The Impact of Readmission on Family Caregivers of Children Following Ventricular Peritoneal Shunt Surgery

By

MARY UWHUBA
B.S.N (University of Phoenix) 2012

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE
in

Nursing Science and Healthcare Leadership
in the

OFFICE OF GRADUATE STUDIES
at the

UNIVERSITY OF CALIFORNIA
DAVIS

Approved:

Amy. A. Nichols, chair RN, Ed. D, CNS

Susan. L. Adams PhD, RN, NP, CNS

Philippe. R. Goldin PhD

Marike Zwienenberg MD

Committee in Charge

2017

Abstract

Objectives: The physical, social, psychological, and financial stress family caregivers suffer is a common experience for millions of Americans who provide unpaid care to loved ones. Family caregivers work tirelessly to ensure their loved ones don't need to return to the hospital after discharge. This study examined the impact of readmission on family caregivers of children who have had ventricular peritoneal shunt (VPS) surgery and who have been readmitted by looking at five dimensions of impact, the financial, social, familial/general, coping/personal strains, and the total impact of caregiving. This study is conducted in a tertiary hospital in Northern California, where children who had hydrocephalus (excessive cerebrospinal fluid in the brain and spinal cord) were treated.

Methods: This study was a descriptive study using survey questions. Seventy-one family caregivers of children who were readmitted after ventricular peritoneal shunt surgery were sent questionnaires by mail and a stamped self- addressed envelope. The Impact on Family Scale (Stein & Jessop, 1985) was used to judge whether these family were affected by readmission.

Results: Family caregivers were parents, and their mean age was 34.5 years. Nine responses were received from 71 questionnaires sent. One response had a missing data and was omitted leaving only eight responses that were analyzed. Data showed there were no significant differences in participants' responses from financial, social, general, coping, and total impact of caregiving.

Conclusion: Sixty-three percent of family caregivers who had a high school diploma were found to have returned to the hospital following surgery. Limited education/health literacy may contribute to low response to survey and also readmission.

Acknowledgements

I would like to thank the following persons who contributed to the successful completion of my study at the Betty Irene Moore School of Nursing. First, to God who saw me through during this important period of my life keeping me healthy to face the challenges every day brings. Second to my husband John, children Onome, Ese, and Ejiro who listened to me, stayed close to me, when I get overwhelmed with school work, work, and family chores. Third, is to my thesis chair Dr. Amy Nichols whom I have come to know as a person; have great respect for, and has guided me through thick and thin. Also, my thesis members Dr. Susan Adams, who never fails to check on me from time to time, you hold a dear place in my heart. Also Dr. Philippe Goldin and Dr. Marike Zwienenberg who contributed to the success of my thesis journey. Many thanks to my adviser Dr. Tae Youn Kim and all faculty members who have one way or the other influenced my life.

Lastly, I want to thank the Betty Irene Moore Foundation and the Schneider's family whose generous contributions and support has enabled me complete this important program.

Table of Contents

Chapter One: Introduction

According to the (National Alliance for Caregiving (NAC), 2009) 65.7 million Americans serve as an unpaid family caregiver for an ill or disabled relation. Of these 65.7 million US caregivers 3.9 million care for children, 48.9 million care for adults, and 12.9 million care for both children and adult recipients. Family caregivers provide complex care and treatment for their loved ones. These caregivers often bear the burden of caregiving because they leave their homes, other family members and sometimes their jobs to care for an ill child. Home-based care may be challenging for family caregivers. Sometimes family caregivers return to the hospital when home caregiving becomes burdensome. In a similar report by NAC and the American Association of Retired Persons, AARP (2009), which focused on caregivers of children reported that an estimated 16.8 million unpaid caregivers provide care to a child with special needs under the age of 18 in the United States. They defined "caregiving as being due to a medical, behavioral, or other condition or disability—whether the condition is ongoing or a serious short-term medical condition, an emotional or behavior problem, or a developmental problem" (NAC & AARP, 2009).

Basics of Caregiving.

NAC and AARP (2009) further reported that half of caregivers of children with special needs take care of one care recipient (51%). They claimed that one-third (36%) care for two people, including any adults and children they might care for, and another 12% care for three or more people. They further stated that caregivers of children are less likely than caregivers of adults to be caring for just one person (51% vs. 68% respectively) because half of caregivers of children are providing care to their own son or daughter (55%). NAC and AARP (2009) stated that child care recipients are commonly a grandchild (18%), another relative such as a niece or nephew (13%), a friend (8%), or some other non-relative (5%) while the remaining 1% provide care to a younger sibling. They concluded that most caregivers of children are females (72%) and on average, they are 40.6 years old, they are younger than caregivers of adults (49.2 years of age, on average). Finally, they reported that caregivers care for a child that is 8.7 years old, on average and one in four caregivers of children (26%) are providing care to a child under the age of 5, 30% care for a 5- to 9-yearold, and 44% care for a child age 10 to 17 (NAC and AARP, 2009).

Caregiving is a special skill and no caregiver is prepared for the task of caregiving. Khanna, Prabhakaran, Patel, Ganjiwale, & Numbalkar (2015) reported that most caregivers feel inadequately trained for the tasks that they perform and have no formal training or education on caregiving. Despite this lack of training, they still need to care for their loved ones. As a result of this lack of training of family caregivers (Khanna et. al 2015) some children who had hydrocephalus (excessive cerebrospinal fluid (CSF) in the brain and spinal cord) and were treated have been found to return to the hospital after the initial treatment.

Children with hydrocephalus are treated surgically by the insertion of a ventricular peritoneal shunt (VPS). This shunt device drains off excessive CSF from the child’s brain and spinal cord to the peritoneum where the fluid is reabsorbed. Most times this surgical procedure fails to correct this anomaly, hence they return to the hospital. Ibrahim and Kulkarni (2015) found that in pediatric populations, 14% of shunts fail within a month of insertion and 35 to 50% require revision within a year. These failures can be caused by shunt malfunction, obstruction (Naradzay, 1999), infection, and displacement (Kulkarni, Drake, & Lamberti-Pasculi, 2001). They claimed that shunt systems require monitoring and regular medical follow-up because of its high morbidity and mortality rates (Naradzay, 1999). However, VPS insertion remains the mainstay treatment for hydrocephalus despite its high rate of complications (Khan, Rehman, Shamim, and Bari, 2015).

Statement of Problem/Background and Need

When a child is ill, a family caregiver typically stays with the child throughout hospitalization until discharge. If the child falls ill again, the family caregiver returns with the child to the hospital. These family caregivers sometimes bear a significant burden when caring for a child during hospitalization (Khanna et al, 2015). Unfortunately, little is known about the effect of a child's readmission after treatment of hydrocephalus and its effect on a family caregiver.

The Center for Medicare and Medicaid Services (CMS) defined readmission as admission to a hospital within 30 days of discharge from the same or another hospital. Tamimi et al. (2014) reported that VPS surgery remains the most common procedure undertaken by pediatric neurosurgeons in the United States with approximately 36,000 shunt-related procedures performed annually at an estimated cost of $100 million and 400,000 hospital days. At an academic surgery center where this study was done an estimated 2,523 children were readmitted after VPS surgery from January 2003 to July 2016. Caregiving is a learned skill, and family caregivers need support from family members and friends to carry it out. Reducing readmission is an important step toward making hospitals safer and cost effective for the health of patients and their caregiver.

Purpose/ Gap

The purpose of this study is to explore the impact of readmission on family caregivers of children by evaluating the economic, social, general/familial, coping, and total impact of caregiving. Chern et al. (2014) reported that there is a significant readmission rate after VPS surgery, and stated that this rate has caught the attention of healthcare purchasers. They claimed that such readmission is both common and preventable. However, there is a gap in the literature regarding the impact of readmission on family caregivers of children. This study will attempt to shed some light on the experiences of family caregivers.

Research Question

Family caregivers who care for their ill children stay in the hospital during their hospitalization. This study will address, “what is the impact of readmission on family caregivers of children following VPS surgery”? Five major themes will be used to answer this question. They are the economic/financial, social, general/familial, coping/personal strains, and the total impact of caregiving.

Relevance to Nursing and Healthcare

A family caregiver might feel overwhelmed with the demands of caregiving especially when caring for an ill child. If the stress and demands of caregiving goes unchecked, a caregiver could become ill. Nurses are at the forefront to notice a caregiver who is at the risk of burnout because they give direct care to patients. To help manage this stressful condition on caregivers’ nurses could ask other family members, a social worker, and sometimes a case manager to help manage caregiver’s concerns and causes of stress. Pediatric readmission after VPS surgery is a quality issue and to date, hospitals that care for children have not been targeted by the Hospital Readmission Reduction Program; the current focus of the CMS is readmission after heart and lung problems and hip and knee arthroscopies. But policies that start in the adult population eventually trickle down to children (Srivastava & Keren, 2013). Despite the magnitude of readmission related to cost, pain, injury, and burden to family caregivers, there are no guidelines for preventing readmissions. Educating family members on caring for children during hospitalization is important because caregivers are at risk of burnout during re-hospitalization (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001).

Chapter Two: Literature Review

A comprehensive literature review was conducted. The purpose of this review was to search recent articles and tools to measure family caregiver burden. Initial selection strategy was limited to published articles within 10 years that addressed family caregiver burden and readmission. Some older articles were included in this study because they specifically dealt with some issues related to study. One of these articles described the tool used for this study (The Impact on Family Scale) which was ultimately chosen that measured the impact of readmission on caregivers (Stein & Jessop1985). A literature search was done on PubMed, Ovid Medline, Embase, Scopu, Google Scholar, and Blaisdale library. Keywords, phrases and MeSh term for the searches were “family caregiver,” “caregiver burden,” “financial,” “social,” “familial strain,” “ventricular-peritoneal shunt surgery,” and “readmission.” Caregiver burden was searched using various databases, initial search yielded 6,843 result. To make the search manageable, children was added to the search engine and the search result became 1170, thereafter financial, social, personal, coping, and general impact of caregiving were searched and produced 103 results.

The concept of caregiver burden is broad. Markman (2014) defined it as the extent to which caregivers perceive caregiving to have had an adverse effect on their emotional, social, financial, physical, and spiritual functioning. The literature about the effect of a child’s illness on a family caregiver revealed several concerns and burdens as stated by (Galbraith, Wong, Kim, Newachek, 2015; Medway et al., 2015b; Chua et al. 2016; Jones & Williams, 2004; Hughes & Caliandron,1996; and Yotani et al. 2014). Caregivers who might be experiencing stress are often ignored when caring for their children. According to Olagunju et al. (2015) they asserted that less attention has been given to the needs of caregivers despite indications that caregivers are potentially vulnerable to develop emotional illness. The five dimensions addressed in this study are sometimes inseparable because sometimes a caregiver may face financial impact, social impact and some other times face the general impact of caregiving. These themes would be addressed in the following discussions.

Economic/Financial Burden

Several studies (Galbraith, Wong, Kim, and Newachek, 2015; Medway et al. 2015; Karaca-Mandic, Choi-Yoo, Lee, Scale, 2013 and Leonard, Brust, & Sapienza, 1992) found that family caregivers suffer substantial financial burdens when their children are hospitalized. Galbraith, Wong, Kim, and Newachek (2015) reported that socioeconomic disparities have been documented among children and adults in access to and use of health care and in health outcomes. They affirmed that socioeconomic disparities exist in the financial burden of illness because low-income individuals are more likely to lack the protection of health insurance. They claimed that financial burden affects all members of a family when a member is ill. They asserted that a burden from healthcare cost could affect other members of the family, acting as a discouragement from other members seeking healthcare, and also making it difficult for the family to afford food or clothing. Medway et al. (2015) conducted another study that aimed to describe parental perspectives on the financial impact of caring for a child with Chronic Kidney Disease (CKD). They found that health care costs and disruptions to work are among the major contributors to economic hardship that families faced when caring for children with chronic diseases.

A similar study by Karaca-Mandic, Choi-Yoo, Lee, and Scale (2013) assessed the relationship between family members' out-of-pocket (OOP) health care spending, unmet needs, and delayed health care due to cost, for children with and without special health care needs (SHCN). They found that among children without SHCN, higher OOP costs among other family members were associated with higher levels of unmet needs or delays in medical, prescription drug, and dental care, while among children with SHCN, higher OOP costs among other family members was primarily associated with unmet or delayed dental care. Similarly, Leonard, Brust, and Sapienza (1992) predicted the average OOP expenses and caregiving time costs incurred by care providers for a severely disabled child to be $193, or 12.5% of income. Meanwhile Karaca-Mandic et al. (2013) reported that in 2001–02, about 11% of American families spent at least 10% of their family income on OOP costs such as deductibles, coinsurance, and copayments. The families in Leonard et al. (1992) study reported that the median caregiving time for a disabled child to be 4 hours and 42 minutes a day. They stated that an important problem in this study is the fact that when parents focus on childcare, they often cannot sustain their employment and this cause more financial hardship for their families. A report by Ianzito (2017) claimed that an average of $6,954 a year, nearly 20 percent of caregivers' income was spent on OOP cost for family members.

These studies and report addressed several different financial burdens on a caregiver. The studies unanimously claimed that family caregivers experience financial burden during hospitalization. It is likely that a readmission to the hospital and the associated OOP spending compounds this financial burden.

General/Familial Impact of Caregiving

Chua et al. (2016) affirmed that informal caregivers' (IC) knowledge about the nature of caregiving burden is often limited. Their study examined the impact of caregiving burden on quality of life (QOL), mental health, and work capacity among local ICs. They described caregiver burden as a negative reaction to the impact of care on an informal caregiver's social, occupational and personal roles. They stated that these reactions encompass the ICs' response to physical, psychological, social and financial challenges and can be prolonged when they are caring for patients with chronic or mental illness. They concluded that burden in caregiving has negative effects on ICs' physical, emotional, social, and financial wellbeing.

In a similar exploratory study, Poley, Brouwer, Exel & Tibbel (2012) reported caregivers' health related quality of life for those families who have children with congenital abnormalities. They suggested that effects on caregivers could be assessed not only with health–related quality of life but with changes in terms of wellbeing. Olagunju et al. (2015) sought to investigate the burden experienced by caregivers of children with obstructive adenotonsillar hypertrophy and the impact of emotional distress on their caregivers. They asserted that knowledge about burden of care among caregivers of children with adenotonsillar hypertrophy is paramount to caregivers and their children because whatever affects the quality of life of children also affects their caregivers.

These studies reviewed the general impact of caregiving on a caregiver, and the quality of life. They concluded that family caregiver's quality of life is affected during caregiving.

Social Burden

Family caregivers are faced with social burdens when caring for their children. Jones & Williams (2004) defined social burden as the cost imposed on society by an illness or disease. They looked at the social burden of malaria and found that the concept of social burden is often ignored because it is an unclear concept. To make the concept clearer, they described how disease causes changes in household behavior that result in social costs, such as decisions about reproduction, education, and finances.

In a similar study, Elliot, Shewchuk & Richard (2001) looked at social problem-solving abilities, distress, and emotional reactions among family members in caregiving roles. They claimed that a negative problem orientation is a dysfunctional set of attitudes related to problem-solving ability. They expected that a negative problem orientation arising from previous experiences would be predictive of depression, distress, and ill health regardless of the caregiver’s age, gender, or ethnicity or the severity of the care recipient’s disability. They found that family caregivers have negative views of their own problem-solving abilities when family members sustain physical disabilities, and they are likely to experience higher levels of depression, anxiety, and ill health throughout the first year of caregiving. During readmission, there are family roles changes within the family. Khanna et al. (2015) argued that a family with a sick child bears a significant burden of care that increases the demands of caregiving and leads to a reorganization of roles within the family.

These studies looked at the social burden of illness and reiterated that caregivers’ behavior, attitude, and decisions making abilities are affected during the period of caregiving. The negative views of problem solving from previous experiences could be deduced as to why caregivers have a higher level of anxiety

Coping/Personal Strain of Burden

The demands of medically complex patients with special healthcare needs can isolate families from sources of support (Yotani et al., 2014). When a child is ill, caregivers leave their homes and other family members to care for the sick child. Khanna et al. (2015) noted that family caregivers experience anxiety and depressive episodes during hospitalization of their children and concluded that parents and caregivers appear to need support for coping with the difficulties they encounter at all stages of their children’s illnesses.

Hughes and Caliandro (1996) conducted a study to explore the relationship between social support, stressors, level of illness, and perceived caregiver burden in caregivers of children with human immuno-deficiency virus/ acquired immune-deficiency syndrome HIV/AIDS. They reported that family caregivers of chronically ill children were less likely to call on their husbands, parents, and extended family members for support. They suggested that there are some reasons why caregivers in this study may lack social support because of insufficient available resources and inability to access resources. They further argued that with HIV positive children family caregivers might not request support from family and friends because of the stigma of the diagnosis. This stigma causes anxiety and depressive episodes as stated by Khanna et al. (2015).

Contrary to this stigmatization, caregivers of children with hydrocephalus might request support from family members and friends because there are no stigma associated with hydrocephalus except changes in the child's physical features. It becomes concerning when caregivers refused to seek help they so much needed because when a child is ill the whole family is affected and families could use any help they could find from friends and relatives.

Visser-Meily, Post, Riphagen, and Lindeman (2004) described a literature review for identifying the aspects of care that caregivers find most burdensome among caregivers of adult stroke patients. They used many different measures to determine the impact of caring for a stroke patient on the caregiver. They included 97 stroke studies with 45 different measures; of which 16 measures burden and 29 measures impact of burden on caregivers. They identified caregivers at risk of burnout and evaluated supportive treatment strategies for them. Of the 16 instruments used to measure burden felt by caregivers, no difference was found between the instruments that were designed for stroke populations and those that were not. Visser-Melly et al. (2004) claimed that little is known about the measurement properties of the 16 scales because they could not determine a "best" burden scale. And it is not clear that the pediatric caregiver burden is the same as caregiver burden associated with of adults

King, King, Rosenbaum, and Goffin (1999) examined whether and to what extent family-centered caregiving reduces the feelings of distress and depression that some people experience when raising children with disabilities. They found that one important predictor of parental well-being was the child's behavior problems, which was related to the distress and depression the parents felt. Family functioning and social support were found to be significant predictors of parental well-being: parents who received satisfactory social support felt less distressed.

Brannan and Heflinger (2001) looked at the ABCX conceptual model on child, family, and caregivers. The ABCX model describes how families survives, endures, recovers, of fails to recover from stressors experienced as a caregiver. The model framed caregiver strain in an attempt to improve understanding of the risk factors that exacerbate it, and the family strengths that protect against it. They looked at families who reported increased financial strain, disruptions to family and social life, limits on personal freedom and time, and other negative effects of caring for family members with a variety of special needs. Brannan et al. (2001) conceived of "caregivers" in two strains: objective and subjective. They stated that the objective strain captures the observable negative occurrences and constraints that result directly from the relative's problems while the subjective strain captures feelings of stigma, guilt, anger, and worry. They found a high correlation between children's symptoms and other life events, suggesting that children's psychological symptomatology's are affected by stressful life events in ways similar to adults. More interestingly, despite the co-occurrence of children's emotional and behavioral problems and other stressful life events in these families, caregivers could distinguish not only between the events, but also between their impacts (e.g., caregiver strain vs. caregiver psychological distress).

These studies addressed strain, stress, burden and distress of caregiving and was able to show the relationship between all these emotional issues of caregiving. Studies did not address the impact of post VPS readmission of children on family caregivers but it did address the burden of caregiving for family members with chronic illnesses. This implies that caregivers experience the same burden whether their children have had surgery or not.

Total Impact of Caregiving.

Finally, a fifth factor; the total impact of caregiving was added by Stein & Jessop, 1985. They claimed that the preliminary data analyzed and reported in 1980 indicated a four factor structure for the Impact on Family Scale which are economic, social, general, and coping by caregivers. They described the total impact as an overall impact on caregivers. They claimed that the total impact reflects the social and familial impact of chronic illness.

In summary, the various studies all demonstrate a common theme of caregiver burden with common components of financial impact, general impact, social impact, coping, and total impact of caregiving. From these literatures reviewed it could be deduced that caregivers bear the burden of caregiving when caring for an ill child.

Measurement: Impact on Family Scale

After careful review of the literature, a search was conducted to locate an appropriate tool to measure these impacts on families. The Impact on Family Scale (Stein& Jessop, 1985) was chosen because this instrument purported to successfully measure the impact of childhood illness on a family in a Pediatric Ambulatory Care Treatment Study (PACTS). They created a preliminary tool, a 27-item inventory that takes 10 minutes to complete and can be used either as a questionnaire, or an interview-administered form. After the preliminary tool, a second tool was created with 32 items. The questionnaire consisted of open-ended questions related to family problems and the child’s condition in order to investigate the extent of impact. The scale was designed specifically for interview administration with the mother as respondent. The Impact on Family Scale by Stein & Jessop, 1985 can be described as a four point Likert scale with a range from Strongly Agree (1) to Strongly Disagree (4). Respondents were asked questions to rate their personal experiences during admission. The investigators claimed that the focus of this scale is on any change in behavior of the family which could be attributed from child’s illness.

They defined impact as the effect of a child’s illness on the family system which was theorized in five dimensions. 1) the financial/economic, which is the extent to which the illness changes the economic status of the family; 2) social impact, which is the quality and quantity of interaction with those outside the family; 3) general/familial impact, which is the interaction within the family; 4) coping/personal strain of caregiving, and 5) the total impact, which is a combination of the social and familial impact.

Stein and Jessop (1985) administered a twenty-four item questionnaire in a qualitative study to 100 mothers. They factored the items: factor one measures financial burden 4 items; factor two was a combination of familial and social impact and contains nine items related to disruption in both within and outside the family which they state is directly related to child’s illness; factor three measures personal strain, the personal disequilibrium experienced by family caregivers and contains six items. They added a factor four, which they called mastery, contains five items. They affirmed that mastery relates to coping strategies employed by families. They concluded that if families experienced an impact in one area they will likely experience impact in other areas as well and decided to add a total score as a total impact of caregiving. Stein and Jessop, (1985) stated that this tool has been tested for internal consistency and reliability as computed by Cronbach’s alpha = .93.

Thirty-three questions asked in the survey included a wide scope of subject matter to capture a complete picture of the experiences of the respondents. However, the 33 questions were sectioned into five separate dimensions of impact to promote a deeper understanding of the data. In the table below, the questions included in each dimension are listed along with a sample question and can be compared to the questionnaire included in Appendix A. The alphabetical grouping is from the scale showing the interconnections between the five dimensions of impact. Find below table showing the five dimensions and their groupings.

Table 1: Dimensions of Impact

	Total Impact	Financial	General/Familial	Social	Coping/Personal Strain
Survey Questions	a, h, j, k, l, n, o, p, s, u, x, y, z, aa, e, b, g	a, h, o	j, n, o, t, x, aa, e, b, g	k, l, o, p, s, u, w, x, z	r, v, w, c
Sample Question	People in the neighborhood treat us specially because of my child's illness	The illness is causing financial problems for the family	Our family gives up things because of my child's illness	We see family and friends less because of the illness	Nobody understands the burden I carry

In a subsequent study, Stein and Jessop (date) analyzed 209 mothers and stated that a large percentage of the mothers were unemployed and concluded that the financial items had little meaning. In view of these findings the scale was re-examined by looking at those families in which someone worked, and those families in which no one worked. They found that the structure of the non-working group is similar and the five categories are more separable while in the working group the five categories differs. In the working groups, they found coping, financial, social or general burden are intertwined. They stated that a higher total impact on family are associated with low education, low family income, the presence of welfare days, absent from school, and the mother's perception that the child's illness has affected her life. Stein and Jessop, (1985) claimed that parents who lack a means of livelihood report more family impact of chronic childhood disorders. They found that childhood illness has an effect on families with lower social economic status.

Another study by Kolk et al. (2000) used the Impact on Family Scale to investigate the suitability for use with Italian mothers of children with chronic illnesses. The Italian version of the scale was administered to mothers whose children had chronic illness to ascertain their responses in various cultures and interpret the items on the scale. They asserted that a cultural difference was found with respect to financial burden and familial/social impact and further argued that without a test of invariance, the difference between the Italian and American mothers on the mastery scale might result in unreliable results. They concluded that this study emphasized the importance of research into the invariance of measures because this scale could be administered in different cultures with the aim of making cultural comparisons. They suggested that the invariance should be routinely tested and retested in the development of instruments used in different cultures or countries.

Chapter Three: Method

This descriptive study was conducted to assess the impact of readmission on family caregivers of children following VPS surgery. The Impact on Family Scale (Stein & Jessop, 1985; see Appendix A) was used to measure the effect of a child's illness in producing an impact on a family caregiver. Five dimensions were theorized as relevant: financial/economic, social (quality and quantity of interaction with people outside the family), general/familial (quality of interaction within the family), coping/ personal strain (subjective burden experienced by the primary caretaker) and a total impact, which is a combination of familial and social impact of caregiving.

Setting/Sample

The setting for this study is at a tertiary hospital located in Northern California. The choice for this setting was convenient because the investigator is an employee of the hospital, and has observed the flow of children returning for revision surgery after the initial VPS procedure.

The sample for this study was retrieved from a review of electronic medical records (EMRs) of children 0-17 years who had VPS surgery and returned for revision surgery to capture their family caregivers. Ninety-five family caregivers returned for surgery from January 2003-July 2016. Of these 95, twenty of them were Non-English speaking individuals and were excluded because the investigator could not understand or interpret their language. Four of the children were deceased, leaving 71 participants.

Measures (Data collection tools, instruments)

The questionnaire, Impact on Family Scale (Stein & Jessop, 1985), was used to measure family burden in this study. The scale consists of statements made by persons about living with an ill child. Participants are asked to strongly agree, agree, disagree, or strongly disagree with each question and questionnaire takes 10 minutes to complete. Basic demographic data was collected such as the age, educational level and whether caregiver was employed or unemployed during the period of caregiving. The questionnaire elicited varied responses from different subject. The differential impact of illnesses varied in the kind of demands they make on families (see Appendix A)

Procedures

A proposal for this study was submitted to the Institutional Review Board (IRB) of the tertiary hospital located in Northern California. After submission, IRB reviewed the protocol for about eight weeks; approved the protocol, and declared the study exempt. The researcher attended a training organized by the Clinical and Translational Science Center (CTSC) of the hospital called cohort discovery. In this training, this researcher found that cohort discovery could help with query of de-identified medical records of children who had VPS surgery and returned for revision surgery. After this training, the researcher submitted a request to CTSC for permission to review the electronic medical records (EMR) of children from January 2013-December 2015. These requests took another seven weeks before review of EMR was allowed. The initial query found only 47 children who had revision VPS surgery. Because of this small sample size, the researcher requested a new query for revision VPS surgery from January 2003 – July 2016 which yielded 2,523 children who returned for revision surgery. Of these, 95 children fell within the time frame of study. Twenty Non-English speaking families were excluded from study and four of these children were deceased. This left 71 participants that were sent questionnaires. Six of the questionnaires were returned because of wrong address and one of the family caregivers opted out leaving 64 family caregivers.

A convenience sampling method was used to recruit participants for study because of the ease of finding participants’ addresses through EMR reviews. Because of this convenience sampling method, no inclusion criteria could be identified because all family members of children who had revision VPS surgery within the time frame of study were all sent questionnaires.

A consent form and questionnaire (see Appendix A) was sent to all 71 family caregivers by mail with a self-addressed, stamped return envelope. The consent form explained the study and its purpose and affirmed that there would be minimal risk to the child or family caregiver and that this study would not affect the child's treatment. In the consent the caregiver was informed that responding to the questionnaire would signify consent, and that responses would be anonymous. The investigator also reassured survey recipients that this study was strictly for learning and they could choose not to participate. Participants were also advised that they could withdraw at any time. Data collected were stored in an encrypted, password-protected flash drive. Paper copies of the responses were stored in a locked cupboard, and only the investigator has access to the key.

Two and half months after these questionnaires were sent to participants, only eight responses had been received. Because of the low response rate, a reminder notice (see Appendix B) was sent to participants. After another eight weeks, of waiting only one more questionnaire had been returned. Due to the continued low response rate, a request for a modification of the research protocol and a script (see Appendix C) was sent to IRB. This request was to allow the investigator to hand questionnaires to family caregivers, either at the surgical unit as they returned for surgery or at the neurosurgical clinic, to enable the researcher to capture as many participants as possible. The request was approved by the IRB, and the researcher visited the clinic at a time and day requested of the surgeon; unfortunately, the surgeon was absent on jury duty. The turn-up rate for those who returned for surgery to the surgical unit remained low, so the researcher was faced with a very low sample size. The researcher assumed that this low response could be attributed to families' desire not to bring to memory past event; since some of these families had their procedures many years ago and may choose not to recollect what happened.

Chapter Four: Data Analysis/Results

This study was conducted to answer the research question “what is the impact of readmission on family caregivers of children after VPS surgery”? To answer this question an evaluation of family caregivers economic, social, general/familial, coping, and total impact of caregiving was done. A convenience sampling method was used to recruit participants from the EMR review of their children as compared to a randomized controlled trial conducted by Stein & Jessop (1985) where they recruited 100 participants.

Seventy-one family caregivers were sent questionnaires and a return self-addressed stamped envelope. Of these 71, six of the questionnaires were returned because of the wrong address and one of the participants opted out of the study, leaving 64 participants. Of these 64 only nine of them returned their questionnaire, and eight of these nine were analyzed because one of the data from a participant was missing. Table 2 shows the demographic detail of participant who returned their questionnaire.

Table 2: Demographics

Age		
Characteristics	*Subjects*	*Percentage*
25-34	4	50%
35-44	4	50%
Employment		
Employed	5	56%
Unemployed	3	44%
Education Level		
High/Secondary	5	63%
Bachelor	2	25%
Master	1	12%

The socio-demographic details on family caregivers such as age, educational level, and whether the caregiver was employed during the readmission period were also captured. Five dimensions were theorized as relevant according to the Impact on Family Scale. These dimensions are financial/economic, social (quality and quantity of interaction with people outside the family), general/familial (quality of interaction within the family), coping/ personal strain (subjective burden experienced by the primary caretaker) and the total impact of caregiving.

Table 3 measures the top 2 box percentage which is the percentage of respondents that selected ‘Strongly Agree’ and ‘Agree.’ As can be seen on all dimensions, more than 50% of respondents indicated agreement with the survey questions. The answers are grouped by dimensions and show that the ‘Impact’ and ‘General’ dimensions evidenced the strongest percentage of agreement.

Table 3: Survey Analysis

Top 2 Box Percentage

Dimensions	***Percentage***
Financial	54.17%
Impact	74%
General	73.60%
Social	70.83%
Coping	50%

Chapter Five: Discussion

This descriptive study addressed the question, what is the impact of readmission on a family caregiver following a child's ventricular peritoneal shunt surgery? In this study children who had VPS surgery where found to return for revision surgery. When these children return to the hospital, their family caregivers return with them also. The purpose of this study was to identify the impact on a family caregiver a child's hospital readmission following VPS surgery using five dimensions of impact. The five dimensions are economic/financial impact, social impact, general/familial impact, coping/personal strain, and the total impact of caregiving. This study will be discussed by looking at the impact of education on a family caregiver, the sample size, and all five dimensions of impact.

Impact of Education on a Family Caregiver

Eight family caregivers were recruited for this study. Following data analysis 63 percent of respondents to questionnaire had a high school diploma while 37 percent has a Bachelor's or a higher degree. Education of a caregiver might play a positive or a negative role on a child's care. A study by Sanders, Federico. Klass, Abrams, & Dreyer (2009) assessed the prevalence of low health literacy among adolescents, young adults, and child caregivers in the United States. They stated that the readability of common child-health information, and the relationship between literacy and child health affects a child's care. They found that at least 1 in 3 US adults has limited health literacy. They defined health literacy as an individual's capacity to obtain, process and understand basic health information and services needed to make appropriate decisions. Sanders et al (2009) concluded that the most clinically significant associations between health literacy and child health occur in the settings of highest clinical demand, especially newborn care and the care of children with special health care needs.

Moreover, it can be argued that an educated family caregiver might be employed, have health insurance, and sometimes earn a higher income as compared to a minimally educated family caregiver who might be unemployed with no health insurance and sometimes no or minimal earnings. For this reason, Cutler & Lleras-Muney (2006) claimed that individuals who are educated tend to eat healthy foods, feel less stressed on daily activities and might have more social network. On the other hand, a minimally educated caregiver might lack social support, exercise less and lack the means of buying nutritious food. However, an unemployed family caregiver could benefit from caregiving because he/she has all the time she needs to care for a sick child.

Sample size

Eight family caregivers were recruited for this study. The small sample size restricts the ability for the investigator to make an inference about the broader study population. Although, sixty-four family caregivers were sent questionnaires, the response rate remained low despite a reminder notice sent to all 64 family caregivers. This study is prone to sampling error because only a sample of the population was observed instead of the whole population. Study is also prone to sampling bias because some non-English speaking families were not included in study.

Total/Financial/General & Familial/Social/Coping &Personal Strain of Caregiving

The dimensions of total, financial, familial/general impact, social impact and coping/personal strain of caregivers are interconnected according to this study. The number of participants who strongly agree to all five dimensions theorized were 50% and above**.** The financial impact faced by family caregivers in this study is similar to the study conducted by Bek et al. (2009) which affirmed that family financial status, educational status, age of child, number of family members may all influence family burden from a child's disability**.** The total impact, general impact, and social impact of caregiving scored the highest in this study which could be compared to Stein and Jessop PACTS, (1985) which states that a higher total impact on family are associated with low education, low family income, the presence of welfare days, absent from school, and the mother's perception that the child's illness has affected her life.

Family caregivers of children often bear the burden of readmission following VPS surgery. Children most often cannot make decisions on their own unless in cases of emancipation. Research has consistently shown that the demands of medically complex children can isolate families from sources of support (Yotani et al. (2014). Family caregivers who are employed compromise their work schedule to care for an ill child.

Data showed there is no significant difference between the 'impact dimension' and the 'financial', 'social' or 'coping' dimensions. However, the descriptive data and survey analyses shows that the financial dimension has a wider range of responses comparatively showing that respondents had varying degree of financial impact depending on their employment/educational level.

Limitations

One limitation of this study was the difficulty encountered recruiting respondents to the questionnaire. Seventy-one questionnaires were mailed out with a self-addressed, stamped return envelope, six of these questionnaires were returned because of wrong address, one of them opted out leaving sixty- four participants. Nine responses were returned and only eight were analyzed because of wrong data entry in one of the surveys. Using the results of a survey depends on the assumption that the respondents are a representative sample, but in this case they were not. The use of incentives such as gift cards might have encouraged greater participation. This study also does not represent the Non-English speaking families who returned for revision surgery. It is possible that if they were included, more participants might have responded.

Implications for Nursing

Hospital readmission is a quality issue, and nurses are in the forefront of addressing it. A question to ponder…was readmission; could it be because of lack of knowledge of family caregiver? Or was it because there was an actual medical reason for needing readmission? In either case readmission could be related to the family caregiver, or related to hospital/medical condition or surgery. When readmissions are related to family caregivers, caregivers are instructed by nurses on how to care for their loved ones at home after discharge. With efficient and effective communication to family caregiver and verifying from caregiver an understanding of health information shared, planning and education nurses could adequately prepare family caregivers for discharge. Nurses could identify concerns that may need interventions during the patient's hospital stay by evaluating health needs and care planning. Communication is paramount when concerns on patients discharge instruction needs to be discussed. Nurses have been known to communicate areas of concern for immediate interventions and sometimes referral. In a study by Nelson & Rosenthal (2015) they stated that it is important to identify a family caregiver who will care for each patient after discharge and involve this person throughout the patient's hospital stay. They claimed that this can ease the feeling of information overload on family caregivers at the end of the hospital stay. They assert that hospital readmission rates have also been found to decline when family caregivers participate in care throughout the child's hospitalization. This participation by family caregivers enables caregivers understand discharge instructions and how to care for their children at home thereby reducing the impact of readmission on a family caregiver.

Future Research

This study does not represent all the families who returned for revision VPS surgery. Non-English speaking families were excluded from study because Researcher would not be able to interpret their languages. The researcher recommends a study in which both English-speaking and non- English families especially the Hispanics families be reviewed in subsequent study to see if language barriers contribute to readmission and to capture as many participants as possible to make the study more meaningful.

Conclusion

Education of family caregivers, and reiterating health information shared, and follow-ups after discharge is important in reducing readmission. Hospitals should implement strategies for decreasing children's readmission rates after VPS surgery by increasing coordination of care and communication between providers, nurses, and family caregivers. One important helpful technology is the electronic health records, which give health professionals easier access to medical history so they can ensure continuity of care. With the use of continuity of care across organizations, when problems develop; appropriate treatment could be given thereby reducing readmission and subsequent burden to family caregivers.

References

Al-Tamimi, Y. Z., Sinha, P., Chumas, P. D., Crimmins, D., Drake, J., Kestle, J., (2014).Ventriculoperitoneal shunt 30-day failure rate: a retrospective international cohort study. Neurosurgery, 74(1), 29-34.

Benbassat, J., & Taragin, M. (2000). Hospital readmissions as a measure of quality of health care: advantages and limitations. Archives of internal medicine, 160(8), 1074-1081.

Brannan, A.M. & Heflinger, C.A. (2001) Distinguishing caregiver strain from psychological distress: modelling the relationship among child, family, and caregiver variables Journal of Child and Family Studies 10: 405. doi:10.1023/A:1016705306848

Can caregivers help reduce hospital readmissions? Retrieved on 10/05/2016 from http://www.aarp.org/politics-society/advocacy/caregiving-advocacy/info-20

Care for the caregiver, National Alliance for Caregiving. Retrieved November 21, 2016 from www.caregiving.org/data/Emblem_CfC10_Final2.pd from caregiving.org

Chern, J. J., Bookland, M., Tejedor-Sojo, J., Riley, J., Shoja, M.M., Tubbs, R. S., & Reisner, A. (2014) Return to system within 30days of discharge following pediatric shunt surgery doi:10.3171/2014.2. PEDS13493

Journal of Pediatric Nursing, 11(6), 347-358

Chua, C. K. T., Wu, J. T., Wong, Y. Y., Qu, L., Tan, Y. Y., Neo, P. S. H., & Pang, G. S. (2016). Caregiving and Its Resulting Effects—The Care Study to Evaluate the Effects of

Caregiving on Caregivers of Patients with Advanced Cancer in Singapore. *Cancers*, *8*(11), 105.

CMS NHE Fact Sheet (2015) https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/nhe-fact-sheet.html

Cultler, D. M. & Lleras- Muney (2006) The national bureau of economic research Education and Health: Evaluating theories and evidence https://www.nber.org/papers/w12352

Elliot, T. R., Shewchuk, R, M, & Richard, J.S (2001) Family caregiver social problem-solving abilities and adjustment during the initial year of the caregiving role. *Journal of Counseling Psychology*, Vol 48(2), Apr 2001, 223-232. http://dx.doi.org/10.1037/0022-0167.48.2.223

Galbraith, A. A., Wong, S. T., Kim, S. E., & Newacheck, P. W. (2005). Out-of-pocket financial burden for low-income families with children: Socioeconomic disparities and effects of insurance. *Health services research*, 40(6p1), 1722-1736

Hydrocephalus Fact Sheet. Retrieved March 20, 2016 from

http://www.ninds.nih.gov/disorders/hydrocephalus/detail_hydrocephalus.htm

Ianzito (2017) The cost of family caregiving: out-of-pocket spending surprisingly high https://careforthecaregiver.me/2017/01/01/the-cost-of-family-caregiving-out-of-pocket-spending-surprisingly-high-a-guest-post-by-christina-ianzito

Ibrahim, G. M., & Kulkarni, A. V. (2015). General Introduction: Why they exist, incidence, social and economic costs, and quality of life. In Complications of CSF Shunting in Hydrocephalus (pp. 3-11). Springer International Publishing.

Jones, C. O., & Williams, H. A. (2004). The social burden of malaria: what are we measuring? The American journal of tropical medicine and hygiene, 71(2 suppl), 156-161. Retrieved from http://www.ajtmh.org/content/71/2_suppl/156.long

Joynt, K. E., & Jha, A. K. (2012). Thirty-day readmissions—truth and consequences. New England Journal of Medicine, 366(15), 1366-1369.

Karaca-Mandic, P., Choi-Yoo, S. J., Lee, J., & Scal, P. (2014). Family out-of-pocket health care burden and children's unmet needs or delayed health care. Academic pediatrics, 14(1), 101-108.

Khan, F., Rehman, A., Shamim, M. S., & Bari, M. E. (2015). Factors affecting ventriculoperitoneal shunt survival in adult patients. Surgical Neurology International, 6, 25. http://doi.org/10.4103/2152-7806.15138

Khanna, A. K., Prabhakaran, A., Patel, P., Ganjiwale, J. D., & Nimbalkar, S. M. (2015). Social, Psychological and Financial Burden on Caregivers of Children with Chronic Illness A Cross-sectional Study. The Indian Journal of Pediatrics, 82(11), 1006-1011.King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centered caregiving and well-being of parents of children with disabilities: linking process with outcome. Journal of pediatric psychology, 24(1), 41-53.

Kolk, A. M., Schipper, J. L., Gerrit J. F. P., Hanewald, Ezio F., Casari., Alga G., &

Fantino (2000) The Impact-on-Family Scale: A test of invariance across Culture. *J Pediatr Psychol* 2000; 25 (5): 323-329. doi: 10.1093/jpepsy/25.5.323

Kulkarni, A. V., Drake, J. M., & Lamberti-Pasculli, M. (2001). Cerebrospinal fluid shunt infection: a prospective study of risk factors. Journal of neurosurgery, 94(2), 195-201.

Markman, J (2014) Outcome measures involving caregiver burden - immpact Retrieved on10/18/16 from www.immpact.org/static/meetings/Immpact17/Markman.pdF

Medway, M., Craig, J. C., Kim, S., Mackie, F., McTaggart, S., Walker, A., & Wong, G (2015) Parental perspectives on the financial impact of caring for a child with CKD. *American Journal of Kidney Diseases*, *65*(3), 384-393.

National Alliance for Caregiving in collaboration with AARP (2009) Caregivers of children: A focused look at those caring for a child with special needs under the age of 18 http://www.caregiving.org/data/Report_Caregivers_of_Children_11-12-09.pdf

National Alliance for caregiving: Care for the family caregiver, a place to start (2010) http://www.caregiving.org/data/Emblem_CfC10_Final2.pdf

Naradzay, J. F., Browne, B. J., Rolnick, M. A., & Doherty, R. J. (1999). Cerebral ventricular shunts. *The Journal of emergency medicine*, 17(2), 311-322.

Needleman, J., & Hassmiller, S. (2009). The role of nurses in improving hospital quality and efficiency: real-world results. *Health Affairs*, 28(4), w625-w633.

Nelson, J. M., Rosenthal, L (2015) How nurses can help reduce hospital readmissions voi. 10

https://www.americannursetoday.com/nurses-can-help-reduce-hospital-readmissions/

Olagunju, A. T., Asoegwu, C. N., Campbell, E. A., Akinbode, A. A., Aina, O. F., & Nwawolo, C. C. (2015). Impact of emotional distress on caregivers burden among Nigerian children with Obstructive Adenotonsillar hypertrophy. *International journal of pediatric otorhinolaryngology*, *79*(6),

Readmissions Reduction Program (HRRP). Retrieved March 30, 2016 from https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/Readmissions-Reduction-Program.html

Reducing cost and improving the quality of health care. Retrieved March 15, 2016 from https://www.whitehouse.gov/sites/default/files/docs/erp2013/ERP2013_Chapter_5.pdf

Reducing unnecessary hospital readmissions: The role of the patient safety organization. Retrieved March 15, 2016 from https://pso.ahrq.gov/Topics#resources

Sanders LM, Federico S, Klass P, Abrams MA, Dreyer B. (2009) Literacy and Child Health A Systematic Review. *Arch Pediatr Adolesc Med.* 2009;163(2):131-140. doi:10.1001/archpediatrics.2008.539

Srivastava, R., & Keren, R. (2013). Pediatric readmissions as a hospital quality measure. Jama, 309(4), 396-398.

Stein, R. E. K., & Jessop, D. J. (1985). Tables documenting the psychometric properties of a measure of the impact of chronic illness on a family. Bronx, NY: Albert Einstein College of Medicine of Yeshiva University.

Tejedor-Sojo, J., Singleton, L. M., McCormick, K., Wrubel, D., & Chern, J. J. (2015). Preventability of pediatric 30-Day readmissions following ventricular shunt urgery. *The Journal of pediatrics*, 167(6), 1327-1333.

The National bureau of economic research: The Effects of Education on Health https://www.nber.org/digest/mar07/w12352.html

Thompson, E. H., Futterman, A. M., Gallagher-Thompson, D., Rose, J. M., & Lovett, S. B. (1993). Social support and caregiving burden in family caregivers of frail elders. *Journal of Gerontology*, 48(5), S245-S254.

Tuli, S., Drake, J., Lawless, J., Wigg, M., & Lamberti-Pasculli, M. (2000). Risk factors for repeated cerebrospinal shunt failures in pediatric patients with hydrocephalus. *Journal of neurosurger*y, 92(1), 31-38.

van den Heuvel, E. T., de Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation*, 15(6), 669-677.

Visser-Meily, J. A., Post, M. W., Riphagen, I. I., & Lindeman, E. (2004). Measures used to assess burden among caregivers of stroke patients: a review. Clinical Rehabilitation, 18(6), 601-623.

Whitman, E (2016) Hospitals face record penalties as CMS expands criteria for readmissions fines Retrieved on 11/24/14 from www.modernhealthcare.com

Wu, Y., Green, N. L., Wrensch, M. R., Zhao, S., & Gupta, N. (2007). Ventriculoperitoneal shunt complications in California: 1990 to 2000.Neurosurgery, 61(3), 557-563

Yotani, N., Ishiguro, A., Sakai, H., Ohfuji, S., Fukushima, W., & Hirota, Y. (2014). Factor associated caregiver burden in medically complex patients with special health-care needs. Pediatrics International, 56(5), 742-747.

Pediatr Psychol 2000; 25 (5): 323-329. doi: 10.1093/jpepsy/25.5.323

Appendix A

Consent Waiver for Study and Questionnaire

Investigators: Mary Uwhuba, RN, BSN, CNOR, Dr. Amy Nichols, RN, PhD

I am a graduate student of the Betty Irene Moore School of Nursing undergoing a Masters of Science in Healthcare Leadership Program. So, myself Mary Uwhuba, and my chair, Dr. Amy Nichols would like to invite you to take part in a research study involving your child's readmission. I am an RN who works at the Children Surgery Center of the UC Davis Medical Center where your child had surgery. The purpose of this study is to assess the impact of readmission of your child on you. This study involves minimal risk to you or your child since I do not intend to use your names or any information that would identify you. I retrieved your names and addresses from your child's medical record so that I could send this consent/questionnaire for this study. Your response to the questionnaire indicates your consent for study. Responses should have no names or any information that identifies you. You may choose not to participate in this study, and withdraw at any time without any effect on your child's care. Little is known about the effect of readmission of a child following Ventricular Peritoneal Shunt Surgery on a family caregiver, and this study would test a supposition that readmission of a child affects a family caregiver. Please contact us if you have any questions.

Thank you ♡

Mary Uwhuba-

Amy Nichols-

IMPACT ON FAMILY SCALE

These questionnaires are statements made by people about living with an ill child. It takes 10 minutes to complete it. For each statement, please tell me at the time your child was readmitted if you strongly agree, agree, disagree, or strongly disagree with the statement.

		Strongly Agree	Agree	Disagree	Strongly Disagree
a.	The illness is causing financial problems for the family	1	2	3	4
b.	Time is lost from work because of hospital appointments	1	2	3	4
c.	I am cutting down the hours I work to care for my child	1	2	3	4
d.	Additional income is needed in order to cover medical expenses	1	2	3	4
e.	I stopped working because of my child’s illness	1	2	3	4
f.	Because of the illness, we are not able to travel out of the city	1	2	3	4
g.	People in the neighborhood treat us specially because of my child’s illness	1	2	3	4
h.	We have little desire to go out because of my child’s illness	1	2	3	4
i.	It is hard to find a reliable person to take care of my child	1	2	3	4
j.	Sometimes we have to change plans about going out at the last minute because of my child’s state	1	2	3	4
k.	We see family and friends less because of the illness	1	2	3	4

l.	Because of what happened we have shared we are a closer family	1	2	3	4
m.	Sometimes wonder whether my child should be treated ‘specially’ or the same as a normal child	1	2	3	4
n.	My relatives have been understanding and helpful with my child	1	2	3	4
o.	I think about not having more children because of the illness	1	2	3	4
p.	My partner and I discuss my child’s problems together	1	2	3	4
q.	We try to treat my child as if he/she were a normal child	1	2	3	4
r.	I don’t have much time left over for other family members after caring for my child	1	2	3	4
s.	Relatives interfere and think they know what’s best for my child	1	2	3	4
t.	Our family gives up things because of my child’s illness	1	2	3	4
u.	Fatigue is a problem for me because of my child’s illness	1	2	3	4
v.	I live from day to day and don’t plan for the future	1	2	3	4
w.	Nobody understands the burden I carry	1	2	3	4
x.	Traveling to the hospital is a strain on me	1	2	3	4
y.	Learning to manage my child’s illness has made me feel better about myself	1	2	3	4
z.	I worry about what will happen to my child in the future (when he/she grows up, when I am not around)	1	2	3	4

aa.	Sometimes I feel like we live on a roller coaster: in crisis when my child is actually ill, OK when things are stable	1	2	3	4
BB.	It is hard to give much attention to the other children because of the needs of my child	1	2	3	4
CC.	Having a child with an illness makes me worry about my other children’s health	1	2	3	4
DD.	There is fighting between the children because of my child’s special needs	1	2	3	4
EE.	My other children are frightened by his/her illness	1	2	3	4
FF.	My other children seem to have more illnesses, aches and pains than most children their age	1	2	3	4
GG.	The school grades of my other children suffer because of my child’s illness	1	2	3	4

Appendix B

Reminder Notice

Dear Participant,

If you have completed the questionnaire recently mailed to you for my Thesis Paper related to the Impact of Readmission on Family Caregivers of Children, please accept my thanks.

If you have not mailed it back, it is not too late! Your participation in this study is very important and valuable to my study.

I appreciate you taking the time from your schedule to help me learn as much as I can on how readmission affects a family caregiver. Please email if you have lost the questionnaire and I will gladly forward it to you at

Thank You,

Mary Uwhuba

Appendix C

Script

Hello, my name is Mary Uwhuba and I work at the Children Surgery Center of UC Davis Medical Center. I would like to speak with you about participation in a research study. Do you want to see if you qualify for this study? List your eligibility questions.

(Child 0-17years)

(English Speaking)

(Had Ventricular-Peritoneal Shunt Surgery)

(Return for Readmission after initial surgery)

If yes, move to next question. If no, thank the individual and move on.

It looks like you qualify

I would like to speak with you about participation in a research study. I am trying to find out the impact of readmission of your child on you as a family caregiver. This research study involves a survey. The surveys are questions asked by someone caring for a sick child, it takes 10 minutes to complete it

Would you like to participate?

If they agree: Thank you for agreeing to participate. Here is the survey. Please return it to me after completing it.

If they do not agree, thank them and move on