, and significance for, an understanding of the human experience,
in part, determines the value of knowledge in nursing (Allen & Jensen, 1990). To further
realize this human experience, nursing knowledge and practice will be enhanced through
a deeper understanding of the mother’s lifeworld. Through this understanding, nursing
will recognize a greater empathy and comprehension of the event, providing information
to guide clinical practice and to act more thoughtfully and tactfully in these situations that
apply to this phenomenon.

Phenomenology offers an approach which enables the needs of the client to be
identified from their perspective, and is of foremost importance in the provision and
justification of high-quality nursing care (Jasper, 1994). The personal need of the client is
of utmost significance with the current reduced length of stay in the acute care environment. The appreciation of this phenomenon by nursing and health care teams may lead to more timely interventions, smoother transition to the home environment with appropriate support referrals, and enhanced therapeutic communication. Partnerships should be developed between the health care professionals and the mother of the child with a disability. This mother has a desperate need to be heard, to be validated, with professional staff listening carefully to her story. The professional nurse needs to encourage the mother to share her feelings of this experiential phenomenon, not to minimize or invalidate the significance of this event.

Informed nurses can fully understand the loss of the perceived perfect child and the loss of future opportunities this mother may feel, while being empathetic and enhancing practical and effective communication, recognizing the daily challenges and frustrations. Empathy as described in Notes from Nursing (Nightingale, 1860/1969, p.54) “is the ability to place oneself imaginatively and sensitively in the world of the other.” Empathetic communication is a role at which nursing excels and is what makes the profession unique. Morse, Anderson, Bottorff, Younge, O’Brien, Solberg, and McIlveen (1992) define empathy within nursing as the ability to subjectively experience and share in another’s psychological state, emotions or intrinsic feelings. This is an attitude of receptiveness, availability and presence with the whole of oneself (Morse, et al., 1992). From a personal perspective, a knowledgeable health care team with the ability to assess the mother’s coping abilities and mental status through the use of simple, open-ended questions will greatly benefit the mother, and expedite the coping process. Nurses have
experience in death, dying and the grief process. However, some nurses have demonstrated the ability to approach, make eye contact, and talk with a mother after the birth of a child with a disability. With this deeper understanding of the phenomenon, potential future nursing interventions and practice with optimal outcomes such as reducing stress, facilitating acceptance and appraisal, normalization, and coping of the situation could be made available. This area of research is acutely needed with advancing technology. High-risk infants are now surviving with complex and intricate health care needs and multiple disabilities. Nurses must be knowledgeable to care for this vulnerable population, the mother and family unit.

Current nursing and allied health research publications about the selected phenomenon use mostly quantitative research methodologies. Current quantitative research explores the multiple roles of the mother, stress, coping, and the adaptation of the mother, father, or family unit (Bennett, Deluca & Allen, 1996; Crowe, VanLeit, Berghmans & Mann, 1997; Damrosch & Perry, 1989; Deatrick, Walsh & Knafl, 1988; Flynt & Wood, 1989; Frey, Greenberg & Fewell, 1989; Gath, 1985; Gowen, Johnson-Martin, Goldman & Appelbaum, 1989; Harris & McHale, 1989; Marji & Upshur, 1989; McCubbin, 1989; Seideman & Klein, 1995; Walker, Hilbert & Rinehart, 1999). Many of the quantitative studies reviewed recommend further exploration through a qualitative research approach, to describe this phenomenon in-depth with richer descriptions. In particular, interpretative phenomenology fills gaps in understanding that are often left by empirical science research (Plager, 1994). By uncovering and explicating hidden meaning, this inquiry will provide a discovery of greater depth of meaning, thus
contributing to understanding (Lauterbach, 1993). At present, there is a significant void in existing qualitative literature on the phenomenon, the mother’s perspective of having a child with a disability. This research focuses on the mother’s response to having a child with a disability, since the mother is an integral part of, and typically the primary caregiver of the child (Flynt & Wood, 1989; Harris & McHale, 1989; Marji & Upshur, 1989; Read, 1991, Walker, Hilbert & Rinehart, 1999). This new knowledge will augment the qualitative research base, which at present is minimal on the selected topic. By heightening awareness and creating dialog, this phenomenological research will lead to further understanding of the mother’s perception, and through that insight may lead to improvement in practice and further nursing’s knowledge base.

The state in which this research was conducted was is New Jersey, therefore statistics from birth years 1985-1994 were obtained from the internet site, Division of Family Health Services, Special Child Health Services Registry, providing a statistical overview of the number of children within this state with a disability. Unfortunately, the birth years of 1985-1994 are the most current statistics posted on this internet site as of May 2002. To obtain an appreciation of the magnitude of the problem, statistics were reviewed to examine the volume of registered children born with a disability in New Jersey. Of the 116,000 births occurring annually to New Jersey residents, over 4,000 children are born with birth defects, between 3% to 5% (Division of Family Health Services, “n.d.”). The Special Child Health Services Registry provides the critical, demographic tracking information on this child population for the state of New Jersey. Demographic tracking can serve as early identification for service referrals to affected
children and their families. Within the state of New Jersey alone, this research will
heighten awareness concerning this phenomenon that affects 4,000 families of children
with a disability each year.

In conclusion the purpose of this research has been to explore the mother’s
perspective on the nature of having a child with a disability. The research question for
this study was: What is the mother’s perspective on the nature of having a child with a
disability? Through this qualitative study, nursing knowledge has been refined to further
direct and enhance clinical nursing practice for positive patient outcomes.

Context of Phenomenon

Present research uses the term “disabled” to describe the disabled child
population. A definition of disability is adopted from the non-profit organization, the
Association of Retarded Citizens (ARC) of New Jersey. A developmental disability, as
defined by New Jersey State law (Association of Retarded Citizens, 1993) is a severe,
chronic disability of a person, which is attributable to a mental or physical impairment or
combination of mental and physical impairments and is manifested before age 22. The
disability is likely to continue indefinitely, results in substantial functional limitations in
three or more areas of major life activity, and reflects the need for a combination of
special or generic services which are lifelong; or of extended duration and are
individually planned and coordinated. The definition further explains that developmental
disabilities substantially limit the individual in at least three of the following areas: self-
care, learning, mobility, communication, self-direction, economic self-sufficiency, and
the ability to live independently.
The specific context in which this researcher conducted the research was within a
two-year time frame (Gath, 1985; S. Levine, personal communication, July 22, 1999)
following the diagnosis of the child’s disability, with the exception of one child who did
not receive a conclusive diagnosis of Angelman syndrome until the age of 6. Literature
supports this approximate two-year time span for the mother to be able to articulate her
feelings and adjusting to life with a child with a disability (Gath, 1985). Varying types of
children’s disabilities were included to present a more global context of the phenomenon.
Some examples of disabilities included in the study were; Down syndrome, Fragile X
syndrome, Cerebral anoxia, Autism, undiagnosed syndromes and neurologically impaired
children. Mothers from homogenous backgrounds and socio-economic status have
participated in this research.

Researcher Assumptions

The research recognizes the following assumptions and biases for this research.

1. Mothers at the two-year mark, post-disability diagnosis of the child, are at a stage of
   individual coping and acceptance and will be able to articulate and provide a
   comprehensive description of the phenomenon (Gath, 1985; S. Levine, personal
   communication, July 21, 1999).

2. Mothers share common experiences during the initial years after the diagnosis of the
disability, regardless of the child’s disabilities, the socio-economic status or ethnicity
   of the mother.

3. Previous lifestyle coping mechanisms of the mother will influence her ability, or
   inability, to adapt to a changed lifeworld with a child who is disabled.
4. The mothers of children with disabilities have a story to tell; they want to share this extraordinary experience.

5. Society views mental and physical disabilities differently; mental disabilities have a greater negative impact upon society, as compared with purely physical disabilities (Noe, 1997).

6. Interviewing mothers alone will provide privacy, and lend for ample descriptions of the feminist perspective and expression of the phenomenon (Millman & Kanter, 1987).

7. The societal expectation of the maternal role is three-fold; preserving the life of the child, fostering the child’s growth, and socialization of the child. (Feminist Ethics, “n.d.”).

8. My personal experience with the phenomenon will promote a non-hierarchical format between the researcher and participant, thereby supporting a feminist methodology (Mac Pherson, 1983).

9. Women will more readily speak with other women, or what is termed by Reinhartz (1992) in the feminist literature as “women-to-women talk.”

10. Women are socially associated with care, therefore, the mother has the majority of the responsibility for the physical, emotional care and overall well being for the child with a disability (Marji & Upshur, 1989; Read, 1991).

11. Understanding of the human person, as individuals, families, communities, and groups, is a focal point of knowledge development in nursing (Jones, 1996).
12. The profession of nursing does not have a complete understanding of the phenomenon of having a child with a disability.

In addition, assumptions of phenomenological research are based on Munhall (1994, p. 10) include:

1. The subjective experience of the individual, or group, is valued and described. Meaning comes from the source and is not presumed, assumed or assigned.

2. Individuals are viewed within an open perspective as active agents, interpreting their own experiences and creating themselves by their inner existential choices.

3. Individuals and specific groups of individuals have varying histories, varying "here and nows," and varying perceptions of the "future."

4. The world and its people are constantly changing and evolving; this assumes a dynamic reality.

A potential bias regarding this research stems from my personal experience and readings on the selected phenomenon. Mothers are the primary caretakers, in most instances, for their children who are disabled (Marji & Upshur, 1989; Read, 1991). In addition, the mother has the greatest responsibility regarding the many physical and emotional demands in caring for the child with a disability. Her multiple roles create heightened stress. Another bias stems from my interactions with the health care team; this team does not interact and communicate adequately with me, the mother, nor have sufficient knowledge in dealing with the mother of a child with a disability. The assumptions and biases acknowledged helped me to attempt to look at this experience and understand this phenomenon for the first time, from the mother's perspective and my
own. Methods used in my research to reduce bias are addressed in Chapter III of this dissertation.

Hermeneutic phenomenology provides a scholarly nursing tradition, associated with the best possible account of the text presented. In addition, this mode of inquiry offers freedom to explore the richness of an experience. An independent, three-credit study has been completed to further this researcher’s knowledge base on the process of phenomenological interviewing and interpretation. Five women were interviewed on their feminist perspective to strengthen this researcher’s knowledge on feminism. All interviews were tape-recorded and transcribed by a professional transcriptionist. Hermeneutic interpretation was the methodology used for data analysis. This study was conducted with an expert nurse phenomenological researcher who guided the inquiry. This independent study greatly enhanced this researcher’s knowledge base on feminism and the hermeneutic methodology.

Qualitative Research Method: Interpretative Phenomenology

Interpretative phenomenology is the chosen method for this research, which will illustrate the personal meaning and interpretation of the mother’s lived experience of having a child with a disability (Benner, 1994). Through the participant’s own self-interpretation, vivid and rich descriptions of the phenomenon have been revealed for a better understanding and appreciation. This self-interpretation is influenced by the world of the participant including valuable and significant circumstances in these lives, but qualitatively different concerns based upon culture, language and individual situations (Leonard, 1994).
Interpretative phenomenology (Benner, 1994) enhances a further understanding of a phenomenon through a science of interpretation. The methodology of interpretation can unveil otherwise concealed meanings of a phenomenon, to attempt to make clear an object of study (Allen & Jensen, 1990). Thorough contextual considerations and wholeness are philosophical conditions for this methodology. Benner (1994) uses the term world in her methodology as; a meaningful set of relationships, practices and language that we have by virtue of being born into a culture. It is my thought that the present world of the mother is expanded as she steps into the uncertain and unfamiliar world of having a child who is disabled. Through interpretative phenomenology, the researcher may enter the mother’s world; one can realize what is valued and significant to that particular mother, therefore enhancing nursing knowledge and practice.

Understanding a person’s experience may guide nurses to better interact with the mother in ways that may differ from people who lack that understanding generated by research (Cohen, 2000). Phenomenological research allows the reader to step into the world of another, to “feel” like coming home to oneself, or knowing the home of another in everyday life (Munhall, 1994).

This research will strive to bring language to perceptions of a human experience to a fuller and richer understanding (Streubert & Carpenter, 1995). Phenomenology will further clarify and give meaning to the phenomenon of having a child with a disability. The research question is best suited for a qualitative methodology, and addresses the existing lack of qualitative nursing literature on this topic.

Philosophical Underpinnings of this Study

The nurse-patient relationship is a dynamic, evolving and transforming partnership grounded in trust and truth (Roy & Jones, 1999). Nurses recognize the uniqueness of each individual synthesizing the dimensions of biophysical, cultural and spiritual beings. The human-to-human relationship, the knowing of the person with respect and acceptance, is the focus of the nursing profession. Dependent upon where a person is in their process of health and wellness, the nurse accepts and incorporates the person’s reality, which facilitates and guides the personal transformation (Roy & Jones, 1999). Through this process, nurses are able to help people make healthy choices that are applicable to their individual status, their self-determination. This process of knowing results in actions that guide patients and groups in making choices and decisions that promote personal growth (Roy & Jones, 1999).

The method of phenomenology discovers what is intangible to measure through quantitative research. Phenomenology captures the complexity and beauty of the nurse
and patient interaction of the everyday lived experiences. Through this discovery, nurses may be able to further describe in language the dynamic and valued interaction that occurs between nurse and patient. This emphasis on the patient expression and personal interpretation of the nurse-patient experience is referred to in this study as the art of nursing. This caring and focus on personal well being of the patient can offer choices and promote self-awareness.

Through a feminist perspective, nurses can continue on the quest of explicating meaning and self-discovery of the phenomenon with consideration and attention to gender and societal expectations of the maternal role. A woman’s expectations within our society emerge from the societal, political, and economic structure of society (Anderson, 1983; Harding, 1987; Millman & Kanter, 1987). The social institutions of motherhood and family lend to the environment of the inequitable position of women in our society. A feminist approach has acknowledged the distribution of power within the context of the family unit and the frequent interaction of the mother with the patriarchal medical system. The philosophical basis for this research has been an understanding of this unequal distribution of power, and the oppression of women, as mothers take on the commitment of caring for the child with a disability.

In some cases, the mother is forced to give up her present employment to care for the child with a disability (10 of 12 mothers in this research have given up employment). Unfortunately, this lack of employment is de-valued in our society. Women usually have less authority, diminished recognition and reward for the work that is accomplished within the private arena of the home. The home is a private realm; the mother is insulated
from wealth, power and prestige (Feminist Ethics, “n. d.”). And yet the dichotomy exists, caring for children is considered by some to give meaning and self-validation for the female within the family and marriage; she is the indispensable backbone of these social institutions (Feminist Ethics, “n.d.”; Sampselle, 1990).

In our society, the meaning of mothers’ lives is intimately connected with the lives of their children (Lauterbach, 1993). The gender-biased expectation, of woman as care provider, is demonstrated in the unequal responsibility mothers think they have for their children’s success and well-being (Sampselle, 1990). Childcare is socially defined as “women’s work”, associated with the feminine characteristics of caring, kindness, nurturing, empathy, compassion, self-sacrifice and compassion (Feminist Ethics, “n.d.”). The normal complex maternal expectations are emphasized by the additional physical and emotional responsibilities that present with caring for the child with a disability. This responsibility is stressful, accentuated by the increasing number of mothers that work outside the home. In addition, child-centered families draw attention away from the experience of the mother by concentrating primarily on that of the child, especially when the child has a disability with multiple needs (Anderson, 1983).

Women are taught to live for and sacrifice for others, no matter what the cost may be. Does this self-deprivation effectively perpetuate the woman’s second-class status? Women care, almost caring too much, to the point of imperiling their own identity, integrity or survival (Feminist Ethics, “n.d.”).

A feminist methodology looks closely at the contextual factors associated with having a child with a disability, specifically related to the mother. With much research
exemplifying a “single society”, with respect to men dominating as the researchers and researched, proper consideration is not given to the different social worlds men and women inhabit (Harding, 1987). The proposed research will explore the mother’s world of having a child with a disability; this is research by women and about women. Historians through research and literature have ignored the stress, strains and struggles of the private world of the mother and child (Feminist Ethics, “n.d.”). This research has explored only the mother’s perspective, to assure single society generalizations, or male generalizations, are not made of the mother’s experience.

A feminist methodology is necessary to understand social and gender expectations previously overlooked in this population. Because nurses so often provide care to women at critical developmental points, it is important that the practice of nursing reflect the principals of feminism (Sampselle, 1990). Furthermore, to analyze the condition and expectations of women’s lives, to understand the causes and consequences of oppression, this understanding will ultimately improve the quality of their lives (Harding, 1987). The primary aim should be to make the world a better place for women, in particular and perhaps also for other vulnerable people like children, the disabled, the elderly, and the infirm (Feminist Ethics, “n.d.”).

Relevance to Nursing

Nursing practice is guided by a holistic approach. This approach is what differentiates nursing from other related health fields. Phenomenology embraces the whole of the human condition, emphasizing holistic, empathetic, individual delivery of care (Munhall, 1994). Phenomenology is an exemplary research methodology for nursing
practice, by expanding the knowledge base of the lived experience of the patient and their families.

There are multiple times of need and interventions for the mother, given the ongoing nature of medical problems and crisis issues of the child with a disability. A variety of nurses may come into contact with the mother of a child with a disability in a multitude of settings. Maternal-child nursing will benefit from further knowledge development with understanding this phenomenon. In the maternal-child context, Van Riper, Pridham, and Ryff (1992) researched the concept of symbolic interactionism, the process of interaction between health care providers and the mother as the disability diagnosis is revealed. The underlying premise of the perspective of symbolic interactionism is that the subjective aspects of a situation must be explored because the meanings people assign to situations ultimately organize their behavior (Van Riper, Pridham & Ryff, 1992). This initial interaction can set the tone for the mother’s interpretation of the diagnosis, ultimately transcending into the future interpretation and well being of the mother and child. Nurses need to look beyond the outward behavior of family members and explore what feelings and perceptions are directing the behavior (Van Riper, Pridham & Ryff, 1992). The mother’s view of the phenomenon is important in aiding maternal-child nursing professionals to exercise sensitivity with this initial interaction, and to assess the need for appropriate interventions that will promote a positive impact upon the adaptation of the mother. These interventions need to be integrated into current maternal-child curriculum, consequently to have the curriculum reflect current nursing research.
Community health nurses are in a prime position to reach out and communicate with mothers during community based post-natal and or future medical or surgical visits. These nurses can reach those mothers that have shut themselves in, retreating from a society that does not understand the pain and turmoil of the initial period following the diagnosis of having a child with a disability. The pediatric nurse practitioner may be capable through this understanding, to support the mothers with health care related decisions, and to continue to assess the functioning and coping of the mother. The multiple specialties of professional nursing and nursing education can benefit greatly and advance nursing knowledge with the dissemination of this nursing research.

Summary

This chapter has made the argument for the research investigating the nature and understanding of the phenomenon of having a child with a disability, from the mother’s perspective. Nursing has recognized having a child with a disability through quantitative literature, but qualitative research on this topic is limited. Consequently, this qualitative study has provided special insight for professionals, by describing what life is truly like for the mother of a child with a disability. Likewise, a feminist perspective added to this insight, exploring and interpreting socially influenced gender roles and how they relate and influence this phenomenon. The knowledge and understanding gained through this research has strengthened nursing knowledge, adding to the body of nursing science and providing insight for potential nursing interventions for the mother.
CHAPTER II

Evolution of the Study

The purpose of this research has been to explore and interpret the nature of having a child with a disability from the mother's unique perspective. To lend further meaning and depth to this research, Chapter II describes the historical perspective of treatment of individuals with disabilities from Neolithic tribes to the 21st century. A brief review of the literature was undertaken to set the context of the current research and non-fiction literature currently available about mothers caring for children with disabilities. The second half of this chapter is devoted to the story of my personal experience on having a child with a disability.

When considering a qualitative study on the disabled, it is necessary to retrace the historical context of people with disabilities, and how they and their families have been dealt with or regarded through time. To examine a disability through time, one must consider humankind's spiritual and functional need for "wholeness" (Prosthetic History Page, "n.d."). Yet, at the most fundamental level, society deals differently with these individuals that are different or standing out from the norm, an outsider. They are different, less than perfect in some way from the general population. Discrimination against people with a disability is rooted deep within the beliefs and respective values of the culture. The cultural values held by the general population are often based on the perception of any form of "imputed deviancy," including disability, as a sign of marginal status (Livneh, 1982). This devalued, deviant status is a negative role imposed on the stigmatized person, and views the sources of this deviancy as stemming from physical,
behavioral, and attributional-based characteristics (Livneh, 1982). This other person, the
disabled person, is viewed as a problem to organized society. In past times, to avoid this
unpleasant problem, society preferred that these individuals be managed by experts such
as politicians, witch doctors, physicians and psychiatrists (Woodhill, “n.d.”).

History of Disabilities

From ancient times, individuals with disabilities were considered outcasts and not
supported by the general society because of their inability to fight in battle and work for
the benefit of the group. Consequently, they could not contribute fully to the welfare of
the group, resulting in rejection, being ostracized, and being left to die (Jablow, 1992). It
was generally believed that the disabled should not and could not work or otherwise be
productive. Individuals in most Western countries are judged on the basis of their ability
to be socially and economically competitive (Livneh, 1982). Without proper education or
training, the disabled were not highly productive for the good of the society; therefore,
they were devalued.

Another postulated belief stems from the notion that evil spirits, or a supernatural
agency, was the cause of a disability: incurring societal avoidance. Neolithic tribes
perceived people with disabilities as possessed by evil spirits; therefore, escape routes
were fashioned by drilling holes in the skulls of people thought to be possessed
(Mackelprang & Salsgiver, 1996).

One of the earliest records of disabled individuals, from approximately 3500-
1800 BC, originates from the utilization of a prosthesis during battle. Discovered through
a poem, the Warrior Queen Vishpla, (3500 BC) lost her leg in battle and was fitted for a
prosthesis to return to battle without evidence of the injury (Prosthetic History Page, “n.d.”). Prostheses were developed for function, cosmetic appearance, and a psychospiritual sense of wholeness. Evidence of prosthetic appliances from this time period has been found in play scripts and actual archeological examples of prostheses. Within a similar time frame, amputation was a judicial punishment in Peru. Striking examples of this punishment were as follows: theft was treated by amputation of the right hand, a foot was removed for laziness, and both arms were amputated for rebellion (Prosthetic History Page, “n.d.”).

Aristotle in 353 BC believed and taught to his scholars that deaf individuals were senseless and incapable of any reasoning. Plato, to whom Western culture owes much of its ethical framework, viewed people with disabilities as standing in the way of a perfect world (Mackelprang & Salsgiver, 1996). To perpetuate this perfect world, people with disabilities would be placed in an unknown place, isolated, and left to die. Continuing through time, the Spartans left disabled newborn children to die of exposure, while the Romans would publicly have parents drown the infant after a gathering of authorities determined that the infant was not fit to live (Disabled, 2000).

During the Middle Ages, from approximately 400 to 1400 AD, people ridiculed disabled people and regarded them with suspicion. Witchcraft was rampant in Europe, the mentally retarded were thought to be witches and were tortured, burned, killed or imprisoned (Jablow, 1992). It is evident through examination of bone structures, that nobles used individuals with disabilities, in particular Down syndrome, for court jesters.
A person with a disability, or disabled was not considered a productive member of the community, which often resulted in a life of begging.

Disabilities were considered a sign of imperfection; consequently, the Church frequently denied religious rites to this population, guaranteeing they would never go to heaven and everlasting-life (Orientation to Rehabilitation, 2000). Judeo-Christian tradition, prevalent among Europeans during and after the middle ages, taught that people with disabilities were expressions of God's displeasure (Mackelprang & Salsgiver, 1996). The Hebrew religious beliefs considered the disabled as sinners, possessed by evil spirits and ostracized.

Amputations, another example of a disability, during the Middle Ages were the result of battle or gangrene due to archaic medical and surgical practices. A prosthesis was more cosmetic than functional, and basically used as an extension of the armor to prevent disgrace.

During the 1600's The Art of Signs was published by G. Bonifacio, which opened-up communication and recognition as to the intellectual capabilities of the deaf. Another disability example from the time period of 1799, takes place in Bethlehem Hospital, the London mental asylum, which has often been quoted as early documented evidence of autism (Firth, 1989). This case study from the London mental asylum describes a boy who never engaged in play with other children or became attached to them, but played in an absorbed, isolated way with toy soldiers. This is an accurate description of a characteristic behavior of autism.
In Europe by the 1800’s, there was an attempt to understand and explain congenital diseases and mental conditions. In 1866, Dr. J. Langdon Down, an English physician, was the first to systematically describe the congenital disease known as Down syndrome (Jablow, 1992). Although there was some scientific explanatory basis for mental retardation, pity remained the general attitude toward the disabled. Shame and disgrace prevailed with the disabled; therefore, families hid them at home or moved these family members to institutions (Disabled, 2000). In the United States, institutions where established to deal with the threat and nuisance of people with disabilities. Institutions in the 1800’s increased dramatically, and these individuals were increasingly isolated and institutionalized, sometimes in sub-human conditions (Mackelprang & Salsgiver, 1996). One positive perspective during this time for the disabled was the advent of Braille. It was invented in 1829 for the blind to communicate, exposing the full mental and intellectual capacity of the blind (Significant Dates in Disability History, “n.d.”).

The course of history brought about two World Wars in the 20th century, where a large portion of battle victims survived due to advanced treatments and antibiotics, but the battle scars of disabilities were blatantly visible to the public. United States Federal legislation prompted the 1918 Soldier’s Rehabilitation Act to provide vocational training for veterans with physical impairments that identified limited career choices (Orientation to Rehabilitation, “n.d.”).

While physical disabilities were discernible, mental disabilities or “feeblemindedness,” referring to the mentally retarded, or those with mental illness, were dealt with in a different manner in the United States. These individuals were placed in
institutions on large campuses in rural areas far away from populated areas. Treatments of mental disabilities within these institutions were activity-based. The inmates (Orientation to Rehabilitation, "n.d.") worked in the area of farming, dairies, metal and wood shops, in addition to remaining part of the day-to-day functioning of the institution. In the beginning of the 20th century, England’s Winston Churchill toyed with Darwinism by suggesting that the mentally retarded should be forcibly sterilized to prevent the replication of the feeble-minded (Jablow, 1992).

In the United States, during the 1950’s, several noteworthy politicians and famous writers’ disclosed their personal stories of immediate family members with disabilities. Pearl S. Buck, the Nobel Prize winning author, wrote the eloquent personal story about her first child, who was diagnosed with mental retardation, The Child that Never Grew, first published in 1950. Buck’s inspiring account of her struggle to understand and help her daughter with mental retardation was perhaps the first disclosure of its kind by a nationally public figure. Within the same time period, President Franklin Delano Roosevelt remained in public office despite the diagnosis of polio, and his confinement to a wheelchair. This highly visible position, the presidency, promoted exemption from the dependent social role, and the devalued social identity typically imposed on people with disabilities (Longmore, 1987). A new image, rejecting the disability related incompetence, began to emerge. Another milestone in the history of disabilities was the Massachusetts Kennedy family’s revelation of a mentally retarded daughter, Rosemary Kennedy (Jablow, 1992). Through this disclosure, President John F. Kennedy, her brother
used his power and presidential leadership to start the movement and guide congressional legislation to improve the lives of the mentally retarded.

In the past 20 years, legislation within the United States has been passed to create more equitable educational, living, and work environments to enhance the productive lives of individuals with disabilities. Public law No. 101-336, the Americans with Disabilities Act passed in July of 1990, is considered the landmark “bill of rights” for those with disabilities. This bill was spearheaded by Senator Robert Dole, himself a disabled veteran of World War II. This act mandates all states give equal access to employment, state and local government services, transportation, public accommodations, services provided by private entities and telecommunications for people with disabilities (Binstock, 1997).

To supplement and specifically apply to the area of educational needs, another piece of legislation exists: the Individuals with Disabilities Education Act (IDEA) 1975 Public Law 94-142 (Binstock, 1997). This act provides the child with a disability with a free, appropriate education within the least restrictive environment possible for the child. Within the language of this legislation, “free education” means at no cost within a public school. If the town’s public school cannot fulfill the child’s educational needs, then it is the responsibility of the school district to send the child to another district where the need can be met. The term “appropriate” is defined in the act in the following way: the needs of a student must be beneficial and decided upon by the family and student. Last, the “least restrictive environment” is defined as disabled students mainstreamed within a regular classroom setting as much as possible with nondisabled students. The least
restrictive environment should be implemented and practiced within any public school system in the United States. Additional information on this educational process is available from the respective school district or the state advocacy network. The acts discussed attempt to ensure an adequate work and educational environment for those children and adults with a disability as we begin the 21st century.

Review of the Literature

A brief review of the literature will be presented to set the context of the current literature on the mother's perspective of having a child who is disabled. Special attention was undertaken within the qualitative literature during the past 15 years to investigate the major topics, and identify missing issues to provide support for this research. It was found that the majority of quantitative literature focused upon segmented, or partial, aspects of raising children with disabilities such as; single mother's perceptions of raising disabled children, the personal impact of these children on the mother and available support services. What continues to be deficient is to understand or obtain an appreciation of the entire experience for the mother. Much of the current literature has shifted focus to the positive adaptation strategies and creative coping, mechanisms which families employ caring for children with a disability. This research has augmented the nursing research base by exploring in its entirety, the experience of having a child with a disability, thus creating an overall representation of the phenomenon.

A specific family structure that has been researched is single-parent and low-income families of children with disabilities. Gabor and Farnham (1996) conducted five, semi-structured interviews of single parent, low-income mothers. Common themes
identified were: stress related to the additional mothering roles, emotional stress related to the diagnosis, the continued chronic stress, fragmented support systems and communication issues. The single mothers in actuality described the child with a disability as a challenge, a personal continued persistence and patience, maintaining a positive attitude, having faith, having patience and continued inner-strength. Validity of this research was enhanced through another expert researcher reviewing the data. Limitations of this research existed with performance of only one interview and the limited generalizability considering a population of single parent, low-income mothers. Ogen, Van Eyk, Armstrong, and Witt (1998) interviewed three mothers on two separate occasions to explore the perspectives on rearing a child with multiple disabilities over time. With a limited sample size, a theme identified was communication with health care providers as problematic. Little or no diagnosis information was provided to the mothers along with minimal consideration for dilemmas with medical insurance. Care of the child was perceived by the single mothers as stressful due to schedules, medications, multiple appointments and careers placed on hold to accommodate the care of the child.

A qualitative study from the United Kingdom by Read (1991) revealed two main themes from mothers interviewed: the impact on the mother of caring for a child with a disability, and fragmented support services, which add to the mother’s workload and stress. Descriptions from the mothers focused upon the apprehension and isolation from the normal society. A term that was described by the mothers is the feeling of being a “world apart” from other parents of ordinary developing children. Stress is compounded by the child’s long-term dependence, financial considerations and the predicament that
mothers usually cannot work outside the home due to the physical care and necessary appointments for the child with a disability. Despite the hardships, a practical down-to-earth approach is assumed to “just get on with life”. The second theme, outside services, the mothers communicated a feeling of powerlessness with professional encounters. They felt their opinions were neither valued nor respected with professionals with the overall decisions for their children. Although the number of mothers participating was not mentioned, that research revealed ample data on the phenomenon of having a child with a disability.

Van Riper and Selder (1989) examined through a qualitative descriptive format the parental responses (n=16) to the birth of a child with Down syndrome. The Life Transition Theory was used as the theoretical basis for this study. A transition is a passage that follows a critical event that is disrupting to an existing reality (VanRiper & Selder, 1989). Concepts identified through distinct parental conversations were; uncertainty, becoming aware, becoming certain, and the consequences related to parenting a child with Down syndrome. The strength associated with this research was the abundant data in conjunction with the application of the Life Transition Theory.

Crowe, Van Leit, Bergmans, and Mann (1997) investigated 135 mothers with children age’s 6 months to 5 years-of-age to examine the additional role demands involved with the care of a child who is disabled. The design employed was a Newman-Keuls multiple comparisons to compare all groups as equals within this study. Mothers with disabled children (n= 90) assumed fewer occupational roles, such as student and worker, as compared with those mothers (n=45) of typically developing children. Fewer
roles were attributed to the complex and time consuming responsibilities involved in caring for a child with a disability. The validity of the role checklist was in question; none of the participants identified themselves as a caregiver, or family member, within the essential selection criteria of the instrument. This omission raised concern as to the participant's comprehension of the instrument.

A quantitative study by Damrosch and Perry (1989) found that mothers and fathers of children with Down syndrome experience distinct differences in adjustment and coping. A majority of mothers (68%) reported higher levels of chronic sorrow in a "peaks-and-valleys" pattern of adjustment, while fathers (83%) described a continual slow increase in their adjustment pattern. The mother provides most of the physical and psychological care of the child with a disability, thus increasing her stress. In addition, the mother reported the focus of the blame of the child with a disability upon herself, when compared with the father. Although a limited sample size (n=40), the research disclosed the difference mothers and fathers have in their perception and interpretation of their child's disability. This research has the potential to guide interventions that are individualized within the family.

Byrne and Cunningham (1985) and Beresford (1994) completed two lengthy and extensive reviews of the literature on how parents cope with the care of the child with a disability. Byrne and Cunningham in 1985, reviewed three different conceptual categories of literature: stress and mediating factors, family practical and material needs and coping and available resources. There was no difference in stress levels among one and two-parent families, parental age, socio-economic status and family size. However,
higher levels of stress have been identified at certain time periods within these families; the initial diagnosis of the disability, when siblings surpass the ability of the mentally handicapped child, puberty, school placement, and housing arrangements to name a few (Byrne & Cunningham, 1985). Services for families of children with disabilities are perceived by parents to be fragmented, impersonal, slow, cumbersome and insensitive.

The final concept within the article of Byrne and Cunningham’s (1985) is the exploration of coping and available resources. A highly supportive network, family, extended family and friends were identified as potential factors for supportive relationships and coping. The conclusion and strength of the Byrne and Cunningham concept analysis advises for a complex and multivariate standpoint for future research, due to the lack of consensus about what problems and needs are most important to these families.

Beresford (1994) conducted the second extensive literature review on how parents cope with the care of a child who is disabled. This review focused upon a body of research to explore the multiple, creative ways families deal with the stress of having a child with a disability using the key concepts Richard Lazarus’ model of stress and coping to guide the synthesis of the literature. The focus of current research is the creative methods families use to cope with this stressful life situation of the child with a disability. A matter-of-fact approach is assumed by most families in order to “just get on with life” to “normalize” life as much as possible. The process model of stress and coping was a strength and usefully operationalized to inform intervention practices with families caring for a child with a disability (Beresford, 1994).
Research emphasis on families with children who are disabled has shifted focus from family distress to the positive adaptation that takes place across life cycles. A qualitative study using a time sample design examined the positive adaptation of 12 families (Bennett, DeLuca & Allen, 1996). Three family support domains were looked at; the role of friends and family, parent groups and professionals. The data revealed that the support of family and friends to just “be there”, acceptance of the child to “take him as he/she is”, was perceived as important in the adaptation process. Parental sharing in support groups was also deemed as an outlet for parents to share emotions, empathy, and a source of current information. Recommendations identified from this study is that health care professionals need to truly listen and encourage parents to take a proactive role in medical decisions for their child, and mobilize their own resources, which leads to empowerment. Limitations of this research existed in the format of the interviews; two research assistants conducted the interviews, five parents were interviewed twice and seven were interviewed once, the order and phrasing of questions varied with each interview lending to a great deal of variability with conduction of the interviews.

Beresford (1996) conducted a longitudinal design study of 20 families caring for a severely disabled child, to identify how parents creatively cope with this long-term care situation. Parents were able to cope by having strategies that actually dealt with the stress such as problem-solving, information seeking, taking control in health care decisions, and planning for vacations and outings. The parents’ approach to life included taking one day at a time, not dwelling on difficulties, and acceptance of the disability and limitations of the child. This unique longitudinal study expanded research a step further by focusing on
the ways parents cope with the stresses and strains of caring for a child with a disability. Once again, a strength of this study was the process model of stress and coping used as a framework to guide this research. This model emphasizes and gives clarity to the importance of coping strategies, and coping resources in mediating the adverse effects of stress (Beresford, 1996).

Two theories were identified in the literature as methodologies for positive parental coping and as a conceptual basis for nursing interventions for parents with a child with a disability. Eakes, Burke, and Hainsworth (1998) presented a middle range nursing theory of chronic sorrow in which the loss of the “perfect” child produced intermittent feelings of sorrow. Chronic sorrow is defined as the ongoing feelings of loss and disparity a parent possesses for years when events occur which remind or present a comparison of the disabled child to a normal child. It is not the nature of the loss as previous thought; it is the disparity that is created by the loss experience that initiates the chronic sorrow. It is recommended that nurses view chronic sorrow as a normal response to loss, and when it is triggered, provide support by fostering positive coping strategies and assuming roles that increase comfort (Eakes, Burke, & Hainsworth, 1998). This theory is useful for analyzing individual responses of people experiencing an ongoing disparity in a multitude of nursing situations. Deatrick, Walsh, and Knafl (1988) explored through qualitative semi-structured interviews of 12 parents of children with osteogenesis imperfecta, the process of normalization. This is an attempt to maintain a normalized existence in the face of the debilitating disease. A sense of control was evident, an active and deliberate management in the situation of providing normalcy, to pay attention to
those matters and situations in which the child was able to participate as a "normal child". Additional research is needed to clarify how families with a child who is disabled achieves or fails to achieve a normalized existence. Normalization and chronic sorrow are two reactions identified within the literature wherein parents vent emotionally, about the psychological challenges of having a child with a disability.

Lastly, Van Riper, Pridham, and Ryff (1992) used the theoretical framework of symbolic interactionism (Stryker & Statham, 1985) through a qualitative methodology exploring how parents were informed by clinicians, the diagnosis of Down syndrome in their newborn. With the unexpected diagnosis of a child with a disability, incongruence exists between the expected mental image of a "perfect" baby, and the reality of the situation. Initial interactions with clinicians may positively influence how parents respond to the diagnosis; and how parents define this situation. Therefore, nurses are in a key position to set the tone and affect the quality of the initial and subsequent interactions, coping and ultimately the self-confidence of the parents. A strength of the study of Van Riper, Pridham, and Ryff (1992) is the secure interventions applicable for these families through the guidance of symbolic interactionism and this research.

Synthesis of the Literature

This literature review has provided insight into the existing context and state of the quantitative and qualitative research literature on the phenomenon of having a child with a disability from the mother's perspective. Qualitative and quantitative studies have addressed in part, the major hurdles and concepts with the care for a child with disabilities such as coping, single-parent family structure, multiple role demands, sorrow
and stress that transpires with having this child. Yet, the research has shifted focus from the negative physical and psychological effects of having this child, to the many positive rewards, challenges and coping patterns that result from this unique experience.

However, what remains lacking within the literature is a holistic view of this ongoing long-term phenomenon, “to know” the whole story and the daily challenges for the mother. This phenomenon has not been studied from a holistic perspective. In addition to this deficiency, at this time in the published literature, only one other mother who is also a researcher with this experience has explored the phenomenon in qualitative format. This research method can only facilitate the epistemology of insiderness, supporting a feminist methodology to contribute to the body of nursing knowledge. As stated by a mother interviewed in a research study conducted in the United Kingdom, “we are ordinary people coping with extra pressures, extra illness, extra work….sometimes you need a secretary just to keep track of the appointments” (Read, 1991, p.561). It is unconditionally necessary for nursing to have an appreciation of the lifeworld of the mother with a child with a disability to enhance nursing assessment, intervention and practice. The appreciation of this phenomenon is captured with this research.

Feminist Perspective

A feminist perspective has been used in the published literature specific to mothers with disabled children, only one published research study was found (Landsman, 1998). My research supports Landsman’s (1998) study; thus, contributing to this unique research topic of mothers caring for children with a disability. This perspective added
depth and a lens for the interpretation of this research, that of mothers with children with a disability. Motherhood is a socially and culturally influenced institution that has immense influence on the multiple assumed mothering and female roles. Mothers are socially associated with caring and overall family well being, creating role overload and strain. Additionally, within the disability literature, mothers caring for children with a disability have extensive compounded roles in addition to routine mothering roles; the additional roles of physical therapist, speech therapist or occupational therapist, that are integrated into an already complex schedule. This feminist perspective lends itself for an intersection, to examine the challenged experience with the multiple and complex roles the mother assumes of having a disabled child, in addition to acknowledging the role of motherhood.

The feminist literature on this research perspective has influenced the research methodology and provides avenues for enhanced interpretation and therefore meaning. An egalitarian focus, through this researcher's personal experience, has strengthened the insiderness lending for this powerful story from the mother. Through this intersubjective construction of meaning, this phenomenon is made public for nursing and health care providers to have a better sense of this experience. This research provides a new dimension of understanding to the complex world and multiple roles of the mother.

Experiential Context

In shifting to a personal account, I would like to present a personal timeline of meaningful events, as children with disabilities have touched several aspects of my life prior to the birth of my son with a disability. My recollections of interactions with, and
recognition of, children with disabilities began in my childhood. In the mid-1960’s, when I was a grammar school student, my older sister was assigned to help a girl in her class who was legally blind. This student was part of our student population at the local grammar school. It is my recollection that most children treated this blind child with respect, and as just one of the other children. Another inclusive situation within the community took place with a young girl who had a learning disability. Even though she was disabled, she attended and actively participated with the local Girl Scout troop. She was included in all programs, trips, and camping expeditions. This was uncommon for that time period, since most children with a disability were either institutionalized for life or segregated from the school and routine social settings. At times, as I was growing up, children or adults with disabilities made me slightly uncomfortable, I felt sorry for them and their disabilities.

As an adult woman and a nurse, my first encounter of an interaction between a mother and a child with a disability was during a graduate clinical rotation in a cardiac surgical unit. The mother was intensely concerned about the progress of her child, who was the patient, and the love that emanated from her for this child was profound and touching. The child had Down syndrome, with a congenital heart abnormality that necessitated surgery to repair defects within the chambers of the heart. This stands out in my mind vividly, because I had just learned that I was pregnant with my first child. Of course, apprehensive thoughts run through one’s mind at this time, such as, “Will my child be healthy?”
Naturally, as a pregnant woman, and a nurse, my thoughts focused upon how this mother felt about having this child. How did she manage to care for a child with a disability? How did she deal with the public, family, friends, and complications?

My sister-in-law has an adult brother with Down syndrome, who is frequently present at family functions. He is a very likeable individual with specific likes and dislikes, just as any one of us. I have had conversations with his mother regarding the time period following his diagnosis. She has shared that the physician had recommended institutionalization for her son. Remarkably, considering the time period of the 1950’s, and society’s thoughts on children with disabilities, the mother had an extraordinary and positive attitude toward bringing this child home to live to his full potential in a loving family structure. The mother’s philosophy was that this was a situation dealt to the family, and the family would certainly make the best of it. The adult children of this family have conveyed the same philosophy, maybe transcending from the mother, this philosophy seems to be: there is no use in deliberating over the situation (just a matter of fact philosophy- get on with life and live it to the fullest). However, this family was unusual in their approach for this time frame.

Personal Perspective

Having a child with a disability is a personal phenomenon I experienced with the birth of my second son. At this time, I had a family with a stepson age 18, a healthy son age 3 and a successful nursing career as a clinical specialist within my community hospital. Having a child with a disability was a shattered illusion; the perfect child one expects and hopes to have is not there. I felt that no one knew the depth of my pain,
making this a very lonely and isolating experience. Many of my friends and family tried to comfort me, which was appreciated, but at that point I just couldn’t accept my newborn child’s disability, and I was not ready to resolve the loss. Likewise, the pediatrician meant well by stating what a beautiful child he could be, but nothing at that point could ease my pain and fears.

Multiple feelings emerged. I felt guilty for my potential contribution of the chromosomal abnormality resulting in Down syndrome. I had placed my career and further education first, before having children, and gave birth to my son at the age of 34. Present statistics support that in 70% of cases of Down syndrome, the mother’s egg causes the inappropriate replication of the trisomy that exists on the 21st chromosome (Dr. Kusman Mohan, personal communication, February 1991). Guilt was a prevalent feeling with the amount of time and overwhelming responsibilities necessary to give this child with a disability, and the lack of attention to my other 3-year-old son; he felt left out and rightfully demanded my attention.

The people with whom I felt comfortable were my sister and the social worker from the local early-intervention center. My sister would just listen and “be there” for me. The social worker knew what to say at the right time, with hopeful encouragement that my son would accomplish all of the normal childhood milestones, just a little later. I unequivocally remember her saying that he would play Little League baseball with the other children in the neighborhood. This small compassionate statement gave me encouragement and hope at time of intense uncertainty.
Living with, and caring for a child with a disability, I felt that I must quickly develop survival skills to learn to live with the unknown. One of the firsts of many unknowns was the process of evaluating my son for the potential of cardiac surgery, within the first six months of his life. A large hole existed between the ventricular chambers of his heart. The physicians were attempting first to take a medical approach to allow time for the hole to close without surgical intervention. Another frightening tension was trying to have this frail infant gain weight for potential cardiac surgery. It appeared like a definite situation as time went on, the medical interventions with cardiac medications was not successful with the closure of the ventricular hole. I was breastfeeding at the time, which put the psychological and physical burden of weight gain upon me. There was the additional difficulty of an infant with Down syndrome who had low muscular facial tone and therefore poor sucking and feeding abilities. I continued breast-feeding to “pass on” the immunological factors present within breast milk. I felt a maternal obligation to do this for my child facing potential upcoming major cardiac surgery; it was the least I could do. The uncertainty, the stress, the fright and the constant medical appointments were a physical and emotional drain, despite my nursing background.

My child's impending cardiac surgery and my planning for his uncertain future inevitably led to anxious feelings. There was personal resentment about the great time commitment, not only of dealing with a new infant, but the countless overwhelming responsibilities that accompany a child with a disability. With all of these emotions flowing, I sought refuge by social isolation from everyone but my immediate family. I
was hesitant to bring my baby to work for fear that others would ask questions that I emotionally would not be able to handle. There was a constant feeling of loss of control, and resentment of these new complex demands.

Dealing with the health care team was yet another difficult, time consuming and emotional process. The multiple, lengthy medical appointments were brimming with insensitive individuals who failed to acknowledge my pain. My life was now planned by the next physician’s appointment, or physical therapy appointment, or blood work appointment. I remember bringing my son for blood work at a medical center at the age of 5 weeks. The technicians were having a very hard time drawing his blood. He was screaming constantly; it was mental torture. I felt such strong guilt and vulnerability at this particular time because of the diagnosis of Down syndrome, and the loss I was experiencing. I just sobbed in the lab, so much that I had all of the technicians crying, because I repeatedly stated, “Mommy is so sorry.”

The uncertain future health of the child with a disability produces long-term medical needs and interventions. This is a financial strain and worry for my spouse and myself because of the uncertain future health of our child. I had multiple folders for different physicians and therapists, as well as checklists to keep accurate records of payments from the insurance company. Compassionate physicians did exist. For us, our pediatrician had the philosophy that a family with a chronically ill child has multiple financial burdens with which to contend. Our pediatrician only accepted insurance payment for services for my son, regardless of the circumstances. I have never paid her additional monies for his medical care over the past 11 years.
Once the cardiac surgery was past, my son started gaining weight and progressing through small developmental milestones. I realized that the Down syndrome was not going away, and I had to learn to live with his disability and limitations. I slowly began to cope with this situation, to integrate a new lifestyle on the road to acceptance. There is no simple way to get to this point of acceptance, for me it was a long, hard period of grieving for the child I had expected, and lost. It was a process of searching for ways to make life bearable; making sense, and coming to terms with the disability.

At times, sorrow continues to resurface in varying levels of intensity for me; this is referred to in nursing and psychological research as “chronic sorrow.” Chronic sorrow occurs when a comparative situation arises wherein the developmental delays, or the decreased intellectual capabilities, are evident in the child with a disability when compared with a child who is not disabled. These events bring a striking reality to the situation.

Yet this phenomenon is a dichotomy. It is living in extreme terms. Once the initial lows of stress, grieving and pain eases, coping and resolution triumph. This child gives so much love and joy to me as a mother, and to our whole family, that a new meaning for love has been realized. Nothing is taken for granted, as each and every small accomplishment of the child is celebrated, maybe as life was intended? When I look back upon the previous years with my son, having him has been one of the most exhausting, painful, and yet enriching, experiences of my life. Emily Pearl Kingsley (1996) in her short story A Trip to Holland (Appendix A) has eloquently captured the experience of having a child with a disability.
My life has entered into a different "world" that I never knew existed. The people who can relate to the situation and talk with true empathy are those who have a child with a disability. It is wonderful to meet the new people within your new world, as this experience opens new doors. A new identity for our family and myself has emerged, with new relationships.

Summary

Through phenomenological research, the nursing profession emphasizes a reverence for the client's experiences, is concerned with the quality of life, and the quality of the nurse-patient relationship (Munhall, 1994). Through this research process, nursing and other related health care team members will encounter the essence of this phenomenon, and become sensitized to this unique human experience.

Tracing through the history of disabilities, one can observe in the 21st century we are at the infancy of recognition and integration of these individuals into our society. The brief review of the literature has set the existing context of the current research available for mothers with children who are disabled, and what remains lacking within this research base. Through an experiential and personal perspective, this researcher attempts to create a vivid and accurate representation of her personal experience in having a child with a disability.
CHAPTER III
Method of Inquiry

Chapter III addresses the methodological issues related to this inquiry, the meaning of having a child with a disability from the mother’s perspective. The historical roots of phenomenology have been presented in support of the chosen method. The details of the methodology, data analysis, access, setting, sample, procedure, data management, and human subject considerations of the study are presented.

Introduction to Phenomenology

Phenomenology was selected as the methodology for this qualitative study due to the nature of the proposed research question, “What is the nature of having a child with a disability for the mother?” This question lends itself to exploring the undivided or holistic approach of this life-experience as described by the twelve mothers. Phenomenology is the appropriate methodology to describe and interpret the particular phenomenon, to answer a question of meaning, to understand an experience as it is understood by those who are having it (Cohen, 2000). The phenomenological approach to this research is a personal insight, which brings the personal language account of a phenomenon. The purpose of this method is to describe, in detail, a particular phenomenon, so that readers can appreciate this unique experience. Through exhaustive individual descriptions of the phenomenon, further understanding and interpretation of the event is realized (Munhall, 1994). It is an attempt to uncover and describe the composition of our every day experiences. In a sense, this permits readers to “see” the deeper significance, or structure, of the lived experience (Munhall, 1994).
Rationale for Hermeneutic Phenomenological Method

Hermeneutic phenomenology rests on the ontological thesis that the lived experience is itself essentially an interpretative process (Allen & Jensen, 1990). The Oxford English dictionary (Brown, 1993 as cited in Cohen, 2000) defines hermeneutics as the branch of knowledge that deals with (theories of) interpretation, especially with scripture. The word hermeneutics is derived from the Greek verb meaning to interpret (hermeneuo), which is derived from the Greek god Hermes, who interpreted and conveyed messages from the gods to the mortals (Cohen, 2000). This interpretive methodological approach seeks to understand how people experience an important event over time, paying attention to the nature of language and meaning. It was proposed that the purposive sample of mothers’ interviews would offer a picture of what it is like to be the mother of a child with a disability, as they interpret and make sense of the experience. The hermeneutic tradition holds that informants have already interpreted the meaning of their lives in the very act of turning their experiences into stories or narrative texts that can be told (Kahn, 2000). This interpretative methodology places the focus of the individual’s narrated account on his/her lived experience. The interpretative researcher’s challenge is to extend reasoning skills, to challenge the ability to be reflective about the impact of their own background on articulating practical, everyday understandings and knowledge of their participants (Benner, 1994). This requires the researcher to have patience, reflective thought, without presuppositions regarding the meaning of the phenomenon. By staying true to the text, one strives to accurately present the voice of the participants (Benner, 1994).
Background of Phenomenology

Phenomenology, a 19th and 20th century philosophical movement is dedicated to describing the structures of experience as they present themselves to our consciousness. Phenomenology can be divided into three phases during the past 160 years: Preparatory phase, German phase, and French phase (Cohen, 1987).

The Preparatory phase, during the first half of the nineteenth century, had two major contributing philosophers, Franz Brentano (1838-1917) and Carl Stumpf (1848-1936). Brentano’s major contribution to phenomenology is the value of inner perception: awareness of our own psychic phenomena, as opposed to unreliable introspection (Cohen, 1987). Stumpf, a student of Brentano, was credited with demonstration of scientific rigor of phenomenology by analysis of empirical material.

Edmond Husserl (1859-1938) and Martin Heidegger (1889-1976) establish the second phase of the phenomenological movement. Husserl is many times credited as the founder of phenomenology. He believed the task of phenomenology was to study the essences, that which makes something what it is, the fundamental nature or most important quality. “To the things themselves”, his well-known slogan, elaborates on his beliefs of the essences (Cohen, 1987).

During World War I Husserl lost his son on the battlefield in action. This motivated his redirection in thoughts of philosophy to one of deeper contact with human concerns. Two concepts are credited to Husserl: intersubjectivity and life-world (Cohen, 1987). First, intersubjectivity relates to what the human science researcher needs the other (the participant) to develop, in order for the dialog relation with the phenomenon to
occur, thus validating the phenomenon as described (van Manen, 1990). This researcher shares a common world with the participants, therefore during the research, bracketing must take place in order to report reliable data. Secondly, the lived-experience, Husserl believed that we take experiences in our every day world for granted, therefore these experiences are taken for granted or not acknowledged. Husserl felt that the deeper examination of this “everydayness”, to really examine what surrounds us is the main task of phenomenology. The second philosopher during the German phase was Husserl’s assistant, Martin Heidegger. His view on phenomenology was to manifest what is a hidden in ordinary, everyday experience. Hermeneutic phenomenology took on the fundamental term of “being” or being in the world to describe the structure of everydayness (Phenomenology, “n.d.”).

The French philosopher, Jean-Paul Sartre (1905-1980) reactivated phenomenology (Cohen, 1987). Sartre returned to the approach of Husserl, that of consciousness. His goal was to understand because “to understand is to change, to go beyond oneself”(Cohen, 1987, p.33). A second French philosopher, Merleau-Ponty, wanted to demonstrate that the science of human beings is possible (Cohen, 1987). He stressed the importance of knowing another’s experience, their perception, opposing the positivist approach. Within his most important book, The Phenomenology of Perception, Merleau-Ponty contrasted the results of examining perception using a phenomenological approach against using a positivistic approach, this revealed the valuable insights this methodology introduces (Cohen, 1987). Phenomenology has had a pervasive influence
on the 20th century, and continues to remain one of the most important schools of
philosophy.

The influence of a feminist perspective with this phenomenological inquiry was
suitable as a complementary lens to answer the research question proposed, “what is the
experience of the mother with a child with a disability?” Phenomenology was the best
approach to delving into this exploration, with the perspective of feminism supporting
and providing a perceptual framework to enhance this methodology.

Feminist Perspective

I used a feminist philosophy to support the interpretation of this inquiry. Feminist
research is essentially research by women for women. Both Harding (1987) and Reinharz
(1992) put forth within their respective books that there is no one distinct feminist
methodology. Reinharz (1992) further illustrates her thoughts on this multi-form method,
that feminist research is the sum of feminist research methods, encouraging many diverse
forms of methodology. The feminist perspective is used with an existing method in a
given field of inquiry, and through this perspective a development of an innovative
flexible method ensues. With feminism, there is a differing cognitive or emotional
framework, an attitude related to a set of guidelines for conducting research with the
shared fundamental tenet underlying all feminist research as the importance of women’s
lives (Reinharz, 1992).

The pursuit of knowledge, through the experience of women, is an
epistemological inquiry in which the researcher examines the knowledge generated
through the experience of women. The researcher uses a personal experience, a personal
origin, for the starting point for research inquiries. This is a unique and distinguishing feature of feminist research. Reinhart (1992) terms it as the *epistemology of insiderness*. Myself, being an insider with this experience, hopefully enabled the mothers participating in the research study to delve and disclose more of their stories, a deeper level to me, as compared to an individual that has not experienced this phenomenon. Traditional methods of research emphasize objectivity, efficiency, and a separateness; while a feminist approach supports a connection and empathy as ways of knowing (Reinhart, 1992). Women have the right to determine what areas of study are most important to them, to further clarify and give meaning to their everyday personal lives.

The goal of feminist inquiry is to provide women with an explanation of a social phenomenon. Harding (1987) supports that noteworthy research and analysis are not separate from the origins of the research problem. This research is supported, and directly related, to the origin of the research problem, that of “silent mothers” (Lauterbach, 1993) with disabled children. The hermeneutic phenomenological methodology allowed mothers to tell their stories of what this daily world is like for them. The origin and the research analysis have direct meaning to me, as the mother of a child with a disability, and are congruent to further exploring the lives of these mothers.

Studying women is not new. Studying them from the perspective of their own experiences, the value and subjectivity of their personal feelings, is enlightening. A new discovered world is brought forth when women understand themselves (Harding, 1987). The term that is used to explain this equal plane of inquiry for the participant and the researcher is termed “studying up” versus “studying down” (Harding, 1987). Feminist
methodology is best accomplished when the investigating researcher and the participant come from a similar context. The inquirer is placed on the same "critical plane" as the overt subject matter (Harding, 1987). This egalitarian research methodology avoids the alienation of the researcher from the researched and is a way of generating a feeling of connection and comfort with the research process.

This feminist research placed the researcher in the same critical plane, the same class, and gender-sensitive strategic plane as the participants. I am from the same world or culture as the participants, the same gender-sensitive critical plane, sharing a common experience, a similar or a common bond that facilitated open communication. There was a primary element of trust and openness with which I could relate, understand and interpret the story of the mother caring for a child with a disability.

Procedure

Gaining Access

To gain access in this study, I contacted a local early intervention program in New Jersey. This program supports any family with a disabled child, within a certain geographical location, by offering services based on the child’s individual need; such as physical therapy, speech therapy, occupational therapy, or social work. The board of directors and program director of the early intervention program were contacted by letter informing them of this research and requesting permission to post information of this research within the reception area of the center to secure participants. Several documents were provided to the administrative staff of this non-profit organization: the mother’s consent form, a clearly stated purpose and the methods employed to protect the mother’s
identity. Verbal and written consent (Appendix B) to proceed with this research was obtained from the early intervention program during March 2001. They have participated and supported other relevant research to further the knowledge about children with disabilities.

A notice explaining the research and a stamped postcard was provided for mothers interested in participation at the early intervention program’s reception area. Each participant was contacted by phone through the returned postcard information to arrange a convenient date and time for the interview. During this time, any preliminary questions or concerns the participant had were addressed.

Participants inclusion criteria for the study was as follows: English speaking, 18 years and older, and having a child diagnosed with a cognitive and or physical disability within approximately the past two years. Children with only a physical disability were excluded from this study.

Description of Study Participants

A purposeful, voluntary sample of 6 to 10 mothers is suggested as an adequate sample size according to Morse (1998). A total number of 13 mothers contacted me and were willing to participate within the study. One mother was excluded from the study after further investigation of her child’s cognitive capacity. This child has Lymphangioma, a very disfiguring disease of the facial and neck area. To maintain an airway, this child has a permanent tracheostomy with humidified oxygen, and at this time she is reaching all developmental milestones both cognitively and physically. This
mother’s conversation will therefore be excluded from the data analysis of the study, but
will supplement the presentation of findings in Chapter V.

The sample included 12 mothers from ages of 30 to 44 years, all of whom
participated in the early intervention program. The participants of this study varied in
terms of age, ethnicity, marital status, work status of the mother, number of disabled
children, number and age of siblings and prenatal diagnosis of the disability. This
information is included in the appendix in the form of tables (Appendix C, Tables C.1-3).

The 12 mothers had a mean age of 37.1 years. One mother was single, and the
remainders of the other 11 mothers were married. There were 10 stay-at-home mothers,
one full-time pre-school director, and one mother worked part-time doing secretarial
responsibilities within her home. The “stay-at-home” mothers described their roles in
varying ways: “full-time homemaker” and “mom”, “homemaker”, “my career is on
hold”, “leave of absence”, and my personal favorite, “the family manager.”

One mother has two children with a disability and the other 11 have one child
with a disability. Four of the disabled children have Down syndrome. The other types of
children’s disabilities include: Encephalitis, Netherton syndrome, Pertussis with cerebral
anoxia, Fragile X syndrome, Autism, Bardet-Biedel syndrome, Angleman’s syndrome,
and lastly, two of the children are without diagnosis at the time of this research. Only one
mother had a prenatal diagnosis of Down syndrome resulting from an amniocentesis
performed in the first trimester.
The total number of children within a family ranged from an only child to 5 children. The position of the child with a disability in the family ranged from the first child born to the fifth child born. All of the children but one had siblings.

Data Collection

Most settings for qualitative research are the field. The field is the place where individuals of interest live or where they experience life (Streubert & Carpenter, 1999). Interviewing within the home had the advantage of seeing and feeling the natural setting, and the interactions of the mother and child where this phenomenon occurs. A feminist perspective also supports this natural environment for the interview process. Thus all of the interviews for this research took place within the comfort of the participant mother’s home. This setting afforded the ability to see the entire natural context in which the mother and child live. The home environment was the best atmosphere for the mother to talk freely, and to provide for enhanced data. Also, meeting the mother in her natural setting provided depth and another viewpoint to enhance my understanding of the phenomenon by observing the mother and child in their environment. The date and time of the interview was determined at the mother’s request and mutually convenient for the mother and myself. A letter of introduction of myself and explaining the research was presented to each mother before the interview began. (Appendix D) Interviews were conducted over the months of August 2001 through the first week of November 2001. The first interviews lasted from 45 minutes in length to 1 hour and 45 minutes. Second interviews were shorter in duration and participant mothers talked from a minimum of 35 minutes to a maximum of 60 minutes. All interviews were tape recorded, and then
transcribed verbatim by a professional transcriptionist. Upon return of the transcripts, I reviewed each of the transcripts with the tapes for accuracy against the typed text.

An open-ended interview format provided the opportunity for the mother to articulate any thoughts relating to this phenomenon (Appendix E). Open-ended interviews provided participants with the opportunity to fully explain their experience of the phenomenon of interest (Streubert & Carpenter, 1999). This method did not restrict or direct the information that the mother felt was important in conveying her story of the phenomenon. Initial questions regarding demographics facilitated the mothers feeling comfortable and knowledgeable (Appendix F). Open-ended questions were posed to the participants, such as, “Tell me about your experience of having a child with a disability.” A feminist perspective on interviews avoids control over others and facilitated a sense of connection with people (Reinharz, 1992). In addition, a feminist approach influenced the choice of open-ended questions, and the ways of relating to the mother. The interview lasted until the participant felt she exhausted her description. The interview allowed entrance into another person’s world and was an excellent source of data (Streubert & Carpenter, 1995).

The first interview encouraged the mothers to share their narrative accounts of events, situations and feelings of having their child with a disability. At this point in the interview, I revealed my experience of my child with a disability to the participant mothers. The intent of disclosing this commonality was to place the mother at ease. This technique likewise supported and is consistent with a feminist perspective.
The second interview took place four to six weeks later, to provide for clarification of information from the first interview, and allowed the mother to share any additional information. The transcripts from the first interview were returned to the mother during the second interview for further clarification. Consistency with feminist research framework, the second interview was conducted to have the participant mothers confirm and further elaborate upon my thoughts of potential themes identified from the first interview. I asked the mother for input as to the preliminary reflection on potential themes. This process of returning transcripts allowed for participation of the mother in the research interpretation. The mothers were comfortable with this format and I was able to elicit further descriptions and information on potential themes. Also, as a mother myself experiencing this phenomenon, it was apparent that the participant mothers were very comfortable with me, through the sharing of very personal and intimate thoughts which gave further depth and understanding of this phenomenon. Complete concentration and rigorous participation in the interview process improved the accuracy, trustworthiness and authenticity of the data (Streubert & Carpenter, 1995). I listened attentively, having a true presence with the participant, and expressed genuine sincerity and interest in the subject, which provided a comfortable environment further endorsing a feminist perspective.

Interviews at times were a challenge with younger siblings in the home and the child with a disability crying frequently. With an interruption, the tapes were rewound prior to the interruption so that the mother could review the conversation and recapture her train of thought. These interruptions were not a significant problem.
Field notes were written as soon as possible after the interview with the mother for synchronous and thorough recollection. I was able to reflect on the home environment and the family dynamics, which confirmed and potentiated the mother’s story. It provided another avenue of validation. Kahn (2000) states written descriptions of things that are observed, such as details of the environments in which the experiences being studied take place, often constitute a layer of the field text. This layer is distanced from the experience, which enhanced objectification and hermeneutical interpretation. The metaphor that fits is that of a person stepping back from a painting to better view it as a whole (Kahn, 2000). Field notes supported and added to the multi-layered text of this inquiry. Mothers were also asked to send photographs to me of their children. The mother's choice of photograph was a valuable source that depicted how she felt about the child.

Data collection continued for a total of 12 of 13 mothers that responded. At this point, it was believed that data saturation had been achieved. Data saturation refers to the point in qualitative research when participants are offering repetitive information; the ideas conveyed by the mothers have been shared before by other mothers. It was felt at this point in my research (12 mothers) that additional mothers would no longer contribute new information.

Data Analysis

A qualitative data analysis software program was not used. St. John and Johnson (2000) support that reduction of data by a qualitative data analysis system can distance the researcher from the data, resulting in loss of meaning and context and creating sterile
and dehumanized data—the very critique that lead to the development of qualitative research. I preferred and used manual analysis of data, which provided for a close interaction with the data.

The hermeneutic interpretation process is a cyclical procedure, frequently referred to as the hermeneutic circle. The smaller units of data are compared to the larger units of data, reflecting a back and forth, which substantiates and builds upon the interpretation. As described in Cohen, Kahn & Steeves (2000), the process focuses attention alternatively between the most local of detail and the most global [of theoretical] structure in such a way as to bring them into simultaneous view. The smallest of statements must be understood within the larger context of the text. Cohen, Kahn, and Steeves (2000) state humans interpret the horizons of others through a circular, hermeneutic process, using trial and error, questioning and correcting, along with the shared meanings that are available to all members of a culture.

The hermeneutic process of analysis involves first a reading of all interviews to gain a sense of the whole. The entire text is read to have a vague and tentative notion of the whole data with reflexive awareness that this notion is an anticipation of meaning (Cohen, Kahn, & Steeves, 2000).

Benner (1994) also suggests the use of a paradigm case as the usual entry point for dialog examination. This paradigm case is used as a comfortable starting point in which other cases are compared and contrasted with the original paradigm case. The cases are examined as a whole for similarities, issues, concerns and differences. Benner (1994) states one world sheds light upon another. A selected paradigm case is presented
in Chapter IV. This paradigm case was preferred since there was a thorough understanding of this particular mother's story. Other mothers’ stories were compared and contrasted to this respective paradigm case; therefore, commonalities and differences were established.

The second portion of the structural inquiry is aimed at identifying significant parts and patterns to explain the text. Referred to as the thematic analysis, threads of commonalities, patterns, concerns and similar developments are identified through the respective stories. The transcripts derived from the two conversations with each mother were the fundamental source for development of the emergent themes. Using the mothers’ direct statements, meanings were derived and these were used to formulate themes and subthemes. The themes represent an embodied understanding of the meaning of having a child with a disability from the mothers’ perspective. The exact language from the mothers aided in the development of the themes and subthemes, with attention to repeating words. An example of mother’s meaning of this phenomenon came from the repeating words; angel, appreciation, best, and life. The themes represent the broadest sense of the phenomenon without reducing any mother’s unique and personal experience. An example of a theme from this research is as follows; (mother’s statement) “You know especially since it came from me. I know there’s nothing I could have done, but I wish I didn’t have the gene.” Subtheme, Self-Blame. Theme, Consuming blame while searching for an explanation for the child’s disability (Appendix G, Table G 1-8).

After the development of themes, a search through the Oxford English Dictionary and Thesaurus (1996) for synonyms and related words was performed on each theme.
This information was taken back to the mother's statements, themes, and subthemes to ensure accuracy. Words and phrases were chosen each was compared and contrasted. All repetition words (Appendix H) were investigated within the Oxford English Dictionary and Thesaurus (1996) for exact definitions and potential synonyms. This was done several times to ensure that the words, phrases, and resultant themes truthfully represented the essence of the mother's experiences.

Through phenomenological reflection, the research has been written several times in differing formats. Writing and re-writing provided a more comprehensive perspective, which was helpful with the interpretation, of the mother's story. Each page and line were numbered for manual thematic analysis. Multiple readings and listening to the tape of each interview revealed the commonalities of words and phrases, these words and phrases were transferred onto large note cards for easy and organized access. A dwelling with the words and phrases, approximately 6 weeks, contributed to the eventual subthemes and themes.

The last step is to return, or go back, and interpret the text as a whole, in order to achieve a thorough and different interpretation. Each of the processes supports and further expands upon the previous knowledge generated. This methodology sees the whole and the parts of the text simultaneously, a constant cycle of understanding, interpretation and critique of the text (Benner, 1994). Through this cyclical interpretation, one develops an emotional relationship with the text, probing a different interpretation and hence a different understanding as the process of interpretation moves forward. Benner (1994) refers to this process as the forward arc of projection and a returning arc of
uncovering. In other words, this constitutes a constant dialogical process of interpretation and evaluation. The interviews were once again read as a whole prior to a final telephone call to the mothers for their thoughts and input on the themes that emerged.

To further articulate a pattern from the text, exemplars are used. Through the grouping of exemplars, nuances have been established, giving further credence to the proposed thematic analysis. Exemplars form a family of resemblance to one another (Benner, 1994). Exemplars are presented in the (Appendix G) to support the emergence of the respective subthemes and themes.

Interpretation and understanding are in a dynamic, dialectical relationship with one another, revealing understanding and understanding, in turn, rewrites interpretation (Allen & Jensen, 1990). Through further understanding of the phenomenon, the nursing profession will exhibit sensitivity with communication and interaction, therefore, better meeting the needs of patients. Since only participants can reveal the meanings they create, hermeneutic phenomenology, which is the study of how people interpret their lives and make meaning of their experiences, is ideally suited to the research of nursing care (Cohen, Kahn & Steeves, 2000).

**Human Subject Considerations**

Following human subject approval from Widener University Nursing Research Review Committee, access was initiated and interviews were soon begun with mothers. In addition, informed consent (Appendix I) and permission to tape-record them was obtained. This research data was maintained so that only this researcher knew the true source of this personal and sensitive data. Data collected was coded to maintain
confidentiality, and kept within a locked file cabinet. Confidentiality of data was a guarantee that any information the participant provided will not be publicly reported or made accessible to parties other than those involved in conducting the research (Streubert & Carpenter, 1999). In the text, all mothers' names have been changed; pseudonyms were used to protect for confidentiality of the mothers.

The quality of the data generated was dependent upon the genuine interest of the participants. This group of mothers had a significant and beautiful story to tell, to be heard and understood relevant to their challenges, the intense emotional terrain, and the joy and rewards of parenting a child with a disability. The Social Worker of 20 years stated the early-intervention program had participated in prior research, and gave verbal consent from the program manager and the board of directors (S. Levine, personal communication, July 1999). The early-intervention center has, and supports, the philosophy of relevant research and the dissemination of findings to help mothers and families of children with disabilities.

Potential risks came from the possibility of the participants becoming distraught, and subsequently unable to complete the interview, or preferring not to participate due to the uncomfortable personal feelings. Although three mothers cried during the interview process, a brief time interval was allowed for the participant to regain composure, and all mothers preferred to go on with their interviews. None of the mothers wanted to reschedule the interview or to withdraw from the research study.
Trustworthiness of Data

A qualitative study is deemed credible if it reveals accurate descriptions, vivid and faithful of an individual's experience. People having a particular experience would immediately recognize their own experience from the descriptions or interpretations, without distortion (Sandelowski, 1986).

Issues of credibility for this qualitative research were addressed with the following methods. Field notes were collected to explicate the researcher-participant relationships such as actions, interactions, and body language during the investigation immediately following the interview. Several mothers were requested to read excerpts from the data to confirm the data as meaningful and applicable in terms of their experiences. The mothers were able to recognize the data as their own without distortion. The paradigm case was given to a mother with a child with a disability, not involved with this research. She evaluated and concurred with my interpretation that these research and resultant themes had captured the essence of the experience.

In addition, the data was shared with one of my committee members, to evaluate once again if my interpretation and essence of this phenomenon was accurate and true to the data. This committee member is recognized as an expert in the field of families with children with Down syndrome, with multiple qualitative and quantitative publications on a similar topic. She made an accurate, objective judgment, that this research accurately captures the phenomenon.

Many of the themes identified in my study can be applied to other similar contextual situation. This contextual application applies to one of the mothers in my
research who had a prenatal diagnosis of Down syndrome with her son. Although, her story was very similar to other mothers, she did acknowledge that she was able to mentally process this diagnosis during her pregnancy by reading literature and contacting the early intervention center. I interviewed another mother, not realizing at the time that her child had a physical disability, and not a mental disability, therefore, this child did not meet the inclusion criteria of my research. This mother’s interview and story were very similar with the themes of the other mothers in which their children had mental or a mental and physical disability.

Audibility or credibility is established when the reader can easily follow a decision trail or audit trail (Appleton, 1995). The reader understands each step of the qualitative research process, with concise justification for each of the respective decisions. An audit trail was maintained throughout this study (Appendix J). In addition, a representation of the mother’s interviews are displayed (Appendix G) to explicate how I came to the respective subthemes and themes.

The expertise of the researcher’s interview technique can be a determining factor for the reliability of the data collected. In preparation for this research, an independent three-credit independent study was completed with an expert nurse researcher in phenomenology. The purpose was to expand this researcher’s knowledge base, practice of interview technique, and interpretation of the data.

A tape recorder was used to record all discussion of the participant and interviewer. A professional transcriptionist transcribed the tapes and each interview was checked and reviewed for completeness and accuracy. This researcher listened to the
tapes many times over, for completeness and to gain a sense of knowing the mothers. A second interview was performed for clarification of data, and to obtain the mother’s additional thoughts on the themes identified from her first interview.

Conclusion

Chapter III reviewed the methodology that was used for this research, with particular attention to hermeneutic phenomenology and a feminist perspective. The historical roots of the phenomenology were traced to provide the philosophic background for the methodology used. A feminist perspective complemented the phenomenological methodology. Application of the methodology is addressed: procedure, gaining access, description of the participants, data collection, data analysis, human subject considerations and the trustworthiness of the data. Finally, methods used to enhance the rigor of the research were outlined.
CHAPTER IV

The Mothers’ Stories

Chapter IV will introduce each of the mothers with attention to their unique personality traits and personal strengths. In addition, my personal reflection on the experience of performing this research as a mother who has experienced the phenomenon of the mother’s perspective of caring for a child with a disability is discussed. Chapter IV also includes a paradigm case. Patricia Benner (1994) suggests the use of a paradigm case to compare and contrast all other cases as a step in the process of understanding and therefore interpretation. All names used are pseudonyms to protect confidentiality of the mothers.

Susan

Susan, age 32 is the mother of a 2 year-old boy with Fragile X syndrome, an only child. Susan is married and recently moved back to New Jersey from California to be closer to her family. Susan’s home is a simple Cape Cod in a suburban, middle class neighborhood. She employs a part-time woman in her home to help with the care of her son, and some of the household responsibilities. She has been married for several years and she mentioned during both interviews that her husband has great interest in and is willing to participate in a future “father” qualitative study.

She was articulate with her descriptions of negotiating the medical maze relative to the original establishment of her son’s diagnosis. Unfortunately, her son was first diagnosed incorrectly at six months of age with, Cerebral Palsy. Further consultations and Susan’s persistence with multiple physicians revealed at 11 months of age, the firm
diagnosis of Fragile X syndrome. This mother went through the process of receiving a disability diagnosis twice. Fragile X syndrome is a genetically linked disorder, which involves varying levels of mental disability, cognitive and motor delays, and as childhood progresses, difficulty with behavioral problems. Fragile X is second only to Down syndrome as the cause of mental retardation.

There are possible future ramifications of Fragile X since Susan is the carrier of the Fragile X gene. Unfortunately, any future children would have a 50/50 chance of genetically receiving this imperfect gene. This is most difficult for Susan; she and her husband definitely want to have another child, but are also fearful of having another child with special needs. Additionally a child with Fragile X mimics others very well; in fact, this is one of his or her unique strengths. Therefore, the child with Fragile X does better in a family where he/she can follow other siblings. This situation presents an ethical dilemma for Susan and her husband.

One of the dynamic personality traits of Susan is her ability to be an incredible advocate for her child. Susan travels with her son to a world-renowned osteopathic doctor who performs cranial-sacral manipulation in California once every month. Susan states this type of manipulation has shown great promise in children with disabilities, through increasing external and internal blood supply to certain areas of the brain. Some children show great improvement in not only cognitive but also motor abilities. Susan reports prior to his cutting edge treatment that her son had a vocabulary of 80 words and after 2 months with this treatment, he rapidly progressed to a vocabulary of 300 words. His
physically abilities have also progressed at a remarkable rate. Susan states her son is
above the developmental milestones set for a child with Fragile X by the age of 2.

What impressed me the most about Susan was her desire to seek any treatments,
including alternative treatments, which may be of help to her son. She is gratified with
her son’s progress, and has no regrets about seeking and implementing alternative
therapies, which have had positive results at this time.

Allison

Allison is an elementary schoolteacher, in a local town. She lives in a large
colonial home, in an upper middle class neighborhood with colorful plants and a
manicured lawn. Allison, age 39, is married to her high school sweetheart. They have one
son, 5 years of age and her “undiagnosed” daughter is 2 years old. The child’s disability
is thought to be a reaction to the diphtheria, pertussis and tetanus vaccine. Her persistence
and continued search for a diagnosis for her child is a visibly frustrating predicament for
her. The child’s cognitive ability is minimal; she cannot speak nor purposefully
communicate. At this point, the child can sit independently, she cannot feed herself, nor
crawl or walk

Allison’s daughter cried the entire two hours during our conversation, Allison
suspected that her daughter was teething. Allison was visibly exasperated, not because
the child was acting this way, but because the conversation was a difficult process. With
these crying episodes, Allison attempts to deductively guess what may be bothering the
child. She tried different handicapped seats, different positions, feeding her child and at
one point just held her tightly and asked, “What can Mommy do to help you?” Allison
reported that her child has been this way most of the summer. Allison said, "I'm connected with her, just she is not connected with me."

Allison is currently taking a leave-of-absence from elementary teaching to care for her daughter. Allison is worried about her son and she stated that he would have progressed academically further if she had been able to spend more time with him. The guilt as an elementary school teacher was evident.

Allison expressed the difficulty of not being able to do things a normal family can do together on a beautiful summer day. This family has not taken a vacation in the past two years since her daughter was born. Due to the behavior and management of the daughter, as well as the financial situation with physicians and hospital bills not covered by insurance is considerable. Allison stated that the medical bills are very costly, and they continue to seek an answer, to obtain a diagnosis. She stated if there was a firm diagnosis, they may have moved forward and been in a positive financial status. Her child’s disability greatly impacts the ability of the family to have normal recreational activities. Her family has a beach house, which they are not able to fully use due to the difficult situation of care-taking and behavioral issues of her daughter outside their own home environment.

**Alyssa**

Alyssa, age 36, is happily married with two children; her first son is 5 and her daughter with a disability is almost 3 years old. She reports that her husband is "wonderfully" supporting of her. Alyssa mentioned him several times in the interview. He has helped her tremendously during difficult times with her daughter. Her husband is
in home construction, and he is currently expanding their home in a beautiful middle-class neighborhood. She is currently on a leave-of-absence from her dental hygienist position.

Alyssa’s story also involved a difficult process with establishing the diagnosis for her daughter, or as she has referred to it, the medical maze. Her daughter became very sick at four weeks of age with what was thought of as an upper respiratory infection, necessitating frequent nebulizer treatments. This went on for a week; Alyssa was exhausted with the constant respiratory treatments, which were not improving her daughter’s condition. Subsequently, she was admitted to the hospital and within 48 hours, her daughter suffered a respiratory arrest with transfer to the neonatal intensive care unit. At one point, Alyssa broke down in the hallway of the hospital and cried for fear of her daughter’s impending death. As time went on, her daughter suffered two more respiratory arrests and then stabilized. Her present condition is related to cerebral anoxia sustained during these respiratory arrests.

This little girl is confined to a walker with a strong support for her back; she can maneuver throughout the house. She cannot crawl, walk, or feed herself. She can say “Mommy”, a great encouragement to her mother.

Alyssa has profound faith in God and her religious beliefs were obvious through her descriptive coping abilities and her personal meaning of the experience of having her child with a disability. She believes that her daughter is alive today due to prayer, her faith, and a community prayer service that was held when her daughter was hospitalized. Her love is tangible toward this little girl. Alyssa calls her, her “guardian angel.”
Taylor

Taylor is married, lives in a suburban neighborhood and is the mother of two children; a daughter 7 years old and a 3-year-old son who is disabled. She has been a stay-at-home mom since the birth of her first daughter. Taylor, age 44, has a raspy voice, an impeccable appearance, and additionally, she is a warm and genuine person.

Taylor’s home is well organized, with no clutter and nothing out of place. She has a no-nonsense, get down-to-business attitude. During our interview, I noticed a list of the day’s activities on her counter top.

Taylor’s son’s disability remains undiagnosed at present. The pediatric geneticists have narrowed his presenting symptoms down to a likelihood of one of three syndromes. Geneticists continue to test and examine her son at 6-month intervals to attempt to confirm a syndrome. Her son’s physical appearance of his disability is minimal. He has abnormalities with his hands and his eyes are slightly almond shaped, resembling a Down syndrome child. Taylor was most concerned about her son’s transition into the local public school for handicapped preschool.

She always obtains copies of her son’s medical records from the respective office and hospital visits, and then reviews them to the best of her ability. She feels this is one way she can stay actively involved and knowledgeable of her son’s medical care. She openly shares the joy her son has given to her and her family.
Barbara

Barbara is a soft-spoken woman with light brown hair and wire-framed glasses. She was the only mother interviewed who has two children with disabilities. Her oldest son is 3 years old and is diagnosed with Autism, and the second child, a girl, has been diagnosed with Bardet-Biedl syndrome. Bardet-Biedl syndrome is an autosomal recessive disorder characterized by obesity, retinal degeneration, extra digits on the hands and feet and mental retardation (Hereditary Obesity- Bardet-Biedl syndrome, "n.d."). She is age 32, married, has three children altogether, and moved back to this area about two years ago to be closer to her parents. Her husband works for a large university in the financial department. Frequently he attends fund-raiser functions in the evening, and does not arrive home until late. She has earned a master’s degree in education, but at the present time, is a stay-at-home mom.

Her patience and gentle nature are evident. She believes the care of her children is the most important job of her life. She enjoys each of them for their unique abilities and is so appreciative of their respective accomplishments. Religious faith permeates her entire life, and she readily admits this faith is what helps her to cope. Barbara described her middle daughter and third daughter’s names are derived from a religious origin. Pictures of Pope John’s visit to the New York area are displayed in a dining room. Barbara stated that she had drifted away from the church previously, however, her marriage has renewed her faith.
Barbara states that she would like to give back to the community through public speaking to families of children with disabilities. This will help to further educate and dispel the common public perceptions of having a child with a disability.

Mara

Mara is the mother of two girls; the oldest is 2-½ year old with Down syndrome and the youngest is a 3-month old infant. She is married and lives in an older home within an upper middle class neighborhood. Mara, age 40, is a schoolteacher, yet her position in her school district is on hold at the present time to care for her girls. She did have a difficult time with conception over a period of seven years. Mara considers this difficulty with conception her first emotional roller coaster in life; the second episode was the first difficult year with her daughter with Down syndrome. Mara has been happily married to her husband of 11 years and she states that through this experience of a child with a disability, she has come to know her husband more deeply than ever before.

Several times in public, unknown individuals approached Mara and would ask peculiar questions or stare at her daughter. She was very taken back by the intrusiveness of these individuals in the public sector. They can be very hurtful.

A realization Mara talked about was that the Down syndrome is something that has happened to her daughter, and not herself. She went on to explain that she cannot “fix it” for her daughter, something that is very frustrating for a mother. After this period of acknowledgement, she feels that she is truly blessed to have her child with a disability; her daughter has changed her entire family for the better.
Michele

Michele is married and lives in a modest neighborhood with four children under the ages of 7 years. Her oldest daughter is disabled; at present she is undiagnosed, but has been clinically evaluated as having Angleman syndrome. Angleman syndrome is due to genetic imprinting. Angleman syndrome occurs when a child fails to get a small piece of the long arm of chromosome 15 from his/her mother (M. Van Riper, personal communication, July 25, 2002). The diagnosis took years to establish after consulting with multiple physicians and geneticists in the New York City and Philadelphia area. Other siblings of this child are: a younger sister age 5, and two younger brothers ages 4 and 2 ½. Michele is currently not working, and describes her occupation as the family manager. Her daughter who is disabled cannot speak, is not toilet-trained, and has to be fed and dressed each day.

Michele’s sense of humor is outstanding. I laughed through out and enjoyed our interview. I believe this is how she copes, caring for a child with a disability and three younger active siblings. It seems that this is her acceptable lifestyle and her home reflects this, a smaller home with lots of toys and clutter. During the first interview over the summer, Michele had all four children in bed by 7:30 p.m. Although she is relaxed, it seems the children have structure and lots of love.

Michele describes the negative public perception regarding the phenomenon of having a child who is disabled. She firmly believes that the public, in general, has a negative perception of raising a child with a disability. Michele firmly disagrees with the public perception. She believes her own positive thoughts focus upon the immeasurable
amount of love, knowledge these children give back to mothers, and a true appreciation for life that would not exist if it were not for the gifts of these children.

Common bonding through mothers with children who are disabled was another point of emphasis for Michele. She expressed a feeling of *esprit de corps* with other mothers, regardless of the amount of time they had known each other. A common bond was there: we are bound together by our children, and our plight.

**Caroline**

Caroline is married, has twin daughters ages 2½ and a basset hound dog, and lives in a secluded middle-class neighborhood. Caroline left a high-powered career in sales when the girls were born, and originally thought she would be able to return to work. This mother also had serious and extensive fertility issues prior to the birth of her twins. Caroline had great difficulty with depression after their birth. She thought all of her hard luck had been expended with the lengthy fertility issues. She said, “I just thought there was only so much hard luck to go around.”

The diagnosis one twin girl of Netherton syndrome took a period of 11 months to determine. The child was managed in a local hospital, but there was great difficulty with management of the child’s lack of weight gain and electrolyte abnormalities. After six weeks, Caroline insisted upon a transfer for her daughter, to a tertiary children’s hospital. Her diagnosis, Netherton syndrome is extremely rare; it is estimated that there are 100 cases in the world. This syndrome is very disfiguring; there is no intact skin. The appearance of the child is one of very sparse hair, very reddened skin that is constantly peeling, resulting in electrolyte imbalances and the inability of the body to regulate its
temperature with potential infection possible at any time. It appeared this syndrome produces a similar condition to that of an extensive burn. Traditionally, these children have a high mortality rate in infancy due to sepsis. Caroline admits that it took a long period of time before she would take her daughter out in public, since she was very conscious of people staring at her daughter’s appearance, as well as the fear of exposure of infection.

During this time, Caroline admits she was extraordinarily depressed, needing medication and psychiatric intervention. She just couldn’t believe that this could happen to her and her children. Her perfect world was shattered with the diagnosis.

Caroline describes her first year as a “horror”. Her facial expression changed while describing the personal agony, loneliness and disappointment she felt with the diagnosis of a child with a disability. As she described her depression, she frequently would look down toward her hands in her lap. She repeated many times her feelings of depression, remorse, and confusion over this diagnosis. There was a sense she wanted the prefect family, and that this could not be going wrong in her life. It took Caroline a long period of adjustment to accept the child’s diagnosis.

Nicole

Nicole, age 39, is a thin, high-energy mother with two boys, ages 2 and 9 months. She and her family live in a brand new home in an exclusive rural area of the county. Nicole’s husband is a contractor; he built this spacious and beautiful home for the family. It was discovered during the conversation that Nicole had a child who died at 18 months of age due to meningitis prior to the birth of her 2-year-old son with Down syndrome.
Nicole was the only mother in the study who had a diagnosis during the pre-natal
time period that her child had Down syndrome. Given the death of her first born, and the
diagnosis of Down syndrome, Nicole passionately felt that God was punishing her. She
had serious concerns about the health of the unborn child with Down syndrome, not
wanting to go through a medical tragedy again, as she previously experienced with her
child with meningitis. She consistently sought a multitude of information on Down
syndrome, in particular her understandable fear of the health status of this unborn child.

Nicole was very passionate about her explanations and enhanced spiritual feelings
of having this child. She said that this experience put many things in her life in proper
perspective. After having her son with a disability, she said, “I now realize how this child
has filled our hearts with love, hearts that were empty for so long.”

Shannon

Shannon is married, has two girls ages 4 ½ and 2 ½ and lives in a beautiful
established neighborhood in an older town. She works part-time at home for her sister’s
advertising agency. Shannon, age 37 also loves to knit; her specialty is to knit Christmas
stockings for celebrities and then to donate the earned money back to the early
intervention program. She enjoys this contribution. Her husband is a lawyer and helps
with the children in the evenings.

Shannon genuinely felt she was not devastated with her 2½ year old daughter’s
Down syndrome diagnosis. She expressed in the conversation that she believes having a
child with a disability was destiny. During her own childhood, she frequently would take
care of neighborhood children who had disabilities, actually enjoying helping these less
fortunate children. She stated, "God knew, someone out there needs my help." She feels a sense of giving, a giving of the self to provide the best possible life for her daughter.

Kathryn

Kathryn is married with three small children, two boys ages 7 and 5 and her daughter with Down syndrome the age of 2 ½. She is a stay-at-home mom in a beautiful suburban home. Kathryn, age 38 was one of two mothers who did not have initial feelings of shock and devastation when her daughter was born. She related that she had asked her physician at the birth of both of her boys, if they had Down syndrome. With the birth of her daughter, as the physician stated he had suspicion that her daughter had Down syndrome, she felt, as if she was having an out-of-body experience, "surreal" was her description. Her husband was not present for this news; in fact she herself had to call her husband to inform him of the potential diagnosis. She felt that somehow, she was the person best prepared to take care of this child. Kathryn had worked at a local camp for children with disabilities and had experience caring for them. She stated that she would pray when she was young that if anyone in her family were to have a child who is disabled, she wanted to be that "chosen" one.

Kathryn’s perception of this phenomenon is that she is one of the chosen. She can’t understand what she has done so well, that she is privileged to have her daughter. Kathryn also has another talent, the gift of writing. She feels strongly that the public perception of having a child with a disability is unjust. She took a chance and wrote about her viewpoint attempting to publish her thoughts on the joys of having a disabled child in our local newspaper’s column, Turning Point (Appendix K). She felt that she could
communicate to the public about its improper perception about disability through her gift of writing.

**Yvonne**

Yvonne’s personal circumstances are considerably different from the other mothers within this research. Yvonne is African-American, age 30, and a single mom raising her 5 children to the best of her ability. Yvonne and the children live in a small rented home in a low-income housing area in a city. Her children’s ages are 9, 7, 6, 4 and 2. The 9-year-old child is a boy; the other children are all girls. Her youngest girl is disabled due to a severe case of meningitis.

Yvonne is a remarkable, focused mother. She has overcome many obstacles in her life. She is not married nor is there a “significant other”; her mother died when she was 13, from diabetes and then she lived with her aunt. The aunt who raised her died one year after the birth of Yvonne’s child with a disability. Yvonne believes there are similarities with these life events. She believes the exposure to medical care for her diabetic mother and diabetic aunt prepared her for the responsibility of a child with a disability. Yvonne also believes that part of her aunt’s soul, or spirit, lives on in her daughter. Yvonne states that due to her daughter’s disability, she is more focused and personally driven for the overall welfare and benefit of her children. She has a strong belief that many mothers would not take care of a child who is disabled; they would resort to escaping through adoption. She is committed to providing the best life that is possible, not only for her daughter who is disabled, but for all of her children and herself.
A Personal Reflection on Researching the Phenomenon

True appreciation for this opportunity was expressed by all of the participant mothers toward me. They opened their hearts, minds and souls to me during the two interviews. It was a distinct advantage for this researcher to be the mother of a child with a disability and to be on an egalitarian research plane as the mothers. Through applying a feminist research perspective, it was evident these mothers held nothing back; their comfort level was apparent with their exposed innermost emotions and passionate stories. At times, throughout the interviews, mothers would say, “well, you understand.” When this type of conversation occurred, as much as possible, I remained neutral with my return comment so not to influence their further responses. We cried together with sensitive stories, communicated and related to each other with that sense of camaraderie, which prevails among the mothers of children with disabilities. They were able to regain composure and talk again without discomfort or embarrassment. Would these mothers be so comfortable revealing and sharing the depth of the stories with an outside researcher? I truly believe the intensity and emotion of the stories would have not existed with a researcher who has not experienced the phenomenon first hand.

An example of this comfort level is evident in the following story. One mother shared her experience of a vivid life-like dream where God came to speak with her regarding her child. The dream focused upon God speaking to her, and he said he would be taking her child back to heaven at the age of 6. The tears we shared through this passionate story were genuine. Such a strong feeling of spirituality and connection prevailed. Many mothers described with fondness that their children have angelic
qualities. I could only confirm and feel that these children do come from a place, which is not known to most of us in this temporal dimension of our world.

It was a great challenge to remain expressionless and neutral as mothers described what I would professionally interpret as the overall poor coordination of treatment of specific children in this research. The mothers’ descriptions of the medical maze were episodes of conflicting medical information, or no medical information, an uncertain prognosis, or just a generalized lack of care and compassion for families who were in crisis. Mothers depicted potential areas of misdiagnosis, or a very prolonged diagnosis that affected the eventual outcome and functional ability of the child. I became unsettled with the description of mothers’ conversations with local pediatricians; these pediatricians felt it was not in the child’s best interest to transfer his or her care to a tertiary care center to determine a firm diagnosis. As mothers came to an emotional saturation point with local pediatricians, they realized that the illness or syndrome was beyond what could safely be medically managed in the local area and insisted that their children be transferred to a tertiary children’s medical center. An incorrect dosage of a liquid medication that was heavily sedating a child due to alcohol content was confirmed by a tertiary medical center. The mother was so distraught with this; she blamed herself for not observing the symptoms of overdose when medical management was less than standard.

In another instance, when a child in the midst of a respiratory arrest, the mother was pushed out into the hallway, with no communication or comfort from anyone on the health care team. In addition, the health care team did not fully communicate with the
mother as to the immediate and potential long-term effects these multiple respiratory
arrests had on the child’s cognitive functioning.

As a nurse of 23 years, I reflected and formed my own nursing opinions regarding
the medical maze stories of the mothers. I had to stay neutral and not communicate my
true professional feelings of poor communication and substandard pediatric medical care.
These unfortunate circumstances may have led to the advanced disability state of two of
the children. One mother was acutely aware of the substandard pediatric care and the
related consequence to her child’s present condition. Yet, the second mother did not
address this potential relationship, in fact, she openly praised the pediatrician during our
conversation.

Through each interview, there was an ease of communication between the
mothers and myself. I had flashbacks of my own experience with my disabled child,
reliving certain instances with many of the similar stories. There were so many
commonalities where my personal experience reflected that of the participant mothers. I
was able to relate and understand the mothers’ feelings, frustrations, challenges and the
special joys of having a child with a disability. It was truly an empathetic, yet validating
experience for me. I believe we are in another culture, another world, and we continue to
speak a common language.

A Paradigm Case

In accordance with Benner’s (1994) methodology, the usual entrance point into
the analysis and interpretation of a phenomenon is to present a paradigm case, one that is
well understood or perhaps perplexing to the researcher. The chosen paradigm case is
well understood by myself and through an expressive conversation, the mother
representing the paradigm case, portrayed many areas of the emergent themes. She spoke
of vivid examples of interactions she had with this phenomenon to illustrate her feelings.
I felt most comfortable with this particular mother and was able to grasp this mother’s
conversation, feelings and emotions. This mother is an elementary school teacher;
potentially the commonality of our background of teaching was unconsciously
established between the mother and myself. We are also very close in age, and both of us
have a child with Down syndrome adding to the connection that was present. Many
mothers of children with disabilities explain about a common and connected feeling
toward each other. I believe this mutual feeling transpired between myself and this
mother of the paradigm case.

A paradigm case can be used as an exemplar to compare and contrast other
conversations or cases presented by other mothers. This examination of comparing and
contrasting the respective cases enhances reflective and provoking thoughts. The
practical world of one paradigm case creates a basis for comparison of similarities and
differences with other paradigm cases (Benner, 1994).

Mara, the mother representing the paradigm case, is a mother of a 2-year-old
daughter with Down syndrome. She experienced several miscarriages over a period of
seven years prior to the birth of her daughter. She voiced how happy she was to have this
beautiful baby girl after many years of trying to conceive. Mara spoke in her interviews
about her negative feelings toward the health care team after her daughter’s birth as they
informed her of the potential diagnosis of Down syndrome. This poor interaction with the
health care team was accentuated, due to the prolonged difficulty Mara had with conception of this child. Her first encounter with the diagnosis of Down syndrome was as follows:

I know when we had her (disabled daughter) the head of neonatology (physician) was probably the worst experience. The worst experience with a doctor I have ever had. Came in and went up and down on one leg about how sorry he was. Never saw the man before in my life. And how they wanted to do the blood test and he needed my permission and that it was a chromosomal abnormality. And I said, "Well, what does that mean?" "Well I'm not at liberty to discuss, we don't know we have to do the test." I said, "Chromosomal abnormality could mean a thousand. What does that mean? Do you mean Down syndrome? Do you mean." I mean this was at least something I was familiar with. "Well, I don't know, I really can't say. We have to do the test. But you know 99.9% I am right. I have been doing this a long time and I am almost always right. So I mean, we do have to wait for the results." And I just thought to myself, "Give me a minute of hope." I was still bouncing off the bed after the delivery. When this all happened. Not to mention I know that this medical center is a teaching hospital. I understand that. As I said earlier, with all the stuff I had done, these residents have seen more of my body than I ever have. I always allowed, residents or, always because it is a teaching hospital. Did he have to bring in seven people that day? To watch and see how this mother reacts as we tell her there is something wrong with her child? They stood around my bed. Never asked if they could bring them in. And here he
is the head of neonatology and I understand that lying there looking at all these people, as they take my child away from me. They had to suction her. And then start telling me this. He single-handedly was the worst, that was the worst. And then kept coming back. "I want you to talk to the clergy. I want you to speak to the clergy." "I think you need this." My husband said, "Do you have the results yet?" "No, but as I told you I am 99% right." It's not about you being right. It's about us getting our feet on the ground and handling this. Give us our time. Nothing hurt me more and I will never forget all of that. Because I felt cheated. I felt cheated. I had a child. I gave birth. I'm supposedly in a reputable hospital. And they took it away from me. They took. I mean I felt something was taken away from me because of her disability, but what the medical professionals, quote, unquote, the people who deal with all this all the time. What they did, I can never get back.

Mara verbalized how furious she was with the health care team regarding their negative approach and assumptions with inept communication of the diagnosis of her daughter. Through this initial, insensitive confrontation, Mara was depleted of her initial joy and happiness about the birth of her long-awaited daughter and the experience of being a new parent. Mara voiced her expectation of an educated health care team who would exhibit a positive presentation to the new parent on the basis of the benefits of excellent health care and cognitive stimulation with early intervention.

Mara became pregnant with a second child and was visiting her obstetrician early in the pregnancy. Her doctor's assumption of having a child with a disability was evident.
in the following statements, “another child with a disability would be a heartache, and there is no reason in this world why you should have another child with a disability when testing and termination are options for you.” Mara states, “I got off the table and that was the last time I saw him. I thought to myself, walk in my shoes and tell me how horrible my life is. Walk in my shoes and tell me how difficult having my child is. And that really, oh God, I'll never forget it as long as I live. And I feel that that's insensitivity. I'm still a mother and she is still my child and there's a bond.”

Mara was stunned by the immense level of insensitivity by the health care team with their projected negative assumptions of this syndrome. She used the term; “life is like a roller coaster.” Mara felt she had been through somewhat of a similar life experience with her infertility difficulties. But throughout the challenges, she has maintained an optimistic focus with her daughter. She states that her daughter brings a positive and different dimension to the entire family’s life, she has touched each and every member of the family.

Public perception was a paramount consideration for Mara in the initial phase of acceptance of her daughter’s disability. She described several instances where the public was, as she termed it, “intrusive and obnoxious toward personal questions toward her daughter.” This seems to be more prevalent with children with Down syndrome, since the disability is visible, and more familiar to the public. The public may have an antiquated societal perception of mental retardation and the cognitive abilities of individuals with Down syndrome. Mara describes the public perception, as she knows it.
And you know I hate the stares and I hate. And I've gone- that's another set of bumps in the road that I've. I used to cry if people would stare. I used to try to hide her if I thought people were looking. And again I thought "what am I doing" and again, that stupid self-inflicted guilt would kick in.

This incidence touches upon the public's continuing insensitivity to these children and produces feelings of blame, and guilt for Mara. Yet, she talks of her own perception of adults with Down syndrome, "the barrette, the pocketbook, the Mary Janes at age 45. I mean that awful stereotypical that we all..." another time, an individual approached Mara about future employment capabilities of her child, their statement was, "the A & P, the Acme or Foodtown, how lucky you are because your daughter can pick which ever one she wants when she grows up." Once again, a negative assumption regarding the future intellectual capabilities of her daughter are made visible.

Mara vividly describes how difficult it was each time she had to write on a document in a doctor's office, the diagnosis of Down syndrome. It was once again a reaffirmation and more public exposure of the syndrome when fragile emotions were so susceptible. She states, "and I have to write Down syndrome. And I have to write that she's got a heart problem. And I've got to write. You know it just brings everything back. Then you take her to the ear doctor, the cardiologist. And you're just going through, and it's reminding you of how different things are. Every first was so difficult."

Mara talks of, as she terms it, the year of the firsts. By this expression, she means the first year after her daughter's birth was a difficult process of transition and acceptance. This process involved the incorporation of the syndrome and the life altering
consequences into their lives. The year of the firsts has frequent and constant reminders of the difference and the disability of their child. Mara describes the firsts seem to come at significant developmental times, or milestones, when she is once again reminded of the difference of her child by comparison to typically developing children.

Through all of the positive and yet difficult times, Mara feels a sense of destiny in having her daughter. She states, “But I still think we are given these children for a reason.” She believes that mothers of children with disabilities are chosen to care for the children. It is a predetermined fate or a fortune of sorts that these extraordinary mothers have children with disabilities.

The motherly self-blame of Mara was evident with her trying to “fix it” and make the predicament of her daughter’s disability better. After the realization that she couldn’t fix it, she was able to move forward and concentrate on the positive aspects of her child. She describes that she must accept the disability and move forward. Mara’s self-blame existed, “Because I would do that to myself, feel guilty about every time I felt bad. And then I’d feel bad. And then I’d feel guilty about feeling bad because what am I feeling bad about because she’s a beautiful little girl?” This is a cyclical pattern that entraps mothers.

The future of Mara’s daughter is a concern. The handicap and innocence of the child is paramount, not knowing how the public will one day treat the child is certainly a scary and unknown thought. She says, “If, God forbid, something happened to me. That would be the worst thing that could happen. If I got sick and couldn’t take care of her or my other child, I mean anything.” As a mother, she feels no one can care for her child as
she can, and it is fearful to contemplate the potential situations in which her daughter may be exposed to through the public sector.

The acknowledgment and the process of moving forward to integrate the disability is evident in Mara’s language, “the long and hard road… bumps out of the road… over the hurdle… our way out of the woods… milestones… the long haul… and now you’re in a different place.” This descriptive terminology reflects through metaphors, the heartfelt thoughts of this mother. There is a lifelong commitment and an uncertain future with her daughter. She is in a different place than what was anticipated with the birth of this child. The disability has brought Mara into a new and unknown world. This life-altering event is now incorporated and realized into the life of this mother. She has moved on to welcome all of the joys, unconditional love and meaningful accomplishments of her daughter.

Summary

Chapter IV presented my personal experience as a researcher and a mother whom has experienced the researched phenomenon. My personal thoughts and reactions of the process of the research were described. A paradigm case was also described in detail; this particular case was used as an exemplar for comparison of similarities and differences with other paradigm cases. A brief introduction to each mother was given to illustrate further depth and context to the text.
CHAPTER V

The Mother’s Experience of Having a Child with a Disability

This research has identified through conversations with 12 mothers caring for a child or children with a disability, what this experience evokes and what routine day-to-day life is like for these mothers. The research question was: What is the nature of having a child with a disability for the mother? Their vivid descriptions of this phenomenon are captured and presented through the emergent themes. The overarching theme of self-transcendence is presented.

The following themes emerged from the first two interview questions revealing the day-to-day experience of having a child with a disability from the mother’s perspective: (1) consuming blame while searching for an explanation for the child’s disability, (2) overwhelming cloud of not knowing in the search for answers, (3) striving to deal with unpredictable public perception in attempt to dispel the hurtful myth of having a child with a disability, and (4) experiencing complex and changing motherhood roles.

The mothers’ meaning of having these children with disabilities from the last interview question came forth as: (1) destiny preparing the mother to care for her child, (2) spirituality giving a deep inner dimension (3) experiencing appreciation of the greatest magnitude for a better life, and (4) becoming, a profound personal growth.

The overarching theme and meaning of this phenomenon is transcendence. Through the experience of this phenomenon, the mothers have transcended; they have excelled onto a higher plane of being. Life is experienced to its fullest in an unparalleled
dimension. The summation of the themes together, each individual theme lends a portion of the total data into the collective term of transcendence. Their stories are heartwarming and genuine; feelings were exposed so that the reader may partake for a moment what this life is like. These mothers have an enthusiastic sense about the human spirit and were able to share that with richness and wisdom.

The overarching theme of transcendence was validated by returning to 11 of the 12 mothers to confirm their thoughts on the interpreted themes. Mothers stated, this research has given words for “What I have felt in my heart for so long, but I was unable to communicate.” The additional usage of a poem, a popular song, and a mother’s own writing for a local newspaper, imparts the feelings that were experienced where words were inadequate.

Existential Investigation

Benner (1994) embraces interpretative phenomenology as concerned with the life world, temporality, embodied lived experience and meanings of everyday aspects of the world. A complete and meticulous understanding is sought with interpretative phenomenology. This understanding transcends to a deeper level, to discover deeper taken-for-granted meanings, practices, habits, skills, and concerns (Benner, 1994) that would otherwise be lost. This considers and incorporates the cultural and social nature of being human. It is posited that understanding is more powerful than explanations for prediction in the human sciences because it stands more fully in the human world of self-understandings, meanings, skills, and tradition (Benner, 1994).
The phenomenon and its context frame the interpretative project of understanding the world of the participants (Benner, 1994). Through this presentation of the mothers’ stories, with consideration to contextual factors so embedded in our humanness; a deeper understanding and therefore interpretation will be provided. The philosophical underpinning, that has guided and is equated with Benner’s methodology and lends structure to this dissertation, is a feminist perspective. A feminist perspective has given depth and structure to the contextual factors of the sociocultural expectations of society with respect to the social institutions of the family and motherhood, and special attention to caring for a child with a disability. Many aspects of feminism are woven into the fabric of the mother’s life world. This research supports and gives further depth to the social and cultural interpretative world of the mother.

To examine this phenomenon, of being the mother of a child with a disability, one must consider the many different lenses through which interpretation has taken place. It is postulated that life, in and of itself, is an interpretative event. We each accomplish this through our daily lives, to interpret and give personal meaning to the life events of being human. Thus, the participating mothers have already developed their own unique interpretation of this phenomenon. Intertwined with interpretation are the individual experiences we bring to any interpretation from which we have come to know ourselves. Another layer of interpretation evolves out of this researcher’s personal experience with the phenomenon. One cannot exclude this researcher’s personal experience, my own practical experience, or background knowledge. This is supported by the feminist perspective of this research.
Through a systemic analysis of the whole text, an introductory holistic perspective is presented of this phenomenon as the first step in hermeneutic interpretation for this dissertation. Benner (1994) indicates that the whole interview text is read for a global understanding of the story. Therefore, this researcher’s global understanding of the phenomenon will be presented prior to moving into a detailed analysis of the themes.

Global Understanding

The mothers have exhausting work, that of physical and mental work for their children on a continuing basis with constant involvement in their individual child’s treatments and therapy. They assume multiple roles, above and beyond the roles of the typical mother. Yet through the arduous and complex struggles, the pervasive love that is felt for the child and received from the child, makes it all worthwhile. Mothers focus on this perspective and this is what moves them forward each day as advocates for their children. They have dealt with complex situations with the health care team advocating for their child. It is a paradox of extreme joy and deeply felt grief.

Mothers have turned toward their religion to seek meaning and spiritual direction from having these children. Whatever the interpretation is, mothers having experienced the phenomenon have developed and derived a keen sense of appreciation for all of life’s smallest wonderful things.
Participant’s Experiences

The Mother’s Experience of Having a Child with a Disability

Four themes emerged from the first two interview questions, the mother’s experience of having a disabled child and what the day-to-day life is like for the mother. The emergent themes and subthemes will be presented with exemplars according to Benner’s (1994) methodology.

Consuming blame while searching for an explanation for the child’s disability

Feelings and thoughts of blame emerged with the interviews of the mothers with many different focuses of blame. Three subthemes of blame emerged through the interviews: self-blame, blame toward the health care team, and blame toward God. Please refer to Appendix G for the representation of the mothers’ statements with the themes and subthemes.

The first subtheme of blame, self-blame, implies a of holding responsibility or personal fault that the participant mothers feel in reference to their child’s disability. In several participant mothers, the transference of a gene, as diagnosed by pediatric geneticists, was responsible for the diagnosis of the syndrome. Consequently, these mothers had the dual emotional circumstance of having the child who is disabled and the realization that her genetic heredity was transferred with conception and is the direct result of the child’s disability. Statements from the mothers represent this notion. Susan described her initial reaction of her son’s diagnosis with Fragile X syndrome. (Her son was first incorrectly diagnosed with Cerebral Palsy).
The day we found out he had fragile X was the worst day. It was much worse than the Cerebral Palsy because of the 50/50. Oh, yeah, there’s definitely some guilt in there. You know especially since it came from my… I know there’s nothing I could have done but I wish I didn’t have the gene.

Another mother, Allison, described her self-blame as related to her potential genetic flaw with her undiagnosed child. The genetics team continues to investigate this child since her daughter’s diagnosis remains unclear. Her description of potentially passing on inferior genes is disconcerting. This discomfort is accentuated with physicians questioning the mother regarding family plans of future children. This situation promotes a sense of fault and potential blame.

You know, you have this guilt feeling that you know some how you have inferior genes that you’re passing on. Whereas, if it’s genetic and hereditary then you’re passing bad stuff on which makes you worry. And also, some geneticists have said to us, are you planning to have any other children? Because they want to know whether or not you’re going to perhaps produce another child with the same problems.

Michele, the mother of a child with Angleman syndrome described this genetic dilemma as “a father can’t give it to the child, the Angleman syndrome, but the mother can. That gives a very high percentage rate of being handed down.”

This similar thought was expressed with Caroline; “it’s apparently passed by a recessive gene, a spontaneous mutation.” Although one of Caroline’s twins was diagnosed with Netherton syndrome, the other child is developing typically. The
consuming blame of this mother is accentuated concerning the current mortality statistics (70%) of children with Netherton syndrome who die in infancy from the high probability of sepsis.

The genetically linked syndromes of many children in the research were confirmed based on genetic testing from the mother. Taylor, a mother with an undiagnosed child, continues diligently to visit a pediatric geneticist every six months. Although genetic testing has been inconclusive with Taylor’s son, the pediatric geneticists believe they may be able to eventually diagnose her son through clinical observation, therefore the need for frequent visits. This mother believes that someday the medical field may have a cure for the undiagnosed syndrome of her child; in addition, other children may be helped “down the road.”

Another segment of this theme that emerged was the mothers voiced self-blame in regard to their physical activity prior to or during the pregnancy. Although the mothers stated multiple reasons, the physicians supported none of these statements. “Why?” was a repeated question of all mothers. Many mothers blamed and related this to specific events during the pregnancy and the delivery. Susan stated, “was it the bath too hot, was it the tennis I played in my first trimester, was it the epidural because I’m selfish for pain relief and I couldn’t push effectively and I needed a vacuum?” Mothers searched for reasons of potential cause or contribution to the child’s disability. This is a prevalent female tendency of mothers, to center their lives on the well being of their children and taking complete responsibility for the welfare of the children even prior to the birth.
Taylor’s son remains undiagnosed at the present. Her focus of potential blame upon herself related to her age, 44 years, and a miscarriage just two months prior to the conception of her son. Her physician told this mother to wait at least 2 months before attempting another pregnancy. Her thoughts focus upon her potential cause for her son’s undiagnosed disability. Taylor states,

I thought I was taking those precautions and on the second cycle I got pregnant.
So I questioned that. Is it my age? I’m a late mother, you know, ah. You know I had people saying how come amniocentesis didn’t show anything? Did I conceive too early, you know. What did I do in my pregnancy?

So many unanswered questions. In this situation, an integral part of mothers turned inward toward them and attempted to take on responsibility for the events that took place prior to and during their pregnancy that may have preceded the child’s disability. The mothers were searching for answers. This is supported in a feminist framework in which the mother feels she is completely responsible for the welfare of the child. This self-blame focuses upon the mother’s actions or lack of action with the child.

Alyssa described her overwhelming feelings and regrets during the first week her infant daughter was seriously ill and managed at home. It is evident by this conversation that she regrets not being more assertive with the physician regarding admission of her daughter for intensive respiratory management. Her emotions were tangible during the interview. Women have difficulty in establishing their authority, and receiving sufficient information to make informed judgments about health care (Sampselle, 1990). However,
being the mother of an infant girl, this mother did not know what to expect, and therefore tried diligently to manage the child’s illness at home upon the pediatrician’s advice.

I should have put her in the hospital a lot sooner. I should have been more aggressive with my doctor about saying I don’t feel comfortable at home doing her nebulizer treatments around the clock. Where I was setting my alarm and getting up and doing all this where I was physically exhausted. But I just should have really put my foot down and said this is enough. I’m having a hard time with that right now.

A single mother of five young children, Yvonne, went through the process alone of her child’s diagnosis of meningitis and subsequent long-term care of her child alone. Yvonne stated, “And you feel like you did something wrong and then you find out you didn’t do anything wrong so you’re still like well, what happened?” Her inward and overwhelmed feelings regarding the responsibility of her child’s diagnosis remain evident. There remains a thread of self-doubt and aloneness.

With the added mothering roles for the child with a disability, mothers blame themselves for the lack of attention toward the other child or children within the family. Allison an elementary school teacher, projects her self-blame with her other child’s lack of educational progress is projected,

And he needs me and wants me and I can enjoy him. And I can teach him things, he’s very bright and I just had always thought that, you know, at this point I thought I could have taken him much farther academically, then he is at this point. If he had been the only child, I know I would have had him reading this summer.
The second subtheme of blame that emerged toward the health care team. Questions to physicians with the delay of six months with the diagnosis of Taylor’s child centered upon, “how come this wasn’t picked up before and of course I didn’t get any clear cut answers.”

Caroline’s child also had an 11-month delay with establishment of a diagnosis. Mothers became more skeptical, apprehensive and restless with a lengthy delay in the diagnosis. With this delay, blame was focused toward the health care team. Caroline explains, “She (her daughter) never even regained her birth weight, and nobody knew why, they were fritzing around with her, they had no clue.” It is a fact that many diagnoses are not clear and straightforward. However, the lack of communication and aggressive treatment for their children frustrated these mothers. There was a void of thorough and mutual communication.

Allison’s child currently remains undiagnosed. It is her belief that physicians do not feel comfortable with her child, the lack of a firm diagnosis perplexes the health care team. Her reflection was,

I felt that everybody was incompetent. Nobody cared about what was happening to this kid. The neurologist came once. The pediatrician never showed up. They were all working out of the Medical Center. They knew we were there. Why didn’t anyone come to see her? I was going to have a nervous breakdown because no one was paying attention to us. The pediatrician was giving us trouble about coming in and having her blood pressure checked. And he really didn’t know
what he was looking for. And I think I said this before, she makes a lot of medical professionals look stupid. So they don’t want to be involved with her. Because they don’t really know what’s going on and they’re used to being pretty smart guys.

Alyssa had several confrontations with physicians. Her frustrations and fear are evident. This mother felt the physicians were mismanaging her daughter,

I want to get out of this area, because by this time, now with her seizures I have this neurologist, I’m not very fond of, who um, medication, medication, medication. Then I have this eye doctor who’s telling me that she’s gonna be blind.

Mothers voiced their thoughts as to the actual and potential incompetence of many physicians who treated their children. A lack of confidence with the typical patriarchal local physicians prevailed; therefore, several mothers requested their children to be transferred to a tertiary hospital center. Through this experience many mothers became increasingly and appropriately assertive with the health care team for their children.

The final subtheme of blame emerged from mothers with prevalent religious backgrounds. They placed the blame toward God; it was God’s action that my child has a disability. Nicole lost her first child to meningitis; in addition, she was the only mother who had a prenatal diagnosis of Down syndrome. Her thoughts of blame toward God focused upon,
I just felt that because, well it kind of stems back from when I lost my first child. You know I had that just a terrible feeling that I was being punished because how could God take my child away from me? And then trying to get through that and then finding out that my child had Down syndrome I felt like it was just like another thing. Another whammy, I felt that God is definitely punishing me for something I’ve done in the past.

This mother had a terrible feeling of spiritual punishment. This feeling appeared in respect to this mother’s previous devastating experience of the death of her first child and then the diagnosis of her second son with Down syndrome.

Barbara is another example of directing blame toward God. Her first two children have disabilities. During Barbara’s second pregnancy, her sonograms of the baby were abnormal, and the survival and potential diagnosis of the baby was uncertain, “what did I do wrong, why is this happening, God why are you doing this to my child?” Her focus was not upon herself, but the welfare of her unborn child.

Concluding, Susan felt the experience of having her son has brought up many provoking thoughts. She states she is agnostic, yet makes the remark, “the whole question of if there is a God, why would God give me a child with special needs and why would he make children out there that have special needs?” Susan attended a service of the Buddhist faith, and had a discussion with the religious leader regarding the potential good or bad karma of having a child with special needs. Through discussion with the Buddhist leader, she came to the conclusion that a child with special needs is not bad karma for something done in the past, but it may be from good karma, or that her son volunteered
for this disability to teach us. All of the aforementioned vivid descriptions support the placement of consuming blame of self and others while feeling a sense of responsibility for the disability.

Overwhelming cloud of not knowing in the search for answers

The overwhelming cloud of not knowing was prevalent in most of the mothers’ conversations of their lives and children. An example of some of the statements to give intensity to this theme are the following: “We were digging for information”, “it was unpredictable, you just never knew”, “we didn’t think she would make it” and “we still have no answers.” Three subthemes emerged with the overwhelming cloud of not knowing in the search for answers; the undiagnosed syndrome, lack of information, and the uncertain future.

Not knowing refers to the lack of available medical information on the child, not being thoroughly informed by the health care team, or the lack of knowledge. Many mothers have children who remain undiagnosed, or a syndrome that has not been confirmed by geneticists at the present time. Not knowing also refers to lack of information during the frequent hospitalizations. Either terminology was used that the mother did not understand or there was total lack of pertinent information. This category also encompasses many acute episodes of not knowing if their children would live or die during a critical period of the child’s illness. The mothers’ statements with derived meanings, the theme, and subthemes are located in Appendix G.

The first subtheme of overwhelming cloud of not knowing is relevant to not knowing a diagnosis for their child, the undiagnosed syndrome. Mothers expressed that
they didn’t have a clear sense of direction, there is a lack of pertinent information, and this lack of diagnosis presents difficulties with insurance coverage. One mother, Michele stated, “You need to know, I think it (a diagnosis) gives relief, it does open doors, it gives you people to belong to.” This same mother described a profound description of a physician’s usage of the term syndrome; “He just left this huge empty word (syndrome) in front of me.”

Taylor has a similar situation. The geneticists are not able to firmly diagnosis her son. Her explanation of this is, “There’s nothing she could tell me except it was some kind of connective tissue disorder, ‘he has tendencies toward a syndrome that I’m not capable of diagnosing,’ I just had to come to grips with the fact that I, we, may never know.”

Barbara is the mother of two disabled children; there were many positive and negative episodes with establishing the firm diagnosis of her second child’s syndrome. She stated, “it’s the unknown, not knowing where she will be at, what she will be able to do because I don’t have anyone to compare her to see if she will do this or that.” Alyssa compliments this statement, “She does have brain damage, but to what extent I don’t know, I just never thought her future was gonna be like this.” Alyssa must deal with total uncertainty with the physical and cognitive outcomes of her daughter. There is no potential prediction as to the future capabilities of her daughter. Ultimately, Allison stated “I don’t know where we’re going. I don’t know what we’ll be doing a year from now or two years or five years from now.” The mothers have to deal with the unknown on a daily
basis presenting additional stress, fear, and uncertainty. The difference of not knowing pours into every aspect in the mother’s life.

A second subtheme emerged from lack of information concerning the child. With a seesaw of lengthy hospitalizations for many of the children, mothers were approached on numerous occasions to inform them that their children may die. Not knowing if the child would live evoked intense feelings of sorrow. There is such a paradox of joy and then grief. Alyssa’s experience of a near-death episode with her child stated, “We didn’t think she would make it, (voice choking) and then I remember I was in a room with her all by myself and she was like turning blue and I was like, what’s going on?” Alyssa voiced another descriptive statement reflecting not knowing if her child would live as she was overwhelmed by emotions, “just tell me the God’s honest truth, is she gonna make it? Or is she not gonna make it? I need to prepare myself. And I remember I just went into the hallway and broke down.” This mother did not have complete medical information on the child’s condition and this unknowing was complicated by the near death episode.

Yvonne’s daughter had meningitis, the prognosis was grim, “Oh my God, what am I supposed to do now, she was here today, gone tomorrow, like you don’t know what to do. I was very scared, I was just crying a lot.”

Due to the loss of a previous child to meningitis, Nicole’s concern focused upon not knowing the complete health and potential severity of the child with Down syndrome. She states,
I didn’t know what to do, it’s the anticipation, and I didn’t know what to anticipate. And I would read and read, you know all these books. I was really trying to figure it out. I wanted an answer and I wasn’t you know, getting an answer.

Allison had serious concerns with the lack of information physicians would share regarding the diagnosis of her daughter. She would frequently argue with her husband regarding this sensitive issue, “Why didn’t you ask him this. He gave no information unless he was asked a question, he gave no extra.” This lack of information presented for an increasingly stressful and nerve racking event for this mother, not to know and not to have enough information on her daughter’s diagnosis. This mother eventually sought information from the Internet for her own education and treatment directions.

Throughout the process of securing a firm diagnosis with the health care team, there was significant lack of thorough communication. Allysa reflects on this situation, “They never bring you like in another room, or just sit down and like maybe explain something to you.” Not knowing potentiates stress levels, placing the mother in an unassertive position with a lack of information that she can act upon and reducing her power over her environment.

The third subtheme of not knowing stems from the undetermined, uncertain future of the child. There is acknowledgement of not knowing the future on the part of the mothers; descriptive terms used by most mothers were the following: the long road… or the long haul… signifying a visual picture of an unpredictable future. Mothers voiced the concern of not fully knowing the future implications of their child’s syndrome and they
prefer to live in the here and now. Nicole’s husband was reading an article on
independent housing for young adults with disabilities and wanted to share this with her.
Her response was, “but I couldn’t continue to read the whole article, I wanted to take it as
it comes and as I’m able to deal with it. And it was great, it was very, you know, great,
but I can’t go there yet.” This mother prefers to stay focused and live in the present.

In contrast, Michele’s thoughts focus on her child’s transition toward independent
housing in the future. She claims, “We need to let her go because we hold on tighter, we
need to take the steps to let go, so that when it’s time to put her in the group home, it’s
not, it’s more this is where we’re going.” Letting go in the here and now will make letting
go more comfortable in the future. The little steps are actually big steps with this mother
and child.

One mother talked about a dream of her child in the future at school. Her dream
focused on a predicament with her daughter with a disability in a school setting in which
children were making fun of her; she was just standing in the corner crying. Mara stated,
“I just get myself so worked-up about when I’m not gonna be there, and that’s of course,
another set of issues as our kids get older.” This mothering and protective feeling is
accentuated with the vulnerability of these children. The unknown treatment of our
children within the public arena is a concern to the mothers.

Lastly, not knowing the future has impact upon family functioning, with special
attention to family recreation. Allison stated her disappointment with this; “will we ever
get to go on a vacation? Will I ever get to put my kid on the rides in Disney World?” The
cloud of not knowing permeates all areas of the life of the mother. The respective
examples of the mothers’ significant statements support the theme of the cloud of not knowing.

**Striving to deal with unpredictable public perception in attempt to dispel the hurtful myth of having a child with a disability**

The first subtheme of striving to deal with unpredictable public perception in attempt to dispel the hurtful myth of having a child with a disability focuses on public perception. Negative public perception refers to how the children are different in physical and mental abilities from what is considered normal in our society. Children with disabilities are unlike typical children, whether it may be due to physical characteristics or behavioral characteristics, these differences draw the attention of the public. Our sociocultural expectations of normal are difficult for one mother (Susan) to deal with, particularly when the diagnosis was new and emotions raw. She grieves the loss of the perfect child she was anticipating. Susan talks about the loss of her hoped for perfect child, she is in a different world:

I just needed to cry, you know. Cause, as you know, you’re mourning the loss of the child you wanted, you thought you would have. It’s a whole different world, so I said you just have to let me be upset and I will come to accept it.

Descriptive statements within this category include: “I thought the public would think she was a freak” … “They were always staring at her.” This public perception produced powerful emotional and hurtful feelings for the mothers.

Mara described her perception of an adult with Down syndrome as, “the barrette, the pocketbook, the Mary Janes at age 45, that awful stereotypical image that we all see.”
This vivid description continues to be a perception held by so many in the public and the mothers stated that they are acutely aware of this.

One mother took the opportunity to use her writing talents to educate the public. Kathryn wrote an article for a local newspaper column entitled *Turning Point* (Appendix K). The intent of her article was to help educate the public from her personal viewpoint that having a child with a disability is not the perceived horrific situation, but a positive experience. Kathryn stated during an interview,

I realized you know, maybe that is the way to get through to people is by writing,

It was called *Turning Points*. I wanted to explain that it’s not as bad as people probably thought it was to have a child with a disability. So I thought maybe it was to help to dispel the myth about Down syndrome.

Two mothers of infants with Down syndrome took the special opportunity to include descriptive poems about disabilities in the child’s birth announcement as a means of communicating and educating their positive thoughts for friends and families.

Michele had very similar thoughts with regard to public perception. She talked about, “It’s always worse to someone else, it’s all perception”. Michele was very emphatic with her thoughts that although the public perceives this situation as hard and the days long and physically exhausting, the rewards they reap are plentiful and outweigh any negativity.

Mara stated, “Walk a mile in my shoes before you make a judgment.” The public makes the assumption that having a child with a disability is a dreadful situation; these mothers continually strive to change this assumption.
The second subtheme is focused upon the perception of the health care team with a child with a disability. Mothers often commented on the insensitivity of the health care field with respect to children with disabilities. Mara spoke of a neonatologist who entered her room soon after her daughter’s birth to inform her of the suspected diagnosis of Down syndrome. ‘This is unfortunate; this isn’t what you planned; this is too bad’, was the statement from the doctor. Mara was hurt and angry, “I felt cheated, something was taken away from me that day. I felt cheated. I gave birth and they took that away from me” she continued on, “what they did, I can never get back, and that, that will bother me forever. I feel that that’s insensitivity. I’m still a mother and she is still my child, and there’s a bond.” This particular chief physician was accompanied by seven residents, surrounding this mother as they informed her of the potential diagnosis of her newborn daughter. Perceptions of health care professionals, according to mothers are negative in general. This initial interaction can set the tone for the future perception and behaviors of the mother.

Kathryn supports this subtheme with her initial experience of a physician informing her of the suspected diagnosis of her daughter’s Down syndrome. The physician in this instance emphasized the positive future capabilities of her daughter. He was confident in his presentation, and as a result her statement was, “In fact I didn’t want him to leave.”

The public’s misperception and lack of understanding can reach down as far as the immediate family. Allyssa’s sister responded to a comment from her that her daughter would be trying to walk soon. In response, her sister bought a typical walker for the child.
Allyssa’s heartfelt response was “Look at what she gave her (the daughter), she has no idea. And this is my sister, one of my sisters. She has no idea what we’re going through and this is just proof.” It was not that this purchase was insensitive, but the sister has minimal comprehension as to the specialized supportive walker this child needs and the full extent of the child’s disability.

The situation of negative public perception is compounded when the public stares and expresses insensitive comments. Mara comments, “People will stare sometimes and I will, I’ll just say, God isn’t she just so dammed cute, you can’t take your eyes off her can you?” Mara had a specific example of the public perception with an insensitive comment, “The A&P, the Acme or Foodtown, how lucky you are because your daughter can pick which ever one she wants to work for when she grows up.” The hurt remains as these mothers are continually reminded by the insensitive public of the difference that exists about their children. It is a degrading and demoralizing experience; mothers are bonded to their children and derive pleasure with the successes and the societal acceptance of their children.

On the contrary, two mothers specifically spoke of positive public attraction to their children, the genuine fascination and appeal. Mothers described this interaction with their children as a magnet, or people gravitate toward them. Yvonne describes her interaction with the public in the mall; “She’s like a magnet to them when we’re in the public.” Nicole had a similar experience,

There are so many wonderful people out there that do just whatever they can do to interact with him, no matter where we are. And we just get so much attention
from people, like I said a perfect stranger; they’re gravitated to him no matter
where we are or where we go.

Experiencing complex and changing motherhood roles

Having a child with a disability necessitates increased and changed mothering
roles on a daily basis. The first subtheme related to experiencing complex and changing
motherhood roles is role strain. Through an early intervention program all mothers were
taught how to perform occupational therapy, speech therapy, and physical therapy as
appropriate for each child. The therapists would guide and encourage the mothers to carry
out these therapies during the week for greater exposure and continuity. However, as the
additional therapy is done, it increased the roles and stress felt by the mother. Women are
placed at a disproportionate risk for stress as a result of multiple role demands
(Sampselle, 1990).

Mothers have a natural tendency to center their lives on the well being of their
child (Feminist Ethics, “n.d.”). The mother carries the primary responsibility for the
welfare of her child in addition to the welfare of the family unit. She is seen as the sole,
and most important, individual to foster the child’s growth, socialization and training in
accordance with societal norms (Feminist Ethics, “n.d.”). In addition, the mother
generally assumes the majority of responsibilities for the care and nurturing of the child.

Taylor questioned her ability to do and follow through on the recommended
therapies. "You know you'd get these little instructions and I'd say I don't think I'm
qualified to be doing that you know. Am I going am I doing it right or am I doing it
wrong? Is it beneficial?" Mothers questioned themselves about proper procedure and
follow through of the therapies. Therapies need to be done frequently and are very time consuming. Mothers spoke to the problem of how multiple therapies can be very costly. Allison spoke of this,

Now I have this little girl who is a lot of fun to dress up and I do her hair and I buy her clothes. But that's where the fun stops. I mean, I'm taking her to the therapists, I'm here, and I'm there. I'm all over the place. You should see my calendar; you wouldn't believe what it looks like every week. This week I have four therapies for her. She falls asleep right in the middle of some of them. She's cranky for others. And that's a problem too, it's a lot of money out of the window. You know it's, you know it's the bills that are just ridiculous.

Considering the multiple additional roles the mother assumes for the child's welfare, many mothers have been forced to leave their previous employment. This predicament causes a decrease in income for the family. In addition the financial stress is accentuated with multiple medical bills. Michele stated that she had great difficulty with medical insurance coverage due to the fact that for many years her daughter did not have a firm diagnosis.

Mothers questioned frequently the husband's lack of involvement with the therapy. One mother said, "Why am I the only one doing it? (therapy) You (speaking to husband) come home from work; you're holding him. You can, you know, bend his feet you know like the way we're supposed to do that loosen the arches."

Another aspect of these complex and changing roles is the physical limitations of the child place a tremendous physical strain on the mother. These children are totally
dependent on their mothers for activities of daily living, eating, dressing, or bathing. It is a physically demanding situation with excessive physical involvement from the mother.

One mother stated,

My daughter is almost three. She does not walk, she does not crawl, and she cannot sit up independently by herself. So it's me, constantly you know picking her up. But she's totally dependent on us; but you know I have a five-year-old boy. He's constantly on the go and some days it's really, really hard. And I feel I should be doing more with her. I don't have a cleaning lady so I still have to keep up with your cleaning, laundry, everything else. I try not to have my son see that we always do so much therapy.

One of the mothers, Michelle, spoke of the everyday physical demands of having a child who has poor motor skills and is unable to independently perform the normal daily tasks for her. It is also a safety issue with her daughter.

But she's more physical demanding. We have gates up. I can't let her go roaming the kitchen because things will be thrown. There's a gate in her bedroom because I can't have her roaming the house at night if she does get up. She can't, you know, if she starts screaming you've got to sit there and figure out what she's screaming about because she doesn't have verbal communication. She's not potty trained, so you're still dealing with diapers. Still dealing with changing of her. You know, you have to feed her, dress her, and feed her.

This mother is just relating what day-to-day life is like having her child and how physically demanding it is. In addition to the physical requirements of moving and
picking up children with no motor function, the mother has difficulty attempting to balance everything with the normal requirements of running the household. Mothers talked about the challenge of balancing time with other children, which necessitates continual adaptation, adjustment, and compromise.

Another aspect of role strain is the difficulty with complex schedules, the scheduling of multiple doctor and medical specialists visits. Most mothers talked about how their schedule is just constant, it is constant involvement with therapies and physicians.

Another aspect of the additional and complex female roles is the paperwork generated by the responsibility of having medical records ready for new consultations with physicians. Mothers would copy medical records, partially for their own knowledge and review. Caroline commented on the amount of time and paperwork regarding applying for and justifying insurance claims. The mothers felt it was very disheartening to constantly argue with insurance carriers to obtain necessary services for the child. These additional roles added to the stress of the existing situation of juggling family demands.

The second subtheme regarding mothering roles is the inability of the mothers to work and care for their child. Ten of the twelve mothers interviewed had given up whatever type of employment they had following the birth of their children. This is a cultural assumption of the female role, that the mother will automatically take responsibility for the near total care and raising of the child (Landsman, 1998). One mother, Caroline, who had a lucrative, powerful position that involved overseas travel
stated, "It changed my whole life, I couldn't work if I wanted to because my daughter gets therapies four or five times a week. We still have to tube feed her at night because she needs a lot of nutrition." This mother is unable to work due to the multiple therapies and nutritional requirements that are maintained in the home for the child.

Katherine felt it was her responsibility, her role, to perform thorough research on her daughter's condition. She took it upon herself to bring the most current growth charts and medical checklists regarding her daughter's Down syndrome to her pediatrician who is fairly well known in the community. The mother took it upon herself to educate herself and seek the information that is most current. She, in turn, educated the child's physician as to these current documents.

The Mother's Meaning of Having a Child with a Disability

The second set of interview questions addressed the meaning of the experience of having a child with a disability from the mother's perspective. Four additional themes emerged from the mother's stories focusing upon the meaning aspect of caring for their child.

Destiny preparing the mother to care for her child

The first theme, with no subthemes, the mothers used to describe the meaning of having a child with a disability was that of destiny, a destiny that prepared the mother to care for her child. "Destiny is defined as the predetermined course of events or fate" (The Oxford Dictionary and Thesaurus, 1996, p.385). Some mothers believed events in their lives are pre-planned by a "higher power" and that they have no influence over how or when these events take place during their lifetime. Susan described destiny as the
following, "So sometimes it feels like was this the life I was supposed to have led." And Yvonne described destiny as "I thought it (my disabled daughter) was my wake-up call."

Other mothers described events earlier in their lives that they felt demonstrated their destiny to be a mother to a child with a disability. Katherine related her experience working as a teenage camp counselor for children with disabilities. The majority of the children she worked with at this camp had Down syndrome. She felt strongly that she was guided to this job, which would help her gain precious insight to the capabilities of children with Down syndrome. This experience helped to meet her destiny as the mother of a child with Down syndrome. In addition, she stated that she had a premonition earlier in her life. Katherine prayed when she was growing up. "I'm the oldest of six children. That if any one of us had to have a handicapped child, I hope it would be me. Because I knew that I would never… that that would be fine."

Another mother, Shannon, also related back to her experiences in childhood that prepared her to take care of a child with a disability. Growing up, she lived near a boy who had Cerebral Palsy and another child who had Down syndrome. She stated that she had always felt very comfortable playing and caring for these children. Shannon quotes from a conversation with her father, "You were always there to help. Don't you think God knew you were the helper? Don't you think that God destined you?" Shannon continued, "For some reason, I tell my husband this. When they came in and told me my child has Down syndrome, I felt like it was destiny. It was my destiny at that point in my life, there was no one left for me to take care of. Someone needed my help."
Katherine and Shannon did not experience the initial feelings of devastation and
grief as their daughters' diagnoses were revealed. They both conveyed they truly felt that
the previous preparation in their lives played an important role in the acceptance of their
children without the emotional turmoil. They believed the preparation in their childhood
was destiny.

Another mother of a Down syndrome child, Mara, related how her mother
reminded her,

You know the one kid in the class that everybody made fun of and I'd say, could
she come home to dinner because everybody is mean to her? You know that kind
of stuff. Though I've just had a soft spot for things. Whatever the thing was, it
never mattered what it was. I tended to gravitate. I have a soft spot for those
things. I don't think this was an accident. I don't. You know, so I think that it does
take special people. And I used to say; I'm not special.

These mothers derived the meaning of having a child with a disability by
reflecting upon into their own childhood. They felt that somehow there was a plan. They
had been prepared previously in order to take good care of this special child and to accept
the diagnosis. Yvonne stated that she cared throughout her childhood and teenage years
for her aunt and mother who both suffered from Diabetes. She felt that this experience
and the medical knowledge she derived from it gave her strength and direction to care for
her child with a disability.

Mothers believe that sharing their lives with and caring for a child with unique
needs is their destiny. They feel that experiences they had throughout the years leading
up to the birth of their child was a logical succession of events that prepared them to care for these children. And, for the most part, they expressed their gratitude to have been selected, "destined" to be given these special children. "I am so fortunate to have this child"... "It is my fortune." And they feel their lives are exceptionally enriched as a result of life with these children.

According to the Oxford Dictionary and Thesaurus (1996), destiny also refers to the term in the Buddhist faith, karma (p. 817). One mother sought the advice of a Buddhist leader regarding her son's disability. During the conversation with this Buddhist leader, the discussion led to the potential role of either good or bad karma with her son. He said that all of the wonderful and fulfilling aspects of life that your son has brought to you, only good karma or destiny was applicable.

**Spirituality giving a deep inner dimension**

The second theme that emerged from the question "what is the meaning of having this child with a disability?" is that of spirituality. Spirituality gives a deep, inner and reflective meaning to this phenomenon. Spirituality can be described as concerned with sacred, religious holy things (Oxford Dictionary and Thesaurus, 1996, p.1467).

The first subtheme of spirituality refers to mothers describing their faith in God. Many mothers specifically used the word "chosen" or "privileged" while describing this meaning. Alyssa said, "God chose me that I am somebody special that he wanted to, me to have my child." Nicole states, "we’re one of the privileged, we have such a wonderful child and that’s what we needed." These mothers state they have been chosen by God; they have been honored or favored by God to take care of these special children. This
belief is also reflected in a poem entitled, *Heaven’s Special Child*, (Appendix L). It is evident by this poem that this belief of being chosen by God reaches into the depths of one’s faith to give meaning to having a child with a disability.

Many mothers derived meaning through spirituality by not truly knowing the reason for this child, but putting their utmost faith in God. God would give them direction and a focus for raising this child. Alyssa specifically talked about how she felt that this was God’s plan,

> You know God, I don't know, there must be somebody very special out there that you want us to meet. I don't understand what you're trying to tell me now, maybe one day I will. Right now I don't know. I honestly, I don't, I don't know what you're trying to tell me, but I'm ready. Whatever it is you have in store for me, I will accept it.

The mothers had an incredible faith that they felt that this child was a gift from God. Gifts are given to chosen people and one chooses who will receive a gift. Kathryn described this gift as, “I don’t know what I did in life so right that God gave me this child and other people didn’t get one.”

Mothers related to this phenomenon as their chosen job, their calling, to do the best and provide the best possible life for this child. Barbara talked about this, “I ask God why is this happening, but I know there’s a reason behind it. It’s my job to… He’s given to me these challenges and he expects that I’m gonna be able to handle them.” She continued on, “I can’t imagine people getting through anything like this without believing there is someone guiding them, there is a purpose, things are a test sometimes.”
Spirituality gives the mother a focus in which to guide them through the daily challenges of having a child with a disability.

Nicole described her pure and positive spiritual feeling the child gives her on a day-to-day basis. Initially there was confusion for this mother; she was confused that God was punishing her again. She could not understand why she had suffered the death of her first child, and then her second child has a disability. But she states, "He is an angel. On a day-to-day basis he is such a joy. Such a joy to our lives. He brings so many other people joy too." She went on to describe,

It's the most incredible feeling. A total spiritual feeling and I couldn't see it then; well, I totally see it now. He (God) gave me my child because my child can give me so much love. He is a true gift from God. We were lost for so long and then he was born. He brought so much joy back into our lives.

The second subtheme that presented with spirituality was the mothers' description of their children's angelic qualities. An angel is a messenger of God, having a sublime beauty or innocence (Oxford Dictionary and Thesaurus, 1996, p.51). Allyssa said, "my little miracle, my little angel. She is my guardian angel."

Shannon described other people's reactions to her child when she was hospitalized in the neonatal intensive care unit. Other people frequently remarked to Shannon, "She's just an angel. She looks --- God if she had wings she'd be an angel. She looks so peaceful, she just looks like an angel."

Innocence was also used to describe children with disabilities. The purity and innocence, the everlasting innocence that these children display is part of the basis for the
usage of the term angelic. Michele refers to her daughter in Sunday school, "first of all, with their minds, how much purer are they going to get?" These children do reflect the term innocent; that of free from moral wrong, simple, and naive (Oxford Dictionary and Thesaurus, 1996, p.770).

Most of the mothers related and expressed this sentiment. It seems that the mothers, when they were most in need, turned to their religion or faith to derive meaning and direction. The children introduce another dimension to our lives, teaching compassion and much patience. Multiple mothers spoke to this, the child with a disability actually teaches us the true importance of life, what really matters. They teach us a deeper and different dimension of appreciation and love. This phenomenon has enlightened these mothers. These children have given them a spiritual insight that was not realized before their births.

**Experiencing appreciation of the greatest magnitude for a better life**

The third theme that emerged from the interview question with respect to the meaning of having a child with a disability was appreciation. The first subtheme presented is appreciation is magnified.

When mothers were asked the meaning of having these children, mothers experienced appreciation of the greatest magnitude for a better life. Mothers described in detail how they have a different dimension of appreciation since having this child. Mothers commented, "Without this disability I would have missed this. I would not have experienced this profound appreciation." Appreciation is magnified and celebrated, especially with the smallest accomplishments of the child, to realize the small steps are
really gigantic steps. Michele said, "How much easier my life would be with a regular seven year old. But then if she were a regular seven-year-old without this, would I appreciate it as much? And that's the big difference."

Kathryn explained, "Of course she's taught us all the typical things. To slow down and take everything, you know, 'one day at a time'. And things mean so much more because it takes her longer to accomplish things."

Barbara speaks to this appreciation, "But I do appreciate even the littlest things. When they can feed themselves. When they can even help me putting their arm in a shirt or something. Where if this wasn't happening (this mother has two children with a disability) would I appreciate the hug as much? I'm not sure"

Nicole explained her experiences with her son's accomplishments. "When he does the smallest thing, I'm just, I'm so elated. I can't even tell you how I get excited over the smallest thing that he does." She goes on to say, "tonight he said 'Mommy'. And that was the first real 'Mommy' that came out of him, and I just wanted to cry." The mothers greatly value the accomplishments of the children, they are very sensitive and acutely aware of the diligence these children must experience to accomplish even the smallest task. Life is not taken for granted at any moment of any day.

There was another dimension to this appreciation. Mothers spoke about the true appreciation and value for acts of generosity and kindness from others. The mothers stated support from others was, at times, overwhelming. People reacted in a positive, caring manner and just wanted to help in any way possible to support the mother and her family. Michele says. "You appreciate more. Appreciate what other people do for you.
The people that do go the extra mile for you. And that the people that do make it easier for you." Kathryn explained following the birth of her daughter that is disabled, "Everybody was so wonderful. Like our friends, our neighbors, people we don't even know. We had dinners for eight weeks, every single night. We had people staying with us. It was just unbelievable."

Another aspect of appreciation was that mothers had a change in perspective of what is really important in day-to-day life. They had a completely different perspective about meaningful priorities following the birth of the children with a disability. Caroline commented, "[I am] a mother who realizes the things I thought were important are really not that important any more." Shannon added to this, "You see people differently. It's just really, it's an eye opening thing." It seems these mothers had a fuller dimension to the value and their interpretation of the world. Taylor states, "Sometimes it let's me put things in a different perspective. Because I'm not the most optimistic person on the planet. Who cares if you're having a bad hair day? Because in the scheme of things, it doesn't really matter" The group of mothers caring for children with a disability compared themselves to mothers with typically developing children. One thing that stands out, which is evident in their comments is that they feel other mothers do not realize what matters in this life and what is truly important. Their perception is mothers of typical children don't have the important priorities in life in proper perspective. "I mean they're (other mother's with children with a disability) not preoccupied with what kind of a stroller you have and stuff that just seems petty."
There is a paradox in appreciation. Actually mothers voiced the opinion that it is the child who teaches us. The child teaches us the true value of this life and within a temporality context to live in the here and now. To appreciate life today for the beauty of what it is, and should be. To live each and every moment to its fullest. A mother said, "She has definitely taught me a lot about life. Life isn't perfect and so wonderful at times. But you know what? It could always be a lot worse. You're thankful for what you have. She makes you stop and smell the roses." The focus is on the good in life, to dwell on the positive and count each blessing.

The last aspect of this subtheme of appreciation is one that the children emanate unique wonderful, peaceful feelings of joy to mothers. They just have such indescribable positive feelings of delight and happiness with these children. Mothers talk about this joy permeating into their family and close friends. Mara explained, "She's wonderful. I mean she has touched everyone. She has touched our entire family." One mother described this feeling of joy. Nicole's statement was, "we were lost for so long and then he was born. He brought so much joy back into our lives." She continued on to say, "It's incredible. It's a complete and utter joy. I worship him, we worship him. A feeling that's indescribable. I couldn't see it then when I was caught up in the whole thing, but it's just so clear to me now."

The second subtheme, a prevailing sense of unity exists between mothers; a commonality is prevalent with other mothers caring for children with disabilities. Mothers' expressed that they felt comfortable and, they could relate genuinely with each other because of the many elements of common ground. Mothers seemed to gravitate
toward each other; they share this special common bond, which creates interdependence, a community, and a connection. These characteristics are closely associated with the relationships and the mutual support of women. Caroline states, "I always gravitated towards people who had kids with problems. Then I didn't feel alone." An additional comment from Barbara, "I feel like the other mothers I met are like my sorority that I was a member of." This bonding and sense of community is present with all of the mothers. As Shannon so eloquently stated, "That I have made genuine friends now for life. And we are bonded by our children. But boy, we have such a wonderful friendship." This demonstrates once again the sincere, true friendships along with a strong common bond. Michele expressed, "It's not as bad as I thought because all these really wonderful people. I feel real comfortable. I feel like I'm at home." There is definitely a wonderful sense of belonging amongst all of the mothers. When together with any mothers with children with a disability, they are totally at ease with one another, conversations have no limitations and they do not need to explain their circumstances. They can express their true inner feelings without feeling inhibited. Mothers openly expressed their feelings that mothers who do not have disabled children can not fully understand the other world, the other culture of a mother with a child who is disabled. One mother spoke of how her truthful feelings can be discussed within the mothers' group without feeling she is being judged. "We have to leave a function and they (other mothers) understand. I don't have to say 'Oh everything is great.' I can actually say, 'No it stinks.' And they are glad to hear it and it doesn't make them feel uncomfortable because they know, they have experienced it too."
Mothers network and converse for strategies to handle physical and emotional problems with the child. Michelle goes on to say, "Instead of commiserating, we've all been able to brainstorm to bring the children to the next level. We all just kind of stuck together. And you what? You don't get that common bond with (the mother of) a regular child."

These mothers have experienced another world. "We are bonded by our children." They have a different perspective and outlook on life that most other mothers can't appreciate, which has frequently expressed during interviews. "We are in another world." ...

"We are in a separate world that other Mothers, with typically developing children, have no sense or appreciation of." The feminist traits of interdependence, community, connection, emotion, peace, and life (Feminist Ethics, “n.d.”) are visible and clear in the connection of these mothers of children with disabilities. I personally had an experience in a local water park. A tall African American woman, whom I did not know, approached me about my son’s swimming. I went on to explain about his swimming capabilities when she informed me that her daughter also has Down syndrome. We talked heart to heart about the many similarities that existed with our two children, miles across the state, that had never met. People were staring at us, over this public show of affection between two mothers that had known each other for just 20 minutes. There was an instantaneous connection between both of us, a deep personal mutuality of spirit.

**Becoming, a profound personal growth**

The last theme that emerged in relation to the meaning mothers derived from having their child with a disability is becoming, a profound personal growth. This
unequaled experience of motherhood has helped them to look inward at their own self-identity. This introspection is a very enriching experience for the mothers. Michele states, "It means a lot. In a lot of ways it defines who I am. Because of her, having the disability, it made me re-evaluate who I am. What I am. What I am about and to refocus myself."

There was an inward reflection of the mothers re-evaluating and refocusing their personal meaning. This is very closely associated with feminism; the mother and child relationship is so closely interwoven that the mother is interconnected with the child. Her self-identity is related to and evident by the accomplishment or failures of her child. She is so bonded with her child, especially a child with a disability, that it is difficult to see where one ends and the other begins.

Other multiple positive qualities of becoming are described throughout the interviews. Mothers describe being calmer, serene, having more patience, not only with the child, but also with the whole family. Many mothers felt initially intimidated by the patriarchal health care team. But as time went on and they experienced a sense of becoming, a sense of confidence and knowing what is best for their child. Then mothers became appropriately assertive with a newfound sense of inner strength. Susan talks about this inner strength, "It's made me also not care so much if people always agree with me. If people always liked me. So, I think, that's changed me, my whole person."

Mothers spoke with regard to a sense of urgency and utmost determination for their child's progress and welfare. This determination focused on the child's accomplishments through therapies or defying the pessimistic medical predictions for their child.
Many mothers stated if they are not an advocate for their child, who else will be? "I need to be strong so that she may be strong." Becoming provided for inner strength. "It has made me stronger and made me realize that I can handle more than I ever thought I could." Mara spoke about her inner strength, "She's brought me to realize a lot about myself I've improved on. She brought the strength out in me." This mother just acknowledges the increase in self-strength as a result of caring for her child who is disabled.

Caroline stated, "It's about you giving someone else the best life. The best start, the best everything possible." Mothers spoke about how they feel this is their job now, their goal in life. Ten out of twelve mothers left their employment and chose to refocus and rededicate their energies into the success of these children. Becoming pertains to the giving of the self, the mother's self, to give these children the best and happiest life possible.

After the initial phase of the devastation of the acknowledgment and acceptance of the diagnosis, there was a change in these mothers. "I have a fuller life because of my child. You know it's hard to believe, but I think it has made me maybe a better mother than I could ever be. And I feel like this has added another dimension to my life. To my whole being." (Caroline).

A sense of becoming is a paradox. During the initial phase of diagnosis, the mothers are deeply distraught and devastated. The child, in many instances, was critically ill, on the verge of death. As one mother made a comparison of her life before her child was born, "It was so unfullfilling. It was so empty to me. And I just wanted to have
something bigger than myself to invest in. I have learned the meaning of mothering."

This sense of seeing clearer now is captured in the Johnny Nash song, *I Can See Clearly Now* (Appendix M). Nicole described this transition as, “And now looking back at it, it’s so clear to me. But then I couldn’t see it. But now looking back at it I realize that we’re so lucky. We’re one of the privileged.”

**Synthesis of the Phenomenon**

Benner’s (1994) methodological process is first a global understanding of the text, moving on to specific themes identified, and lastly to synthesize this interpretation into a new found interpretation of the phenomenon. The movement of the parts of the text as fully as possible, identifying puzzles, incongruities, and mysteries (Benner, 1994).

The participant mothers are providing the best life for their children that they possibly can, considering the intensity of the daily challenges of having a child with a disability. Mothers managed complex local therapy schedules as well as seeking alternative treatment measures for their children in other parts of the United States. They are devoted, dedicated, and courageous women, wanting only the best life for their children. They consider that this challenge is their goal in life, their job, the most important job of their lives, and they will rise to the occasion.

Mothers described the medical maze of the health care system and health care teams in profound detail. It was frequently a long and arduous process to secure a firm diagnosis for the child, thereby producing a continuous roller coaster of emotions. This correlates with the mothers’ feelings of not being heard, invalidated, or misunderstood by health care teams.
A lesson learned by this select group of mothers was to be an advocate, and rightly assertive, for their children, even if professionals disagreed with them. Three mothers, at the opposition of pediatricians, had their children transferred to a tertiary health care facility for further diagnostic treatment to attempt to obtain a correct diagnosis. An attempt at external control was evident with whatever fragment of their lives where they possibly could have influence and control over, such as: frequency of therapies; copying of medical records; seeking alternative therapies; changing physicians or insisting on a hospital transfer. As time progressed, they became more assertive, skillful, knowledgeable and the single most important advocate for the welfare and survival of their children.

Mothers likewise talked frequently of feelings of guilt, self-blame and the possibility of what element of responsibility they may have had for the occurrence of the disability. Many thoughts of self-blame came directly from genetic transference of the gene, or potentially an activity that was carried out during the pregnancy that may have harmed the fetus. Another belief of self-blame came from a spiritual perspective; “Was this was a punishment from God,… why me, …why my family,… what have I done wrong,… what did I do wrong during my pregnancy?”

Profound appreciation of life is evident. Considerations such as life’s beauty, the smallest accomplishments of their children, neighbor who were supportive, or a deeper appreciation for life in its whole context. Without the experience of their children, they would miss out on this genuine and deeper appreciation of life. This was described in the conversations as “another world.” The rest of the world, or the general parenting public,
does not appreciate the intensity or hardships of the challenges, and yet the paradox of the immense joy and unconditional love the children bring to their lives. The "other world" travels another avenue, the interconnection the mothers with children with disabilities feel amongst each other. It is not necessary for the mother to intimately or personally know another mother. They can encounter each other in a public place, by chance, but once the commonality of the child who is disabled is established, there is an instant spontaneous feeling, a commonality that is felt between the two. They speak a common unique language and share unspoken thoughts.

These mothers feel that the general public mostly has a negative viewpoint of the experience of raising a child with a disability. Not true, it is a paradox at its best. Once the mother is able to move ahead, accepting the diagnosis of the disability, she moves forward as the child's advocate, and reaps the rewards of a fuller, more loving life. Many mothers have said in our interviews that the children teach us the true meaning of life.

It seems that mothers move forward once they see the child first, and the disability second. They are a child first and foremost. Many have spoken to this; the world would be a better place if more families had the experience of a child with a disability.

Mothers viewed this phenomenon as a privilege, "I am chosen by God or a higher being." These children bring indescribable joy. As one mother termed it, "We were lost for so long, and then my child was born with Down syndrome. He filled our hearts with love for what had been so empty for so long." Two mothers felt and believed that this was a plan, "God chose me for this challenge in life. He knew I could handle it and
therefore I was the privileged, the chosen one. It has brought me such joy, that clearly he had a plan for me. I can see it now, I can see clearly now.” Most mothers could cite specific instances, maybe in childhood during the care of a neighborhood child with a disability that related to this plan of preparing the mother for this challenge. These mothers proceeded by working tirelessly through a period of loss or devastation with the diagnosis of the disability, but then through a growing process, whereby they have transcended onto a higher plane of being.

The interpretation of the phenomenon of having a child with a disability from the mother’s perspective is that of an inner personal movement, a transition into another unequivocal level of being. The experience of having a child whom is disabled like crossing over a beautiful stone arched bridge. Once the initial devastated feelings are integrated and accepted into life, the mother develops an extraordinary ability to accept this and move on, to move across to another plane of being. Mothers described this other side as a most positive experience. The living experience of having this child and integration of the diagnosis takes time and comes prior to the meaning, the transcendence into the richer and fuller dimension. In an excerpt from a book entitled *From the Heart, On Being the Mother of a Child with Special Needs* (Marsh, 1995) is a bittersweet description of transcendence:

Just after Joel was born, the fabric of my life was dipped in a dye of “Down syndrome,” and it wasn’t a very pretty color. But the years have softened the shade, and although I never would have chosen it, I can now see the beauty in it and truly take pleasure in it. After five years, I’m proud of it, confident it will be
liked by others after they ponder it some. I'm excited about the way the hues continue to change as time goes on (p.105).

This excerpt provides a visual description of the transcendence that has taken place with the mothers participating in this research. The word transcendent, under which transcendence is listed as a noun (Oxford Dictionary and Thesaurus,1996) is described as; excelling, surpassing, transcending human experience (p. 1623). Mothers described situations in which they seemed to be addressing transcendence, but yet did not use this exact word with their descriptions.

For 11 of 12 mothers having a child with a disability resulted in explicit transcendence within their lives. Transcendence, according to the Oxford Dictionary and Thesaurus (1996), means "to go beyond the range or grasp of a human experience; to excel or surpassing. Incomparable (p. 1623)."

Through phenomenal reflection, the day-to-day life of this mother has transcended and changed significantly. Although this experience of having a child with special needs was tremendously difficult at first, the mothers found once the initial phase of blame, not knowing, and dealing with public perception had passed, the mother was able to incorporate her old life into a new life with full acceptance of the diagnosis and the child. Transcendence seems to take place when the mother sees the child first and the disability second.

The mother's meaning of this experience focused on the themes of destiny, spirituality, and appreciation. They had re-framed this loss of the perfect child and felt it had encouraged them to move on to a higher level of being. The mothers feel they are
living life to its fullest. They are hopeful and they are living in a different dimension. All mothers speak of how they are dedicating themselves to giving these children the best life possible, concentrating on fulfilling that goal each and every day. There is a stronger, more urgent, purpose to their lives, and they all feel their lives are now superior. Transcendence into a new life is a paradox, for most mothers this experience started with heartache and pain of the acknowledgment of the child’s disability. However, they have transcended beyond this pain and heartbreak to face the reality of the syndrome and disability. They have moved on. They are hopeful and are experiencing a better and fuller positive dimension of life.

The Phenomenological Nod

The phenomenological nod occurs when participants from the respective research population reading or hearing your presentation nod in agreement. The interpretation provides for a truthful and complete representation of their story (Munhall, 1994). Munhall (1994) states that the phenomenological nod is present when the research mirrors the experience, therefore "ringing true for participants." This is paramount, since this nod indicates agreement or recognition that I have truthfully represented the essence of the phenomenon according to the mothers, providing merit and rigor to the study.

Eleven of twelve mothers were available for comment by phone to ascertain if my interpretation is truly reflective, in the mother’s opinion, of her experience with her child with a disability. One mother was unable to be reached by telephone after several attempts. The mothers reflected and concluded that I have captured the essence of the experience and meaning of this phenomenon.
The majority of the mothers' experiences were accurate and portrayed in several of the themes. Not every mother experienced each and every theme. Each participant will not experience every single theme because this truly represents the multiple and different situated context. Munhall (1994) supports a representation in different situated contexts, this tells us about our differences, and the variation of the attached meanings.

The first theme presented to the mothers during our phone conversation was whether they felt any blame regarding their child. Some mothers voiced that they honestly do not now blame anyone for the resultant disability. They have come to accept their child's disability and have moved on. Other mothers concur they did have negative feelings toward the health care team and blame them for not expediting their child's diagnosis and potential transfer to a tertiary health care facility. Caroline spoke of her expectations of having the perfect "Gerber baby." She was in denial and incapacitated by depression for the first few months after her child's birth, but finally came to fully accept her child's disability. Once she reached the point of acceptance of her baby's disability, she went on to say that "life is not perfect and this is just a different road than I ever thought I would take."

One mother, Katherine, did not place any blame on herself, the health care team or God elaborated. "It could have been me or my husband. My child with Down syndrome, it really doesn't matter any more who was responsible for the chromosomal abnormality. We love her and accept her just the way she is."

The second theme of not knowing, impacted and rang true with many of the mothers. Not to have a diagnosis, to have an uncertain future, and to not know the
outcome of a critical event with the child, was the focus of several mothers’ conversations. Mothers were most concerned with the health care team not providing adequate information, not to have any diagnosis and contemplating an uncertain future. Not to have a diagnosis was valid for Michele, Allison and Taylor. When the health care team did not provide adequate information, the mothers referred to the expression of the “roller coaster of emotions.” The emotions of fear and anger were prevalent in this theme according to the mothers.

Public perception was an overriding focus of most mothers. Two mothers, Nichole and Yvonne, have had very positive experiences with the public. They related stories of how people in the public offered positive comments or interacted with their child in a playful way. Unfortunately, most mothers, including Mara, Caroline, Shannon and Barbara, had negative experiences in public. Barbara is the mother of two children with disabilities who have difficult behavioral issues to manage within a public setting. Caroline talked about how she is very conscious of the public reaction to her daughter when they are in public due to her daughter's disability significantly alters her skin appearance. Shannon referred to a party she attended with her family. A family member insinuated that it wasn't appropriate for her daughter to attend since her daughter is not able to walk at this time because of low muscle tone with her Down syndrome.

Every single mother concurred with the theme of complex and changed mothering roles. Although many mothers did not specifically mention roles, they all alluded, described and gave examples of complex and accentuated mothering roles. Mothers all spoke of the complexity of coordinating occupational therapy, speech therapy, physical
therapy, doctors and specialists appointments for their children with a disabilities in addition to the regular, hectic schedule of running a household and family. Additionally, families were financially strained by multiple insurance coverage difficulties, services not covered by insurance, financial strain from the purchase of specialized equipment, and the inability of 10 out of 12 mothers to return to work.

The theme of destiny was a common experience for most mothers. There were mothers in particular who when contacted by phone said, "Yes, I have experienced this feeling." Barbara talked about a college friend who told her before she was married, or had any children, that she (Barbara) would be very compassionate, kind and would do so well with a child with special needs. Another mother, Shannon, said that after she had her daughter with Down syndrome, her brother's friend commented that there could be no better choice than Shannon to care for this special child. Many mothers were amazed when other people acknowledged and recognized the mothers had an extraordinary capacity to give love, kindness, and compassion.

Spirituality had a very strong presence for most of the mothers when contacted by phone. Many spoke of how they feel honored to have been chosen by God to receive the wondrous gift of these children. Mothers all mentioned how these children bring so much joy, peace, and balance into their lives. Mothers likewise stated that spirituality enhances coping with difficult portions of this phenomenon.

The last theme reviewed with mothers via telephone conversation was appreciation of the greatest magnitude. Mothers were united in collective agreement that they had all experienced greater appreciation in all dimensions of their lives. Each mother
spoke specifically of her true appreciation for her child. Each and every accomplishment is a milestone and nothing is too trivial for celebration. They all agree appreciation keeps them grounded so they feel they recognize what is truly important in this life. Appreciation keeps their priorities and values in order and the view of their life events with proper perspective. Becoming was recognized by most mothers when contacted by phone. They believe they have a more fulfilled and better life.

Secondary Findings

Secondary findings are patterns identified within the mothers' interviews that were evident, but not as influential and consistent as the eight main themes identified. These secondary themes presented throughout the interviews yet did not fit into any respective theme. Each of the secondary themes may further nursing knowledge by exposing a fuller dimension of the story of a mother caring for a child with a disability.

The most prominent secondary finding in this dissertation is how the mothers are actively involved in helping, supporting, and encouraging each other. This was manifested through volunteer work at the early-intervention center or organizing outside volunteer efforts. One example is that of Taylor and her son who has an undiagnosed syndrome. She stated in her conversation that she brings her son to the pediatric geneticist every six months for clinical evaluation in an attempt to classify his disability or syndrome. Taylor is conscientious about this not only for her own information and knowledge, but also for help with predicting future health concerns for her child. This may also enable professionals to gain education and insight, which may help other children who have the same or a similar syndrome.
Shannon also talked about helping. Her efforts are mainly targeted to the early-intervention center. She is a very talented and skillful knitter, so she has established what she calls her "loop of love". She knits beautiful personalized Christmas stockings for celebrities, which she sends to them as a gift. Along with the stocking she encloses a letter introducing the early intervention center and explains that she encourages each celebrity to express their appreciation for their stocking by sending a monetary donation to the center. She also had a period in which she could not contribute as much financially to the early intervention center as she would like. Consequently, whenever her daughter was having therapy at the center, Shannon would volunteer secretarial skills, preparing mailings, filing, and filling-in where ever there was a need.

Alyssa also spoke about giving back to the early-intervention center. She and her husband sponsored and hosted a benefit dinner, and then donated the proceeds to the center. Barbara has a background in human resources. She is currently a stay-at-home Mom for her three children; however, she feels her human resource background will enable her to reach out to other parents of disabled children in the future. She states, "What I've experienced with my child can definitely help someone else." Her future plans are to conduct classes or seminars where she can advise and counsel family members who are dealing with the difficult issues associated with having a disabled child. Katherine also feels the need to share her experience and knowledge. She obtains current information from the Internet that pertains to her daughter, for example, growth charts for children with Down syndrome. She shares this data with her pediatrician to be sure this valuable and timely information is available for other parents who may have children
with Down syndrome. As mentioned in the previous chapter of this dissertation, Katherine also has a talent for writing. After the birth of her daughter, she wrote an article depicting the positive experience she was having as the mother of a child with a disability. This article was submitted and published in a local newspaper (Appendix K).

Another secondary theme that emerged in this dissertation concerned three mothers who stated they did not feel a total sense of devastation when they were informed of their children’s diagnosis. Shannon spoke in depth about destiny. She related that she had a great deal of exposure to children with disabilities throughout her life, which she now feels was preparation for her having a child with a disability. She stated that when she was told about the diagnosis of Down syndrome for her daughter, "It didn't affect me at all." Katherine also feels she had been prepared in her lifetime by being exposed to children and young adults with Down syndrome when she was a college student. She stated that when the physician came in and spoke with her about the diagnosis of Down syndrome, he was extremely positive and offered her hope. She felt the physician’s positive attitude, along with her camp counseling experience, helped her in the immediate period after she was informed of her child’s diagnosis. She also believes her happiness just to have her little girl contributed to her acceptance and her hope.

Michelle states the lengthy process to formulate her child’s diagnosis actually made it easier over time to accept the diagnosis. Her daughter was not diagnosed with Angelman’s syndrome until she was six years old. Michelle felt a profound sense of relief to finally have a diagnosis and some direction as to what the future hold may for her child. She compared the length of time to obtain a diagnosis for her daughter versus a
mother with a newborn with Down syndrome who is confronted soon after birth with this life altering diagnosis. She stated she felt the time element helped give her time to prepare and accept whatever the diagnosis would bring; it was a growing process.

Another secondary theme is the role of the husband as supportive spouse, as well as parent and caregiver. Shannon’s husband stopped by during our conversation, popped his head in and introduced himself. He had a warm personality and appeared to be a caring father. Shannon mentioned how helpful her husband is in the evening when he assumes responsibility of her two girls. He takes the responsibility of bathing, helping them with pajamas, reading good night stories and tucking both children into bed. Shannon says this with a big smile on her face. Another mother, Susan, said on numerous occasions that her husband is most interested in future research to investigate the perception of the father of a child with a disability. Nicole’s husband was present during our conversations. In fact, her husband asked several probing questions regarding my research prior to starting the interview. He sat with us briefly during the beginning of the interview observing but not contributing. Nicole acknowledged his presence by seeking his affirmation to her statements, although he did not contribute or offer any input. Katherine related the story of how she had to telephone her husband and inform him their newborn daughter’s diagnosis of Down syndrome. He was devastated by the news and was much more emotional in reaction to the diagnosis than she. Another mother, Mara says she knows and understands her husband at a deeper and more intense emotional level since their daughter with a disability was born. She related how he is totally
involved with their daughter and he “idolizes” her. Mara stated that her daughter with Down syndrome has brought her marriage and extended family closer to each other.

The last secondary theme to present from this research is related to mothers seeking alternative treatments for their children. Allison has a child with an undiagnosed syndrome. She explained that she uses different colored, indirect lightening that could potentially stimulate cognitive activity. She laughingly said she has installed this light that shines indirectly in her daughter's play area. Allison sheepishly admits that she talks to a telephone psychic. This mother has tried integrative manual therapy, also referred to as cranial sacral manipulation. This therapy manipulates the muscles of the head and neck, which is believed to increase blood supply to the brain. Another mother, Susan, also brings her son with Fragile X syndrome for integrative manual therapy. She originally started with this therapy when she lived in California, two years ago. Susan continues to travel to the West Coast on a monthly basis to take her son to a particular therapist. She stated that her son was unable to crawl when he was 10 months old. He went for his first session, and at the completion of the session, as she put him down, he was able to crawl. Susan stated that after three months of treatments, her son went from a word base of 80 words to over 200 words. He can also place two and three word sentences together. This is a remarkable accomplishment in a Fragile X child before the age of five years. Susan is a strong proponent of this therapy, and absolutely believes her son is benefiting tremendously from these alternative treatments.

One of the mothers, Alyssa, spoke of a vivid dream and a conversation with God. She is a devout Catholic and she did mention religion several times in both of her
interviews. It was extremely touching and rewarding that she felt so comfortable with me as a nurse researcher and mother of a child with a disability to relate this deeply personal experience. Alyssa told me of this vivid dream that she had, in which God appeared to her. She described white light, a glow around this God-like figure and how articulate he was. He told her that her child with a disability was one of his guardian angels who were sent especially to her. However, he would be taking her back when she was six years old. She awoke from this dream shaking, confused and terrified, yet she truly believes she did speak with God. The most disturbing aspect of this situation is that her child is now three years old, and Alyssa is already anticipating how fearful and anxious she will be when her child approaches her sixth birthday. In conclusion, several secondary themes have been presented with information that was not evident within the literature, yet it is significant to tell these portions of the mothers’ stories.

Summary

In Chapter V, the experiences and meaning of having a child with a disability is viewed from the mother’s perspective. Twelve mothers were interviewed on two different occasions each to discuss three interview questions for the research. Mothers were asked, what is day-to-day life with your child? Tell me about the entire experience of having your child and the last question: what meaning does caring for this child have for you?

Following the two interviews, through analysis and interpretation, eleven of the twelve mothers were contacted by telephone to see if the interpretation authentically captured the essence of their experiences. Four thematic categories emerged as a result of the first two questions, which addressed the day-to-day life routine, and the experience of
having a child with a disability. Those categories were blame, not knowing, the public's perception, and complex mothering roles.

When asked to describe the personal meaning of having these children, the mothers talked about destiny, spirituality, appreciation, and becoming. The majority of mothers were contacted by telephone following interpretation. The mothers concurred and supported the themes through the phenomenological nod. They were positive that this interpretation truly did reflect the essence of the unique experience of having a child with a disability.
CHAPTER VI
Reflection on the Findings

According to Munhall (1994) reflection on the findings provides for a discussion of the meaning and a thorough understanding of the phenomenon. Munhall (1994) states the goal of interpretative phenomenology is to uncover commonalties and differences. The commonalties and differences, according to Benner’s (1994) methodology will be used as a foundation for discussing the themes of this research. Implications for nursing will be discussed from this research of the mother’s perspective of caring for a child with a disability. This final chapter presents a reflection of the findings as well as the current literature with respect to the identified themes.

Overview of the Findings

The purpose of this study was to explore, through a hermeneutic phenomenological methodology using a feminist perspective, the mother’s meaning of caring for a child with a disability. The research question was: “What is the nature of having a child with a disability for the mother?” My research was developed as a result of personal experience with my own disabled child and a literature search that revealed minimal qualitative research on the phenomenon. My research analyzed the experience of having a child with a disability, so that health care professionals may know and be sensitized to the experience of the mother.

A total of 8 themes emerged, 4 from the experience of having the child and 4 from the meaning of the mother’s experience of having a child with a disability. A literature search was conducted to investigate the depth of support, or lack of support, for
the emergent themes. Some of the themes were supported from very recent (2000, 2001) qualitative nursing literature. In addition, 2 international research articles supported the multiple themes in my research. One study was the mother’s experience of having a child with Down syndrome in Hong Kong, Japan (Lam & Mackenzie, 2002) and the second on parental reactions to children with a developmental disability from Australia (Kearney & Griffin, 2001). There was an emergence of new themes in my research that were not presented in the current literature, further supporting the need to explore the personal experience of these mothers.

The experience of having a child with a disability has been researched primarily from a quantitative perspective, exploring select segments of the experience. Minimal qualitative research has been conducted to explore the overall, comprehensive experience for these mothers. The current research reveals that the phenomenon of having a disabled child is very stressful and creates many additional roles for the mother to incorporate. This study delved into this experience during the first two years following diagnosis and revealed a paradoxical situation. According to the Oxford Dictionary and Thesaurus (1994), a paradox is defined as “a person or thing conflicting with a preconceived notion of what is reasonable or possible” (p. 1081). Once the mothers are able to accept and incorporate the child’s disability into their everyday lives, the immeasurable pleasures that the child brings are paramount. Although the initial phase of this phenomenon is most difficult for the mother, as time went on and the disability is assimilated into the everyday life of the mother, she transcends onto a higher plane of being, or experiences transcendence.
New themes identified from this research are the following: overwhelming cloud of not knowing in the search for answers; striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability; destiny preparing the mother to care for her child; spirituality giving a deep inner dimension; and experiencing appreciation of the greatest magnitude for a better life. Literature will be presented to provide support and incorporation of the research findings into current literature in addition to the themes found here, which have not been evident in any current literature.

Commonalties

Benner (1994) states the goal of interpretative phenomenology is to uncover commonalities and differences of the phenomenon through culturally grounded meanings. Benner (1994) further states the usage of commonalities will assist decontextualization the phenomenon. Therefore, Patricia Benner’s criterion of sources of commonalities will be used as a format to explore the commonalities in relation to this qualitative research.

The five sources of commonalities include situation, embodiment, temporality, concerns, and common meanings. Situation refers to how a person is situated, both historically and currently. This phenomenon was interpreted initially by most mothers as a breakdown of a situation, one of confusion or conflict in their lives. There is a loss of the “illusionary or perfect” child. Mothers felt a sense of society’s placement of blame for their child’s disability and some personally accepted a degree of blame. In this study, several mothers had significant difficulties with fertility; therefore, the child’s diagnosis of their condition was not quite as devastating to these mothers. One single mother had
several other small children to worry about; therefore, the impact of the disabled child was altered. The focus of this single mother was her ability to raise this child alone and the day to day survival in a lower economic status. Most mothers described their husband and nuclear families as supportive. All mothers had support systems with close, extended family or friends available to help.

The second criterion for examining commonalities or differences is embodiment. Benner (1994) describes embodiment as an understanding of embodied knowing that encompasses skillful comportment, perceptual, and emotional responses. The initial devastation felt by mothers resulted in strong emotional feelings of crying, breaking down in public, inability to eat, or inability to breast-feed their infants. Mothers spoke about the painful and dreaded feelings when their children experienced near-death episodes or when physicians initially informed parents of their child’s diagnosis. Mothers also used the phrases during the interview, “the long road... the long haul...” signifying their anticipation and unknown future about the life long process of raising these children.

Temporality, the third criterion, is the experience of lived time, the way one projects oneself into the future and understands oneself from the past (Benner, 1994). Mothers experienced timelessness with the immediate revelation of the child’s diagnosis. Time also seemed to halt or freeze with the near-death events of these children. It was described by most mothers as a “surreal” experience, in which the mother felt she was having an “out-of-body” experience as the news was disclosed. Mothers also spoke to
their true appreciation for life, to live life to the fullest, in the here and now. Their purpose in life was to live for today, to appreciate everything that is precious.

Concerns, the fourth criterion is defined as the way the person is oriented meaningfully in the situation (Benner, 1994). What matters to the person will show forth in the concerns. One concern identified by mothers was public perception of their child. Public perception was of greater importance when the diagnosis of the disability was new and emotions were tender. As time progressed, public perception problems surfaced differently: a concern about how the public would treat the child as they grew, entered the school setting and moved toward independent housing/living. Also, what mattered to the mothers was providing these children the best life, the best start, and how to be the best mother for this child.

Common meanings, the fifth criterion, are taken-for-granted linguistic and cultural meanings that create what is noticed and what are possible issues, agreements and disagreements between people (Benner, 1994). The most prominent common meaning within this research is obtained with a feminist perspective lens, specifically the role of motherhood. Through a socio-cultural perspective, mothers believe that they are fully responsible for a child's welfare. Our mothering abilities and efforts determine the ultimate result and accomplishments of our children (Sampselle, 1990). Women are socially associated with the care of children, accepting the full responsibility of rearing the child, with all the challenges and additional mothering roles. It is a natural female tendency to center our lives on the well being of our children.
Landsman (1998) introduces cultural meanings in a slightly different context; she examines exactly what constitutes perfection in a child. Regardless of the emotional devastation mothers describe as their early response to news of disability, fore-grounded in the stories of mothers whose children have already been diagnosed for some time are re-definitions of quality itself, reflections on what constitutes or should constitute perfection in a child (Landsman, 1998). The mothers within my research have redefined what is meaningful and what is quality, what is most important for happiness in this life. Mothers through this phenomenon of caring for a disabled child have re-defined the value of personhood and through adaptation and transcendence, they reconstruct motherhood.

These five sources of commonalities and differences give a central focus for the analysis with this research. Each source gives a focus or direction to examine the mothers' stories, to explore the commonalities or differences.

A Phenomenological Approach to Study

the Mother's Perspective of Caring for a Child with a Disability

Interpretative phenomenology is a stringent set of disciplines in a scholarly tradition associated with giving the best possible account of the text presented (Benner, 1994). This interpretation offers to expose the life world of the mother caring for a child with a disability, to offer increased understanding of the phenomenon so that nurses and health care professionals may become more sensitive to this phenomenon. As a nursing profession, we may then be able to help the mother at any vulnerable time, to acknowledge her challenges and participate in her joys. Once again, the paradox of having a child with a disability.
From a feminist research perspective, I became deeply involved with the multiple layers of text, dwelling over the interviews and analysis. Speaking with all mothers a second time, experiencing the special bond and commonalities, was a validating and rewarding experience. We are truly in another world, one that is more enlightening than others would ever imagine. Thoughts on my personal experience of having a son with a disability have been re-framed; a more enriching life has been realized from this research process. It has been a rewarding experience due to the validation of my personal thoughts on this phenomenon, and to witness the energy that exists between the mothers. A social worker who has had 20 years, dealing with mothers and their disabled children, told me that her personal motivation has been sustained by the interaction with these dynamic mothers, making it all worth while.

The experience of the phenomenological research for the mothers was just as rewarding and fulfilling. They were delighted that someone “out there” cares enough to perform research and explore what their experiences are like. So much of the attention is naturally focused upon the disabled child; the mothers at times are minimized or shifted toward the background. This research has brought their unique experience to the forefront.

The philosophical underpinnings of the research methodology reflect the importance of the context of the mothers’ world and truly representing and articulating the phenomenon. Through this research, I was able to understand the context of each mother; this context would give the basis of a further understanding of important concerns of each respective mother. Mothers who are teachers placed more of an
emphasis on the cognitive development of their child with a disability, and on the
progress of other children within the family. Yvonne spoke of the importance of raising
the child on her own, to make the best of this circumstance, and not placing the child for
adoption. This meaning stemmed from her own childhood experience. Yvonne’s mother
died during her adolescence, and an aunt raised Yvonne instead of her being placed in
foster care. This issue was dwelled upon since raising this child in her own care, and to
the best of her ability was very important to her.

This is one of the first qualitative studies to fully explore the meaning of caring
for a child with a disability from the mother’s perspective. The full range of responses
and emergent themes are broader and richer in depth than the existing quantitative
research on this phenomenon. This research gives an abundant and comprehensive
account of the mother’s story.

Discussion of Findings

The findings of this research will be discussed in accordance to the interview
questions and the emerging themes as a result of the interview questions. The first
discussion follows from the mothers’ descriptions of their experience and day to day life
with their child with a disability. Four themes emerged from the mothers’ responses to
the first two interview questions addressing experience and day-to-day life with their
child. The second discussion is derived from the third and last interview question, what is
the meaning of having this child? Four themes emerged from this interview question.
Current literature will be presented to support the themes. Speculation that this may be a
global phenomenon is considered.
Themes Related to Mothers’ Experiences
of Caring for a Child with a Disability

Consuming blame while searching for an explanation for the child’s disability

In this research, blame involved the mother’s self and inward thoughts of responsibility for the occurrence of the disability of her child. The theme of blame has been supported in the current literature in several studies. Ogden, Van Eyk, and Armstrong (1998) interviewed three single mothers who were caring for children with multiple disabilities. The term “guilt” was used in the research study rather than blame, in which the three mothers felt that they had some contribution to the development of the child’s disability occurring during the pregnancy, or wishing the child had died. One of the mothers stated she felt tremendous guilt when strangers would look at her daughter with her complex monitoring equipment. The mothers’ guilt focused upon themselves and the potential portion they may have contributed to the child’s disability. The focus of blame holds true with an international qualitative study by Lam and Mackenzie (2002) with Chinese mothers of children with Down syndrome. The Chinese mothers believed that the birth of a disabled child constituted heaven’s punishment for their ancestor’s wrongdoing or something they have done in the past to deserve this child. With consideration of the Chinese culture, mothers felt strong fear of the potential blame for the birth of a defective child.

Another study explored parent’s attributions of blame with the unexpected birth of a child with Down syndrome (Hall, 1997). Through semi-structured interviews a correlation was established with the process of blaming with higher reported levels of
depression and anger. An additional study (Damrosch & Perry, 1989) involved parents of Down syndrome children with comparison of the coping patterns of mothers and fathers respectively. It was shown that mothers showed higher frequencies of negative behaviors, such as self-blame, as compared with the fathers. Landsman (1998) also supported self-blame, the mothers in her study personally struggled to determine what they might have done wrong to bring about a disability or felt that they were being wrongfully judged by others as having done something improper such as using drugs or smoking cigarettes. Mothers in the supporting research studies many times turned their thoughts and responsibility inward, attempting to seek meaning during the phase of adjustment to their child’s disability. This blame is part of the ongoing process of acceptance and incorporation of the child’s diagnosis.

A recent study in three European countries showed that prenatal screening is the single most important factor influencing both lay people and health professionals’ attribution of blame to mothers for the birth of a child with Down syndrome (Landsman, 1998). It seems that this informed choice to retain the pregnancy regardless of the results made available through prenatal testing, implies a responsibility of blame for the birth of a child with a disability.

**Overwhelming cloud of not knowing in the search for answers**

The exact term of not knowing was not supported in the current literature, although not knowing was part of the participants’ descriptions. A similarity of words was noted within the literature search for the theme of not knowing. Within this search, many research articles on this theme used the term “uncertainty.” There may be some
value to examine the term uncertainty as a close metaphor to not knowing. Cohen (1993) discusses the implications of sustained uncertainty with parents of children with chronic illnesses. Parents went from a stable, taken-for-granted world, to a reconstituted uncertain world (Cohen, 1993). Although mothers did experience a portion of uncertainty, the underlying difficulty was not knowing a diagnosis, not knowing if their child would live, not knowing adequate information, and not knowing the future. Not knowing produced stress, inadequate feelings, and lack of empowerment for mothers. Ogden, Van Eyk, Armstrong and Witt (1991) explored, through interviews with single-parents, the experience of parenting a child with multiple disabilities. One mother in that study was told of her child’s syndrome, but to wait for the next clinic appointment prior to discussing the implications. In Ogden et al. (1991) parents received little or no information about the status of their children for varying periods of time.

Chinese mothers had limited knowledge of the characteristics and needs of children with Down syndrome upon discharge from the hospital (Lam & Mackenzie, 2002). There was also a sense of not knowing, with the child’s future. Of particular concern to the mothers was the health status of the child, school placement, self-caring ability, and becoming independent. The similarities between Chinese mothers and American mothers are significant and represent global similarities with this phenomenon. To give further support to a global perspective with the theme of not knowing, is a research study from Australia (Kearney & Griffin, 2001). The parents in this study referred to not knowing what to expect and sometimes not knowing what to do. They had
entered a world in which they had no experience and no knowledge, and there were no signposts or maps (Kearney & Griffin, 2001).

Striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability

The third theme, striving to deal with unpredictable public perception, is supported within the allied health literature. Van Riper and Selder (1989) through a qualitative, descriptive study revealed the responses of parents to the birth of their child with Down syndrome. Supported in this study was the concern of new parents to the response of society, in general regarding their child. Parents wanted society to see their child first and the disability second. Mothers were conscious of the difference of their children. This feeling is emphasized within the first months after the establishment of the diagnosis. The issue of mothers of disabled children was addressed as the health care teams’ initial interaction with the parents with infants with Down syndrome from the perspective of symbolic interactionism (Van Riper, Pridham, & Ryff, 1992). The theory of symbolic interactionism postulates that, if the initial interaction with the parents is presented in a positive light, it will assist the parents to focus on the positive. Damrosch and Perry (1989) surveyed mothers and fathers of children with Down syndrome to further investigate patterns of adjustment, frequency of chronic sorrow and coping behaviors. This research substantiates findings in my research of the mothers’ feelings of embarrassment or self-consciousness of their child’s disability.

The dilemma of public perception is global, as demonstrated in the research conducted by Lam and Mackenzie (2002). The stigma of having a child with a disability
in Chinese culture is evident in the mothers’ responses. They care about the attitude of other people toward themselves and their children. For example, mothers in China are taught ways of handling potential negative public responses to enable coping.

Experiencing complex and changing motherhood roles

The complex roles of a mother caring for a disabled child are strongly supported within the literature as a theme and as a variable. Ogden, Van Eyk, Armstrong and Witt (1991) interviewed three single mothers in an attempt to capture their story. To expose the additional roles, one of the participant mothers described her daily routine with numerous medications and gastrostomy tube feedings on a strict schedule. In addition, to attempt organization, the scheduled appointments for the child with five different medical specialists, this mother had two calendars and two appointment books. Single mothers again were the five participants of semi-structured interviews, which explore the impact of children with chronic illness and/or developmental disabilities (Garbor & Farnham, 1996). The researchers report from their interviews the stress mothers feel related to the multiple roles, such as, schedules the mother must adhere to, issues with child care, transportation, lack of resource management, and insurance or paperwork.

Marji and Upshur (1989) researched the issues of caretaker burden and social support of mothers with and without disabled children. The mothers with disabled children experienced more difficulty in care taking of the child, physical, emotional strain, and financial burden when compared to mothers without disabled children. This study spoke to the frustration of mothers with the additional roles, the mothers having almost no time for themselves. Lam and Mackenzie (2002) presented the additional roles
of Chinese mothers caring for Down syndrome children. The similarities are striking, inability to work and contribute financially to the family, heavy physical care, and psychological and social demands on the mother.

An additional study examined the impact of a child’s disability on role perception of the mother. Crowe, VanLeit, Berghmans, and Mann (1997) presented the difference between caregiver roles of mothers with and without disabled children. Mothers with disabled children had fewer occupational roles than those counterpart mothers of children without disabilities. Mothers with disabled children have many more complex roles associated with the care of the children; therefore, there exists a reduction in the occupational roles, specifically, the role of student and worker. The lack of working in the mother of a child with a disability causes financial hardship to the family unit and reduces her interaction with the outside working world.

A theory of transformed parenting by Seideman and Kleine (1995) presented the additional and exhausting complex roles of the mother caring for a disabled child. Concerns about the physical care of a disabled child were a paramount influence on marital stress. One mother described her physical exhaustion from the care of the disabled child, and other children determined her inability to work, thus impacting on the financial stability of the family.

The theme of caregiver burden was presented in a study (Glasscock, 2000) of with mothers caring for a child with cerebral palsy. The additional caregiver roles impacted the work status for the mother and represent the first layer of the financial stressors of having a disabled child. Mothers spoke of the lack of complete health care benefits,
equipment purchases, medications, the costly specialists and physician’s bills adding to the stress of the phenomenon. Glasscock (2000) presented a commonality with my study, out of 15 participant mothers, only one mother was able to work. The unemployment furthers potentiates a lower status situation for the mother in addition to the financial burdens (Feminist Ethics, “n.d.”).

**Themes related to the Mother’s Meaning of Caring for a Child with a Disability**

**Destiny preparing the mother to care for her child**

The exact word many mothers used to describe the meaning of caring for a child with a disability was destiny. Although, this could not be found in the supportive literature, mothers eloquently spoke of their thoughts of the plan in their life of having and caring for this disabled child. This is a new theme that emerged from this research. The implications of this finding suggest that mothers reflected back and referred to their positive caretaking experiences dealing with and caring for disabled children to derive meaning.

Mothers also spoke to the belief that their particular personality was one that was well suited for raising a child with a disability. It was somewhat of a compatible match. This concept is also explicated in a short story by author Erma Bombeck (Appendix N). The story unfolds as an angel is speaking to God about the choice of parents for a disabled child; the necessary personality traits this mother must have in order to properly care for the child and endure this experience. This exact thought process has been communicated through the theme of destiny; mothers felt they were prepared and chosen
by God, because they can give something to this child that other mothers may not possess.

**Spirituality giving a deep inner dimension**

Spirituality involves a pervasive feeling mothers acquired focusing upon their religious beliefs that a higher spiritual power would provide direction toward a positive experience of having this child. Spirituality brought comfort and strength when a disabled child was desperately ill or a community of neighbors prayed together for the wellness of the child. Mothers related spirituality to a deep sense of appreciation toward God for giving this child to them.

Many supportive and current research studies have prevalent themes of religion or spirituality, which further support my theme of spirituality. A study by Seideman and Kleine (1995), on a theory of transformed parenting, exhibits significant similarities and components of spirituality which soundly resonate in my research. Mothers described seeking and receiving spiritual help, which they reported had come as the result of trusting God or praying. From the outcome of transformation, Scorgie and Sobsey (2000) found that changes in philosophical or spiritual values was a dominant theme for those parents of children with a disability.

Another study focused upon the positive adaptation of families with disabled children. Bennett, DeLuca, and Allen (1996) explored the adaptation process of 11 mothers and 1 father. A significant theme emerged from their study, that of religion as a personal, coping resource. Religious beliefs stated from the interviews of the parents were: the child is a gift from God; God chose me because He knew I could handle it; God
will take care of things; supernatural healing is possible, and God will give me the
strength to handle anything that arises. Shepard and Mahon, (2000) state that family
functioning can be enhanced if parents have a more positive than negative interpretation,
the child is a gift from God, not a punishment for prior sins. Beresford (1994) produced a
meta-analysis of the literature on the resources and strategies of coping with the care of a
disabled child. Spiritual or religious beliefs offer a way for parents to interpret or redefine
their child’s disability. This literature also supported the concept of the mother to be
selected to care for the child and that they will be given the strength by God to do this
task. Religious beliefs also play an important role in the way the mother handles stress. In
this meta-analysis, there was a strong reliance on religion as an important aspect of
coping. This religious reliance enabled parents to generate their own explanations for the
course of events.

Garbor and Farnham (1996) interviewed single-parent, low-income families about
the impact of their child’s chronic illness and/or developmental disability. One comment
is the feeling mothers have of being blessed with this child; this child brings a different
dimension of joy and happiness. Landsman (1998) found that the child with a disability
becomes a lesson, sometimes delivered by God to reassess priorities or to learn true
values. There are amazing similarities with the language used by the parents in this study
and the mothers in my study. It is apparent that spirituality helps mothers initially cope
with the diagnosis of the disability, and then guides them in their efforts to attain the best
futures for their children.
Experiencing appreciation of the greatest magnitude for a better life

Many mothers in this current study expressed the true appreciation for small accomplishments of the child and appreciation for the connection of the other mothers is evident through this experience. A seemingly matter of fact philosophy was experienced once the diagnosis was accepted and incorporated into the life of the mother and family. Beresford (1994) found this appreciation and personal philosophy, the ability to focus on the positive aspects of their child has been found to correlate positively with adjustment. Although two mothers within my study do not have a conclusive diagnosis, one mother has accepted this uncertainty and has moved forward. The second mother seems to continue to search for answers regarding her child’s undiagnosed disability. Beresford (1996), through in-depth qualitative interviews, also found parents’ strategies with positive approaches to life included: taking on day at time, not dwelling on difficulties, comparing self to others worse off, accepting the impairment and limitation that their situation may impose, and yet hoping for improvement.

Appreciation was termed as “adjusting celebrations” in an article by Seideman and Kleine (1995). This description includes celebrating the little things that parents of normal children take for granted. Ogden et al. (1991) presented single parent perspectives of raising a child with a disability. Within the theme of coping, one mother from this article used the exact same words when compared to mothers in my study. Her statement was, “I don’t feel like God gives everybody children like him... I feel like to me it’s a gift (Ogden, et al., 1991, p.196)” Mothers referred to their children as a “gift”,

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as if they were selected or chosen. One mother in my study said she doesn’t know what
she did so right to deserve her daughter.

A subtheme of appreciation is the “common bond of other mothers with disabled
children”. This subtheme was not found in the current allied health literature. Only one
article written by Robertson (1991) spoke to the commonality and support that was very
valuable to a father. The camaraderie among these mothers can support one another with
the awareness that they are not alone in this experience, and to ease the desperation a bit
while gaining new hope. This is very important for early-intervention teams. A majority
of available services for children with disabilities is now being brought to the home
environment. Ten years ago, services were mostly held within the early intervention
center where mothers could informally talk about the challenges common to all. It was
wonderful networking and support mechanism. “We are bonded by our children” as one
mother said within my research study, a “sorority of sorts.” This information must be
used to further support these mothers.

**Becoming, a profound personal growth**

The final theme identified is becoming, and this theme is briefly addressed and
identified in the literature. Becoming refers to a movement toward a better place of being,
to become better at the role of mothering, a fuller dimension to oneself. The mothers feel
personally complete and satisfied with what they are doing in their lives. Becoming is to
feel contentment and this is a gratifying dimension to our being. In one research study,
parents spoke briefly to believing they are better people, and they have been strengthened
(Kearney & Griffin, 2001). Larson (1998) found mothers had positive evaluations of
themselves. Their view of life was positive and fulfilling. Personal growth is cited in several research studies: (Larson, 1998; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & McDonald, 1996; Stainton & Besser, 1998) identified the theme of personal transformations, focusing on parental achievement, endurance, and strength through this qualitative inquiry. One mother’s response in a research study by Landsman (1998) identified that the child with a disability enriches life. This research (Landsman, 1998) also indicated that mothers of children with disabilities revise their interpretations of “normal,” “disabled,” and “lives worth living,” as they reconstruct motherhood.

One qualitative research study was found in the literature in which the principal researcher was the mother of a child with a disability. Landsman (1998), through unstructured interviews, sought to investigate the meaning mothers give to the act of mothering a child with a disability. This research was reported within the framework of a feminist perspective and the sociocultural implications of having a child with a disability. The themes identified through her research are the following: producers of defective merchandise, real mothers and authoritative knowledge, restructuring motherhood and the discourse of love (Landsman, 1998). Mothers of children with disabilities make their way within a society that devalues their children and in which their motherhood has “failed” to follow the culturally appropriate trajectory (Landsman, 1998). In Landsman’s research (1998), the mothers’ statements of self-blame were distinct and the societal placement of blame for the responsibility of this child was evident. The paradoxical nature of this phenomenon was apparent in her research. Mothers essentially told two stories. One story in which they feel hurt for their children and wish the disability would
go away, and yet this experience in mothering has taught them that their children are normal and their lives are deeply enriched. With this paradox in mind, it is enlightening to know that humanity is found in all forms different from those that may appear to be acceptable. This realization suggests the need to examine not only how some mothers do or do not adapt to a child with a disability, but how mothers of children with disabilities reconstruct motherhood (Landsman, 1998).

This is the paradox of this phenomenon. The mothers’ described the initial time period of learning of their child’s disability as very difficult and challenging. Once the mother is able to move forward, and incorporate the disability into the overall scheme of life, transcendence can take place. These mothers feel that they are better off, and more appreciative, than the general population of parents. Mothers of disabled children are able to live life, and appreciate life to its fullest, while having a deep spiritual connection providing comfort and joy. A mother’s quote to capture this theme is the following from Landsman’s (1998) qualitative research, “we’re just so grateful to have her. It’s okay if she’s not perfect. …What’s really important in life is family and love” (p.91).

The respective themes that emerged from this research have been presented in Chapter VI. An additional literature search was completed to support the themes of my research with the most current literature available. It is interesting and encouraging to note that more qualitative research studies have been published in the past two years.
Overarching Theme

Self-Transcendence

The overarching theme of this research is self-transcendence. Eleven of twelve mothers described their feelings of a movement toward a positive feeling of well being, of wholeness in and of life itself. A definition of self-transcendence is offered from a simultaneous concept review as, “the experience of extending one’s self inwardly in introspective activities, outwardly through concerns about the welfare of others, and temporally such that the perceptions of one’s past and anticipated future enhance the present.” (Haase, Britt, Coward, Leidy, & Penn, 1992, p.143)

Pamela Reed (1991) has developed a mid-range nursing theory of self-transcendence. Her definition of self-transcendence is a developmental correlate of mental health and happiness in persons who are approaching the end of the life span or who are otherwise confronted with personal mortality through some life event. Life events mentioned in this theory are: a disability, childbirth, and other life crisis. (1991a) presents several words to describe the self-transcending person, one who has become compassionate, wise, receptive, creative, open, connected, intuitive, and spiritual. Further discussion of this theory will be presented in a discussion of nursing theory.

To give further depth and explanation to the overarching theme of transcendence, the concept analysis of Haase et al. (1992) is used as a framework to explore self-transcendence since this concept analysis provides the antecedents of the concept of self-transcendence. The first antecedent is an inherent tendency of humans to move beyond their own self-interest, to lose their self-preoccupation and become aware of infinite
possibilities or sources of purpose. The mothers’ behaviors reflected this antecedent; they described the meaning of having their child was to move forward beyond themselves and to give their child the best start, the best life possible. Mothers experienced a focused sense of purpose in their life, to accept this ultimate challenge. At times, this challenge was related back to God, that God had given them this challenge knowing that these mothers would be able to handle it.

The second potential antecedent, a spiritual perspective, encourages one to reach out beyond one’s self (Haase et al., 1992). Spirituality was a theme described within the category of meaning of this phenomenon for the mothers. This spiritual perspective was presented in many different contexts: the mother’s true faith in God, the child having angelic qualities, and the belief that they are privileged to have this child. Overall mothers felt they are the chosen few and felt blessed by having this child. The theme of spirituality seemed to enhance the mother’s coping abilities, gave her meaning from a higher spiritual dimension, “a calling” that they are special people, and are unequivocally chosen to care for this child. One mother stated she couldn’t imagine people getting through anything like this without believing there is someone up above guiding them.

A third potential antecedent of self-transcendence is the occurrence of a pivotal life event or stressful stimuli (Haase et al., 1992). The pivotal life event in this research is the birth of a child with a disability or the disclosure of the child’s disability. This event may initiate cognitive restructuring processes that lead to choices, the outcomes of which can be views and behaviors indicative of self-transcendence. Their statements of self-transcendence were reflected in their ability to “just get on with life,” to accept the
diagnosis, to reframe this event, and to enjoy life to its fullest. There is a sense of peace, a sense of well being. Although mothers took varying periods of time to accept and then incorporate the diagnosis, 11 of the 12 mothers have experienced self-transcendence.

The fourth potential antecedent in the concept analysis of self-transcendence is described as human work that enlarges the goals and visions of a person (Haase et al., 1992). Work can be the context of physical work, but more so of human self-creation, of shaping the world, and structuring human relationships. Mothers distinctly describe this antecedent in the interviews; they want to help others. One mother knits Christmas stockings for celebrities in return for monetary donations for the early intervention center. Three mothers spoke specifically about using this experience to further educate the public, through their personal talents of writing in local newspapers, public speaking to new parents of children with disabilities, and working with the health care team to further their knowledge of their child’s condition. Structuring human relationships within this antecedent relates to the connection that mothers feel toward each other, the mutuality, the common bonding to help each other, and strategizing with other mothers for the benefit of their children regarding day-to-day challenges.

The fifth and last potential antecedent for self-transcendence is an acceptance of an inescapable situation (Haase et al., 1992). By accepting the disability, this frees energy for moving beyond, or transcending the situation, and may lead to broader perspectives, activities and purpose. Mothers spoke of the acceptance process. Their attitude was one of a “matter of fact approach.” “Let’s get on with our lives.... Let’s move forward and make the absolute best of this situation... to make the best life for my child possible.”
Through this acceptance comes a superior, caring and compassionate life for the mothers. It is a paradox. This phenomenon begins with devastated feelings and results in a better life than ever imagined by the mother. A deeper sense of gratitude for all of life’s little pleasures is realized. There is an appreciation for the smallest accomplishment of the child and appreciation for life in its fullest dimension. And lastly, there is a sense of “becoming” as described by these mothers. They have voiced that there is a deeper sense to their whole being, a re-evaluation of their whole being, “who I am,” and “what I am about.”

Scorgie and Sobsey (2000) spoke to the outcome of caring for a child with a disability through a transformation process. Although I believe this transformation is part of the mother’s process, I do not believe transformation discloses and captures the entire story. In this research, parents indicated that they have changed perceptions of what is really important and valuable in life. They have reframed their priorities. One respondent commented that parenting a child with a disability “compresses life’s lessons, creating opportunities to develop wisdom or discernment earlier than parents whose circumstances do not require them to confront some of the more difficult aspects of life until much later” (Scorgie & Sobsey, 2000, p. 203). These mothers’ redefine motherhood through nurturing their children as fully human and valuable as any other children. Although mothers spoke of transformation, along with transformation the mothers experienced a higher spiritual dimension and feeling of wholeness and well being, therefore this research mirrors the overarching theme of self-transcendence.
The outcomes of self-transcendence offered in the conceptual analysis of Haase et al. (1992) are congruent and reflect the mothers' descriptions of the meaning of having a child with a disability. Mothers described a fuller sense of becoming, a fuller dimension to themselves, and that they are happier than ever before. The outcomes of self-transcendence are: a sense of well-being, enhanced feelings of self-worth, a greater sense of connection with others, nature and God, personal growth, finding purpose and meaning in life, and a sense of being healed (Haase et al., 1992). The outcomes of self-transcendence reflect a nursing perspective of holistic health. A state of being in which the body, mind and spirit are united with an inner-dimension of happiness and peace. This conceptual analysis provides validity for the overarching theme of self-transcendence from within and directly impacts this research.

Nursing Theory

Reed (1991) has formulated a mid-range nursing theory on self-transcendence in working with the elderly population and their relationship of mental health and self-transcendence. This theory has been applied to two distinct populations thus far, the elderly and those individuals with a terminal illness. Reed (1991) investigated the pattern of self-transcendence with the oldest of old, ages of 80 to 100 years of age and the effect of self-transcendence with their state of mental health. It is my thought that the theory of self-transcendence may be applicable to other populations, such as mothers caring for children with a disability. My future goal is to further investigate this theory by speaking with the author, Pamela Reed about her theory and to investigate the instrument that has been developed for this theory. Would Pamela Reed’s instrument to evaluate self-
transcendence be applicable with my research population? Would this further substantiate my qualitative research findings in a quantitative perspective?

An assumption of this mid-range theory rests upon the belief that human beings are open systems. They impose perceived boundaries on their openness to define their reality and provide a sense of connectedness and wholeness (Reed, 1991). My research may substantiate the theory of self-transcendence and broaden the population base of this current nursing theory with another select population, mothers caring for children with disabilities. The author of this mid-range theory has developed an instrument to measure self-transcendence within the respective populations. I would like to use the instrument of self-transcendence in my population of mothers providing further substantiation to my over-arching theme and broadening and validating the mid-range theory of self-transcendence.

The concept analysis of Haase et al. (1992) substantiates self-transcendence through the descriptions of the antecedents, which strongly agree with the themes that emerged from my research. Another strength and supportive element of self-transcendence is the common thread that exists throughout the four concepts analyzed; spiritual perspective, hope, acceptance and self-transcendence, and that is of the common outcome of connectedness (Haase, et al. 1992). In the concept analysis, connectedness is proposed to have a broad definition. It is a “significant, shared and meaningful personal relationship with another person, spiritual being, nature or perhaps an aspect of one’s inner self” (Haase, et al. 1992, p.146). This concept is strongly evident in my research by the respective themes of destiny, spirituality, and appreciation. In particular, with the
theme of appreciation, the unity mothers felt for each other, supports this common theme of connectedness identified in the concept analysis. The results of my research coincide and support the respective concept analysis and the mid-range nursing theory on self-transcendence.

Unique Presentation of Two Mothers

A brief description of the unique presentation of two mothers is worthwhile mentioning since they may serve as potential areas for future nursing research.

One mother was interviewed prior to an investigation of her child's cognitive ability. The child has a syndrome called lymphangioma, a very physically disfiguring syndrome with an extremely enlarged neck and jaw line. This child has a permanent tracheotomy to secure an airway. Although this child has a very disfiguring appearance, her cognitive abilities and motor abilities are normal at this time, according to the early-intervention center. The mother participated in the first interview prior to this additional knowledge of her child's abilities. This mother spoke of many of the current themes that emerged in this dissertation, which included: overwhelming cloud of not knowing in the search for answers; striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability; experiencing complex and changing motherhood roles; spirituality giving a deep inner dimension; and experiencing appreciation of the greatest magnitude for a better life. This group of mothers should be investigated, concerning caring for children with only physical disabilities, to see if the experience is similar.
The second mother, Allison, has not yet reached the level of appreciation, or the overarching theme of transcendence. Allison’s daughter at this time remains undiagnosed; however, there is a potential diagnosis of infantile spasms from a diphtheria, pertussis and tetanus shot in infancy. It continues to be a very lengthy course of attempted diagnosis for this child. This child is very disabled. She cannot feed, dress, nor bathe herself. She is dependent upon her mother for all daily functioning. Allison does not have additional help for these daily tasks, and as the child grows, she is physically more difficult to manage. Of particular concern is the child’s inability to communicate with Allison. Allison stated, “I’m connected with her, but she is not connected with me.” Hence, there exists the grueling frustration of not having reciprocation of feelings or communication with this child. The lack of independent functioning, the long-term potential of reduced functioning, along with the inability to communicate, have impacted this mother and her ability to move forward. She does state in her interviews, “I don’t think we’d spend as much money searching for answers, if we had a definitive answer as to her diagnosis.”

Conclusions

Based on this qualitative research study, the following conclusions can be drawn:

1. From the mothers’ perspective, the experience of having a child with a disability, for 11 of the 12 mothers, begins with an abundance of adversity, but transcends to a higher level of positive being.

2. Some health care professionals have incorrect, negative biases, as to the mother’s ultimate interpretation of having a child with a disability.
3. Communication within health care professionals needs improvement from the mother's perspective. She needs to be advised and informed about proceedings/options impacting her child.

4. The majority of mothers who have a disabled child seek ways to help other families with children who are disabled.

5. A unique bond is evident among the mothers caring for children with disabilities.

6. The mother of a child with a disability embraces spirituality as a resource of comfort, joy, and coping.

7. The mother of a child with a disability accepts the many additional and complex responsibilities of mothering, particular to this circumstance.

8. Most mothers believe destiny has designated their union with these children who are disabled and that there was a preordained plan.

9. The mother's paradoxical perspective is a sobering, maturation process, which enhances the overall quality of life for the child with a disability.

10. The phenomenon of caring for a child with a disability, from the mother's perspective, is quite comparable across the diverse disabilities studied in this research.

Nursing Implications

Through the art of the profession, nursing needs to be fully aware of not only of the technical and clinical aspects of caring holistically for a patient, but also to be aware of the personal meaning of a phenomenon. By being cognizant of the meaning of this
phenomenon and by being sensitive to this mother's experience, nurses can exercise empathy through a comprehensive understanding. Nurses have frequent contact with these mothers, allowing for multiple chances for potential interactions and interventions. Shepard and Mahon (2000) recommend the following three interventions for nurses as the diagnosis is revealed to a family member: (1) be concrete, give the families as much information as is immediately necessary, but not much more, this will overwhelm them (2) provide resources to; the primary health care provider, other key members of the health care team supply them with what comes next, (3) help the family put the diagnosis and treatment plan in perspective. This guidance can be accomplished by ascertaining what expectations and knowledge the family has and clarify any misconceptions. Help identify the child's strengths. There are no right or wrong responses for family members at the time of diagnosis (Shephard & Mahon, 2000).

Nurses are in a strategic position to intervene for mothers having psychological difficulties with the situation of self-blame for the disability and the acceptance of the diagnosis. Nurses usually practice empathetic communication; therefore, mothers will most likely be more comfortable with communicating their concerns. Nurses can facilitate thorough comprehensive communication with the health care team, in particular, when the mother and family may be in a crisis situation and desperately seeking information and guidance. When physicians speak to mothers, the nurses can be present as support for them, giving simple and direct explanations they will understand, while facilitating, encouraging, and answering their questions. The nurse can also coordinate with other members of the health care team to help with other concerns the
mother may have including financial questions, additional therapies, and early-intervention agencies. Awareness of the complexity of the issues of having a child with a disability for the mother is a key element.

This study uncovered a number of negative perceptions that mothers of children with disabilities have toward the health care team. Lack of affirmation and communication intensifies the division some mothers feel toward the health care team. Mothers would appreciate collaboration and to be involved with the health care team and respect for what she has to offer in reference to her child.

Maternal child nurses have the unique ability to be present and have positive impact during the initial event of informing the mother of the child’s diagnosis. Through the theoretical perspective of symbolic interactionism (VanRiper, Pridham, & Ryff, 1992), one can guide the interpretation for the mother toward a positive perspective. The health care team’s behavior may ultimately determine the mother’s reaction and perception to this unexpected event. Nurses can play an important role in setting a positive tone.

A tenant of feminism embraces that mothers believe that no one can take care of her children like she can, and the everlasting innocence and vulnerability of these children accentuate this maternal feeling. It is the mother’s instinctual feeling that she must care for her children throughout their lives; they are directly responsible for their welfare and safety. As other typically developing children mature, become independent and move away, children with disabilities differ. They in some faction will always be dependent upon their mother. Mothers’ comments are as follows: “I’m more afraid of
death because of her…” “I want her to stay with me always…” “Who’s gonna take care of her like me?”… “I will take care of that child forever and ever and ever, that’s a mother’s guilt”… and “What’s gonna’ happen to him after I die?” Nurses must be aware of the fear of the long term commitments and responsibilities the child with a disability will impact not only on the mother, but the entire family. To talk openly about this concern and acknowledge the potential future ramifications will enhance sensitivity and communication between the nurse and mother.

Nurses need to be conscious and communicate to other professionals the potential for role strain, overload. The mother of a child with a disability has additional and complex roles, through the expectations of the multiple home therapies and appointments with the disabled child. Open communication and support for the mother while giving positive feedback for her interventions with the child is paramount in the relationship between the nurse and mother.

Finances are an issue for many parents because there are many additional expenses beyond those directly associated with the care of the child with a disability such as: special diets, transportation, baby-sitters for siblings while the child receives treatment or other care, time lost from school or work to name some (Shepard & Mahon, 2000). There may be structural changes necessary at the home, counseling and mental health services and respite homemaker services some (Shepard & Mahon, 2000). These type of expenses are usually not covered by medical insurance and if costs are covered the amount of reimbursement is likely to be minimal (Shepard & Mahon, 2000). The pediatric nurse practitioner can influence the challenges this mother will have throughout
childhood. The pediatric nurse practitioner can be there for empathetic communication, referrals to pediatric specialists, and be available for medical questions and referrals to other supportive therapies. Likewise, the community health nurse may have frequent contact with the mother over time. Coming into the home, speaking and establishing a relationship with the mother may be timely and a helpful resource for the mother.

Because nurses often provide care to women at critical developmental points, it is important that the practice of nursing reflect the principals of feminism (Sampselle, 1990). Through this research, nurses must be cognizant of the additional strains and stressors, and the role overload mothers face on a daily basis with the care of these children. Mothers are viewed in society in a supporting role and responsible for the family well being. The eventual progress and successes of the child is reflected back upon the mother's efforts, her determination to succeed for the child and, therefore her maternal identity. Many mothers sought with devotion and passion the multiple therapies and appointments enhancing the progress of their child. These mothers challenged themselves to defy the medical system with the progress and eventual abilities and outcomes of their children. In a sense they worked diligently to defy the odds, to prove the physician's predictions wrong. Advocacy for one's disabled child becomes part of her identity and of one's fear that the full value of the child is missed by others (Landsman, 1998). Through this phenomenon, mothers realize the incredible value of their child. Mothers have come to re-define motherhood and the value of personhood. Their children are as fully human and valuable as any other children (Landsman, 1998). Nurses must be
aware of the experience of having a child with disability produces compounded roles, additional stressors and the mother's personal meaning of the value of this child.

The birth of a child with a disability challenges the current United States imagery of good motherhood (Landsman, 1998). The mother's turn to an inward deliberation and self-blame is evident and prevalent with these mothers; they have not been able to fulfill the societal expectation of raising the perfect child. In an age of "perfect" babies, these mothers must break new ground and struggle with developing a vocabulary to explain the meaning of their children and of their own motherhood (Landsman, 1998). Nurses aware of this potential self-blame can counsel the mother and facilitate appropriate psychological help.

Nurses should be aware of the role of spirituality plays for these mothers. This may be a source of comfort, helping to seek meaning of this event, and helping the mother to cope and manage personally through difficult times. The knowledge of the theme of destiny may also be of help for the mother searching for meaning when the child's diagnosis is disclosed. Some tactful words referring to destiny may provide comfort. Not every mother is devastated with the knowledge of the child's diagnosis, each mother is individual and nurses must be sensitive and alert to interpret this potential impression.

Many mothers seek alternative treatments for their children. The nurse should be cognizant of the potential of this through interviewing techniques and not to pass judgment. These mothers are pursuing potential avenues for improvement for their child's development. To incorporate this into the nursing assessment and discuss
alternative therapies in a non-judgmental method is best for open communication and a trust.

Mothers may benefit from meeting other mothers caring for children with disabilities. Early intervention is now focused in the home environment, removing the opportunity for mothers to network and speak with others that share this commonality. As revealed in this research, mothers derived a wonderful sense of commonality and mutual support from other mothers of children with disabilities. Opportunities for sharing and networking would be of benefit for these mothers.

Nursing Education

Nursing students should be aware of the psychological impact of having a child with a disability from the mother’s perspective. They are the future population of nurses and need to be aware of the total impact of this phenomenon. The psychological impact should be included within the nursing curriculum. Initially, the mother perceives this event as the loss of the “perfect child” that was anticipated. To delve into the mother’s feelings of loss will give the student an enhanced perspective and clinical experience with the concept of loss. Potentially, this experience may help the student in the future with similar loss experiences of patients.

One mother, Alyssa, remarked that during her daughter’s initial hospital stay her daughter was being sent home on multiple medications with varying schedules. A student nurse made her a large chart to hang on her home refrigerator with the medications and varying time intervals for reinforcement. This mother greatly appreciated the creativity and the basic help this schedule provided with an overwhelming situation for this mother.
going home with an acutely ill infant. Additionally, students may have more time than staff nurses to converse with the mother and address her psychological needs.

Scullion (1999) wrote a conceptualization of disability with the input of nursing students and their teachers about attitudes toward individuals with disabilities. Disability was found to be conceptualized primarily as an individual medicalized phenomenon, as a form of deviation, a condition of dependency or a notion which defies definition (Scullion, 1999). It was recommended that an increased social orientation of disability would potentially raise the profile of disability as an equal opportunity issue. Individuals with disabilities could assist with curriculum planning and be guest speakers regarding their disability issues. It is suggested that critical incident analysis be used with students related to their reactions of caring for the disabled. Nurses must make a positive contribution to the lives of those with acquired impairments that may need nursing care.

Future Nursing Research

Through the conduction of this research, two new themes were identified to further build the nursing knowledge base. There are many potential areas for future nursing research that has been identified as a result of this research and the literature review.

The majority of the mothers, 11 out of 12, were from the same race and socio-economic background. One African-American single mother participated in this research. She was on welfare at the time of the study with 5 children all under the age of 10. The remainder of the mothers were Caucasian, married, and from a middle socio-economic status. Future nursing research is warranted on mothers from another geographical
location, studying their experience of the disabled child, to investigate the commonalities and differences.

The mothers represented a diverse sample of children's disabilities. This research has shown that the mothers' experience is remarkably similar, despite the child's disability. An additional area of future nursing research is to investigate what the health care team's perspective is of the mother caring for a disabled child and the family unit that has a child with a disability. It would be most important to identify their perceptions of this phenomenon.

During this research process, many mothers expressed that their respective husbands had significant interest in participating and providing the father's point of view. Fathers have differing levels of involvement with the child; this would provide additional information on the same, or differing, perceptions of the father. Would fathers of disabled girls have a different perception than fathers of disabled boys? Another potential research question asked of the fathers would be their feelings and thoughts as to the financial stability of the family with the impact of mothers not working and the additional financial strains on the family unit. Likewise, there is no documented research on the impact of siblings of children with disabilities. Varying age groups would be most interesting, examining how they feel with friends, their interactions with the disabled sibling, and their overall perception of this situation.

Education needs to be addressed in the medical and nursing fields, perhaps using the theoretical perspective of symbolic interactionism. Although many physicians today approach the birth of a disabled child in a positive frame of mind, through this research
many continue to view this event in a negative light. This feeling of negativity at the birth of the child with a disability is passed on to the mother and family through the initial interactions and can adversely impact the child’s future well being. The initial reaction is a defining moment of the utmost importance and worth investigating.

Future nursing research may benefit by continuing to explore the fit of this research with the middle range nursing theory of self-transcendence (Reed, 1996). This middle-range nursing theory and instrument has not been used with this particular population. This could further substantiate the validity and rigor of my research and in turn advance and verify the middle-range theory of self-transcendence.

Previous research on the mother with a child with a disability has focused upon the quantitative aspect of research giving only a partial view of this phenomenon. Further qualitative research needs to be explored and documented. Another area of qualitative research to further expand the knowledge of this phenomenon is grounded theory. Are there key social processes or structures that all mothers typically experience? The documented process could be of great help, by expanding the knowledge of this phenomenon, and then identifying potential steps of the process of caring for the child with a disability. Longitudinal studies of the mothers may identify changes over time thus enhancing long term goals with care. As noted, there are many potential areas for nursing research on the phenomenon of having a child with a disability.

Summary

The purpose of this research was to explore in its entirety the story of mothers caring for children with a disability. The research question guiding this study was: “What
is the nature of having a child with a disability for the mother?” An interpretative methodology by Patricia Benner was used for the interviews of 12 mothers from a New Jersey early intervention center.

This chapter has discussed the findings of the experience of having a child with a disability from the mother’s perspective. The mother's experience of having this child resulted in the following themes: consuming blame while feeling a sense of responsibility for the child’s disability, overwhelming cloud of not knowing in the search for answers, striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability, and experiencing complex and changing mothering roles. When addressing the meaning of having these children with a disability, mothers sought meaning through: destiny preparing the mother to care for her child; spirituality giving a deep inner dimension, and experiencing an appreciation of the greatest magnitude for a better life, and becoming, a profound personal growth. Themes, not currently in the nursing literature, have been identified with the mother’s experience. Other themes were substantiated and presented within the context of the current health care literature. Two mothers that had unique situations were presented as an addition to the themes identified here. This research has broadened the knowledge base of nursing on this phenomenon. Nursing will be able to further appreciate this complex phenomenon, offering timely and appropriate nursing interventions for the welfare of the mother, the child and family unit.
References


Lauterbach, S. S. (1993). In another world: A phenomenological perspective and discovery of meaning in mother’s experience with death of a wished for baby:


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Appendix A

Welcome to Holland

By Emily Pearl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It’s like this….

When you’re going to have a baby, it’s like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make wonderful plans. The Coliseum. The Michaelangeolo. The gondolas in Venus. You may learn some handy phrases in Italian. It’s all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later the plane lands. The stewardess comes in and says, “Welcome to Holland.”

But there’s been a change in flight plans. They landed in Holland and there you must stay.

The important thing is that they haven’t taken you to a horrible, filthy disgusting place, full of pestilence, famine and disease. It’s just a different place.

So you must go out and buy new guidebooks. And you must learn a new language. And meet a whole new group of people you would have never met.

It’s just a different place. It’s slower paced than Italy, less flashy than Italy, but after you look around… and you begin to notice windmills and Holland has tulips. Holland even has Rembrants.

But everyone you know is busy coming and going from Italy… and they’re all bragging about what a wonderful time they had there. And for the rest of your life, you will say, “Yes, that’s where I was supposed to go. That’s what I had planned.”

And the pain of that will never, ever, ever go away. Because the loss of that dream is a very, very significant loss.

But if you spend you’re life mourning the fact that you didn’t go to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

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Appendix B

July 12, 2001

Family Resource Associates
[Redacted]

Dear Nancy Phalanukorn,

I am a Doctoral student at Widener University and the mother of a child with a disability. I have a great interest in exploring the experience of mothers of children with a disability. I would like your permission to use the site of Family Resource Associates to seek interested mothers for this research study. If approved, I plan to post information on the research study with a return post card so that I may contact the interested mothers.

Enclosed for your review is my dissertation proposal, an abstract with the purpose of this study and the consent form for the participants. Methods employed to protect the mothers is outlined in Chapter III, pages 62-63.

I look forward to your response. This study will expand the research on the experience of mothers with a disability, therefore nurses and health care professionals can have a deeper appreciation of the experience.

Sincerely,

Joyce Wright
### Table C1

**Demographic profile of mothers**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Marital Status</th>
<th>Work Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>32</td>
<td>M</td>
<td>Not Working</td>
</tr>
<tr>
<td>2</td>
<td>39</td>
<td>M</td>
<td>Leave of Absence</td>
</tr>
<tr>
<td>3</td>
<td>36</td>
<td>M</td>
<td>Career on hold</td>
</tr>
<tr>
<td>4</td>
<td>44</td>
<td>M</td>
<td>Homemaker</td>
</tr>
<tr>
<td>5</td>
<td>32</td>
<td>M</td>
<td>Stay at home</td>
</tr>
<tr>
<td>6</td>
<td>40</td>
<td>M</td>
<td>At home Mom</td>
</tr>
<tr>
<td>7</td>
<td>39</td>
<td>M</td>
<td>Family Manager</td>
</tr>
<tr>
<td>8</td>
<td>40</td>
<td>M</td>
<td>Full time homemaker and Mom</td>
</tr>
<tr>
<td>9</td>
<td>39</td>
<td>M</td>
<td>Pre-school Director</td>
</tr>
<tr>
<td>10</td>
<td>37</td>
<td>M</td>
<td>Part-time secretarial work at home</td>
</tr>
<tr>
<td>11</td>
<td>38</td>
<td>M</td>
<td>Stay at home Mom</td>
</tr>
<tr>
<td>12</td>
<td>30</td>
<td>S</td>
<td>Stay at home Mom</td>
</tr>
</tbody>
</table>

*Work Status = the mother's own descriptive words*

**Legend:**
- **S** = Single
- **L** = Living with father of children, although not married
- **M** = Married
- **D** = Divorced
- **W** = Widowed
- **Sp** = Separated
Appendix C

Table C.2
Demographic profile of mothers

<table>
<thead>
<tr>
<th>Participant</th>
<th># of children in family</th>
<th>Ages of children</th>
<th>Position of disabled child</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1</td>
<td>2 years</td>
<td>N/A only child</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>2, 5 years</td>
<td>Youngest</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>2(^{1/2}), 5 years</td>
<td>Youngest</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>3, 7 years</td>
<td>Youngest</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>1, 2, 3 years</td>
<td>First &amp; Second</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>2(^{1/2}), newborn</td>
<td>First</td>
</tr>
<tr>
<td>7</td>
<td>4</td>
<td>2(^{1/2}), 4, 5, 7</td>
<td>First</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>2, 2 (twins)</td>
<td>First</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>2, 9 months</td>
<td>First</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>2(^{1/2}), 4 (^{1/2})</td>
<td>Second</td>
</tr>
<tr>
<td>11</td>
<td>3</td>
<td>3, 5, 7</td>
<td>Last</td>
</tr>
<tr>
<td>12</td>
<td>5</td>
<td>2, 4, 6, 7, 9</td>
<td>Last</td>
</tr>
</tbody>
</table>
Appendix C

Table C.3

Demographic profile of mothers

<table>
<thead>
<tr>
<th>Participant</th>
<th>Child's Diagnosis</th>
<th>Aware of Diagnosis prior to birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Fragile X syndrome</td>
<td>No</td>
</tr>
<tr>
<td>2</td>
<td>Undiagnosed, multiply disabled</td>
<td>No</td>
</tr>
<tr>
<td>3</td>
<td>Cerebral Anoxia Pertussis</td>
<td>No</td>
</tr>
<tr>
<td>4</td>
<td>Undiagnosed syndrome</td>
<td>No</td>
</tr>
<tr>
<td>5</td>
<td>First - Autism,</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Second - Bardet-Biedl syndrome</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Down syndrome</td>
<td>No</td>
</tr>
<tr>
<td>6</td>
<td>Undiagnosed, clinically</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Angelman's Syndrome</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Netherton syndrome</td>
<td>No</td>
</tr>
<tr>
<td>9</td>
<td>Down syndrome</td>
<td>Yes</td>
</tr>
<tr>
<td>10</td>
<td>Down syndrome</td>
<td>No</td>
</tr>
<tr>
<td>11</td>
<td>Down syndrome</td>
<td>No</td>
</tr>
<tr>
<td>12</td>
<td>Encephalitis, seizures</td>
<td>No</td>
</tr>
</tbody>
</table>
Appendix D

Sample Letter to Potential Study Participants

Hello, my name is Joyce Wright and I am the mother of a disabled child. Additionally, I am a registered professional nurse completing a doctoral degree at Widener University, School of Nursing. As part of my studies, I am working on my doctoral dissertation research project that involves talking with mothers about their experience of having a child with a disability. I am most interested in talking with you on the topic of being a mother of a child with a disability, what this experience is like for you.

Your participation in this research would involve talking to me, at your convenience, someplace where you feel comfortable in sharing your thoughts and feelings about having a disabled child. The information you share with me will help me; nurses and other health care professionals have a better understanding of this experience. Your involvement in this project would consist of meeting with me two times, the first for approximately 1 to 2 hours. During this first meeting, I would tape record our conversation so that I can review your statements and remarks. All of your information is personal and private and will be kept confidential. On the second meeting, I would review with you your thoughts, feelings and experiences to make sure that I knew what you meant and allow time for any further thoughts you may have.

I am hopeful that you will participate in this important research. If you are interested in participating, please complete and mail the attached post card to me so that I may contact you. Once I receive it, I will call you on the telephone to discuss your possible participation.

Thank you for your time and consideration to participate.

Joyce Wright
Appendix E

Sample Interview Questions

1. Tell me about your family.

2. I would like to talk with you regarding your experience of having a disabled child. Could you tell me what life is like now for you having a child with a disability?

3. Tell me every thing you can remember, your feelings, how you felt physically, your interactions with family, friends and professionals. Describe what it is like on a day to day basis having this child (name of child).

4. Based on your experience of having a disabled child, what meaning, if any, does it have for you? Please include both positive and negative meanings.

5. Additional exploration using an open-ended format will occur when the participant replies and uses certain terms to describe their experience. For instance, if the participant replies it is a “challenge” every day, the researcher will probe in an attempt to fully describe what the term challenge means to the participant.
Appendix F
Demographic Profile

1. Name:__________________________  2. Participant #__________________

3. Age: __________________

1. Marital Status: (place a check):
   _____ Single, never married
   _____ Living with father of children, although not married
   _____ Married
   _____ Divorced
   _____ Widowed
   _____ Separated

2. Work status of Mother:__________________________________________

3. Number of children in your family: ____  Ages of children ______

4. The position of the disabled child in relation to other children:
   ________________________________________________________________

5. Child's Diagnosis:____________________________________________

6. Where you aware of the child's diagnosis prior to the birth?
   _____ yes
   _____ no
Appendix G

Table G_1

**Consuming blame while searching for an explanation for the child's disability**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>You know especially since it came from my. I know there's nothing I could have done but I wish I didn't have the gene. (#1, p.8).</td>
<td>Self-blame</td>
<td>Consuming blame while searching for an explanation for the child's disability</td>
</tr>
<tr>
<td>I should have put her in the hospital sooner. (#3, p.20)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was the bath too hot, was it the tennis I played in my first trimester, was it the epidural, because I'm selfish, for pain relief. (#1, p.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>She never even regained her birth weight and nobody knew why, they were futzing around with her, they had no clue. (#8, p.4)</td>
<td>Blame toward the Health Care Team</td>
<td></td>
</tr>
<tr>
<td>I was going to have a nervous breakdown because no one was paying attention to us. And I think I said this before, she makes a lot of medical professionals look stupid. So they don't want to be involved with her. Because they don't really know what's going on and they're used to being pretty smart guys. (#2, p.21).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I felt like it was just like another thing. Another Whammy, I felt that God is definitely punishing me for something I've done in the past. (#9, p.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What did I do wrong, why is this happening? God why are you doing this to my child? (#5, p.7)</td>
<td>Blame toward God</td>
<td></td>
</tr>
</tbody>
</table>
### Appendix G

#### Table G2

**Overwhelming cloud of not knowing in the search for answers**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>He just left this huge, empty word (syndrome) in front of me. (#7, p.10)</td>
<td>The undiagnosed syndrome</td>
<td>Overwhelming cloud of not knowing in the search for answers</td>
</tr>
<tr>
<td>There's nothing she could tell me except it was some kind of connective tissue disorder: he has tendencies toward a syndrome that I'm not capable of diagnosing. (#4, p.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Just tell me the honest truth, is she gonna make it? Or is she not gonna make it? I need to prepare myself. And I remember I went into the hallway and broke down. (#3, p.5)</td>
<td></td>
<td>Lack of Information</td>
</tr>
<tr>
<td>He gave no information unless he was asked a question, he gave no extra. (#1, p.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>But I couldn't continue to read the whole article, I wanted to take it as it comes and as I'm able to deal with it. And it was great it was very, you know great, but I can't go there yet. (#9, p.12)</td>
<td></td>
<td>The uncertain future.</td>
</tr>
<tr>
<td>We need to let her go because we hold on tighter, we need to take steps to let go, so that when it's time to put her in a group home, it's not, it's more this is where we're going. (#7, p.28)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Table G3

Striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability.

<table>
<thead>
<tr>
<th>Participant’s Quotes</th>
<th>Subthemes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>The barrette, the pocketbook, the mary-janes at age 45, the awful stereotypical image we all see. (#6, p.7)</td>
<td>Public Perception</td>
<td>Striving to deal with unpredictable public perception in an attempt to dispel the hurtful myth of having a child with a disability.</td>
</tr>
<tr>
<td>There are so many wonderful people out there that do just whatever they can do to interact with him, no matter where we are. And we just get so much attention from people, like I said perfect strangers; they’re gravitated to him no matter where we are or where we go. (#9, p.11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(MD) this is unfortunate, this isn’t what you planned, this is too bad. (#6, p.13)</td>
<td>Perception of the health care team</td>
<td></td>
</tr>
<tr>
<td>What they (Health Care Team) did, I can never get back, and that, that will bother me forever. I feel that that’s insensitivity. I'm still a mother and she is still my child and there's a bond. (#6, p.12)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Table G4

Experiencing complex and changing motherhood roles

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>My daughter's almost three she does not walk. She does not crawl. She does not sit up independently by herself. So it's me constantly, you know, picking her up. But she is totally dependent on us. And you know I have a 5-year-old boy, he's constantly on the go. And some days it's really, really hard. And, um, you know I feel like I should be doing more with her. I don't have a cleaning lady, you know you still have to keep up with your cleaning and laundry and everything else you do. And then I try not to have my son see that we do so much therapy like we're always with her. (#3, p.17)</td>
<td>Role strain</td>
<td>Experiencing complex and changing motherhood roles</td>
</tr>
<tr>
<td>But she's more physically demanding. Like, we have gates up. I can't let her go roaming the kitchen because things will be thrown. There's a gate in her bedroom because I can't have her roaming the house at night if she does get up. She can't you know, if she starts screaming you gotta sit there and figure out what she's screaming about because she doesn't have verbal communication. She's not potty trained. So you're still dealing with diapers, still dealing with changing of her. You know you have to change her, dress her, feed her. (#7, p.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It's been life altering with the scheduling. She has four therapists a week. (#10, p.6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Table G4, continued

**Experiencing complex and changing motherhood roles**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>It changed my whole life. I couldn't work if I wanted to. Because she gets therapies 4 - 5 times a week. Um, we still tube feed her at night because she needs a lot of nutrition. (#8, p.2)</td>
<td>Inability to work</td>
<td></td>
</tr>
<tr>
<td>I would have gone back to work right when he was two, but I feel still that is more so than before that it would be much harder to go back to work. Especially now overseeing his therapies and all of that, um, we definitely couldn't put him in day care and it would be hard to leave him alone with a nanny or something. (#1, p.15)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix G

**Table G5**

**Destiny preparing the mother to care for her child**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I always prayed growing up. I'm the oldest of six children. That if any of us had to have a handicapped child, I hope it would be me because I knew that I would never, . . . that that would be fine. (#11, p.9)</td>
<td>Destiny preparing the mother to care for her child</td>
</tr>
<tr>
<td>Do you think it was an accident we lived next door to them (family with adult with Down syndrome) for six years? (#6, p.9)</td>
<td></td>
</tr>
<tr>
<td>So sometimes it feels like was this the life I was supposed to have led. (#1, p.15)</td>
<td></td>
</tr>
<tr>
<td>When they came in and told me my child has Down syndrome, I felt like it was destiny. It was my destiny at that point in my life, there was no one left for me to take care of. Someone needed my help. (#10, p.10)</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Table G.6

Spirituality giving a deep inner dimension

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Like God was there, you saw the bright light, you saw everything. And he said to me</td>
<td>Faith in God</td>
<td>Spirituality giving a deep inner</td>
</tr>
<tr>
<td>&quot;I sent you A... she is one of my guardian angels and one day I will be calling her</td>
<td></td>
<td>dimension</td>
</tr>
<tr>
<td>back.&quot; (#3, p. 11)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>He (God) gave me my child because my child can give me so much. (#9, p. 5-6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>She looks God, if she had wings, she'd be an angel. (#10, p. 11)</td>
<td>Children's</td>
<td></td>
</tr>
<tr>
<td>He's such an angel, on a day-to-day basis he's such a joy. Such a joy to our lives,</td>
<td>Angelic</td>
<td></td>
</tr>
<tr>
<td>he brings so many other people joy too. (#9, p. 5)</td>
<td>Qualities</td>
<td></td>
</tr>
</tbody>
</table>
Appendix G

Table G7

**Experiencing appreciation of the greatest magnitude for a better life**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>You appreciate life; you understand it a little bit better. You understand you know that life is not perfect. ... What if he was a normal five-year-old? How much easier would life be? But then I say to her, but you wouldn't appreciate it though. (#7, p.29)</td>
<td>Appreciation is magnified</td>
<td>Experiencing appreciation of the greatest magnitude for a better life</td>
</tr>
<tr>
<td>You see people differently. It's just really; it's an eye-opening thing. (#10, p.22)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel like the other mother's I've met are like my sorority that I was a member of. We have to leave and they (other mothers) understand. I don't have to say, &quot;Oh, everything's great.&quot; I can actually say, &quot;No it stinks&quot;. And they're glad to hear it and it doesn't make them feel uncomfortable because they know they've experienced it too. (#5, p.11)</td>
<td>A sense of unity exists between mothers</td>
<td></td>
</tr>
<tr>
<td>I don't know where I would be if it wasn't for them and meeting so many other Moms. How we can lean on each other and we're all friends and you can call on them any time. (#3, p.24)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Appendix G

**Table G8**

**Becoming, a profound personal growth**

<table>
<thead>
<tr>
<th>Participant's Quotes</th>
<th>Subthemes</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>It has made me stronger and made me realize that I can handle more than I ever thought I could. (#3, p.16)</td>
<td></td>
<td>Becoming, a profound personal growth</td>
</tr>
<tr>
<td>I have a fuller life because of my child. You know it's hard to believe but I thinking this has made me maybe a better mother than I could ever be. And I feel like this has added a whole dimension to my life, to my whole being. (#8, p.17)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of having the disability it made me reevaluate who I am. What I am. What I am about. And refocus myself. (#7, p.20)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix H


Appreciation - (noun) “favorable or grateful recognition” (p.64).

Best - (adjective) “of the most excellent or outstanding or desirable kind” (p. 129).

Blame - (noun) “responsibility for a bad result; culpability” (p.141.)

Destiny - (noun) “the predetermined course of events” (p. 385)

Different - (adjective) “unlike; distinguishable in nature, form or quality (from another)” (p. 395).

Knowing - (noun) “the state of being aware or informed of anything” (p.830).

Perception - (noun) “the intuitive recognition of the truth, aesthetic quality” (p. 1106).

Role - (noun) “a person’s or thing’s characteristic or expected function” (p. 1307).

Spiritual - (adjective) “concerned with sacred or religious things; holy; divine; inspired” (p. 1466).
Appendix I

Informed Consent Form

Study Title: A Feminist Phenomenological Perspective of the Mother’s Experience of Having a Child with a Disability

Investigator: Joyce Wright, RN, MSN, CCRN

Address: [Insert Address]

New Jersey [Insert Zip Code]

Telephone: [Insert Telephone Number]

Purpose of Research:
You have been asked to participate in this study because within approximately the past two years your child has been diagnosed with a disability. The purpose of this research is to discover the mother’s experience and meaning of having a disabled child in order to develop better ways for nurses and health care professionals to help them.

Procedure:
In an interview with a researcher you will be asked some background information and then will be asked general questions about what it is like for you to have a disabled child. The first interview will last approximately an hour, will be tape-recorded, transcribed word for word, and analyzed for common content. This same procedure will be carried out for the second interview. No information that identifies you will be included on the written copy of your interview. Your name and the names of others you mention will be replaced by a code.

Risks:
You may experience some inconvenience due to the time involved in being interviewed. You may feel uncomfortable discussing this sensitive topic. If this occurs, we can reschedule the planned interview session for another convenient time or cancel if you wish.

Benefits:
Possible benefits for you include the value of reflecting on your experiences. You will have the opportunity to discuss this topic with an interested nurse. You may also experience some satisfaction from participating in this study that may help determine the most useful way nurses to provide care to meet the needs of mothers with disabled children.
Alternatives:
The alternative to participating in this research is not being interviewed. You are free to withhold any information you prefer not to discuss and can refuse to answer any questions asked. You can participate in the first interview and refuse to talk at later times.

Confidentiality:
This researcher will maintain the confidentiality of your interview. Tapes and computer discs will be stored in a locked cabinet until the end of the study and then erased.

Offer to Answer any Questions:
Any questions or concerns, which you may have about this research study, may be directed to Joyce Wright, RN, MSN, [Redacted], NJ [Redacted]. Or any human subject considerations can be addressed to the chairperson of the Nursing Research Committee, Widener University School of Nursing, 1 University Place, Chester, Pennsylvania 19013 [Redacted].

Withdrawal Statement:
If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time.

Financial Responsibility Statement:
There is no cost to you for participating in this research and you will not be compensated for participation with this research study.

Agreement:
Your signature indicates that you have decided to participate having read the information provided above. You will be provided with a copy of this consent for your personal records.

Signature of Participant

____________________________

Signature of Witness

____________________________

Date

____________________________
Appendix J

Audit Trail

1. All interviews were transcribed by a professional transcriptionist.

2. All interviews were checked for accuracy with typed text and taped interviews.

3. The original typed interview transcripts were given to the respective mother at the second interview for her input on accuracy and discussion of emerging potential themes.

4. After completion of both interviews, manual data analysis began using Patricia Benner’s (1994) hermeneutic methodology.

5. All pages and lines of the text were numbered.

6. Each interview was read and listened to several times for a global context.

7. A paradigm case was chosen, in accordance with Patricia Benner’s methodology.

   This particular case I felt close to with understanding. This respective paradigm case was used to compare and contrast other interviews of other mothers.

8. Recurrent and significant words were extracted, and a list was formulated, I dwelled with these words for approximately 2 weeks.

9. These significant words were researched in the Oxford dictionary and Thesaurus (1996) to investigate their meaning and potential synonyms.

10. Commonalties were established and these respective words were recorded on a large note card and dwelled with for another 1-2 weeks.

11. Emerging themes and subthemes were devised.
12. I returned to the mother's original statements for each subtheme and theme to ensure clarity of chosen themes.
Appendix K

A Perfect Baby Girl

By Stephanie C

On Oct. 3, 19__, my husband and I gave birth to our third child and first daughter, Katherine Anne C whom we call Katie. We knew that this baby would be a girl, but what we did not know was that our baby would be born with Down syndrome.

Needless to say, it was a big shock. What happened to our perfect baby girl?

After, and during, much grieving, we moved ahead akin to the bulls running in Pamplona! We called the proper persons on the state level and we assigned to an agency, Family Resource Associates in Shrewsbury.

What luck! With their great knowledge and help, Katie started to receive therapy at 6 weeks old on a weekly basis. Her therapists have become our heroes.

Now that Katie was receiving the proper care, the real challenge for our family had begun. How were we going to raise this child? What would our two sons feel when they came to realize that their sister was "special"? Would everyone look at us differently? Would Katie live with us forever? Would my husband and I ever have the so-called "golden years"?

So many "what ifs." So much fear and loneliness on my part. But I needn't have felt alone. Our family and friends were so wonderful and there are no words to describe it. I can imagine an extremely spiritual priest needing to give his Sunday sermon on
loving thy neighbor using our family and friends as his guide. I never realized how
important they are to me and I to them. This was a big turning point for me.

Another turning point came when I reread a note that a friend of my sister, whom
I have never met, sent to me when Katie was 3 days old. It said:

*Remember what they say about someone who is blind or deaf. Their other senses
become more highly developed, and they and those around them learn to appreciate the
other attributes and contributions that these special people are capable of - and we are
all made better by their being.*

*Although children with Down syndrome may not have the same capacity for
certain types of cerebral learning; they have a huge capacity to give and to receive love.
They are great teachers in matters of the heart, and can show us what is really important
in life through the eyes of innocence and one who is unaware of the evil and hate in the
world. These are things that are learned and harsh realities I hope she will be spared.*

*Remember this, not all the angels are in Heaven, and they don't all have wings
and halos, and they don't all float around on clouds playing harps. Sometimes, they come
in disguise.*

This wise woman's words made me realize that so many of the things in life that I
thought to be so important were actually inconsequential. The important things in life are
the things that make us happy. Like my husband, children, family and friends.

People always say that Katie is blessed to have us as parents, but if the truth be known,
we are blessed to have Katie as our child. She is our perfect baby girl.
Appendix L

Heaven's Very Special Child

A meeting was held quite far from earth,

It's time again for another birth.

Said the Angels to the Lord above,

This special child will need much love

His progress may seem very slow,

Accomplishments he may not show.

And he'll require extra care,

From the folks he meets down there.

He may not run or laugh or play,

His thoughts may seem quite far away.

In many ways he won't adapt,

And he'll be known as handicapped.

So let's be careful where he's sent,

We want his life to be content.

Please Lord find foster parents who,

Will do a special job for You.

They will not realize right away,

The leading role they're about to play.

But with this child sent from above,

Comes stronger faith and richer love.
And soon they'll know the privilege given

In caring for this gift from Heaven.

Their precious child so meek and mild,

Is Heaven's VERY SPECIAL CHILD.

Edna Massionilla (1981)
Appendix M

I Can See Clearly Now

The Rain Has Gone

I can see clearly now, the rain is gone,
I can see all obstacles in my way
Gone are the dark clouds that had me blind
It's gonna be a bright (bright), bright (bright)
Sun-shiny day
I think I can make it now, the pain is gone
All of the bad feelings have disappeared
Here is the rainbow I've been prayin' for
It's gonna be a bright (bright), bright (bright)
Sun-shiny day
Look all around, there's nothin' but blue skies
Look straight ahead, nothin' but blue skies
I can see clearly now, the rain is gone,
I can see all obstacles in my way
Gone are the dark clouds that had me blind
It's gonna be a bright (bright), bright (bright)
Sun-shiny day

- Johnny Nash
Appendix N

How God Chooses Mothers for Disabled Children

By Erma Bombeck

Most women become mothers by accident, some by choice, a few by social pressures and a couple by habit.

This year, nearly 100,000 women will become mothers of handicapped children. Did you ever wonder how mothers of handicapped children are chosen?

Somehow I visualize God hovering over Earth selecting his instruments for propagation with great care and deliberation. As he observes, he instructs his angels to make notes in a giant ledger.

"Armstrong, Beth; son; patron saint, Matthew."

"Forrest, Marjorie; daughter; patron saint Cecelia."

Rudledge, Carrie; twins; patron saint... give her Gerard. He is used to profanity."

Finally, he passes a name to an angel and smiles, "Give her a handicapped child."

The angel is curious. "Why this one God? She is so happy."

"Exactly," smiles God. "Could I give a handicapped child a mother who does not know laughter? That would be cruel."

"But has she patience?" asks the angel.

"I don't want her to have too much patience or she will drown in a sea of self pity and despair. Once the shock and resentment ears off, she'll handle it. I watched her today. She
has that feeling of self and independence. She will have to teach the child to live in her world and that's not going to be easy."

"But, Lord, I don't think she even believes in you."

God smiles. "No matter. I can fix that. This one is perfect. She has just enough selfishness."

The angel gasps, "Selfishness? Is that a virtue?"

God nods. "If she can't separate herself from the child occasionally, she'll never survive. Yes, there is a woman whom I will bless with a child less than perfect. She doesn't realize it yet, but she is to be envied. She will never take for granted a 'spoken word'. She will never consider a 'step' ordinary. When her child says 'Mommy' for the first time, she will be present at a miracle and know it! When she describes a tree or a sunset to her blind child, she will see it as few people ever see my creations."

"I will permit her to see clearly the things I see - ignorance, cruelty, prejudice - and allow her to rise above them. She will never be alone. I will be at her side every minute of every day of her life because she is doing my work as surely as she is here by my side."

"And what about her patron saint?" asks the angel, his pen poised in mid-air.

God smiles, "A mirror will suffice."