Caregivers of Medically Fragile Children with Technology Needs

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CAREGIVERS OF MEDICALLY FRAGILE CHILDREN
WITH TECHNOLOGY NEEDS

A DISSERTATION
SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN NURSING
THE UNIVERSITY OF TEXAS HEALTH SCIENCE CENTER AT HOUSTON
CIZIK SCHOOL OF NURSING
BY
VUONG TRUNG-TRAN PRIETO, MSN, RN, CHSE

MAY, 2020
Approval Form D-3

The University of Texas Health Science Center at Houston
Cizik School of Nursing
Houston, TX

2/25/2020

Date

To the Dean for the School of Nursing:

I am submitting a dissertation written by Vuong Prieto and entitled "Caregivers of Medically Fragile Children with Technology Needs." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Nursing.

Dr. Geraldine Wood, PhD, RN, FAAN, Committee Chair

We have read this dissertation and recommend its acceptance:

Dr. Cathy Roznatis, PhD, RN, FAAN

Dr. Hyal Cohen, MD, M.Sc., FRCP (C)

Accepted: __________

Dean for the Cizik School of Nursing
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To God, I thank Him for all the blessings and challenges in my life that has strengthened me over the past several years. I look forward to future endeavors and the will to do all things through His grace and name.
Abstract

Background: Medically fragile children (MFC) have complex and challenging health care needs in the home. Providing care can have both negative and positive psychological and social impacts on the caregivers’ health related quality of life (HRQOL).

Aims: To examine the relationship between caregiver burden, caregiving satisfaction, and HRQOL in caregivers of MFC and to identify caregiver and child related variables of caregiver burden and caregiving satisfaction.

Methods: A cross sectional study was conducted at a hospital and outpatient clinics. Caregivers completed three surveys - Zarit Burden Interview, Caregiving Satisfaction Scale, and the Health Survey Short Form – 12 version 2. Socio-demographics of the caregivers and MFC and clinical characteristics of the MFC were also collected.

Results: Of 32 participants, 93.8% were female and 81.3% were biological mothers. A moderate, inverse relationship was found between caregiver burden and caregiving satisfaction ($r = -0.396, p = 0.025$). Caregiver burden had a strong, negative association with the mental health component of the caregivers’ HRQOL ($r = -0.837, p < 0.001$). Caregiving satisfaction had a moderate, positive association with the mental health
component of the caregivers’ HRQOL ($r = .437$, $p = .012$). Education level of the caregivers had a moderate, positive correlation with caregiver burden ($r_s = .462$, $p = .008$) and a moderate, negative correlation to caregiving satisfaction ($r_s = -.353$, $p = .047$). A moderate, positive association was found between family income and caregiver burden ($r_s = .507$, $p = .005$). Caucasian caregivers had greater caregiver burden ($M = 30$, $SD = 17.5$) compared with caregivers who were of Other race ($M = 16.7$, $SD = 14.6$); $t(28) = 2.11$, $p = 0.044$. Caucasian caregivers also had lower caregiving satisfaction ($M = 48.4$, $SD = 7.3$) compared with caregivers of Other race ($M = 55.4$, $SD = 5.1$); $t(28) = -2.80$, $p = 0.009$.

**Conclusions:** Despite caregiver burden, caregivers of MFC with technology needs have caregiving satisfaction. The associations of the caregivers’ mental HRQOL to caregiver burden and caregiving satisfaction highlight the importance of identifying caregivers at risk who become overwhelmed with care.

**Keywords:** medically fragile, caregiver burden, caregiving satisfaction, health related quality of life
# Table of Contents

APPROVAL .................................................................................................................................................. ii

ACKNOWLEDGEMENTS ........................................................................................................................ iii

ABSTRACT .................................................................................................................................................. v

SUMMARY OF STUDY ............................................................................................................................. 1

PROPOSAL ................................................................................................................................................ 3

Specific Aims ............................................................................................................................................ 4

Background and Significance .................................................................................................................. 6

Research Design and Methods ............................................................................................................... 18

Human Subjects ....................................................................................................................................... 27

References ................................................................................................................................................ 29

Letter to the Editor .................................................................................................................................. 40

DISSENTATION MANUSCRIPT

Caregivers of Medically Fragile Children with Technology Needs ......................................................... 41

APPENDIXES

A. Approval of Proposal by Dissertation Committee (D2 Form) ......................................................... 88

B. UT Health Science Center at Houston CPHS Approval of Proposal ............................................... 90

C. Memorial Hermann Healthcare System Approval For Memorial Hermann –
Texas Medical Center & Children’s Hospital ......................................................................................... 93
Summary of Study

The research protocol “Caregivers of Medically Fragile Children with Technology Needs” began following approval from the Committee For the Protection of Human Subjects (CPHS) of The University of Texas Health Science Center at Houston on July 10, 2019 and from the Memorial Hermann Clinical Innovation and Research Institute on July 19, 2019 for Memorial Hermann – Katy; on July 22, 2019 for Memorial Hermann – Memorial City; and on July 30, 2019 for Memorial Hermann – Texas Medical Center & Children’s Hospital. The following were the aims of the descriptive, cross-sectional research study:

1. Examine the relationship between caregiver burden, caregiving satisfaction, and health related quality of life (HRQOL) in caregivers of medically fragile children (MFC) with technology needs cared for in the home.
2. Identify caregiver and child related variables of caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs cared for in the home.

Data collection began on August 7, 2019 and ended on December 11, 2019. Caregivers of medically fragile children with technology needs were surveyed in the inpatient and outpatient setting at Children’s Memorial Hermann – Texas Medical Center and at a clinic at UT Physicians. Of the 138 caregivers approached to participate or recommended, 75 caregivers were excluded because they did not meet inclusion criteria. Of the 63 caregivers that met the inclusion criteria, 32 caregivers consented to participate.
Descriptive statistics were utilized to describe sample characteristics of the caregivers and children. The correlation coefficient, Pearson’s $r$, was used to determine the strength and direction of the associations between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL. Spearman’s rho tested the correlation between the dependent variables and independent variables that violated normality. A moderate, inverse relationship was found between caregiver burden and caregiving satisfaction. Caregiver burden had a strong, negative association with the mental health component of the caregivers’ HRQOL. Caregiving satisfaction had a moderate, positive association with the mental health component of the caregivers. Education level of the caregivers had a moderate, positive correlation with caregiver burden and a moderate, negative correlation to caregiving satisfaction. A moderate, positive association was found between family income and caregiver burden. Caucasian caregivers had greater caregiver burden and lower caregiving satisfaction compared with caregivers of Other race.

A manuscript was written describing the background and significance of the research aims and included the methods, results, and implications for nursing practice and nursing research. Appendices A-Q include supplemental information from the study – D2 approval form, IRB and CPHS approval documents, Memorial Hermann Research System approval documents, study consent form, study flyer, letter of invitation, original study instruments, Qualtrics version of study instruments, demographics and clinical characteristics form, and human subjects research training certificates.
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JUNE, 2019

Dissertation Committee:
Dr. Geraldine Wood, PhD, RN, FAAN - Chairperson
Dr. Cathy Rozmus, PhD, RN, FAAN
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Specific Aims

Medically fragile children (MFC) depend on technology for survival and rely on their primary caregivers, generally their mothers, to provide both complex and challenging care in the home. The simultaneous care that MFC with technology needs require, in conjunction with other family associated responsibilities, can have both negative and positive psychological and social impacts on the caregivers’ health related quality of life (HRQOL). As the caregivers provide optimal caregiving to their medically fragile child, the caregivers’ HRQOL may be overlooked and potentially lead to caregiver burden and decreased caregiving satisfaction.

Caregivers of MFC with technology needs have poor HRQOL, especially those caregivers who care for their child in the home compared to those who have their child cared for in the long-term care setting (Caicedo, 2014; Chan et al., 2019). The negative impacts of providing long-term care to MFC with technology needs by maternal caregivers, especially those who are single caregivers include having higher levels of depression, less family supportiveness, and less opportunity for social activities when compared to maternal caregivers of children with acute illnesses (Thyen et al., 1998, Thyen et al., 1999). In a review of studies of caregivers of children with chronic disorders, higher caregiver burden was found to be related to caregiver age, female gender, marital status, ethnicity of African/European descent, low income, and unemployment (Macedo et al., 2015). Negative associations have also been found between caregiving burden and the caregivers’ quality of life (Crespo et al., 2016; Khanna et al., 2011; Silva et al., 2015a). The same correlation also occurred between caregiving burden and caregiving satisfaction, but among caregiving grandmothers of
healthy children (Pruchno & McKenney, 2002). Among caregivers of MFC, significant predictors of caregiver burden that have been identified include the type of technology needs of the child, presence of younger/older siblings in the home, and nursing care coordination (Suzuki et al., 2017; Yotani et al., 2014). Although caregivers of MFC in the integrative study by Rehm (2013) described positive impacts of caregiving such as empowerment, increased empathy, and personal growth, caregiving satisfaction has yet to be studied among these caregivers. What remains unclear in the existing literature are the associations between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL and what additional factors are associated with caregiver burden and caregiving satisfaction among caregivers of MFC dependent on technology. Understanding the association among these variables is imperative as caregivers of MFC with technology needs have long-term caregiving demands that may extend into the child’s adulthood. Over time, the instances of caregiving burden or caregiving satisfaction may fluctuate when caregiving demands become overwhelming and inadvertently compromise their child’s health, their own health, and family function. The overall objective of this study is to determine the relationship between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL and to determine what factors are related to caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs. The long-term goal of this proposal is to identify burdened caregivers of MFC dependent on technology and ensure they have the support and resources necessary to manage the care of their child and to maintain their own health. To address the gap in knowledge for this specific population of caregivers and children, the specific aims and hypotheses of this proposal will be the following:
Aim 1 – Examine the relationship between caregiver burden, caregiving satisfaction, and HRQOL in caregivers of MFC with technology needs cared for in the home. **Hypothesis:** It is hypothesized that increased caregiver burden will be negatively related to caregiving satisfaction and HRQOL. **Aim 2** – Identify caregiver and child related variables of caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs cared for in the home. **Hypothesis:** It is hypothesized that caregivers’ gender, age, socioeconomic status (SES), ethnicity, marital status, duration of caregiving, and number of other children living in the family and the child’s age, gender, primary diagnosis, duration of disease, number of hospitalizations, and type of technology will be associated to caregiver burden or caregiving satisfaction.

The expected outcomes of this proposal will determine the hypothesized relationship between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL and will determine factors related to caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs. The positive impact of this study will provide the evidence necessary to identify variables that necessitate consideration for the development of future intervention studies to support caregivers of MFC dependent on technology for survival.

**Background and Significance**

MFC who are technology dependent require both medical devices to compensate for vital body functions and ongoing nursing care to deter death/further disability (U.S. Congress, Office of Technology Assessment, 1987). MFC have also been described using other terms including children with technology dependency (CTD), technology – dependent children, children with medical complexity, or children with complex chronic
conditions (Cohen et al., 2011; Rehm 2013; Suzuki et al., 2017). Despite the various terms, these children share the need for continuous care and dependency on technology for survival. There is no unique and distinct chronic condition, disease, or diagnosis that classifies MFC. Some examples of diagnoses that may lead to a child being categorized as medically fragile are cerebral palsy, congenital heart disease, bronchopulmonary dysplasia, microcephaly, and muscular dystrophy (The Medically Fragile Children Work Group Report, 2013). Children born with severe genetic disorders, seizure disorders, gastrointestinal disorders, and renal disorders are also within the scope of MFC. The Office of Technology Assessment (OTA) identifies four groups of children as technology dependent (1987). Group I consists of children who require mechanical ventilators. Mechanical ventilators used in the home setting can be invasive requiring children to have a tracheostomy or non-invasive via continuous airway pressure (CPAP) or bi-level positive pressure (BPAP) (Preutthipan, 2015). Group II consists of children who require parenteral nutrition/intravenous requirements (OTA, 1987). The third group requires daily dependence on oxygen support, tube feedings, tracheotomy tube care, suctioning, and other device-based respirators. Group IV includes children who require cardiorespiratory monitoring, renal dialysis, urinary catheters, or colostomies. Despite the different technology dependent groups, MFC may fall under some or all groups depending on their chronic condition/conditions, comorbidities, and overall technology needs. While MFC are dependent on technology to survive, their survival also falls upon their caregivers who bear the burden of care.

**Caregiver Burden.** Caregiver burden is the discomfort or stress that occurs when caregivers provide direct care to their family member (Hunt, 2003). The care that MFC
initially receive in the hospital normally transitions to their primary caregivers who will ultimately be responsible for all their caregiving needs. In most families of MFC with technology needs, mothers are identified as the primary caregivers who provide daily care in the home (Kuster & Badr, 2006; Rehm, 2013; Toly & Musil, 2015). The majority of the mothers of MFC with technology needs are also unemployed, as the complexity of care requires them to stay home at all times (Kuster & Badr, 2006; Thyen et al., 1999). Unlike healthcare professionals who receive formal education and training to care for MFC with technology needs in the clinical setting, caregivers of MFC must acquire the knowledge and skills to care for their child in a short time period and display competent care before their child is discharged to home. Caregivers have reported needing at least 6 months to become accustomed to the technological aspects of their child’s health care (Ray, 2002). In studies of MFC, greater than 60% of the children had more than one technology need (Caicedo, 2014; Toly & Musil, 2015). The technology that MFC depend on for survival require their caregivers to monitor and maintain their child’s health status, to recognize signs of distress or deterioration, to program the technology, to troubleshoot the technology, and to acquire any other skills related to their child’s care. Technology use also varies among caregivers of MFC depending on the type of technology need or needs. Heaton et al. (2005) identified three patterns of technology usage among caregivers of technology dependent children being constant usage throughout 24 hours (i.e. home ventilation), at regular intervals (i.e. enteral or intravenous feedings), or at irregular times (i.e. suctioning). For families with MFC, the needs of the medically fragile child may supersede the needs of the individual family members within the family leading to psychological and social consequences. In an integrative review (Rehm, 2013),
parents of children with complex chronic conditions and their families found that parents experience emotional distressing impacts (stress, worry, fear, anxiety, being overwhelmed, depressed) when providing home care. The stressors and worries were related to the health and appearance of the child; fear and anxiety arising from the technological needs of the child, and managing those needs; feeling overwhelmed and depressed from being solely responsible for the child in the home setting. Besides the emotional impacts of caregiving, caregivers of MFC dependent on technology endure social impacts of feeling isolated from extended family, friends, or strangers in public due to their unacceptance or ignorance of their child’s technology needs, from the embarrassment of their child’s behavior displayed, or from the inability to travel or take vacations (Ratliffe et al., 2002). In conjunction with the caregiving responsibilities, other obligations unrelated to caregiving may conflict with one another and produce caregiver burden among caregivers of MFC with technology needs.

Factors associated with caregiver burden that have been reported among caregivers of MFC with technology needs include the children’s type of technology need, the presence of younger or older siblings in the family, single parent, and help from grandparents (Yotani et al., 2014). Among the variables, home mechanical ventilation (HMV) with tracheostomy and the presence of younger siblings in the group of MFC > than 15 years significantly predicted caregiver burden. Another study of parental caregivers of technology dependent children examined the association between caregiver burden and nursing care coordination by nurses who visit caregivers and their MFC to assist with daily caregiving (Suzuki et al., 2017). The results indicated greater nursing care coordination predicted lower caregiver burden (Suzuki et al. 2017). The two studies
on associated factors related to caregiver burden by Suzuki et al. (2017) and Yotani et al. (2014) were conducted in Japan; therefore, the results are difficult to generalize to other countries and other ethnic groups of caregivers who care for MFC with technology needs. Furthermore, not all caregivers who care for MFC with technology needs qualify for home health assistance or even respite care (Mah et al. 2008; Rehm & Bradley, 2005; Wang & Barnard, 2008). Even if caregivers have home health nurses, some nurses did not have pediatric specific training to care for MFC, which in turn frustrated caregivers who either supervised and trained the nurses themselves or dismissed the nurses entirely (Nageswaran & Golden, 2017). Due to poor home health care, caregivers would ultimately decide to care for their child themselves alone. In addition, financial burdens that these caregivers endure may be unaccounted for and underreported depending on what type of insurance coverage the family has and other expenses related to equipment use, medications, electricity costs of the technology or technologies, unpaid caregiving, and travel expenses to various follow-up appointments (Wang, 2004).

**HRQOL.** HRQOL is the individual’s perceived impact of health on their physical and psychological functions. (Defenderfer et al., 2017). A study of caregivers of MFC with HMV needs self-reported lower perceived quality of life compared to caregivers and families of healthy children (Gonzalez et al., 2017). Another study reported decreased HRQOL in caregivers (primarily mothers, but also including fathers, grandmothers, guardians, and adoptive mothers) of MFC with one or more technology needs in the home setting compared to caregivers of MFC in the long-term care setting (Caicedo, 2014). The parents and caregivers also reported physical problems of fatigue, emotional problems of anger, frustration, anxiety, and social problems of isolation regarding
HRQOL (Caicedo, 2014). Other studies on caregivers of MFC have found decreased quality of life or decreased HRQOL in relation to sleep disruption and depression (Chan et al., 2019; Heyman et al., 2004; Keilty et al., 2018; Meltzer et al., 2015). Approximately 40-45% of maternal caregivers of MFC with technology needs score over the cutoff of ≥16 on the Center for Epidemiology Studies Depression Scale (CES-D) indicating increased risk for clinical depression (Kuster & Badr, 2006; Meltzer et al., 2010; Toly & Musil, 2015). Caregivers with health problems also report higher adverse effects on their quality of life when providing HMV home care for their child compared to those caregivers of MFC without health problems (Seear et al., 2016). Caregiver burden among parents and caregivers of children with chronic conditions that do not have technology needs have reported negative associations between caregiving burden and quality of life (Crespo et al., 2016; Khanna et al., 2011; Silva et al., 2015a). Despite the findings on decreased HRQOL among caregivers of MFC dependent on technology, associated concepts such as caregiver burden and caregiving satisfaction have not been examined together with caregivers’ HRQOL among this population of caregivers. In addition, other variables of interest in studies among caregivers of children with chronic diseases without technology needs or in studies that did not distinguish the use of technology among the children in their study require investigation for their association to caregiver burden and caregiving satisfaction.

Caregiver burden studies are extensive among caregivers of children with chronic diseases (Allen & Babin, 2013; Carona et al., 2014; Crespo et al., 2016; Klassen et al., 2007; Kobos & Imiela, 2015; Macedo, 2015; Molebatsi et al., 2017; Piran et al., 2017; Salvador et al., 2015; Silva et al., 2015a; Wijesinghe et al., 2015). Of these studies,
Crespo et al. (2016), Klassen et al. (2007), and Salvador et al. (2015) specifically focused on caregivers of children with cancer. Carona et al. (2014) and Wijesinghe et al. (2015) studied caregivers of children with neurological disorders (cerebral palsy and epilepsy). The review by Macedo et al. (2015) and Piran et al. (2017) studied caregivers of children with different types of chronic disorders. Silva et al. (2015a) primarily focused on caregivers of children with asthma whereas Molebatsi et al. (2017) focused on caregivers of children with psychiatric morbidity and Kobos & Imiela (2015) on caregivers of children with Type I diabetes. Of the children in these studies with various primary diagnoses, it is possible that some of these caregivers cared for children with technology needs, especially caregivers of children with cerebral palsy and those caregivers of children with respiratory disorders requiring constant supplemental oxygen. Inverse associations have also been found between the child’s age and duration of disease to caregiver burden in caregivers of children with other chronic diseases (Piran et al., 2017). It is likely that caregiving needs of the children are greater at a young age and progressively lessen the burden of care as the children become independent as they grow older and that the caregivers become accustomed to caregiving their child over time. In a study of caregivers of children with Type I diabetes, caregiver burden was associated with the children’s number of hospitalizations (Kobos & Imiela, 2015). As mentioned before, a significant predictor of caregiver burden that has been identified among caregivers of MFC with technology needs in Japan include the type of technology needs of the child (Yotani et al., 2014). MFC with technology needs have varied primary diagnoses and have varied number of technology needs. In addition, they require chronic caregiving as their disease is a life-long illness and require frequent hospitalizations when
their condition worsens in the home. In addition to the variable of type of technology, the associations between caregiver burden and the variables of the child’s age, gender, primary diagnosis, duration of disease, and number of hospitalizations warrant investigation among caregivers of MFC with technology needs to determine if these associations found in caregivers of children with chronic diseases also exist in this specific population of caregivers.

Several socio-demographic variables of the caregiver, such as caregiver age, female gender, ethnicity of African/European descent, unemployment, and greater number of other children in the household, have been found to be associated with caregiver burden among caregivers of children with various chronic diseases (Macedo et al., 2015). Caregivers with lower socioeconomic status are also more prone to experience caregiving burden (Macedo et al., 2015; Silva et al., 2015b; Wijesinghe et al., 2015). Although studies on caregiver burden primarily consist of maternal caregivers, other primary caregivers experiencing caregiving burden include fathers, grandmothers, guardians, and relatives of the children (Crespo et al., 2016; Macedo et al., 2015; Piran et al., 2017; Salvador et al., 2015). Compared to maternal caregivers of children with psychiatric morbidity, male caregivers report less burden of care (Molebatsi et al., 2017). In a review of studies of mothers caring for children with broncho-pulmonary dysplasia (BPD), cerebral palsy (CP), asthma, eating disorders, hemophilia, autism, sickle cell, cancer, and other diseases, the absence of a partner was related to increased caregiver burden (Macedo et al., 2015). Compared to married caregivers, being a single or separated caregiver of children with psychiatric morbidity was significantly associated with caregiver burden (Molebatsi et al., 2017). The duration of caregiving has also been
found to be negatively correlated with caregiver burden in caregivers of children with chronic diseases (Piran et al., 2017). As mentioned before, caregivers of MFC with technology needs are primarily female and in some social situations, are single caretakers of these children (Thyen et al., 1998, Thyen et al., 1999). These caregivers must also tend to and parent other healthy children living in the home. Although Yotani et al., (2014) identified the presence of younger siblings as a predictor of caregiver burden for caregivers of MFC with technology needs in Japan, the number of other children living in the home was not investigated for its association to caregiver burden (Yotani et al., 2014). Therefore, the socio-demographics of the caregiver (age, gender, socio-economic status (SES), race, ethnicity, marital status, duration of caregiving, and number of children living in the home) warrants investigation to determine if their association to caregiver burden among caregivers of children with chronic diseases also exist in the specific population of caregivers who care for MFC with technology needs.

**Caregiving Satisfaction.** The association between caregiver burden and caregiving satisfaction has also not been explored among caregivers of MFC with technology needs. Caregiving satisfaction are the feelings of happiness, awareness of strength, and self-development that arise from the caregiving experience (Kim & Chung, 2016). Studies on caregiving satisfaction and its predictors are lacking among caregivers of MFC. Only one study examined predictors of caregiving satisfaction among White and Black grandmothers raising healthy grandchildren (Pruchno & McKenney, 2002). Of the predictors examined, the quality of the relationship between White grandparents and the child’s parents, the centrality of the grandparents’ role, and greater caregiver burden were associated with caregiving satisfaction (Pruchno & McKenney, 2002). Although the
study collected information on the grandmothers’ marital status, occupation, income, and number of grandchildren in the household, these variables were not investigated for their association with caregiver burden and caregiving satisfaction. Qualitative studies have reported the positive experiences that caregivers of MFC with technology needs have when caregiving their child (Brotherton et al., 2007; Kawakami & Fujiwara, 2013; Mah et al., 2008; Wang & Barnard, 2008). For caregivers of MFC on home mechanical ventilation (HMV), caregivers expressed appreciation for the technology that sustained their child’s respiratory function, becoming an expert care provider of their child, and for the positive outlook on life it provided when caring for their child (Mah et al., 2008; Wang & Barnard, 2008). In a study of caregivers caring for MFC with gastrointestinal tube feedings, feedings and medications were easier to administer compared to feeding their child by mouth especially when their child vomited or refused to eat (Brotherton et al., 2007). Another study among parents of MFC on home parenteral nutrition described parents gaining self-confidence from learning about their child’s disease through collaboration in treatment and care of their child with healthcare providers (Kawakami & Fujiwara, 2013). Given that quantitative literature on caregiving satisfaction and its associated factors have not been done in caregivers of MFC dependent on technology, this proposal seeks to objectively measure caregiving satisfaction, examine its relationship to caregiver burden and caregivers’ HRQOL, and utilize the caregivers’ socio-demographics and child’s socio-demographic and clinical characteristics as possible associated variables of caregiving satisfaction.

**Conceptual Model.** Underlying the specific aims of this proposal is the proposed conceptual model of the Parental Caregiving Model developed based on previous
caregiver literature and the Two-Factor Model of caregiving appraisal and psychological well-being by Lawton et al. (1991). Parental caregiving is conceptually defined as the ability of the parental caregiver to provide holistic and skillful long-term care to a dependent child with a physical, psychological, or developmental chronic health condition in the presence of the caregiving burdens and caregiving satisfactions that occur when caring for the child, self, and family. Figure 1 displays the Parental Caregiving Model. This conceptual model utilizes the constructs of socio-demographics of the caregiver and socio-demographics and clinical characteristics of the child based on evidence found in caregiver literature of Kobos & Imiela (2015), Macedo et al. (2015), Piran et al. (2017), and Yotani et al., (2014). The variables in this construct, being the socio-demographics of the caregiver (age, gender, SES, race, ethnicity, marital status, duration of caregiving, number of other children living in the family) and socio-demographic and clinical characteristics of the child (age, gender, primary diagnosis, duration of disease, number of hospitalizations, and type of technology needs) are hypothesized to be associated to either caregiving burden or caregiving satisfaction as described in Aim 2. The concepts of caregiving burden and caregiving satisfaction originate from the Two-Factor Model by Lawton et al. (1991). The model addresses the possible relationship between caregiving burden and caregiving satisfaction and how each concept may be associated with each other. Lastly, the outcomes of the caregiving model is the caregivers’ HRQOL with its hypothesized association to caregiving burden and caregiving satisfaction as described in Aim 1 of the proposal.
Research on caregivers who care for MFC with technology needs in the home setting has reported that caregivers have decreased HRQOL compared to caregivers of MFC who have their children cared for in the long-term care setting (Caicedo, 2014). Previous research studies on caregivers of MFC with technology needs lack consideration of the caregivers’ HRQOL to its association to caregiving concepts such as caregiver burden and caregiving satisfaction. Knowing that caregivers of MFC with technology needs have decreased HRQOL is only a minimal understanding of what happens in the dynamics of their life. There is more to what their experiences are as caregivers and more to what they must endure when they provide constant caregiving to their children. This research proposal is innovative as it is the beginning point towards the development of knowledge, especially in the area of caregiving satisfaction, which no other studies have done with caregivers of MFC with technology needs.

*Figure 1. Parental Caregiving Model*
The contributions of this research will be significant to nursing research, future nursing practice, and will complement the existing pediatric caregiving literature. This research will first address the gap in knowledge on the hypothesized association between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL among caregivers of MFC with technology needs, which previous studies have not examined. Second, this research seeks to identify the variables related to caregiver burden and caregiving satisfaction among these caregivers, which is essential for nurses and other health care teams to recognize, as they are the professionals who have frequent interactions with these caregivers and their MFC during hospitalizations and outpatient clinic visits. Besides asking questions on the child’s medical history, family history, and social history during admission into the hospital or at outpatient clinic visits, future nursing practice can assess for caregiver burden and caregiving satisfaction during the admissions process and during visits at outpatient clinics. Any indications of severe caregiving burden or decreased caregiving satisfaction should prompt the initiation and facilitation of support services and continue after discharge. Lastly, the research contributions of this study will potentially lead to investigations of other concepts of caregiving (caregiver stress, caregiver appraisal, meaning making through caregiving) and concepts related to caregiving (coping, resilience, adaptation) in this population of caregivers.

Research Design and Methods

The design of this study is a descriptive, cross-sectional study. Permission and approval from the University of Texas Institutional Review Board (IRB), Committee for the Protection of Human Subjects (CPHS) will be requested to conduct the study at the
following hospitals: Children’s Memorial Hermann Hospital TMC and Memorial Hermann Memorial City that admit MFC in the inpatient setting. Outpatient affiliated clinics (i.e. UT Physicians) of these two Memorial Hermann Hospitals and affiliated outpatient clinics at Memorial Hermann Katy that MFC and their caregivers visit for health care needs will also be requested as study sites.

**Sample**

A consecutive sampling of both male and female caregivers (18 years and older) who identify themselves as primary caregivers of the inpatient or outpatient medically fragile patient with technology needs will be recruited for the study by the primary investigator. Consecutive sampling minimizes volunteerism and selection bias (Hulley et al., 2013). For caregivers of MFC to participate in the study, the caregivers and their child must meet the following inclusion criteria. The adult male or female caregivers designated as the primary provider of care in the home of the medically fragile child with technology needs must be primarily responsible for the child’s care at home for at least 6 months or more. Caregivers must be able to read, write, and speak English. The medically fragile patient with technology needs must be currently hospitalized at the selected inpatient children’s hospitals (Children’s Memorial Hermann TMC and Memorial Hermann Memorial City) or currently seen at outpatient-affiliated clinics. The children that these caregivers are responsible for will need to be ages 6 months to 18 years of age. The medically fragile child that the caregivers provide care for must have one or more technology needs such as home mechanical ventilation, oxygen support via other device-based respirators (nasal cannula, facemask), tube feedings
(gastrointestinal/duodenal/jejunal), intravenous feedings, tracheostomy suctioning, cardiorespiratory monitoring, urinary catherizations, renal dialysis, or colostomies. Caregivers of MFC with technology needs not cared for in the home, caregivers of children with diseases that do not have technology needs, caregivers of children receiving palliative care, caregivers who have severe mental conditions, and caregivers who cannot read or speak the English language will be excluded from the study. Flyers describing the study with the primary investigator’s contact information will be posted at the study sites for caregivers to contact the primary investigator. An online flyer will also be posted using online social media – Facebook.

Using the exact test family and correlation: bivariate normal model statistical test with two tails, correlation $p_{H1} = 0.3$, alpha = 0.05, power = 0.80, and correlation $p_{H0} = 0$, the total sample size for the study will need to be 67 participants (Faul et al., 2007).

According to Polit and Sherman’s study, the average correlation in nursing studies was reported as 0.2 (Polit & Beck, 2017).

**Instruments**

**Caregiver Burden.** Caregiver burden will be measured using the revised 22-item Zarit Burden Interview (ZBI22) with Likert ratings from 0 (never) to 4 (nearly always) for items 1-21 and 0 (not at all) to 4 (extremely) for item 22 (Zarit et al., 1980). The scale assesses feelings of subjective burden and the negative impact associated with caregiving tasks, effects of caregiving on the caregiver, beliefs and expectancy of the caregivers’ capacity, and the relationship between the caregiver and child (Calderon et al., 2010). The Zarit Scale has been used in the pediatric parent population and has demonstrated adequate evidence of reliability (Cronbach’s alpha = .91) and test-retest reliability (.91)
Evidence of validity has shown the Zarit Scale to be strongly correlated to the Burden Assessment Scale (BAS) and General Health Questionnaire (GHQ-28) (Seng et al., 2010). Scores for the Zarit Scale range from 0 – 20 indicating little/no burden, 21 – 40 indicating mild-moderate burden, 41 – 60 indicating moderate to severe burden, and 61 – 88 indicating severe burden (Dada et al., 2011).

**Caregiving Satisfaction.** Caregiver satisfaction will be measured using the 15-item Caregiving Satisfaction Scale (CSS) with ratings on a 4-point Likert scale (Strongly Agree = 1 and Strongly Disagree = 4) (Strawbridge, 1991). The CSS measures the long-term satisfaction and rewards of caregiving and does not include subscales (Family Caregiver Alliance, 2012). The CSS has evidence of scale reliability, in addition to evidence of construct validity for correlation between paired items (Cronbach’s alpha = .90; Pearson’s r = .86, t = -.35, p > .05) (Son et al., 2000). Items will be reversed scored and summed with scores ranging between 15 and 60. Higher scores indicate higher caregiving satisfaction.

**Caregivers’ HRQOL.** Caregivers’ HRQOL will be measured using the Health Survey Short Form – 12 version 2 (SF – 12 v2) (Khanna et al., 2018). The survey assesses the health and functioning of the individual during the past four weeks and also provides the summary physical (physical component score; PCS) and mental health (mental component score; MCS) scores. The physical health-related domains consists of General Health (GH), Physical Functioning (PF), Role Physical (RP), and Body Pain (BP) (Huo et al., 2018). The mental health-related domains consist of Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH) (Huo et al., 2018). The reliability coefficient for the summary physical component and mental health
component score has been reported as 0.89 and 0.86 (Khanna et al., 2018). Using the known-groups method to compare scale scores between groups known to differ in physical and mental health clinically, adequate evidence of construct validity was compared between four groups of patients using the SF-12 and Short Form Health Survey (SF-36) (effect size = 0.93, \( p < 0.001 \)) (Ware et al., 1996). Norm-based scores for the physical component and mental health component will be calculated using the survey score guide. Higher scores indicate better health.

**Data Collection**

The primary investigator will reach out to staff in the inpatient hospital setting to assist in referring caregivers of MFC with technology needs currently hospitalized at the selected hospitals who possibly meet inclusion requirements for the study. For caregivers who are present in the patient’s hospital room, the primary investigator will approach these caregivers in the patient’s room, explain the study, and determine if the caregivers are interested in participating in the study. For those who express interest and want to participate in the study, the primary investigator will obtain electronic consent on Qualtrics before caregivers complete the online surveys using an electronic device provided by the primary investigator or through the caregivers’ own personal electronic device. For caregivers who are referred by staff and who are not present in the patient’s room, the primary investigator will leave a letter inviting the caregiver to participate in the study and the Qualtrics link to the study surveys and questions if they choose to participate in the letter. Electronic consent will also be obtained from these caregivers who are not present in the rooms with the patients. In the outpatient setting, the primary investigator will also reach out to staff to refer caregivers of MFC with technology needs
scheduled for appointments with their physician. Before the caregivers’ scheduled visit with their child in the clinic, caregivers will be asked to participate in the study by the primary investigator. Electronic consent will be obtained from caregivers willing to participate in the study. Caregivers will also be able to use the primary investigator’s electronic device to complete the surveys and questions or use their own personal electronic device. The primary investigator will also inform all caregivers who willingly participate from the inpatient and outpatient setting about the confidentiality of the data obtained for the study.

In the inpatient setting, data collection for Aim 1 and Aim 2 will involve each caregiver accessing the Qualtrics study link to provide information on their own socio-demographics, their medically fragile child’s socio-demographics and clinical characteristics, and completing three one-time self-report surveys on caregiver burden, caregiving satisfaction, and health related quality of life. Caregivers who are present in the inpatient setting will be asked to answer the questions and complete the surveys in their child’s hospital room and will be told an estimated 20 -30 minutes will be required to complete questions and surveys. Before caregivers begin the study surveys and questions, their ability to proceed to the rest of the survey will depend on whether they and their children meet inclusion criteria for the study. If they choose answers that exclude them from the study, the survey will end and thank them for their time. The caregivers who meet inclusion criteria for the study will be asked to provide the following caregiver related socio-demographic variables: caregivers’ gender, age, socio-economic status (SES), race, ethnicity, marital status, duration of caregiving, and number of other children living in the family home. The child related variables will ask caregivers
to provide the child’s socio-demographic and clinical characteristics (age, gender, primary diagnosis, duration of disease, type of technology, and number of hospitalizations). While caregivers are taking the surveys, the primary investigator will be available to answer any questions that caregivers may have about the questions. At the end of the survey, caregivers will click to a separate Qualtrics link asking only for their email address to send them the electronic thirty-dollar gift card. The separate Qualtrics link to send the gift cards ensure the caregivers’ responses to the Qualtrics study survey do not link them to their email addresses. The electronic gift cards will be provided through the expense of the primary investigator. For caregivers in the inpatient setting who are not present in their medically fragile child’s hospital room, the link to the Qualtrics study will be provided in the letter inviting caregivers to participate. The length of time necessary to complete the surveys and questions will also be stated before the caregivers begin the survey. At the end of the survey, caregivers will click to a separate Qualtrics link asking only for their email address to send them the electronic thirty-dollar gift card.

In the outpatient setting, caregivers will access the Qualtrics study link and be asked to complete the questions and surveys in the waiting area using the primary investigator’s electronic device or the personal electronic device of the caregivers’. The caregivers will be told an estimated 20 - 25 minutes will be required to complete the questions and surveys. Upon completion, the caregivers will be asked to provide their email address to receive the electronic thirty dollar gift card. For caregivers who wish to participate in the study from seeing recruitment flyers from study sites or from Facebook posts and who personally contact the primary investigator through email or text message,
the primary investigator will email or text the Qualtrics study link to these caregivers. Again, electronic consent will be obtained, in addition to providing caregivers the time necessary to complete surveys and questions, and compensating caregivers using the Qualtrics incentive link.

Table 1 below is the estimated timetable for the research proposal. IRB approval for the study will begin the month of June 2019. Data collection and participant recruitment will occur concurrently throughout the months with final data analyses at the end of September/October 2019. If the primary investigator requires more time to conduct the study and to recruit more participants, the IRB will be notified.

Table 1

*Study Timeline*

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<th>TIMETABLE</th>
<th>AIMS</th>
<th>June 2019</th>
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*Data Analysis*

Data in the study will be analyzed using IBM SPSS version 25. Descriptive statistics will be used to assess sample characteristics and demographics. The first table in the study will display descriptive statistics (means ± standard deviations (SD), percentages) of the variables (socio-demographics of caregivers/children and clinical characteristics of the children). Another table will display the mean scores and SD for all
total survey results and subscales results for the HRQOL measure. The reliability (Cronbach’s alpha) will be reported for all three surveys. A third table will display the inter-correlations between the dependent variables in the study (caregiver burden, caregiving satisfaction, caregivers’ HRQOL. The correlation coefficient, Pearson’s $r$, will be used to determine the strength and direction of the associations (Polit & Beck, 2017). The criterion for strength and direction of the correlations between the dependent variables will be positively or negatively weak (0 to 0.3/0 to –0.3), moderate (0.3 to 0.7/-0.3 to –0.7), or strong (0.7 to 1/-0.7 to –1) (Ratner, 2009). The level of significance will be set at $p < .05$. Using this criterion, the hypothesis for Aim 1 will determine the relationship between caregiver burden, caregiving satisfaction, and HRQOL in caregivers of MFC with technology needs in the home setting.

Aim 2 of the study is to identify caregiver related variables and child related variables of caregiver burden and caregiver satisfaction among caregivers of MFC with technology needs cared for in the home setting. Bivariate analysis will be utilized to analyze data. The independent $t$-test will be utilized to determine the association between dichotomous variables and the dependent variables of caregiver burden and caregiving satisfaction (Polit & Beck, 2017). For variables with more than two categories, one-way analysis of variance (ANOVA) will be used to estimate their association to caregiver burden and caregiving satisfaction. The level of significance will also be set at $p < .05$, two-tailed. If assumptions are violated with the selected statistical tests for Aim 2, non-parametric tests (Mann-Whitney $U$ test or Wilcoxon signed-rank test) will be used.
Study Limitations

Because the study proposal will investigate the associations of the variables, establishing causality is difficult in the study (Hulley et al., 2013). Another study limitation is obtainment of the sample size necessary for the proposal as it is expected that not all caregivers will want to participate. Because the proposal is seeking to survey caregivers of MFC, there is non-response bias in the proposal with caregivers who choose not to participate (Sedgwick, 2014). A limitation of data collection procedures is reliance on caregivers’ self-report of their child’s clinical characteristics. In addition, the sample of MFC with technology needs sampled does not differentiate those children born with a condition requiring technology or who were born without complications, but then acquired a condition or disease requiring technology. The generalizability of any significant findings in the proposal would be limited given sample demographics and location of the study proposal. Variables not addressed or probable mediating or moderating variables not addressed in the proposal to the hypothesized associations may warrant notice in the discussion of the study such as depression, stress, or anxiety level of the caregivers, caregivers’ coping mechanisms, and other avenues of support may influence the associations between caregiver burden, caregiving satisfaction, and HRQOL in these caregivers. Other possible confounders in the study include the children’s developmental disability and some children having more hospitalizations may be due to how invasive the technology is (i.e. children with central lines, tracheotomies, ostomies) that are prone to infection due to poor infection prevention methods used in the home setting.
Human Subjects

Besides the gift card offered to the caregivers in the study, there will not be any other benefits for the caregivers and the children. There will be no risk to children whose caregivers’ participate in the study. For caregivers taking the surveys, the answers they provide regarding caregiver burden and caregiver satisfaction may cause them to feel guilty if they select ratings that show poor caregiver satisfaction and high caregiver burden. At the completion of the survey, caregivers at risk for feelings of guilt will be provided a resource to a healthcare professional (physician or parent support group) to contact to express their concerns. While there are potential risks to confidential data being compromised, procedures to protect data will consist of only the principal investigator having access to data in the hospital and clinical setting and in the UT Health network. Computers used to store data will be username and password protected and will have firewall protection and anti-virus protection. If data needs to be accessed anywhere other than at the UT Health nursing campus, users will be required to assess information via the virtual private network (VPN) using Duo two factor authentication. In addition, the computer used to analyze and collect data will be double locked (locked cabinet and locked office in Cizik School of Nursing Room 437).
References


Chan, Y., Lim, C., Bautista, D., Malhotra, R., Ostbye, T., & Chan, Y. (2019). The health


https://doi.org/10.1111/jar.12166


https://doi.org/10.1007/s00520-007-0243-x


https://doi.org/10.1016/j.apnr.2014.09.008


https://doi.org/10.1080/01612840600840588


https://doi.org/10.1590/0104-1169.0196.2613

The parent experience of caring for a child with neuromuscular disease on home mechanical ventilation. *Neuromuscular Disorders, 18*(12), 983-988.

https://doi.org/10.1016/j.nmd.2008.09.001


https://doi.org/10.5664/jcsm.4538


https://doi.org/10.1016/j.acap.2017.04.019


https://doi.org/10.19082/5380


https://doi.org/10.1046/j.13652648.2003.02858.x


https://doi.org/10.1111/ped.12339

Zarit, S. H., Reever, K. E., Back-Peterson, J. (1980). Relatives of the impaired elderly:

https://doi.org/10.1093/geront/20.6.649
April 1, 2020

Janice M. Bell, PhD, RN
Editor-in-Chief

The Journal of Family Nursing

Dear Dr. Bell,

I am submitting our manuscript, “Caregivers of Medically Fragile Children with Technology Needs” for the board’s consideration of publication into your journal, The Journal of Family Nursing. The associations between caregiver burden, caregiving satisfaction, and the caregivers’ health related quality of life has not be studied in this population of caregivers. We believe the findings from this study will be of interest to your readers and will provide information for future implications in nursing research and nursing practice.

The final manuscript has been read and approved by all the authors. We look forward to your review and response of our manuscript.

Sincerely,

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832 – 433 – 0115 (cell)
Vuong.T.Tran@uth.tmc.edu
Caregivers of Medically Fragile Children with Technology Needs

Introduction

Medically fragile children (MFC) depend on technology for survival and rely on their primary caregivers, generally their mothers, to provide both complex and challenging care in the home. MFC who are technology dependent require both medical devices to compensate for vital body functions and ongoing nursing care to deter death/further disability (U.S. Congress, Office of Technology Assessment, 1987). The simultaneous care that MFC with technology needs require, in conjunction with other family associated responsibilities, can have both negative and positive psychological and social impacts on caregivers’ health related quality of life (HRQOL).

As the caregivers provide care for their medically fragile child, the caregiver’s HRQOL may be overlooked. Caregivers of MFC with technology needs have been found to have poor HRQOL, especially those caregivers who care for their child in the home as compared to caregivers whose children are cared for in the long-term care setting (Caicedo, 2014; Chan et al., 2019). The negative impacts of providing long-term care for MFC by maternal caregivers, especially those who are single caregivers include higher levels of depression, less family supportiveness, and less opportunity for social activities as compared to maternal caregivers of children with acute illnesses (Thyen et al., 1998, Thyen et al., 1999). Among caregivers of MFC, significant predictors of caregiver burden that have been identified include the child’s type of technology, presence of younger/older siblings in the home, and nursing care coordination (Suzuki et al., 2017; Yotani et al., 2014). Rehm (2013) in an integrative review found that although caregivers of MFC described positive impacts of caregiving such as empowerment, increased
empathy, and personal growth, caregiving satisfaction had yet to be studied among these caregivers. What was unclear in the existing literature were the associations between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL and what additional factors were associated with caregiver burden and caregiving satisfaction. Understanding the association among these variables is imperative as caregivers of MFC with technology needs have long-term caregiving demands that extend into the child’s adulthood. Over time, the instances of caregiving burden or caregiving satisfaction may fluctuate when caregiving demands become overwhelming and inadvertently compromise their child’s health, their own health, and family function.

Background

There is no unique and distinct chronic condition, disease, or diagnosis that classifies MFC. Other terms used to describe MFC include children with technology dependency (CTD), technology – dependent children, children with medical complexity, or children with complex chronic conditions (Cohen et al., 2011; Rehm 2013; Suzuki et al., 2017). Despite the various terms, these children share the need for continuous care and dependency on technology for survival. The Office of Technology Assessment (OTA) identifies four groups of children as technology dependent (1987). Group I consists of children who require mechanical ventilators. Mechanical ventilators used in the home setting can be invasive requiring children to have a tracheostomy or non-invasive via continuous airway pressure (CPAP) or bi-level positive pressure (BPAP) (Preutthipan, 2015). Group II consists of children who require parenteral nutrition/intravenous requirements (OTA, 1987). The third group requires daily dependence on oxygen support, tube feedings, tracheotomy tube care, suctioning, and
other device-based respirators. Group IV includes children who require cardiorespiratory monitoring, renal dialysis, urinary catheters, or colostomies. Despite the different technology dependent groups, MFC may fall under some or all groups depending on their chronic condition/conditions, comorbidities, and overall technology needs. While MFC are dependent on technology to survive, their survival falls upon their caregivers who bear the burden of care.

**Caregiver Burden**

Caregiver burden is the discomfort or stress that occurs when caregivers provide direct care to a family member (Hunt, 2003). In most families of MFC with technology needs, mothers are identified as the primary caregivers who provide daily care in the home (Kuster & Badr, 2006; Rehm, 2013; Toly & Musil, 2015). The majority of the mothers are unemployed, as the complexity of care requires them to remain home at all times (Kuster & Badr, 2006; Thyen et al., 1999). Unlike healthcare professionals who receive formal education and training in the clinical setting, caregivers of MFC must acquire the knowledge and skills in a short time period and display competent care before their child is discharged home. In studies of MFC, greater than 60% of the children had more than one technology need (Caicedo, 2014; Toly & Musil, 2015). The technology that MFC depend on for survival requires caregivers to monitor and maintain their child’s health status, to recognize signs of distress or deterioration, to program and troubleshoot the technology, and to acquire other skills related to their child’s care. For these families, the needs of the child may supersede the needs of the individual family members leading to psychological and social consequences.
In an integrative review, Rehm (2013), noted that the parents of children with complex chronic conditions experience emotional distressing impacts (stress, worry, fear, anxiety, being overwhelmed, depressed) when providing home care. The stressors and worries were related to the health and appearance of the child; fear and anxiety arising from the child’s technological needs, and managing those needs; feeling overwhelmed and depressed from being solely responsible for the child in the home. Besides the emotional impacts, caregivers endure social impacts of feeling isolated from extended family, friends, or strangers in public due to unacceptance or ignorance of their child’s technology needs, from the embarrassment of the child’s behavior displayed, or from the inability to travel or take vacations (Ratliffe et al., 2002). In conjunction with the caregiving responsibilities, other obligations unrelated to caregiving may conflict with each other and produce additional caregiver burden.

Yotani et al. (2014), identified variables associated with caregiver burden. Among the variables, home mechanical ventilation (HMV) with tracheostomy and the presence of younger siblings in the group of MFC greater than 15 years significantly predicted caregiver burden (Yotani, et al., 2014). In a study of caregivers of children with a tracheostomy, caregiver burden was significantly correlated with the parents’ perception of the child’s physical health and to the increased economic costs of care (Hartnick et al., 2003). Another study of parental caregivers examined the association between caregiver burden and nursing care coordination by nurses who visit caregivers and assist with daily caregiving (Suzuki et al., 2017). The results indicated greater nursing care coordination predicted lower caregiver burden (Suzuki et al. 2017). The two studies on associated factors related to caregiver burden by Suzuki et al. (2017) and Yotani et al. (2014) were
conducted in Japan; therefore, the results may be difficult to generalize to other countries and other ethnic groups of caregivers. Furthermore, not all caregivers who care for MFC with technology needs qualify for home health assistance or respite care (Mah et al. 2008; Rehm & Bradley, 2005; Wang & Barnard, 2008). Even if caregivers had home health nurses, some nurses did not have pediatric specific training to care for MFC, which in turn frustrated caregivers who either supervised and trained the nurses themselves or dismissed the nurses entirely (Nageswaran & Golden, 2017). In addition, financial burdens that caregivers endure may be unaccounted for and underreported (Wang, 2003).

**HRQOL.** HRQOL is an individual’s perceived impact of health on their physical and psychological functions (Defenderfer et al., 2017). A study of caregivers of MFC with HMV needs reported lower perceived quality of life compared to caregivers and families of healthy children (Gonzalez et al., 2017). Another study reported decreased HRQOL in caregivers (primarily mothers, but also fathers, grandmothers, guardians, and adoptive mothers) of MFC with one or more technology needs in the home setting compared to caregivers of MFC in a long-term care setting (Caicedo, 2014). The parents and caregivers also reported physical problems of fatigue, emotional problems of anger, frustration, anxiety, and social problems of isolation regarding HRQOL (Caicedo, 2014). Specific to caregivers of children who require a tracheostomy, caregiver burden was significantly correlated with the Mental Component Score (MCS) of the caregivers’ HRQOL, but was not significantly correlated to the Physical Component Score (PSC) of the caregivers’ HRQOL (Hartnick et al., 2003). Although Keilty et al. (2018) did not find significant differences in HRQOL between caregivers of children who depend on
technology (CMT) compared to caregivers of healthy children, they did find significant associations of sleep disturbance to sleepiness, fatigue, and depression among the caregivers of CMT. Approximately 40-45% of maternal caregivers of MFC with technology needs score over the cutoff of ≥ 16 on the Center for Epidemiology Studies Depression Scale (CES-D) indicating increased risk for clinical depression (Kuster & Badr, 2006; Meltzer et al., 2010; Toly & Musil, 2015). Caregivers with health problems also report higher adverse effects on their quality of life when providing HMV home care for their child compared to those caregivers of MFC without health problems (Seear et al., 2016). Despite the findings on decreased HRQOL among caregivers of MFC dependent on technology, associated concepts such as caregiver burden and caregiving satisfaction have not been examined together with caregivers’ HRQOL among this population of caregivers.

In a review of caregivers of children with chronic disorders, higher caregiver burden was found to be related to marital status, ethnicity of mixed African/European descent, low income, greater number of children in the household, and unemployment (Macedo et al., 2015). Negative associations also have been found between caregiving burden and the caregivers’ quality of life (Crespo et al., 2016; Khanna et al., 2011; Silva et al., 2015). The same association also occurred between caregiving burden and caregiving satisfaction with caregiving grandmothers of healthy children (Pruchno & McKenney, 2002). Although studies on caregiver burden primarily consist of maternal caregivers, other primary caregivers experiencing caregiving burden include fathers, grandmothers, guardians, and relatives of the children (Crespo et al., 2016; Macedo et al., 2015; Piran et al., 2017; Salvador et al., 2015). Compared to male caregivers of children
with psychiatric morbidity, female caregivers had significantly higher burden scores (Molebatsi et al., 2017).

In a review of studies of mothers caring for children with broncho-pulmonary dysplasia (BPD), cerebral palsy (CP), asthma, eating disorders, hemophilia, autism, sickle cell, cancer, and other diseases, the absence of a partner was related to increased caregiver burden (Macedo et al., 2015). Compared to married caregivers, being a single or separated caregiver of children with psychiatric morbidity was significantly associated with caregiver burden (Molebatsi, Ndetei, & Opondo, 2017). The duration of caregiving has also been found to be negatively correlated with caregiver burden in caregivers of children with chronic diseases (Piran et al., 2017). Caregivers of MFC with technology needs are primarily female and in some social situations, are single caretakers of these children (Thyen et al., 1998, Thyen et al., 1999). These caregivers must also tend to and parent other healthy children living in the home. Although Yotani et al., (2014) identified the presence of younger siblings as a predictor of caregiver burden for caregivers of MFC in Japan, the association of caregiver burden and number of other children living in the home was not investigated (Yotani et al., 2014). Therefore, the sociodemographic of the caregiver (age, gender, socio-economic status (SES), race, ethnicity, marital status, duration of caregiving, and number of children living in the home) warranted investigation to determine if these variables are associated to caregiver burden among caregivers of children who care for MFC with technology needs.

Inverse associations have been found between the child’s age and duration of disease to caregiver burden in caregivers of children with other chronic diseases (Piran et al., 2017). It may be likely that caregiving needs of the children are greater at a young age.
and progressively lessen the burden of care as the children become independent as they grow older and that the caregivers become accustomed to caregiving their child over time. In a study of caregivers of children with Type I diabetes, caregiver burden was associated with the children’s number of hospitalizations (Kobos & Imiela, 2015). A significant predictor of caregiver burden that has been identified includes the type of technology needs of the child (Yotani et al., 2014). MFC with technology needs have varied primary diagnoses and a varied number of technology needs. In addition, they require continuing care as their disease is a life-long illness with frequent hospitalizations. In addition to type of technology, the associations between caregiver burden and the variables of the child’s age, gender, primary diagnosis, duration of disease, and number of hospitalizations warranted investigation to determine if these associations found in caregivers of children with chronic diseases also exist in this specific population of caregivers.

**Caregiving Satisfaction**

Caregiving satisfaction are the feelings of happiness, awareness of strength, and self-development that arise from the caregiving experience (Kim & Chung, 2016). Studies on caregiving satisfaction and predictors are lacking among caregivers of MFC. Only one study examined predictors of caregiving satisfaction among White and Black grandmothers raising healthy grandchildren (Pruchno & McKenney, 2002). Of the predictors examined, the quality of the relationship between grandparents and the child’s parents, the centrality of the grandparents’ role, and greater caregiver burden were associated with caregiving satisfaction (Pruchno & McKenney, 2002). Although the
study collected information on the grandmothers’ marital status, occupation, income, and number of grandchildren in the household, these variables were not further investigated.

Qualitative studies have reported the positive experiences that caregivers of MFC with technology needs (Brotherton et al., 2007; Kawakami & Fujiwara, 2013; Mah et al., 2008; Wang & Barnard, 2008). For caregivers of MFC on home mechanical ventilation (HMV), caregivers expressed appreciation for the technology that sustained their child’s respiratory function, becoming an expert care provider and for the positive outlook on life it provided when caring for their child (Mah et al., 2008; Wang & Barnard, 2008). In a study of caregivers caring for MFC with gastrointestinal tube feedings, feedings and medications were easier to administer compared to feeding their child by mouth especially when their child vomited or refused to eat (Brotherton et al., 2007). Another study among parents of MFC on home parenteral nutrition described parents gaining self-confidence based on learning about their child’s disease, through collaboration in treatment and care of their child with healthcare providers (Kawakami & Fujiwara, 2013). Based on the lack of studies on caregiving satisfaction and related factors in caregivers of MFC dependent on technology, this study sought to measure caregiving satisfaction, and its relationship to caregiver burden and caregivers’ HRQOL including caregivers’ and child’s sociodemographic and the child’s clinical characteristics as possible variables associated with caregiving satisfaction.

Conceptual Model

Figure 1 displays the conceptual model of the Parental Caregiving Model that guided this study (Lawton, 1991). The model is based on the caregiver literature and the
Two-Factor Model of caregiving appraisal and psychological well-being (Lawton et al., 1991). Parental caregiving is defined as the ability of the parental caregiver to provide holistic and skillful long-term care to a dependent child with a physical, psychological, or developmental chronic health condition in the presence of the caregiving burdens and caregiving satisfactions that occur when caring for the child, self, and family. This model utilized the variables of socio-demographics of the child and caregiver and the child’s clinical characteristics based on evidence found in caregiver literature of Kobos & Imiela (2015), Macedo et al. (2015), Piran et al. (2017), and Yotani et al., (2014). The caregiver socio-demographics variables and socio-demographic and clinical characteristics of the child were hypothesized to be associated to either caregiving burden and caregiving satisfaction (Figure 1). The concepts of caregiving burden and caregiving satisfaction originate from the Two-Factor Model by Lawton et al. (1991). The model addresses the possible relationship among caregiving burden and caregiving satisfaction and how each concept may be associated. Lastly, the outcomes of the caregiving model is the caregivers’ HRQOL with its hypothesized association to caregiving burden and caregiving satisfaction.

The overall objective of this study was to determine the relationship between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL and to determine what factors are related to caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs. To address the gap in knowledge for this population of caregivers and children, the specific aims and hypotheses of this study were:

**Aim 1** – Examine the relationship between caregiver burden, caregiving satisfaction, and HRQOL in caregivers of MFC with technology needs cared for in the
Hypothesis: It was hypothesized that increased caregiver burden would be negatively related to caregiving satisfaction and HRQOL.

Aim 2 – Identify caregiver and child related variables of caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs cared for in the home. Hypothesis: It was hypothesized that caregivers’ gender, age, socioeconomic status (SES), ethnicity, marital status, duration of caregiving, and number of other children living in the family and the child’s age, gender, primary diagnosis, duration of disease, number of hospitalizations, and technology type would be associated with caregiver burden and caregiving satisfaction.

Method

Design

This study was a descriptive, cross-sectional design.

Sample

A consecutive sampling of both male and female caregivers (18 years and older) who identified as primary caregivers of the medically fragile patient with technology needs were recruited. Inclusion criteria were: an adult male or female caregiver designated as the primary provider of care in the home for a medically fragile child with technology needs for at least 6 months or more. Caregivers had to be able to read, write, and speak English. The children had to be ages 6 months to 18 years of age. In addition, the medically fragile child had to have one or more of the following technology needs - HMV, oxygen support via other device-based respirators (nasal cannula, facemask), tube
feedings (gastrointestinal/duodenal/jejunal), intravenous feedings, tracheostomy suctioning, cardiorespiratory monitoring, urinary catherizations, renal dialysis, urostomy, ileostomy, or colostomy.

Caregivers of MFC with technology needs not cared for in the home, caregivers of children with diseases that did not have technology needs, caregivers of children receiving palliative care, caregivers with severe mental conditions, and caregivers who could not read or speak the English language were excluded.

**Instruments and Variables**

**Caregiver Burden.** Caregiver burden was measured using the revised 22-item Zarit Burden Interview (ZBI22) with Likert ratings from 0 (never) to 4 (nearly always) for items 1-21 and 0 (not at all) to 4 (extremely) for item 22 (Zarit et al., 1980). The scale assesses feelings of subjective burden and the negative impact associated with caregiving tasks, effects of caregiving on the caregiver, beliefs and expectancy of the caregivers’ capacity, and the relationship between the caregiver and child (Calderon et al., 2010).

The Zarit Scale has been used in the pediatric parent population and has demonstrated evidence of internal consistency (Cronbach’s alpha = .91) and test-retest reliability (.91) (Calderon et al., 2010). Evidence of validity has shown the Zarit Scale to be strongly correlated to the Burden Assessment Scale (BAS) and General Health Questionnaire (GHQ-28) (Seng et al., 2010). Scores for the Zarit Scale range from 0 – 20 indicating little/no burden, 21 – 40 indicating mild-moderate burden, 41 – 60 indicating moderate to severe burden, and 61 – 88 indicating severe burden (Dada et al., 2011) (Appendix I and Appendix J). Permission to utilize the ZBI22 was granted by Mapi Research Trust.
(2019). The Mapi Research Trust (2019) e-Booklet guidelines were utilized to ensure a
standardized and validated electronic version of the ZBI-22 in Qualtrics to administer the
survey.

**Caregiving Satisfaction.** Caregiver satisfaction was measured using the 15-item
Caregiving Satisfaction Scale (CSS) with ratings on a 4-point Likert scale (*Strongly
Agree* = 1 and *Strongly Disagree* = 4) (Strawbridge, 1991). Permission to utilize the CSS
was granted by the originator of the survey, William Strawbridge, PhD. The CSS
measures the long-term satisfaction and rewards of caregiving and does not include
subscales (Family Caregiver Alliance, 2012). The CSS has evidence of internal
consistency, in addition to evidence of construct validity for correlation between paired
items (Cronbach’s alpha = .90; Pearson’s *r* = .86, *t* = -.35, *p* > .05) (Son et al., 2000).
Items were reversed scored and summed with scores ranging between 15 and 60. Higher
scores indicate higher caregiving satisfaction (See Appendix K and Appendix L).

**Caregivers’ Health Related Quality Of Life (HRQOL).** Caregivers’ HRQOL
was measured using the Health Survey Short Form – 12 version 2 (SF – 12v2) (Khanna et
al., 2018). Permission to utilize the SF -12v2 was granted by Optum, Inc. (2020). The
HRQOL assesses the health and functioning of the individual during the past four weeks
and also provides a summary physical (physical component score; PCS) and mental
health (mental component score; MCS) scores. The physical health-related domains
consists of General Health (GH), Physical Functioning (PF), Role Physical (RP), and
Body Pain (BP) (Huo et al., 2018). The Likert scales vary between the items in the
physical domains: GH has a 5-point Likert scale (*1 = Excellent, 5 = Poor*), PF has a 3-
point Likert scale (*1 = Yes, limited a lot to 3 = No, not limited at all*), RP has a 5-point
Likert scale \( (1 = \text{All of the time} \text{ to } 5 = \text{None of the time}) \), and BP has a 5 – point Likert scale \( (1 = \text{Not at all} \text{ to } 5 = \text{None of the time}) \) (Maruish, 2012). The mental health-related domains consist of Vitality (VT), Social Functioning (SF), Role Emotional (RE), and Mental Health (MH) (Huo et al., 2018). All items in the mental health-related domains have 5-point Likert ratings \( (1 = \text{All of the time} \text{ to } 5 = \text{None of the time}) \) (Maruish, 2012). The items in the SF – 12v2 that are reversed scored include GH01, BP02, MH03, and VT02 (Maruish, 2012). The reliability coefficient of the physical component and mental health component scores have been reported as 0.89 and 0.86 (Khanna et al., 2018).

Using the known-groups method to compare scale scores between groups known to differ in physical and mental health clinically, adequate evidence of construct validity was compared between four groups of patients using the SF-12 and Short Form Health Survey (SF-36) (effect size = 0.93, \( p < 0.001 \)) (Ware et al., 1996). Scoring of the SF - 12v2 uses norm-based scoring from data of a 2009 US general population sample (Maruish, 2012). The scores assume a mean of 50 and a standard deviation (SD) of 10 with higher scores greater than 50 indicating better health (See Appendix M and Appendix N). The SF – 12v2 survey was also administered using Qualtrics.

The caregivers were also asked to provide the following caregiver related socio-demographic variables: caregivers’ gender, age, socio-economic status (SES), race, ethnicity, marital status, duration of caregiving, and number of other children living in the family home (Appendix O). The child related variables will ask caregivers to provide the child’s socio-demographic and clinical characteristics (age, gender, primary diagnosis, duration of disease, type of technology, and number of hospitalizations) (Appendix P).
Data Collection

Flyers describing the study with the primary investigator’s contact information was provided to caregivers at the study sites for caregivers to contact the primary investigator (See Appendix F). An online study flyer was also posted using online social media – Facebook. Staff in the inpatient hospital setting and outpatient settings referred caregivers of MFC who were hospitalized and met the study’s inclusion requirements. Caregivers were approached in the patient’s room, the study was explained, and determined if the caregivers were interested in participation. The primary investigator obtained consent before caregivers completed the online surveys using an electronic device provided by the primary investigator (Appendix H). For caregivers referred by staff and who were not present in the patient’s room, the primary investigator left a letter inviting the caregiver to participate in the study and contact information of the primary investigator to call or email if they chose to participate (Appendix G). In the outpatient setting, before the caregivers’ scheduled visit with their child in the clinic, caregivers were asked to participate in the study by the primary investigator.

While caregivers were completing the surveys, the primary investigator was available to answer questions. For caregivers in the inpatient setting who were not present in their medically fragile child’s hospital room, but texted the primary investigator wishing to participate, the link to the study was sent to caregivers for survey completion. In the outpatient setting, the primary investigator provided caregivers access to the study link to complete the surveys in the waiting area. Upon completion, all caregivers were
asked to provide their email address to receive a thirty dollar gift card. Data collection and participant recruitment occurred between August 2019 to December 2019.

**Ethical Considerations**

Permission and approval from the University of Texas Health Science Center at Houston Institutional Review Board (IRB), Committee for the Protection of Human Subjects (CPHS) and the Memorial Hermann Clinical Innovation and Research Institute was granted to conduct the study at two Children’s Memorial Hermann hospitals and the hospitals’ affiliated outpatient clinics (UT Physicians) in Houston, TX (Appendix C – E).

**Data Analysis**

Data were exported from Qualtrics and analyzed using IBM SPSS version 26 (2019). Optum’s PRO CoRE software version 1.4 (2019) was used to score results from the SF – 12v2 and transferred to IBM SPSS version 26. Descriptive statistics were used to assess sample demographics and the variables (caregiver burden, caregiving satisfaction, HRQOL). In addition, descriptive statistics, histograms, and boxplots were used to examine the general distribution of continuous independent and dependent variables.

**Aim 1** – Examine the relationship between caregiver burden, caregiving satisfaction, and HRQOL in caregivers of MFC with technology needs cared for in the home. The Pearson’s $r$, was used to determine the strength and direction of the associations between the variables in the study (Polit & Beck, 2017). The criterion for strength and direction of the correlations between the dependent variables were interpreted as positively or negatively weak (0 to 0.3/ 0 to – 0.3), moderate (0.3 to 0.7/
0.3 to – 0.7), or strong (0.7 to 1/ -0.7 to -1) (Ratner, 2009). The $P$-values were reported for associations with a two-sided level of significance of 0.05 set as the prior.

**Aim 2** – Identify caregiver and child related variables of caregiver burden and caregiving satisfaction among caregivers of MFC with technology needs cared for in the home. Bivariate analysis was utilized to analyze data. The Pearson’s $r$, was used to determine the strength and direction of the associations between variables (Polit & Beck, 2017). Nonparametric variables (age of the child, number of hospitalizations, child’s duration of disease, education, family income, caregivers’ years of caregiving, and number of other children in the household) were analyzed using Spearman’s rho correlation.

The independent $t$-test was utilized to determine mean differences between dichotomous variables (occupation, gender of caregiver, gender of child) and the dependent variables of caregiver burden and caregiving satisfaction (Polit & Beck, 2017). Prior to analysis, assumptions were checked. As the majority of subjects were female caregivers, gender of the caregivers remained descriptive. Although the caregiver variable of race had more than 2 categories during data collection, the variable was reclassified as Caucasian, Other (Black or African American or More than one race), and Unreported to balance group sizes for analysis. Unreported or unknown race was coded as missing and excluded from the final analysis ($n = 30$). For the variable of Ethnicity, unreported or unknown ethnicity was also coded as a missing value and excluded from the final analysis ($n = 29$). Marital status was also reduced to two categories as Married/Single with Partner and Other (Single, Divorced, Separated, or Widowed). Race, ethnicity, and marital status were analyzed using the independent $t$-test with reported $P$-
values and 95% confidence intervals. A two-sided level of significance of 0.05 was set as the prior. The type of technology and primary diagnosis of the child did not meet assumptions for ANOVA nor for the non-parametric Kruskal-Wallis H test; therefore, the variables were retained as descriptive.

Results

Caregiver’s Sociodemographics

One hundred and thirty eight caregivers were approached and asked to participate in the study. Seventy five caregivers were excluded as they did not meet inclusion criteria. Of the 63 caregivers that met the inclusion criteria, 32 caregivers consented to participate. The remainder either declined, did not respond to letters of invitation, or left the outpatient clinic after their scheduled appointments and did not have time to complete the surveys. Fifteen caregivers were recruited from the outpatient setting, 12 caregivers from the inpatient setting, and the other 5 caregivers contacted the primary investigator via text message. Table 1 displays the socio-demographics of the caregivers. The majority of caregivers who participated were Caucasian, female, biological mothers of the children, and married. The majority of caregivers reported income levels of < $20,000. The education level of most caregivers was some college and high school graduate. Table 1 displays the demographic information.

Child’s Sociodemographics and Clinical Characteristics

Table 2 displays the socio-demographics and clinical characteristics of the medically fragile children. The majority of children were male with a mean age of 64.4 months and mean hospitalizations of 18.4. The main primary diagnosis of the children
were neurological followed by gastrointestinal. The type of technology utilized most frequently was gastrostomy feedings and supplemental oxygen.

**Correlation Between Caregiver Burden, Caregiving Satisfaction, and Caregiver’s HRQOL**

Aim 1 hypothesized that increased caregiver burden would be negatively related to caregiving satisfaction and HRQOL. Table 3 displays the descriptive data and correlation between caregiver burden, caregiving satisfaction, and caregiver’s HRQOL. Caregiver burden had a negative, moderate relationship to caregiving satisfaction \( (r = -0.396, p = .025) \). Caregiver burden had a negative, strong relationship to the Mental Composite Score \( (r = -0.837, p < .001) \), but a weak correlation with the Physical Composite Score. There was a positive, moderate relationship between caregiving satisfaction and the Mental Composite Score \( (r = 0.437, p = .012) \), but a weak correlation with the Physical Composite Score.

**Relationship Among Caregiver and Child Variables and Caregiver Burden and Satisfaction**

Aim 2 hypothesized that caregivers’ gender, age, socioeconomic status (SES), ethnicity, marital status, duration of caregiving, and number of other children living in the family and the child’s age, gender, primary diagnosis, duration of disease, number of hospitalizations, and technology type would be associated with caregiver burden and caregiving satisfaction. The only caregiver variable that met assumptions for Pearson’s \( r \) was caregiver age. The age of the caregiver and caregiver burden and caregiving satisfaction were weakly associated and non-significant \( (r = 0.328, p = 0.067, n = 32; r = -0.125, p = 0.495, n = 32) \). Table 4 displays the results of the Spearman’s rho correlation for
caregiver burden and caregiving satisfaction. The education level of the caregivers had a positive, moderate correlation with caregiver burden ($r_s = .462, p = .008$). In contrast, education level had a moderate negative correlation with caregiving satisfaction ($r_s = -.353, p = .047$). A moderate, positive association was found between family income and caregiver burden ($r_s = .507, p = .005$). Family income had a weak relationship to caregiving satisfaction, but was not statistically significant. Years of caregiving, number of other children in the household, age of the child, duration of disease, and number of hospitalizations had weak associations with caregiver burden and caregiving satisfaction (See Table 4).

Table 5 displays the caregiver variables of caregiver ethnicity, occupation, caregiver race, and the child variable of gender and comparisons between groups to caregiver burden. Table 6 displays the same variables and the comparisons between groups to caregiving satisfaction. Caregivers who were Caucasian had greater caregiver burden as compared to caregivers of Other race ($30 \pm 17.5$ vs $16.7 \pm 14.6, p = 0.044$). Caucasian caregivers also had lower caregiving satisfaction as compared to caregivers of Other race ($48.4 \pm 7.3$ vs $55.4 \pm 5.1, p = 0.009$). For all other variables of ethnicity, occupation, marital status, and gender of the child, there were no differences between groups for either caregiver burden or caregiving satisfaction.

**Discussion**

In this study, similar to the existing literature on caregivers of MFC with technology needs (Kuster & Badr, 2006; Rehm, 2013; Thyen et al., 1998, Thyen et al., 1999; Toly & Musil, 2015), the primary caregivers were female and the biological mother. Most caregivers in this study reported little to no burden. The mean score for
caregiver burden was lower than the ZBI mean score for caregivers of MFC in the study conducted by Suzuki et al. (2017). MFC in the Suzuki et al. study (2017) mainly consisted of children with nasogastric or nasojejunal feedings, tracheostomy, and ventilator management needs. The children in the present study mainly required gastrostomy feedings, had fewer tracheostomy and fewer mechanical ventilation needs. Although Yotani et al. (2014) found a significant positive association between caregiver burden and type of technology (HMV with tracheostomy) of the MFC, the present study was unable to determine the association between caregiver burden and the type of technology needs due to children having one or more technology needs rather than only one type of technology.

**Caregiver Burden and Caregiving Satisfaction**

The present study found a negative association between caregiver burden and caregiving satisfaction. The inverse nature of this relationship may be due to the need for MFC caregivers to provide constant, complex care that eventually may become more burdensome when stressed with care and the other demands of work and family, which in turn decreases caregiving satisfaction. A similar association was also found between caregiver burden and caregiving satisfaction in a sample of grandmothers raising their healthy grandchildren (Pruchno, 2002). What may account for similarities may be due to the differences in age of the caregivers and the health status of the children. In addition, the moderate strength of the association found between caregiver burden and caregiving satisfaction indicates that despite caregivers experiencing burden, the satisfaction they obtain from the care they provide their children may buffer the negative impacts.
**Caregiver Burden and HRQOL.** The results indicated a negative association among caregiver burden and the mental health of the caregivers as measured by the Mental Composite Score of the caregivers’ HRQOL. Hartnick et al. (2003) also found a correlation between caregiver burden and the Mental Composite Score of caregivers’ HRQOL who care for children with a tracheostomy, but a positive moderate correlation. The association between caregiver burden and the Physical Composite Score of the caregivers’ HRQOL was also non-significant (Hartnick et al., 2003). The low group mean for the Mental Composite Score in this sample of caregivers may indicate the presence of psychological distress, social/role limitations due to emotional problems, and poor general health (Mariush, 2012). The strong positive association found between caregiver burden and the caregivers’ mental health supports the evidence in the literature – the emotional distressing impacts (stress, worry, fear, anxiety, being overwhelmed) of providing home care to MFC with technology needs experienced by caregivers (Rehm, 2013) and the caregivers’ increased risk for clinical depression in providing long term care to their child (Kuster & Badr, 2006; Meltzer et al., 2010; Toly & Musil, 2015). The high group mean for the PCS in this group of caregivers indicate few or no physical limitations or disabilities (Mariush, 2012). The lack of associations between caregiver burden and the Physical Composite Score may be attributed to caregivers in the study being of young age and middle age.

**Caregiving Satisfaction and HRQOL.** The results determined caregiving satisfaction was positively correlated with mental health of the caregivers’ HRQOL, but not to physical health. Greater caregiving satisfaction was correlated to better mental health of the caregivers. Greater caregiving satisfaction coincides with the caregivers’
ability to maintain work or regular activities without feeling depressed or anxious. Positive aspects of caregiving has mainly been described qualitatively in the literature (Brotherton et al., 2007; Kawakami & Fujiwara, 2013; Mah et al., 2008; Wang & Barnard, 2008). The present association found among caregiving satisfaction and the mental health component of the caregivers’ HRQOL provides objective evidence for future studies to explore caregiving satisfaction with other caregiver variables, child variables, and health outcomes that were not investigated in this study.

**Caregiver Burden and Caregiver/Child Variables**

The results revealed that caregiver education and family income were associated positively with caregiver burden. This is contrast to Macedo et al. (2015), which found increased burden when related to low educational level in their literature review of caregivers caring for children with chronic disorders. Another finding in the present study was the positive association between the caregivers’ family income and caregiver burden. This finding also differs from previous studies of caregivers caring for children with chronic disorders, in which lower socioeconomic status was associated to higher caregiver burden (Macedo et al. 2015).

In Texas, the yearly family income to qualify for Children’s Medicaid is $16,612 for one family member and increases up to a yearly income of $57,762 for 8 family members that includes health care coverage for both adults and children (Texas Health and Human Services, 2020). To possibly qualify for the Children’s Health Insurance Program (CHIP), the yearly family income would need to be $25,105 for one family member up to $87,295 for 8 family members that includes health care coverage for both
adults and children (Texas Health and Human Services). Considering caregivers in the study who reported income levels of > $80,000 and reported having 0 – 8 other children in the household, it offers a possible explanation for caregivers with higher family income having higher caregiver burden who either pay out of pocket for their child’s healthcare needs or who pay higher copays through workplace insurance or private insurance. Another explanation could be that these caregivers, who were all married, bear the burden of care more so than their spouse. However, the present study did not find significant associations of caregiver burden to the caregivers’ marital status.

Compared to previous literature, increased burden was related to the absence of a partner (Macedo et al., 2015). Single/separated caregivers compared to married caregivers was associated to caregiver burden among caregivers of children with psychiatric morbidity (Molebatsi et al., 2017). In this study, married caregivers and single caregivers living with their partner was combined together and compared to Other (Single - never married, Separated, Divorced, Widowed). This categorization of marital status may have accounted for the lack of differences found although previous literature were unclear on whether single caregivers in their study were single, but possibly living with a partner. The race of the caregivers was significantly associated to caregiver burden in this study. Caregivers in the present study were predominantly Caucasian, followed by Black/African American; therefore, caregivers of other races are underrepresented.

Similar to the study conducted by Molebatsi et al. (2017) on caregivers of children with psychiatric morbidity, there were no significant associations of caregiver burden to the occupation of the caregiver being employed or unemployed, duration of caregiving, other children in the household, and age of the child. The findings of the
present study contrasts to associations found between caregiver burden to unemployed caregivers and greater number of children in the household (Macedo et al., 2015) and the inverse associations found between caregiver burden to the child’s age and duration of disease (Piran et al., 2017). Approximately half of the MFC in the present study were 7 months to 24 months whereas the remainder of the children were 3 years to 18 years. This sample of caregivers in the present study had a mix of caregivers becoming accustomed to the care of their medically fragile child with the mix of other caregivers who have been caregiving for years, which may account for the lack of significant associations between caregiver burden to the child’s age, duration of disease, and years of caregiving. The children’s number of hospitalizations were also not associated to caregiver burden, which is contrast to the findings for Kobos & Imiela (2015). The variable was treated as a continuous variable in this study whereas Kobos & Imiela (2015) categorized number of hospitalizations.

**Caregiving Satisfaction and Caregiver/Child Variables**

The present study found that caregiver education and caregiver race were associated to caregiving satisfaction. This finding is interesting and would yet again require further investigation in future studies to determine other factors involved. Caucasian caregivers in this study had lower caregiving satisfaction as compared to caregivers who were of Other race. As this is the first study to determine the association between caregiving satisfaction and race, it would be prudent to include a better representation of the different races of caregivers who provide care for their medically fragile child with technology needs in future studies to provide comparisons.
Study Strengths and Limitations

This study addressed the gap in knowledge on the hypothesized association between caregiver burden, caregiving satisfaction, and caregivers’ HRQOL among caregivers of MFC with technology needs, which previous studies have not examined. Second, this research identified variables related to caregiver burden and caregiving satisfaction among these caregivers. A limitation of the study was the small sample size obtained. The study also investigated the associations of the variables; therefore, establishing causality is difficult in the study (Hulley et al., 2013). Because the study surveyed caregivers of MFC, there was non-response bias with caregivers who chose not to participate (Sedgwick, 2014). A limitation of data collection procedures was reliance on caregivers’ self-report of their child’s clinical characteristics (primary diagnosis, recall of number of hospitalizations). In addition, the sample of MFC with technology needs sampled did not differentiate those children born with a condition requiring technology or those children who were born without complications, but later acquired a condition or disease requiring technology after birth. Another limitation of the study was the consolidation of the multiple categories of the race and marital status of the caregivers in the study to two categories. A weakness of the data analyses methods used was non-parametric testing, but was unavoidable due to violations of assumptions for Pearson’s correlation coefficient. The generalizability of any significant findings in the study would be limited to the sample demographics and location of the study. Variables not addressed or probable mediating or moderating variables not addressed in the study to the hypothesized associations may warrant future investigation such as depression, stress, or anxiety level of the caregivers, caregivers’ coping mechanisms, and other avenues of
support may influence the associations between caregiver burden, caregiving satisfaction, and HRQOL in caregivers. Other possible confounders in the study include the children’s developmental disability, children having behavioral disorders, and some children having more hospitalizations due to how invasive the technology was (i.e. children with central lines, tracheotomies, ostomies) that are prone to infection due to poor infection prevention methods used in the home setting.

**Implications for Nursing Practice**

While the care of MFC is the main focus of the healthcare team during hospitalizations, it is essential for nurses and other health care teams to also focus on the health and well-being of the caregivers. Healthcare professionals have frequent interactions with caregivers and their MFC during hospitalizations and outpatient clinic visits. Besides asking questions on the child’s medical history, family history, and social history during admission into the hospital or at outpatient clinic visits, health care teams need to assess for caregiver burden and caregiving satisfaction over time as these families maintain the long term care required in this population of children. Any indications of severe caregiving burden or decreased caregiving satisfaction should prompt the initiation and facilitation of support services and continue after discharge from the hospital with follow up in the outpatient setting.

**Implications for Nursing Research**

The present study focused on adult caregivers of MFC with technology needs. Future research could include caregiver dyads who share in the responsibilities of caring for MFC to compare the associations of caregiver burden, caregiving satisfaction, and
their HRQOL. In addition, considering there are healthy siblings in families caring for MFC, their HRQOL would be another important outcome to be investigated with caregiver burden and caregiving satisfaction. The present study was cross-sectional in design, a longitudinal study following caregivers of MFC from the beginning of care to when their child’s technology is no longer required or to when their child becomes deceased. Attrition would be problematic with longitudinal designs, but would be able to capture changes in caregiver burden, caregiving satisfaction, and caregivers’ HRQOL over time as the child grows mentally and physically. Future studies would need larger sample sizes for more diversity in the sample which would support an analysis that could determine mediating or moderating factors that the present study did not address (coping, anxiety, stress, fatigue, sleep, depression, normalization, functional status of child). Other possible associated factors to be explored with caregiver burden and caregiving satisfaction could also include religion, marital dissatisfaction, and presence/absence of home health nurses. Lastly, the research contributions of this study will potentially lead to investigations of other concepts of caregiving (caregiver stress, caregiver appraisal, meaning making through caregiving) and concepts related to caregiving (coping, resilience, adaptation) in this population of caregivers.

**Conclusion**

Overall, the study was partially able to support the conceptual model of the Parental Caregiving Model that guided this study with respect to caregivers’ family income, education, and race only as caregiver variables associated to caregiver burden and caregiving satisfaction. Caregiving satisfaction was positively correlated to the mental health of the caregivers’ HRQOL and caregiver burden was negatively correlated
to the mental health of the caregivers’ HRQOL. The present study found that despite
caregiver burden, caregivers of MFC with technology needs have high caregiving
satisfaction. The significant associations of the caregivers’ mental HRQOL with
caregiver burden and caregiving satisfaction highlight the importance of identifying
caregivers at risk who may become overwhelmed with care, decreasing their caregiving
satisfaction and increasing their caregiver burden. Despite higher family income and
higher education of caregivers in this study, which would seem to be an advantage, this
was not the case with caregivers having higher caregiver burden. No matter what the
education and family income of the caregivers, assessment of caregiver burden and
caregiving satisfaction should begin after caregivers begin primary care of their
medically fragile child and continuously reassessed overtime as the caregivers provide
complex care for their child. Although findings on caregiver race were associated with
both caregiver burden and caregiving satisfaction, further investigation is necessary with
larger sample sizes and better racial representation of caregivers.
References


Hartnick C.J., Bissell, C., & Parsons, S.K. The impact of pediatric tracheotomy on


Optum’s PRO CoRE software version 1.4 (2019). Optum PRO CoRE smart measurement


https://doi.org/10.3109/01612840.2015.1009662


https://www.princeton.edu/~ota/disk2/1987/8728/8728.PDF


https://doi.org/10.1046/j.1365-2648.2003.02858.x


https://doi.org/10.1111/ped.12339

https://doi.org/10.1093/geront/20.6.649
Table 1

*Socio-Demographics of Caregivers*

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Frequency (N = 32)</th>
<th>Percent (%)</th>
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<tbody>
<tr>
<td>Age of Caregiver (years)</td>
<td>34.3 (9.5)</td>
<td>21 – 58</td>
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<tr>
<td>Number of other children in household</td>
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<td>0 – 8</td>
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<tr>
<td>Years of Caregiving&lt;sup&gt;a&lt;/sup&gt;</td>
<td>62.7 (51.8)</td>
<td>6 – 216 months</td>
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<td>Female</td>
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<tr>
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<td>Unknown or not reported</td>
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<td></td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>13</td>
<td></td>
<td>40.6</td>
<td></td>
</tr>
<tr>
<td>Not Hispanic or Latino</td>
<td>16</td>
<td></td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Latino</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown or not reported</td>
<td>3</td>
<td></td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single, never married</td>
<td>5</td>
<td></td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>19</td>
<td></td>
<td>59.4</td>
<td></td>
</tr>
<tr>
<td>Single, never married (living with partner)</td>
<td>3</td>
<td></td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td></td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td></td>
<td>3.1</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td></td>
<td>3.1</td>
<td></td>
</tr>
<tr>
<td>Family income</td>
<td>&lt; 20,000</td>
<td>10</td>
<td>31.3</td>
<td></td>
</tr>
<tr>
<td>Income Range</td>
<td>Count</td>
<td>Mean</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td>-------</td>
<td>-------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20,000 – 40,000</td>
<td>7</td>
<td>21.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>40,001 – 60,000</td>
<td>2</td>
<td>6.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>60,001 – 80,000</td>
<td>4</td>
<td>12.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt; 80,000</td>
<td>6</td>
<td>18.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>3</td>
<td>9.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Education

<table>
<thead>
<tr>
<th>Education</th>
<th>Count</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>High school or less</td>
<td>2</td>
<td>6.3</td>
</tr>
<tr>
<td>High school graduate</td>
<td>10</td>
<td>31.3</td>
</tr>
<tr>
<td>Some college</td>
<td>13</td>
<td>40.6</td>
</tr>
<tr>
<td>College graduate</td>
<td>5</td>
<td>15.6</td>
</tr>
<tr>
<td>(Associates or Bachelor’s degree)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed graduate school (Masters, Doctoral)</td>
<td>2</td>
<td>6.3</td>
</tr>
</tbody>
</table>

Occupation

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Count</th>
<th>Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>14</td>
<td>43.8</td>
</tr>
<tr>
<td>Unemployed</td>
<td>18</td>
<td>56.3</td>
</tr>
</tbody>
</table>

*Note.* SD = Standard deviation; N = total sample size; ^ One caregiver did not indicate months/years of caregiving, \( n = 31 \)
Table 2

Socio-Demographics of MFC with Technology Needs

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Range</th>
<th>Frequency (N = 32)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of Children (months)</td>
<td>64.4 (54.9)</td>
<td>7 – 216</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of disease (months)</td>
<td>58.1 (9.3)</td>
<td>7 – 216</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>20</td>
<td></td>
<td>62.5</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>12</td>
<td></td>
<td>37.5</td>
<td></td>
</tr>
<tr>
<td>Primary diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological</td>
<td>12</td>
<td></td>
<td>37.5</td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>2</td>
<td></td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Cardiac</td>
<td>2</td>
<td></td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td>7</td>
<td></td>
<td>21.9</td>
<td></td>
</tr>
<tr>
<td>Genitourinary</td>
<td>2</td>
<td></td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Genetic</td>
<td>3</td>
<td></td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Multiple</td>
<td>4</td>
<td></td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td>Type of technology/technologies&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mechanical ventilation</td>
<td>4</td>
<td></td>
<td>12.5</td>
<td></td>
</tr>
<tr>
<td>IV (intermittent)</td>
<td>6</td>
<td></td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>IV (continuous)</td>
<td>3</td>
<td></td>
<td>9.4</td>
<td></td>
</tr>
<tr>
<td>Tracheostomy suctioning</td>
<td>5</td>
<td></td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>Gastrostomy feedings</td>
<td>26</td>
<td></td>
<td>81.3</td>
<td></td>
</tr>
<tr>
<td>Duodenal/jejunal feedings</td>
<td>5</td>
<td></td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>Supplemental oxygen</td>
<td>14</td>
<td></td>
<td>43.8</td>
<td></td>
</tr>
<tr>
<td>(nasal cannula, facemask, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IV feedings (TPN, lipids)</td>
<td>9</td>
<td></td>
<td>31.3</td>
<td></td>
</tr>
<tr>
<td>Cardiorespiratory monitoring</td>
<td>7</td>
<td></td>
<td>21.9</td>
<td></td>
</tr>
<tr>
<td>Urinary catherization</td>
<td>5</td>
<td></td>
<td>15.6</td>
<td></td>
</tr>
<tr>
<td>Renal dialysis</td>
<td>2</td>
<td></td>
<td>6.3</td>
<td></td>
</tr>
<tr>
<td>Colostomy, ileostomy, Urostomy</td>
<td>7</td>
<td></td>
<td>19.4</td>
<td></td>
</tr>
</tbody>
</table>

<sup>Note</sup>. SD = Standard deviation; N = total sample size; <sup>a</sup> Children had 1 or more technology need
Table 3

Means, Standard Deviations, and Correlation Between Caregiver Burden, Caregiving Satisfaction, and Caregivers’ HRQOL (N = 32)

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Caregiver Burden</td>
<td>25</td>
<td>17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Caregiving Satisfaction</td>
<td>51.3</td>
<td>7.2</td>
<td>-.396*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Physical Component Summary (PCS)</td>
<td>51</td>
<td>6.5</td>
<td>-.303</td>
<td>.051</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Mental Component Summary (MCS)</td>
<td>45.6</td>
<td>12</td>
<td>-.837**</td>
<td>.437***</td>
<td>.290</td>
<td></td>
</tr>
</tbody>
</table>

Note. M = Mean; SD = Standard deviation

* p = .025, ** p ≤ .001, *** p = .012, two-tailed
Table 4

*Correlation Between Caregiver and Child Variables to Caregiver Burden, and Caregiving Satisfaction (N=32)*

<table>
<thead>
<tr>
<th>Caregiver Variables</th>
<th>Caregiver Burden</th>
<th>Caregiving Satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Education</td>
<td>.462*</td>
<td>-.353***</td>
</tr>
<tr>
<td>Family Income(^a)</td>
<td>.507**</td>
<td>-.347</td>
</tr>
<tr>
<td>Number of Other Children in Household</td>
<td>-.117</td>
<td>.092</td>
</tr>
<tr>
<td>Variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Years of Caregiving(^b)</strong></td>
<td>.147(^b)</td>
<td>-.204(^b)</td>
</tr>
<tr>
<td><strong>Child Variables</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age of Child</td>
<td>.174</td>
<td>-.139</td>
</tr>
<tr>
<td>Duration of Disease</td>
<td>.128</td>
<td>-.061</td>
</tr>
<tr>
<td>Number of Hospitalizations</td>
<td>.118</td>
<td>-.062</td>
</tr>
</tbody>
</table>

\(^* p = .008, \ ** p = .005, \ *** p = .047, two-tailed; \(^a\) Missing value for category of ‘Unknown or not reported, n = 29; \(^b\) n = 31
Table 5

*Caregiver’s Socio-Demographic Variables and Child’s Demographic Variables Association to Caregiver Burden (N = 32)*

<table>
<thead>
<tr>
<th>Caregiver/Child Variable</th>
<th>Category</th>
<th>n</th>
<th>Mean (SD)</th>
<th>t</th>
<th>Mean difference (SE)</th>
<th>95% CI</th>
<th>p – value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity(^a)</td>
<td>Hispanic or Latino</td>
<td>13</td>
<td>19.9 (13.7)</td>
<td>(t (27) = -1.15)</td>
<td>-6.3 (5.5)</td>
<td>(-17.5 – 4.9)</td>
<td>0.262</td>
</tr>
<tr>
<td></td>
<td>Not Hispanic or Latino</td>
<td>16</td>
<td>26.2 (15.4)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married/Single with Partner</td>
<td>22</td>
<td>27.0 (18.2)</td>
<td>(t (30) = 1.06)</td>
<td>-6.8 (6.5)</td>
<td>(-6.3 – 20.0)</td>
<td>0.297</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>10</td>
<td>20.2 (13.5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>Employed</td>
<td>14</td>
<td>22.9 (15.6)</td>
<td>(t (30) = -.58)</td>
<td>-3.5 (6.1)</td>
<td>(-16 – 9)</td>
<td>0.569</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>18</td>
<td>26.4 (18.2)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race(^a)</td>
<td>Caucasian</td>
<td>19</td>
<td>30 (17.5)</td>
<td>(t (28) = 2.11)</td>
<td>13.2 (6.3)</td>
<td>(0.4 – 26.1)</td>
<td><strong>0.044</strong></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>11</td>
<td>16.7 (14.6)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender of child</td>
<td>Male</td>
<td>20</td>
<td>23.3 (14.3)</td>
<td>(t (30) = -.71)</td>
<td>-4.4 (6.3)</td>
<td>(-17.2 – 8.3)</td>
<td>0.484</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>12</td>
<td>27.7 (21.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. n = sample size; SD = Standard deviation; t = t – value; CI = Confidence interval; \(^a\) Missing value for category of ‘Unknown or not reported’*
<table>
<thead>
<tr>
<th>Caregiver/Child Variable</th>
<th>Category</th>
<th>n</th>
<th>Mean (SD)</th>
<th>t</th>
<th>Mean difference (SE)</th>
<th>95% CI</th>
<th>p–value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Hispanic or Latino</td>
<td>13</td>
<td>52.1 (7.4)</td>
<td>$t_{(27)} = .54$</td>
<td>1.5 (2.7)</td>
<td>(-4.0 – 6.9)</td>
<td>0.591</td>
</tr>
<tr>
<td></td>
<td>Not Hispanic or Latino</td>
<td>16</td>
<td>50.6 (7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marital Status</td>
<td>Married/Single with Partner</td>
<td>22</td>
<td>50.0 (7.7)</td>
<td>$t_{(30)} = -1.46$</td>
<td>-4.0 (2.7)</td>
<td>(-9.5 – 1.6)</td>
<td>0.155</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>10</td>
<td>54 (5.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupation</td>
<td>Employed</td>
<td>14</td>
<td>49.3 (7.6)</td>
<td>$t_{(30)} = -1.40$</td>
<td>-3.5 (2.5)</td>
<td>(-8.8 – 1.7)</td>
<td>0.173</td>
</tr>
<tr>
<td></td>
<td>Unemployed</td>
<td>18</td>
<td>52.8 (6.8)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td>Caucasian</td>
<td>19</td>
<td>48.4 (7.3)</td>
<td>$t_{(28)} = -2.80$</td>
<td>-7.0 (2.5)</td>
<td>(-12.1 – -1.9)</td>
<td>0.009</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>11</td>
<td>55.4 (5.1)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender of child</td>
<td>Male</td>
<td>20</td>
<td>52.5 (7.1)</td>
<td>$t_{(30)} = 1.19$</td>
<td>3.1 (2.6)</td>
<td>(-2.2 – 8.5)</td>
<td>0.244</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>12</td>
<td>49.3 (7.3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note. n = sample size; SD = Standard deviation; t = t – value; CI = confidence interval; a Missing value for category of ‘Unknown or not reported’*
Figure 1. Parental Caregiving Model
Appendix A

Approval of Proposal by Dissertation Committee (D2 Form)
Approval Form D-2

APPROVAL OF DOCTORAL DISSERTATION PROPOSAL

Student Principal Investigator: Vuong Prieto
Title of Study: Medication Fatigue Children with Technology Needs

This research proposal has been reviewed and approved by the Principal Investigator's Dissertation Committee.

Committee Chair: Date: 6/6/19
Committee Members: Date: 6/6/19
Date: 6/6/19

Dissertation Committee Recommendation:

X Approval

Approval with Reservations

Disapproval

Original to Associate Dean for Academic Affairs; Copy to Chair, Committee members, and IRB(s)

I:\Common\SON Everyone\Dissertation_Thesis Manuals\Dissertation Manual rev 2006
Appendix B

UT Health Science Center at Houston CPHS Approval of Proposal
HSC-SN-19-0554 - Caregivers of Medically Fragile Children with Technology Needs

The above named project is determined to qualify for exempt status according to 45 CFR 46.101(b)

CATEGORY #2: Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:

a. information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; AND,

b. any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

(Note: The exemption under Category 2 DOES NOT APPLY to research involving survey or interview procedures or observation of public behavior when individuals under the age of 18 are subjects of the activity except for research involving observations of public behavior when the investigator(s) do not participate in the activities being observed.)

CHANGES: Should you choose to make any changes to the protocol that would involve the inclusion of human subjects or identified data from humans, please submit the change via iRIS to the Committee for the Protection of Human Subjects for review.

INFORMED CONSENT DETERMINATION:
Waiver of Documentation of Informed Consent

INFORMED CONSENT: When Informed consent is required, it must be obtained by the PI or designee(s), using the format and procedures approved by the CPHS. The PI is responsible to instruct the designee in the methods approved by the CPHS for the consent process. The individual obtaining informed consent must also sign the consent document. Please note that only copies of the stamped approved informed consent form can be used when obtaining consent.

HEALTH INSURANCE PORTABILITY and ACCOUNTABILITY ACT (HIPAA):
Exempt from HIPAA
STUDY CLOSURES: Upon completion of your project, submission of a study closure report is required. The study closure report should be submitted once all data has been collected and analyzed.

Should you have any questions, please contact the Office of Research Support Committees at 713-500-7943.
Appendix C

Memorial Hermann Healthcare System Approval for Memorial Hermann

– Texas Medical Center & Children’s Hospital
7/30/2015

MEMORIAL HERMANN HEALTHCARE SYSTEM APPROVAL FOR
MEMORIAL HERMANN – TEXAS MEDICAL CENTER & CHILDREN’S HOSPITAL

Thank you for choosing Memorial Hermann as your service provider for this research study.

IRB ID: HSC-MS-13-0554  PRINCIPAL INVESTIGATOR: Vuong Trung-Tian Prieto, RN

STUDY TITLE: Caregivers of Medically Fragile Children with Technology Needs.

NUMBER OF SUBJECTS: 67

Approval is hereby granted by Memorial Hermann Healthcare System to initiate this research study at the Memorial Hermann – Texas Medical Center & Children’s location. This approval is subject to the Principal Investigator’s acceptance of the following stipulations:

STUDY SPECIFIC STIPULATIONS:

Research Informed Consent:
1. The Joint Commission requires that a copy of the signed consent form for hospital-based studies be in all subjects’ hospital medical records. In addition, the MHHS Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects’ hospital medical records. The informed consent and disclosure form must remain in the subjects’ charts.

Data Security and HIPAA:
2. All data security computer devices and Protected Health Information used in this study must be password protected and/or data encrypted.

3. The Principal Investigator will use a “linking log” that contains the MRN (Medical Record Number) and study number to identify subjects. The MRN must not be used on the data collection tool.

Other Stipulations:
4. Please remember to acknowledge the Memorial Hermann Health System in any publications resulting from this study, and provide a copy of the publication to the Director of Clinical Research Operations for Memorial Hermann Clinical Innovation & Research Institute (Sheila.Ryan@memorialhermann.org). The methods of acknowledgement may include:
   a. Memorial Hermann – Texas Medical Center as an author’s affiliation;
   b. mention in an “acknowledgement” section; or
   c. as a footnote.

5. To request data extracts, please submit an online form available at: http://datarequest.memorialhermann.org. You will need to be connected to the Memorial Hermann Network to access the form. You may also contact a member of the Clinical Innovation and Research Institute to submit this form on your behalf. In the online request, this letter authorizing release of the data as well as the approved UT IRB document will be required as an attachment. You will be contacted within 5 business days of submitting the form to begin the process of determining the scope of work and deliverable timeframe.

Please sign and return a copy of this letter to the Memorial Hermann Clinical Innovation & Research Institute to the attention of Elspora.Rabolta@memorialhermann.org to indicate your acceptance of our terms and policies (guidelines attached).

This study may not be initiated until the letter is signed and returned to the Memorial Hermann Clinical Innovation & Research Institute.
If you have questions or need additional information, please contact the Memorial Hermann Clinical Innovation & Research Institute at (713) 704-5655.

APPROVED:  

[Signature]  
Shaila Ryan, JD, MPH, CCRA  
Director, Clinical Research Operations  
Clinical Innovation & Research Institute

ACCEPTANCE:  

[Signature]  
Vuong Trung-Tran Prieto, RN  
Principal Investigator

7/31/2019

Click here to enter a date.

cc:  
Paul Lamp - Director, Technical Services  
CPHS

Attachments:  
Memorial Hermann Clinical Innovation and Research Institute Guidelines  
Research Certification
IN SERVICE EDUCATION
The Investigator will provide in-service education regarding study procedures and requirements to all unit, clinic and/or department staff participating in the study including unit directors and managers.

PATIENT RECORDS/INFORMED CONSENT
The Joint Commission requires that the signed copy of the informed consent form for hospital-based studies be in all subjects’ hospital medical records. In addition, the MHHS Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects’ hospital medical records. The informed consent and disclosure form must remain in the subjects’ charts.

RESEARCH ORDERS
Investigator must document in the medical record the subject’s participation in the research study including consent process, study procedures, and treatments, with notation of research related procedures.

FINANCIAL RESPONSIBILITIES
Investigator agrees to make payment on the research account within 15 days of the billing date and according to the rates set forth in the attached Budget Worksheet. The budget provides a standard discount for research-related services. Research billing statements are distributed on a monthly basis. Please contact the MH Research Institute at (713) 794-2220 with billing questions. Past due accounts may be referred by Memorial Hermann to the appropriate Medical School Department Chair or Memorial Hermann Hospital CFO.

MEDICAL RECORD ACCESS
Requests for medical records must be submitted three (3) business days in advance. The Investigator must provide copies of the signed informed consent and MHHS Authorization for Disclosure of Protected Health Information for Research for each record requested. Records will be held in the Research Room for one week. There is a 20 record limit per request. At Memorial Hermann–TMC, the Research Room is open Monday through Friday, 8am-5pm. Please contact Health Information to make arrangements for after-hours access to records. Investigator must also provide three (3) business days notice of all monitoring visits to the Health Information Department (Medical Records).

DATA SECURITY
All data security computer devices used in this study must be password protected and/or data encrypted.

INVESTIGATIONAL DRUG SERVICE (IDS) PHARMACY
Upon receipt of the Memorial Hermann Approval Letter, IDS will need approximately two weeks to prepare the pharmacy protocol, create a distribution system, and in-service the Pharmacy staffs before enrollment of patients can begin. The Study Set-Up/Administrative Fee will be charged to the Research Billing Account once the preparation process is completed.

CONTINUING IRB REVIEW
Memorial Hermann requires continuous approval by the IRB for all research studies. The Principal Investigator is responsible for maintaining continuous review approval during the conduct of the study.

FEDERAL REGULATORY AGENCY
The MH Clinical Innovation & Research Institute must be notified, in advance, of any regulatory agency visit or review. Contact Sheila Ryan, MHHS Director of Clinical Research Operations.
Appendix D

Memorial Hermann Healthcare System Approval for Memorial Hermann

– Memorial City
7/22/2019

MEMORIAL HERMANN HEALTHCARE SYSTEM APPROVAL FOR
MEMORIAL HERMANN – MEMORIAL CITY

Thank you for choosing Memorial Hermann as your service provider for this research study.

IRB ID: HSC-MS-19-0554

PRINCIPAL INVESTIGATOR: Vuong Trung-Tran Prieto, RN

STUDY TITLE: Caregivers of Medically Fragile Children with Technology Needs.

NUMBER OF SUBJECTS: 67

Approval is hereby granted by Memorial Hermann Healthcare System to initiate this research study at the Memorial Hermann – Memorial City location. This approval is subject to the Principal Investigator’s acceptance of the following stipulations:

STUDY SPECIFIC STIPULATIONS:

Research Informed Consent:
1. The Joint Commission requires that a copy of the signed consent form for hospital-based studies be in all subjects’ hospital medical records. In addition, the MHH’s Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects’ hospital medical records. The informed consent and disclosure form must remain in the subjects’ charts.

Data Security and HIPAA:
1. All data security computer devices and Protected Health Information used in this study must be password protected and/or data encrypted.
1. The Principal Investigator will use a “linking log” that contains the MRN (Medical Record Number) and study number to identify subjects. The MRN must not be used on the data collection tool.

Other Stipulations:
1. Please remember to acknowledge the Memorial Hermann Health System in any publications resulting from this study, and provide a copy of the publication to the Director of Clinical Research Operations for Memorial Hermann Clinical Innovation & Research Institute (Sheila Ryan @memorialhermann.org). The methods of acknowledgement may include:
   a. Memorial Hermann – Texas Medical Center as an author’s affiliation;
   b. Mention in an “acknowledgement” section; or
   c. as a footnote.

5. To request data extracts, please submit an online form available at: http://datarequest.memorialhermann.org. You will need to be connected to the Memorial Hermann Network to access the form. You may also contact a member of the Clinical Innovation and Research Institute to submit this form on your behalf. In the online request, this letter authorizing release of the data as well as the approved UT IRB document will be required as an attachment. You will be contacted within 5 business days of submitting the form to begin the process of determining the scope of work and deliverable timeframe.

Please sign and return a copy of this letter to the Memorial Hermann Clinical Innovation & Research Institute to the attention of Eleonora Balebaita @memorialhermann.org to indicate your acceptance of our terms and policies (guidelines attached).

This study may not be initiated until the letter is signed and returned to the Memorial Hermann Clinical Innovation & Research Institute.
If you have questions or need additional information, please contact the Memorial Hermann Clinical Innovation & Research Institute at (713) 704-5955.

**APPROVED:**

Sheila T. Ryan  
7/22/2019  
Sheila Ryan, JD, MPH, CCRP  
Director, Clinical Research Operations  
Clinical Innovation & Research Institute

**ACCEPTANCE:**

7/23/2019  
Vuong Trung Tran Prieto, RN  
Principal Investigator

cc:  
Paul Lamei - Director, Technical Services  
CPHS

**Attachment:**  
Memorial Hermann Clinical Innovation and Research Institute Guidelines  
Research Attestation
MEMORIAL HERMANN CLINICAL INNOVATION & RESEARCH INSTITUTE GUIDELINES

INSERVICE EDUCATION
The Investigator will provide in-service education regarding study procedures and requirements to all unit, clinic and/or department staff participating in the study including unit directors and managers.

PATIENT RECORDS/INFORMED CONSENT
The Joint Commission requires that the signed copy of the informed consent form for hospital-based studies be in all subjects’ hospital medical records. In addition, the MHHS Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects’ hospital medical records. The informed consent and disclosure form must remain in the subjects’ charts.

RESEARCH ORDERS
Investigator must document in the medical record the subject’s participation in the research study including consent process, study procedures, and treatments, with notation of research-related procedures.

FINANCIAL RESPONSIBILITIES
Investigator agrees to make payment on the research account within 45 days of the billing date and according to the rates set forth in the attached Budget Worksheet. The budget provides a standard discount for research-related services. Research billing statements are distributed on a monthly basis. Please contact the MH Research Institute at (713) 794-1490 with billing questions. Past due accounts may be referred by Memorial Hermann to the appropriate Medical School Department Chair or Memorial Hermann Hospital CFO.

MEDICAL RECORD ACCESS
Requests for medical records must be submitted three (3) business days in advance. The Investigator must provide copies of the signed informed consent and MHHS Authorization for Disclosure of Protected Health Information for Research for each record requested. Records will be held in the Research Room for one week. There is a 20 record limit per request. At Memorial Hermann-TMC, the Research Room is open Monday through Friday, 8am-5pm. Please contact Health Information to make arrangements for after-hours access to records. Investigator must also provide three (3) business days notice of all monitoring visits to the Health Information Department (Medical Records).

DATA SECURITY
All data security computer devices used in this study must be password protected and/or data encrypted.

INVESTIGATIONAL DRUG SERVICE (IDS) PHARMACY
Upon receipt of the Memorial Hermann Approval Letter, IDS will need approximately two weeks to prepare the pharmacy protocol, create a distribution system, and in-service the Pharmacy staffs before enrollment of patients can begin. The Study Set-Up/Administrative Fee will be charged to the Research Billing Account once the preparation process is completed.

CONTINUING IRB REVIEW
Memorial Hermann requires continuous approval by the IRB for all research studies. The Principal Investigator is responsible for maintaining continuing review approval during the conduct of the study.

FEDERAL REGULATORY AGENCY
The MH Clinical Innovation & Research Institute must be notified, in advance, of any regulatory agency visit or review. Contact Sheila Ryan, MHHS Director of Clinical Research Operations.
Appendix E

Memorial Hermann Healthcare System

Approval for Memorial Hermann – Katy
7/19/2019

MEMORIAL HERMANN HEALTHCARE SYSTEM APPROVAL FOR
MEMORIAL HERMANN – KATY

Thank you for choosing Memorial Hermann as your service provider for this research study.

IRB ID: HSC-MS-19-0554  PRINCIPAL INVESTIGATOR: Vuong Trung-Tran Prieto, RN

STUDY TITLE: Caregivers of Medically Fragile Children with Technology Needs.

NUMBER OF SUBJECTS: 67

Approval is hereby granted by Memorial Hermann Healthcare System to initiate this research study at the Memorial Hermann – Katy location. This approval is subject to the Principal Investigator's acceptance of the following stipulations.

STUDY-SPECIFIC STIPULATIONS:

Research Informed Consent:
1. The Joint Commission requires that a copy of the signed consent form for hospital-based studies be in all subjects' hospital medical records. In addition, the HMHS Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects' hospital medical records. The informed consent and disclosure form must remain in the subjects' charts.

Data Security and HIPAA:
2. All data security computer devices and Protected Health Information used in this study must be password protected and/or data encrypted.

3. The Principal Investigator will use a “linking log” that contains the MRN (Medical Record Number) and study number to identify subjects. The MRN must not be used on the data collection tool.

Other Stipulations:
4. Please remember to acknowledge the Memorial Hermann Health System in any publications resulting from this study, and provide a copy of the publication to the Director of Clinical Research Operations for Memorial Hermann Clinical Innovation & Research Institute (Sheila Ryan@memorialhermann.org). The methods of acknowledgement may include:
   a. Memorial Hermann – Texas Medical Center as an author’s affiliation;
   b. mention in an “acknowledgement” section; or
   c. as a footnote.

5. To request data extracts, please submit an online form available at: http://datarequest.memorialhermann.org. You will need to be connected to the Memorial Hermann Network to access the form. You may also contact a member of the Clinical Innovation and Research Institute to submit this form on your behalf. In the online request, this letter authorizing release of the data as well as the approved UT IRB document will be required as an attachment. You will be contacted within 5 business days of submitting the form to begin the process of determining the scope of work and deliverable timeframe.

Please sign and return a copy of this letter to the Memorial Hermann Clinical Innovation & Research Institute to the attention of Eleonora Bailaita@memorialhermann.org to indicate your acceptance of our terms and policies (guidelines attached).

This study may not be initiated until the letter is signed and returned to the Memorial Hermann Clinical Innovation & Research Institute.
If you have questions or need additional information, please contact the Memorial Hermann Clinical Innovation & Research Institute at (713) 794-5655.

APPROVED:

Sheila Ryan, JD, MPH, CCRP
Director, Clinical Research Operations
Clinical Innovation & Research Institute

7/22/2019

ACCEPTANCE:

Vuong Trung-Tran Prieto, RN
Principal Investigator

7/23/2019

Click here to enter a date.

CC:
Paul Lampe - Director, Technical Services
CPAS

Attachments:
Memorial Hermann Clinical Innovation and Research Institute Guidelines
Research Attestation
MEMORIAL HERMANN CLINICAL INNOVATION & RESEARCH INSTITUTE GUIDELINES

INSERVICE EDUCATION
The Investigator will provide in-service education regarding study procedures and requirements to all unit, clinic and/or department staff participating in the study including unit directors and managers.

PATIENT RECORDS/INFORMED CONSENT
The Joint Commission requires that the signed copy of the informed consent form for hospital-based studies be in all subjects' hospital medical records. In addition, the MHHS Authorization for Disclosure of Protected Health Information for Research (with IRB approval stamp) must be placed in all subjects' hospital medical records. The informed consent and disclosure form must remain in the subjects' charts.

RESEARCH ORDERS
Investigator must document in the medical record the subject's participation in the research study including consent process, study procedures, and treatments, with notation of research related procedures.

FINANCIAL RESPONSIBILITIES
Investigator agrees to make payment on the research account within 45 days of the billing date and according to the rates set forth in the attached Budget Worksheet. The budget provides a standard discount for research-related services. Research billing statements are distributed on a monthly basis. Please contact the MH Research Institute at (713) 796-1220 with billing questions. Past due accounts may be referred by Memorial Hermann to the appropriate Medical School Department Chair or Memorial Hermann Hospital CFO.

MEDICAL RECORD ACCESS
Requests for medical records must be submitted three (3) business days in advance. The investigator must provide copies of the signed informed consent and MHHS Authorization for Disclosure of Protected Health Information for Research for each record requested. Records will be held in the Research Room for one week. There is a $20 record limit per request. At Memorial Hermann–TMC, the Research Room is open Monday through Friday, 8am-5pm. Please contact Health Information to make arrangements for after-hours access to records. Investigator must also provide three (3) business days notice of all monitoring visits to the Health Information Department (Medical Records).

DATA SECURITY
All data security computer devices used in this study must be password protected and/or data encrypted.

INVESTIGATIONAL DRUG SERVICE (IDS) PHARMACY
Upon receipt of the Memorial Hermann Approval Letter, IDS will need approximately two weeks to prepare the pharmacy protocol, create a distribution system, and in-service the Pharmacy staffs before enrollment of patients can begin. The Study Set-Up/Administrative Fee will be charged to the Research Billing Account once the preparation process is completed.

CONTINUING IRB REVIEW
Memorial Hermann requires continuous approval by the IRB for all research studies. The Principal Investigator is responsible for maintaining continuing review approval during the conduct of the study.

FEDERAL REGULATORY AGENCY
The MH Clinical Innovation & Research Institute must be notified, in advance, of any regulatory agency visit or review. Contact Sheila Ryan, MHHS Director of Clinical Research Operations.
Appendix F

IRB Approved Flyer for Study
Are you the caregiver of a medically fragile child with technology needs?

This research study seeks to survey the caregiving experiences of caregivers who provide care for medically fragile children (MFC) with technology needs.

Who is eligible for the study? Caregivers:
- 18 years or older
- Provide care of a child in the home setting for greater than 6 months

Caregivers:
- Child has one or more technology needs (i.e., tube feedings, intravenous feedings, home mechanical ventilation, and more)
- Child is 6 months of age -- 18 years of age
- Child is currently hospitalized at Children's Memorial Hermann TMC, Memorial City OR seen at affiliated Memorial outpatient clinics OR seen at UT Physician clinics

Benefits: No direct benefits
Compensation: Yes
Risks: Minimal risks
Location of research: Children's Memorial Hermann Hospital – TMC, Memorial Hermann Memorial City, Memorial Katy, and UT Physician clinics

Contact researcher: Vuong Prieto; 832-433-0115; UT Health Cizik School of Nursing; Vuong.Tran@uth.tmc.edu

IRB NUMBER: HSC-19-0554
IRB APPROVAL DATE: 07/10/2019
Appendix G

Approved Letter of Invitation for Study
LETTER OF INVITATION
TO TAKE PART IN RESEARCH

Study Title: Caregivers of Medically Fragile Children with Technology Needs

Principal Investigator: Vuong Prieto MSN, BSN, RN, CHSE, PhD(c); UT Health School of Nursing

IRB Number: HSC-SN-19-0554

The purpose of this study is to survey the caregiving experiences of caregivers who provide daily care in the home to medically fragile children with technology needs and to determine the relationship of these caregiving experience to the caregiver's health related quality of life. The study will also determine caregiver and child factors that are related to the caregiving experiences of the caregivers. You are invited to take part in this study because you are the primary caregiver of a medically fragile child with technology needs. To be eligible for the study, you must also be 18 years or older, have cared for your child in the home for 6 months or more. In addition, your child who you care for must have one or more technology needs, be 6 months - 18 years of age, and currently hospitalized at Children's Memorial Hermann TMC or Children's Memorial Hermann Memorial City or seen at affiliated Memorial Hermann outpatient clinics or seen at UT Physician clinics. This study will help us better understand the possible burdens on caregivers.

If you agree to participate, you will be asked to complete three one-time surveys and be asked questions regarding you and your child. Specifically, survey questions will ask you about how you feel when caring for another person's needs, about the satisfactions in caring for someone, and any problems that occur physically, emotionally, socially, or cognitively for you when caring for your child. We will ask specific questions regarding your age, gender, race, ethnicity, marital status, relationship to your child, estimated family annual income, your highest level of education, occupation, duration of caregiving your child, and the number of other children living in your home. Specific questions regarding your child will include gender, age of child, his/her primary diagnosis, his/her type of technology needs at home, and overall number of hospitalizations (not including birth). The amount of time asked of you to complete the survey will range from 20 – 25 minutes.

There will be no risk to your child if you choose to participate in the study. The answers you provide regarding caregiver burden and caregiving satisfaction may cause you to feel guilty if you select ratings that may indicate poor caregiving satisfaction and high caregiver burden. At the completion of the survey, if feelings of guilt are present, please contact the primary investigator, Vuong Prieto, at 832-433-0115 and you will then be provided a resource (parent support group) to contact to express your concerns.

You will not have any benefits from participating in this study. There are no costs to you for participating in the study. At the end of the survey, you have the option of receiving an electronic thirty dollar gift card, which will require you to provide your email address. The link to provide the email address is separate from the study survey link and will not link your responses to this survey. Child names will not be personally identified in any reports or publications that may result.
information about you that is gathered during this study will remain confidential to the extent of the law.

You can refuse to answer any questions asked in the study survey. Your decision to take part is voluntary. You may refuse to take part or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change the services available to you from your healthcare provider and research staff with the University of Texas Health Science Center at Houston (UTHealth) and Memorial Hermann Healthcare System or Harris Health System.

If you have questions at any time about this research study, please feel free to contact the primary investigator, Vuong Prieto, at 832-433-0115

This research project has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston, HSC-SN-19-0554. For any questions about your rights as a research subject, please call CPHS at (713) 500-7943.

LINK TO STUDY SURVEY: https://uhmtac.a2.qualtrics.com/jfe/form/SV_8kyTmlAkrR2FQAy9 (test survey, not the actual survey to be used)
Appendix H

Consent Form
CONSENT TO TAKE PART IN RESEARCH

Simple Study Title: Caregivers of Medically Fragile Children with Technology Needs

Principal Investigator: Vuong Prieto MSN, BSN, RN, CHSE, PhD(c); UT Health Cizik School of Nursing

Study Contacts: Vuong Prieto; Vuong.t.tran@uth.tmc.edu, 832-433-01152

You are invited to take part in this research study. This consent form has important information about this study to help to decide whether or not to take part in this study. Your decision to take part is voluntary. You may refuse to take part or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change the services available to you from your healthcare provider and research staff with the University of Texas Health Science Center at Houston (UTHealth) and Memorial Hermann Healthcare System or Harris Health System.

What is the purpose of this research study?

The purpose of this study is to survey the caregiving experiences of caregivers who provide daily care in the home to medically fragile children with technology needs and to determine the relationship of these caregiving experience to the caregiver’s health related quality of life. The study will also determine caregiver and child factors that are related to the caregiving experiences of the caregivers.

Who is being asked to take part in this study?

You are being asked to take part in this research study because you have a child that requires technology as part of their health care needs in the home. This study is being conducted at Children’s Memorial Hermann Hospital and UTHealth pediatric affiliated clinics. About 67 or more participants will be asked to take part in the study who live in Houston, TX or live in counties surrounding the Houston-Galveston, TX area.

What will happen if I take part in this study?
If you agree to be in the study, you will be asked to answer questions that will determine whether you meet inclusion criteria to participate in the study. If you meet inclusion criteria for the study, you will be asked to complete three one-time surveys and be asked questions regarding you and your child. Specifically, survey questions will ask you about how you feel when caring for another person’s needs, about the satisfactions in caring for someone, and any problems that occur physically, emotionally, socially, or cognitively for you when caring for your child. Specific questions regarding you will ask your age, gender, race, ethnicity, marital status, relationship to your child, estimated family annual income, your highest level of education, occupation, duration of caregiving your child, and the number of other children living in your home. Specific questions regarding your child will include gender, age of child, his/her primary diagnosis, his/her type of technology needs at home, and overall number of hospitalizations (not including birth). The amount of time asked of you to complete the survey will range from 20 – 25 minutes.

What are the risks of taking part in this study?
There will be no risk to your child if you choose to participate in the study. The answers you provide regarding caregiver burden and caregiving satisfaction may cause you to feel guilty if you select ratings that may indicate poor caregiving satisfaction and high caregiver burden. At the completion of the survey, if feelings of guilt are present, please contact the primary investigator, Vuong Prieto, at 832-433-0115 and you will then be provided a resource (parent support group) to contact to express your concerns.

What are the benefits to taking part in this study?
There are no direct benefits to taking part in the study.

Subject compensation
You will be compensated a thirty dollar gift card/electronic thirty dollar gift card for completion of the surveys and questions.

Can you stop taking part in this study?
You may decide to stop taking part in the study at any time. To withdraw from the study, you may either discontinue completing the online survey or please contact the primary investigator, Vuong Prieto, at 832-433-0115.
If you stop participating in this study after submitting the survey, the information already collected about you will still be used in the data analysis. However, no further information will be collected without your permission.

**What are the costs of taking part in this study?**

There are no costs in taking part in the study.

**How will privacy and confidentiality be protected?**

Your privacy is important and your participation in this study will be kept confidential, including information about you and your child. If you provide your email to obtain the electronic gift card, the information you provide in the surveys and questions will not be linked to you and your child as the incentives link is separate from the survey study link.

**Who can I contact if I have questions about the study?**

If you have questions at any time about this research study, please feel free to contact the primary investigator, Vuong Prieto, at 832-433-0115, as they will be glad to answer your questions. You can contact the primary investigator to discuss problems, report injuries, voice concerns, obtain information in addition to asking questions about the research.

The Committee for Protection of Human Subjects at the University of Texas Health Science Center has reviewed this research study. You may contact them for any questions about your rights as a research subject, and to discuss any concerns, comments or complaints about taking part in a research study at (713) 500-7943.

- I agree to participate in the study.
- I do not agree to participate in the study.
Appendix I

Zarit Burden Interview - Original
BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?

2. Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

4. Do you feel embarrassed over your relative’s behavior?

5. Do you feel angry when you are around your relative?

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

7. Are you afraid what the future holds for your relative?

8. Do you feel your relative is dependent upon you?

9. Do you feel strained when you are around your relative?

Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit

Contact information and permission to use: Mapi Research Trust, Lyon, France – Internet:

https://eprovide.mapi-trust.org/
10. Do you feel your health has suffered because of your involvement with your relative?

11. Do you feel that you don’t have as much privacy as you would like, because of your relative?

12. Do you feel that your social life has suffered because you are caring for your relative?

13. Do you feel uncomfortable about having friends over, because of your relative?

14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

15. Do you feel that you don’t have enough money to care for your relative, in addition to the rest of your expenses?

16. Do you feel that you will be unable to take care of your relative much longer?

17. Do you feel you have lost control of your life since your relative’s illness?

18. Do you wish you could just leave the care of your relative to someone else?

19. Do you feel uncertain about what to do about your relative?

20. Do you feel you should be doing more for your relative?
21. Do you feel you could do a better job in caring for your relative?

22. Overall, how burdened do you feel in caring for your relative?

Copyright 1983, 1990, Steven H. Zarit and Judy M. Zarit

Copyright 1980, 1983, 1990 Steven H Zarit and Judy M Zarit

Contact information and permission to use: Mapi Research Trust, Lyon, France – Internet:

https://eprovide.mapi-trust.org/
Appendix J

Zarit Burden Interview – Qualtrics
Burden Interview

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

Copyright 1983, 1990, Steven H. Zant and Judy M. Zant
1. Do you feel that your relative asks for more help than he/she needs?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990, Steven H. Zarit and Judy M. Zarit
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990, Steven H. Zant and Judy M. Zant
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1996, Steven H. Zarit and Judy M. Zarit
4. Do you feel embarrassed over your relative's behavior?

○ 0. Never
○ 1. Rarely
○ 2. Sometimes
○ 3. Quite Frequently
○ 4. Nearly Always

Copyright 1983, 1990, Steven H. Zarit and Judy M. Zarit
5. Do you feel angry when you are around your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990, Steven H. Zanit and Judy M. Zanit
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always
7. Are you afraid what the future holds for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always
8. Do you feel your relative is dependent upon you?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1993, 1996; Steven H. Zant and Judy M. Zant
9. Do you feel strained when you are around your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1999; Steven H. Zant and Judy M. Zant
10. Do you feel your health has suffered because of your involvement with your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1993, 1990, Steven H. Zaut and Judy M. Zauti
11. Do you feel that you don’t have as much privacy as you would like, because of your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990; Steven H. Zarit and Judy M. Zarit
12. Do you feel that your social life has suffered because you are caring for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990; Steven H. Zarit and Judy M. Zarit
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

☐ 0. Never
☐ 1. Rarely
☐ 2. Sometimes
☐ 3. Quite Frequently
☐ 4. Nearly Always

Copyright 1993, 1996; Steven H. Zant and Judy M. Zant
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always
17. Do you feel you have lost control of your life since your relative’s illness?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

Copyright 1983, 1990, Steven H. Zalt and Judy M. Zalt
18. Do you wish you could just leave the care of your relative to someone else?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

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19. Do you feel uncertain about what to do about your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

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20. Do you feel you should be doing more for your relative?

- 0. Never
- 1. Rarely
- 2. Sometimes
- 3. Quite Frequently
- 4. Nearly Always

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21. Do you feel you could do a better job in caring for your relative?

☐ 0. Never
☐ 1. Rarely
☐ 2. Sometimes
☐ 3. Quite Frequently
☐ 4. Nearly Always

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22. Overall, how burdened do you feel in caring for your relative?

- 0. Not at all
- 1. A little
- 2. Moderately
- 3. Quite a bit
- 4. Extremely

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Appendix K

Caregiving Satisfaction Scale - Original
E. Caregiving Satisfactions

Now I am going to read some statements that other people have made about satisfactions that they found in caring for someone. Some, all, or none of these statements may apply to you. Again, as I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree I will then ask you if you moderately or strongly agree or disagree.

Let's begin with (READ E-1). Do you agree or disagree? [Moderately or strongly?]

<table>
<thead>
<tr>
<th>E-1. Caring for (care-receiver) gives my self-esteem a boost.</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-2. It helps to know that I am doing my best in caring for (care-receiver).</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-3. Caring for (care-receiver) helps keep (him/her) from getting sicker than (he/she) otherwise would.</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-4. By providing care I am living up to my religious or moral principles.</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-5. I have grown closer to (care-receiver) as a result of caring for (him/her).</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-6. I feel better about myself for being willing to care for (care-receiver).</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E-7. I feel that there is more purpose and meaning in my life as a result of caring for (care-receiver).</th>
<th><strong>AGREE</strong></th>
<th><strong>DISAGREE</strong></th>
<th><strong>MS/DK/NA</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strongly</td>
<td>Moderately</td>
<td>Strongly</td>
</tr>
<tr>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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bill.strawbridge@ucsf.edu
<table>
<thead>
<tr>
<th>Question</th>
<th>AGREE</th>
<th>DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>E-8. Caring for (care-receiver) has helped me realize that I can do things I never knew before that I could do.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-9. I feel useful because I know I am helping someone.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-10. Caring for (care-receiver) has brought some of our family closer together.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-11. Caring for (care-receiver) has taught me to deal better with my emotions.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-12. Caring for (care-receiver) has taught me to distinguish the important things in life from the not-so-important.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-13. I have been able to use special skills that I have to help (care-receiver) continue to do the things that (he/she) enjoys doing.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-14. Caring for (care-receiver) has taught me some important things about myself.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>E-15. Caring for (care-receiver) gives me small but important upliffs now and then.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

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bill.strawbridge@ucsf.edu
Appendix L

Caregiving Satisfaction Scale – Qualtrics
Caregiving Satisfaction Scale (CSS)

Now I am going to read some statements that other people have made about satisfactions that they found in caring for someone. Some, all, or none of these statements may apply to you. Again, as I read each statement I would like you to tell me if you agree or disagree with it. After you decide if you agree or disagree I will then ask you if you moderately or strongly agree or disagree.

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1. Caring for (care-receiver) gives my self-esteem a boost.
   - Strongly agree
   - Moderately agree
   - Moderately disagree
   - Strongly disagree
   - MS/DK/NA

2. It helps to know that I am doing my best in caring for (care-receiver).
   - Strongly agree
   - Moderately agree
   - Moderately disagree
   - Strongly disagree
   - MS/DK/NA

3. Caring for (care-receiver) helps keep (him/her) from getting sicker than (he/she) otherwise would.
   - Strongly agree
   - Moderately agree
   - Moderately disagree
   - Strongly disagree
   - MS/DK/NA

4. By providing care I am living up to my religious or moral principles.
   - Strongly agree
   - Moderately agree
   - Moderately disagree
   - Strongly disagree
   - MS/DK/NA
5. I have grown closer to (care-receiver) as a result of caring for (him/her).

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA

6. I feel better about myself for being willing to care for (care-receiver).

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA

7. I feel that there is more purpose and meaning in my life as a result of caring for (care-receiver).

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA

8. Caring for (care-receiver) has helped me realize that I can do things I never knew before that I could do.

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA
9. I feel useful because I know I am helping someone.
   - Strongly agree
   - Moderately agree
   - Moderately disagree
   - Strongly disagree
   - MS/DK/NA

10. Caring for (care-receiver) has brought some of our family closer together.
    - Strongly agree
    - Moderately agree
    - Moderately disagree
    - Strongly disagree
    - MS/DK/NA

11. Caring for (care-receiver) has taught me to deal better with my emotions.
    - Strongly agree
    - Moderately agree
    - Moderately disagree
    - Strongly disagree
    - MS/DK/NA

12. Caring for (care-receiver) has taught me to distinguish the important things in life from the not-so-important.
    - Strongly agree
    - Moderately agree
    - Moderately disagree
    - Strongly disagree
    - MS/DK/NA
13. I have been able to use special skills that I have to help (care-receiver) continue to do the things that (he/she) enjoys doing.

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA

14. Caring for (care-receiver) has taught me some important things about myself.

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA

15. Caring for (care-receiver) gives me small but important uplifts now and then.

- Strongly agree
- Moderately agree
- Moderately disagree
- Strongly disagree
- MS/DK/NA
Appendix M

Health Survey Short Form – 12 version 2 (SF – 12 v2) - Original
Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please mark an x in the one box that best describes your answer.

1. In general, would you say your health is:

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing several flights of stairs</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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3. **During the past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

- Accomplished less than you would like: □ 1 □ 2 □ 3 □ 4 □ 5
- Were limited in the kind of work or other activities: □ 1 □ 2 □ 3 □ 4 □ 5

4. **During the past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

- Accomplished less than you would like: □ 1 □ 2 □ 3 □ 4 □ 5
- Did work or other activities less carefully than usual: □ 1 □ 2 □ 3 □ 4 □ 5

5. **During the past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
</tbody>
</table>

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6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

- Have you felt calm and peaceful? □ 1 □ 2 □ 3 □ 4 □ 5
- Did you have a lot of energy? □ 1 □ 2 □ 3 □ 4 □ 5
- Have you felt downhearted and depressed? □ 1 □ 2 □ 3 □ 4 □ 5

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

<table>
<thead>
<tr>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 3</td>
<td>□ 4</td>
<td>□ 5</td>
</tr>
</tbody>
</table>

*Thank you for completing these questions!*

---

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(SF-12v2 Health Survey Standard United States (English))

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Appendix N

Health Survey Short Form – 12 version 2 (SF – 12 v2) – Qualtrics
Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. Thank you for completing this survey!

For each of the following questions, please mark in the one box that best describes your answer.

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1. In general, would you say your health is:

- Excellent
- Very Good
- Good
- Fair
- Poor

2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

2A. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all
2B. Climbing several flight of stairs

- Yes, limited a lot
- Yes, limited a little
- No, not limited at all

3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

3A. Accomplished less than you would like

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
3B. Were limited in the kind of work or other activities

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

4A. Accomplished less than you would like

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
4B. Did work or other activities less carefully than usual

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- Not at all
- A little bit
- Moderately
- Quite a bit
- Extremely
6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

6A. Have you felt calm and peaceful?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

6B. Did you have a lot of energy?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
6C. Have you felt downhearted and depressed?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time
Appendix O

Socio-Demographics of the Caregivers – Qualtrics
**Instructions:** Please answer the following statements or questions about yourself, the caregiver.

**Gender:**
- Male
- Female

**Race (Mark ONLY one which you MOST CLOSELY identify):**
- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- More than one race
- Unknown or not reported

**Ethnicity (Mark ONLY one with which you MOST CLOSELY identify):**
- Hispanic or Latino
- Not Hispanic or Latino
- Unknown or not reported

**What is your age? (years):**
What is your relationship to child with technology needs?
- Biological mother
- Biological father
- Adoptive mother
- Adoptive father
- Grandparent
- Other relative
- Foster parent
- Guardian

Estimated annual family income? (U.S. dollars)
- < 20,000
- 20,000 - 40,000
- 40,001 - 60,000
- 60,001 - 80,000
- > 80,000
- Unknown

What is your highest level of education?
- High school or less
- High school graduate
- Some college
- College graduate (Associates or Bachelor’s)
- Graduate school
- Completed graduate school (Masters, Doctoral, etc.)

Occupation
- Employed
- Unemployed
How long have you been caring for your child with technology needs? (please indicate how many months OR years)

_________________________

Number of other children living in the family home:

_________________________

Powered by Qualtrics
Appendix P

Socio-Demographics and Clinical Characteristics of the Child - Qualtrics
**Instructions:** Please answer the following statements or questions about your child with technology needs.

Gender of child:

- Male
- Female

Age of child (please indicate months or years):

[Blank]

Primary diagnosis of child:

[Blank]

How long has your child with technology needs have their disease or condition requiring the use of technology? (please indicate months or years)

[Blank]
Type of technology or technologies used by your child (multiple choices possible)

- Mechanical ventilation
- IV (intermittent)
- IV (continuous)
- Tracheostomy suctioning
- Gastrostomy feedings
- Duodenal/jejunal feedings
- Supplemental oxygen (nasal cannula, facemask, etc.)
- IV feedings (TPN, lipids)
- Cardiorespiratory monitoring
- Urinary catherization
- Renal dialysis
- Colostomy/ileostomy, urostomy care

Other technology or technologies not listed:

________________________

Number of child's total hospitalizations not including birth:

________________________
Appendix Q

Human Subjects Research Training Certificates (CITI)
This is to certify that:

Vuong Prieto

Has completed the following CITI Program course:

Human Research
Group 2 Social and Behavioral Researchers and Key Personnel
2 - Refresher Course

Under requirements set by:

University of Texas Health Science Center at Houston

Verify at www.citiprogram.org/verify?x319844a7-b9cd-4613-9964-4b52d4763fd4-32274220
**COLLABORATIVE INSTITUTIONAL TRAINING INITIATIVE (CITI PROGRAM)**

**COMPLETION REPORT - PART 1 OF 2**

**COURSEWORK REQUIREMENTS**

*NOTE: Scores on this Requirements Report reflect quiz completions at the time all requirements for the course were met. See list below for details. See separate Transcript Report for more recent quiz scores, including those on optional (supplemental) course elements.*

- **Name:** Vuong Tran (ID: 5861831)
- **Institution Affiliation:** University of Texas Health Science Center at Houston (ID: 661)
- **Institution Email:** vuong.t.tran@uth.tmc.edu
- **Phone:** 7135002151
- **Curriculum Group:** Human Research
- **Course Learner Group:** Group 2 Social and Behavioral Researchers and Key Personnel
- **Stage:** Stage 2 - Refresher Course
- **Record ID:** 32274220
- **Completion Date:** 23-Sep-2019
- **Expiration Date:** 22-Sep-2022
- **Minimum Passing:** 80
- **Reported Score:** 91

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<th>REQUIRED AND ELECTIVE MODULES ONLY</th>
<th>DATE COMPLETED</th>
<th>SCORE</th>
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<tr>
<td>SBE Refresher 1 - Instructions (ID: 943)</td>
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<tr>
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<tr>
<td>SBE Refresher 1 - Defining Research with Human Subjects (ID: 15028)</td>
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<tr>
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<td>SBE Refresher 1 - Research in Educational Settings (ID: 940)</td>
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<td>SBE Refresher 1 - International Research (ID: 15028)</td>
<td>23-Sep-2019</td>
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Verify at: [www.citiprogram.org/verify](http://www.citiprogram.org/verify?sid=74280c477f77-4f603-ad53-b56f778f8fca&rec=32274220)

Collaborative Institutional Training Initiative (CITI Program)

Email: support@citiprogram.org
Phone: 866-529-5929
Web: [https://www.citiprogram.org](https://www.citiprogram.org)
**NOTE:** Scores on this Transcript Report reflect the most current quiz completions, including quizzes on optional (supplemental) elements of the course. See list below for details. See separate Requirements Report for the reported scores at the time all requirements for the course were met.

- **Name:** Vuong Tran
- **Institution Affiliation:** University of Texas Health Science Center at Houston (ID: 661)
- **Institution Email:** vuong.tran@uth.tmc.edu
- **Phone:** 713.500.2151
- **Curriculum Group:** Human Research
- **Course Learner Group:** Group 2 Social and Behavioral Researchers and Key Personnel
- **Stage:** Stage 2 - Refresher Course

- **Record ID:** 28274220
- **Report Date:** 18-Jan-2020
- **Current Score:** 91

### REQUIRED, ELECTIVE, AND SUPPLEMENTAL MODULES

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**Collaborative Institutional Training Initiative (CITI Program)**

*Email: support@citiprogram.org*

*Phone: 866-529-5929*

*Web: [https://www.citiprogram.org](http://www.citiprogram.org)*
CURRICULUM VITAE

Vuong Prieto, PhD(c), RN, CHSE

EDUCATION

- Doctor of Philosophy in Nursing
  UT Health Cizik School of Nursing Houston – Houston, TX
  09/2015 – 05/2020

- Masters of Science in Nursing
  University of Texas Medical Branch – Galveston, TX

- Bachelors of Science in Nursing
  UTHSC-School of Nursing – San Antonio, TX
  05/2004 – 05/2006

- Prerequisites for Nursing
  University of St. Thomas – Houston, TX
  08/2001 – 05/2004

LICENSE & CERTIFICATION

- RN No. 728998
  Texas Board of Nursing
  Expiration 12/31/2020

- Pediatric Advanced Life Support
  American Heart Association
  Expiration 08/2021

- Basic Life Support
  American Heart Association
  Expiration 07/07/2020

- Certified Healthcare Simulation Educator
  Society for Simulation in Healthcare
  Expiration 09/2021

PROFESSIONAL EXPERIENCE

- Children’s Memorial Hermann Hospital
  Project Manager, Charge Nurse, Staff RN II
  06/2006 – 05/2015
- Lone Star Community College – Cy Fair
  Adjunct Faculty
  08.2012 – 01/2013

- UTHSC – Cizik School of Nursing
  Clinical Educator
  03/2013 – 08/2019

- UTHSC – Cizik School of Nursing
  Teaching Associate
  09/2015 - present

**Professional Memberships**

- Sigma Theta Tau International Honor Society – Member
  05/2006 – present

- National League for Nursing – Member
  08/2012 – present

- International Nursing Association for Clinical Simulation and Learning – Member
  03/2013 – 12/2019