Title
Experiences of Parents Whose Disabled Child Resides in a Subacute Skilled-Nursing Facility

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Experiences of Parents Whose Disabled Child Resides in a Subacute Skilled-Nursing Facility

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy in Nursing

by

Victoria Katrina Abatay

2023

ABSTRACT OF THE DISSERTATION

Experiences of Parents Whose Disabled Child Resides in a Subacute Skilled-Nursing Facility

by

Victoria Katrina Abatay

Doctor of Philosophy in Nursing

University of California, Los Angeles, 2023

Professor Eunice Eunkyung Lee

Professor Carol L. Pavlish

Background: There are approximately 50,000 children worldwide living in an "unresponsive wakefulness state/vegetative state" (UWS/VS). Technological advancements continue to extend life expectancy for people with life-threatening health conditions that would not have survived otherwise.

Purpose/Aims: To understand the experiences of parents Whose Disabled Child is in a UWS/VS and residing in a skilled nursing facility (SNF). Specific aims include: (1) describing the impact on parents' well-being, (2) exploring unique parental experiences during their child's first year of residency at a SNF, (3) identifying key influences on parents' decision-making and coping, and (4) examining factors that influence parental engagement with their child and social networks.

Methods: This qualitative study utilizes narrative inquiry using a semi-structured interview guide and inductively analyzed the data to identify themes and codes that best inform the research question.

Results: After eligibility screening, nine singles and five couples participated in interviews. Line by line coding was performed on all interview transcripts with reliability checked by two senior qualitative researchers. Four primary themes with 2-3 sub-themes organically emerged from the participants' narratives to form a coherent and interconnected storyline that depicted a very subtle chronology of events and experiences. The four main themes include: (1) Enduring the Unexpected, (2) Navigating the Unknown, (3) Prioritizing Values in Decision-Making, and (4) Changing Relationships.

Implications: Nursing research on this topic is limited and yet nurses play a key role in providing family-centered care and support for this vulnerable population. A deeper understanding of parent caregiving for these fragile children could be a valuable resource for healthcare professionals. Potential future interventions and suggestions to improve parental and family support were identified in the areas of emotional, social, and decision-making through the trajectory of the child's chronic illness.

The dissertation of Victoria Katrina Abatay is approved.

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University of California, Los Angeles

2023

Dedication Page

This study could not have been accomplished without the invaluable contributions of all the parents who openly shared their vulnerable experiences.

To all the children and families impacted by UWS/VS and other disabilities, may this study and future research contribute to enhancing the caregiving experiences both at home and in SNFs.

Dr. Eufemia Jacob – for enlightening me about the potential for positive change within nursing and academia and revealing a path I aspire to join.

And lastly, I extend my gratitude to those who have offered me support and care during my academic journey - especially my husband and our Baby Cairo, my siblings, and parents.

Dear Dad – I'm finally "done with [my] paper."

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VITA

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Implementing A Pediatric Early Warning Score (PEWS) Tool
Presented to: Faculty of California State University, Fullerton School of Nursing
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Abatay, V., & Robertson, S. *Implementing A Pediatric Early Warning Score Tool.* May 2014. Sigma Theta Tau International – Upsilon Beta Chapter.

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Chapter One

Introduction

Technological advancements continue to make lifesaving contributions to medical science. These advances allow medical practitioners to gain new methods to cure illnesses, establish early diagnoses, and ultimately extend life expectancy for people with life-threatening health conditions that would not have the opportunity to survive otherwise (Gale & Namestnic, 2013; Glader & Palfrey, 2009; Strauss et al., 2000). As a result of sophisticated medical technology, a population of people with complex healthcare needs has evolved: those who are "technology-dependent" (Glader & Palfrey, 2009). Technology-dependent is a term used to describe a person with a chronic condition due to a loss of vital organ(s) function and consequently requires a medical device to compensate for their loss to sustain life (Glader & Palfrey, 2009; Okido et al., 2012). The type of technology that a person with a chronic condition relies on for medical needs vary substantially. Some examples of technologies include mechanical ventilation through a tracheostomy for respiratory support, or a gastrostomy tube for nutritional support(Glader & Palfrey, 2009). The idea of life-sustaining technology and interventions can initially sound very appealing to the public and have produced lifesaving outcomes for people who have complex health needs and are technology-dependent. In contrast, there are also technology-dependent people whose outcomes are overlooked and undocumented – especially the population of healthcare patients that are in varying states of disorders of consciousness (DoC).

"Consciousness" is defined as "the state of awareness of the self and environment... that requires adequate arousal and awareness of content" (Giacino et al., 2018) (p. 1711). Severe brain injuries can disrupt the normal function of the neurological system and result in a DoC that can range from a minimally consciousness state (MCS), to a persistent vegetative state (PVS) (Giacino et al., 2018).

"Persistent vegetative state" or "vegetative state" (VS) is a disorder of consciousness where patients cannot demonstrate purposeful movements, expressions, or sounds (Bastianelli et al., 2016). The single definition of "PVS" that is still utilized in healthcare was established in 1994 by The Multi-Society Task Force as "complete unawareness of self and the environment…with either complete or partial preservation of… brainstem functions" (p. 1499). The American Academy of Neurology (AAN) later established the widely accepted term "unresponsive wakefulness syndrome" (UWS) to be used synonymously with PVS/VS in an updated systematic review of disorders of consciousness (DoC) (Giacino et al., 2018). For the purpose of this study, the researcher will use the acronym "UWS/VS," as provided by the AAN, to appropriately acknowledge the historical diagnostic term "PVS/VS," while promoting usage of the updated and widely accepted and medically sensitive term, "UWS." UWS/VS is defined as irreversible and persistent after three months for people who sustained non-traumatic injuries (due to congenital defects or chronic illnesses), and at 12 months after traumatic injuries (Bastianelli et al., 2016).

The main function of the brainstem is to regulate autonomic functions including heart rate, blood pressure, breathing, blinking, and sleep-wake cycles (Ashwal, 2004). Due to preserved hypothalamic and brainstem functions despite loss of other neurological capabilities, people in a UWS/VS appear to be awake with movement, but do not show evidence of purposeful interaction to external stimuli, purposeful responses, visual tracking, nor bowel and bladder control (Ashwal, 2004). By definition, such people have a chronic condition and are technology-dependent to sustain life. Depending on the severity of neurological devastation, some may require additional respiratory support through a tracheostomy and a mechanical ventilation machine, and all people will require a gastrostomy tube to meet their nutritional needs due to the severely impaired abilities to chew and swallow (Ashwal, 2004; Glader & Palfrey, 2009; Montagnino & Ethier, 2007).

The possibility of recovery from a UWS/VS into adequate cognitive functioning with varying levels of mild neurologic deficit is usually very rare and oftentimes dependent upon the etiology of the UWS/VS. A UWS/VS that stems from traumatic brain injuries has a slightly higher chance of recovery as compared to a UWS/VS from non-traumatic injury or degenerative malformations (Ashwal & Cranford, 2002; Giacino et al., 2018). The life expectancy for patients in a UWS/VS has dramatically increased with technological advancements such as feeding pumps and ventilators that can be maintained outside of the acute care hospital. In 1995, the AAN reported a life expectancy of up to five years. Currently, medical technology-dependence allows people with this to survive more than 10 years post-UWS/VS diagnosis (Bastianelli et al., 2016; Cipolletta et al., 2014).

Epidemiologic studies published by The Multi-Society Task Force (1994) about UWS/VS remain to be the historical reference and primary statistics available in literature regarding this patient population (Multi-Society Task Force, 1994). In 1994, it was estimated that there were approximately 93,000 children worldwide under the age of 15 living in a UWS/VS (Multi-Society Task Force, 1994). Though quality of life (QOL) for patients in a UWS/VS can appear poor from a medical standpoint, many parents and legal guardians choose to prolong their child's life through technology-dependence for many different reasons. Data from 1994 reported that the cost to provide care for children in a UWS/VS at their home totaled approximately $97,000, where residency and care at a subacute skilled nursing facility (SNF) could range between

$126,000- $180,000 annually, and exceeds $1,00,000 over a lifetime (Giancino et al., 2018; Multi-Society Task Force, 1994).

The scarcity of published research has made statistical data about the prevalence of UWS/VS difficult to obtain (Shavelle et al., 2008). Data from a survey provided to parents and caregivers from the Children with Special Healthcare Needs organization (CSHCN) indicated that approximately 1.2 million children and adolescents in the U.S. require durable medical equipment, however the details of the equipment and their purpose are unknown (Spratling, 2015). The 2016 National Survey of Children's Health also indicated that 19% of all children up to 18 years old have special complex healthcare needs, where 42% of this population are also diagnosed with brain injuries (Lebrun-Harris et al., 2018). Currently, incidence and prevalence reports for technology-dependent children remain unknown.

Analysis of the data provided by CSHCN and National Survey of Children's Health estimates that approximately 500,000 children are technology-dependent with varying ranges of brain injuries (Lebrun-Harris et al., 2018; Spratling, 2015). The data do not provide information about the pediatric population with UWS/VS, however, children in a UWS/VS share similar neurological characteristics as those children included in the data with severe brain injury that are also technology-dependent because UWS/VS is the end result of a severe brain injury that devastates the neurological system (Kirk et al., 2015). The residual effects from severe brain injuries become static after the initial recovery has reached a plateau – at this point in the child's recovery process, the child's condition becomes a chronic illness that can lead to long-term physical, cognitive, and behavioral difficulties for the child and their parents (Corrigan & Hammond, 2013; Kirk et al., 2015). Children in a UWS/VS and those who suffered severe brain injuries require the same levels of total care and manipulation of medical technology devices from healthcare providers to avoid secondary health complications and deterioration (Kirk et al., 2015; Roscigno & Swanson, 2011). Children that fit these descriptions of severe neurological and cognitive damage are also commonly known as being considered intellectually and developmentally disabled (Friedman & Kalichman, 2014).

Data regarding the population of technology-dependent children living in a sub-acute facility are also difficult to obtain. According to the California Association of Health Facilities (CAHF, 2016), the cost for an adult patient to reside at a subacute facility ranges $300 - $600 daily ($109,500 - $219,000 yearly), dependent upon the patient's healthcare needs (CAHF, 2016). In 2000, the Centers for Medicare and Medicaid Services reported that there were 4,886 children with special complex healthcare needs residing in SNFs, of whom 1,222 had intellectual and developmental disabilities (similar to those children in a UWS/VS) (National Institutes of Health, 2010). Technological improvements in medicine are likely to continue contributing to the rising rates of children living with disabilities and chronic conditions (Friedman et al., 2014).

Guardianship of children in UWS/VS

Parents will naturally fill the role of guardianship in situations where their child's life is threatened with illness or injury (Friedman et al., 2014). Among children who are diagnosed with UWS/VS, in many cases their biological parents remain legal guardians who maintain consenting rights to all medical-related decisions for the child. Inevitably, there are some cases of children who live in a SNF whose families retain legal consenting and decision-making rights, but for unknown reasons, do not play a regularly active role in their child's care after placement into a SNF. For children whose disability is a direct result of illegal abuse or neglect and the state Department of Child and Family Services (DCFS) cannot appoint another family member or non-related adult close to the child as the legal guardian, the child may become a ward of the state child welfare agency to remove the child from their harmful environment. As a ward of the state, the child may be admitted to skilled residential care to receive licensed-professional care for their complex developmental and health needs (Friedman et al., 2014).

Decision-Making for Children with Chronic Critical Illness

The concept and recurring theme of decision-making is heavily burdened with the pressure to make the "best" decision. The "best" decision is an abstract, yet psychological construct that is central to comprehending information to communicate choice (Clarke et al., 2013). Unique to "decision-making" is the idea that there is not always a "right" or "wrong" decision. Decisions, in accordance to a pragmatic philosophical stance, are made to serve the unique and individual interest of the decision-maker (Cornish & Gillespie, 2009).

Children under the age of 18 years are legally considered as "minors" who do not have the autonomy to make personal health care decisions or write advanced directives for their care at the end-of-life. Families with healthy children are not often concerned with the probability of chronic debilitating or life-changing illnesses or injuries until tragic events occur. Therefore, life-sustaining considerations are rarely documented ahead of serious conditions. Families and children across the globe will continue to experience life-altering events that require parents to make life-or-death decisions daily. Sensitive decisions among families surrounding medical treatments for children bring about varying levels of decisional conflict, especially with a child whose responses to external stimuli are suddenly reduced to brainstem reflexes after a traumatic event, similar to the characteristics of UWS/VS. The decision-maker in the context of this paper and proposed study is the biological parent who maintains the legal guardianship rights to make healthcare decisions for their child in a UWS/VS or similar neurological compromise.

Clinicians and caregivers are often faced with challenging decision-making situations that surround a child's life. One of the most critical decisions along the trajectory of a chronically ill child in critical condition is deciding on the most suitable approach and location for ongoing medical care and treatment. Literature related to UWS/VS caregiver decision-making encompasses a wide range of factors that help to mediate this process, including the ethical and moral obligations.

The terms "futility" and "best interests" are heavily emphasized in medical decision-making, where clinicians work to perform appropriate medical care and treatment that will balance the benefits and burdens of treatment choices. These terms continue to raise further questions that include topics such as: people that are designated to decide on the patient's 'best interest,' and how a fair quality of life is determined and interpreted (Clarke et al., 2013; Lotz et al., 2016).

The "best interest" standard is the current criterion utilized in medical science (Clarke et al., 2013; Haque, 2011; Lotz et al., 2016). This standard considers the weight of futile treatments versus benefits of continuing treatment to aid in selecting an appropriate intervention that is in the "best interest" of that specific patient. Though the term is easily defined, variations amongst the medical staff and decision-maker's perceptions of life, suffering, and best interests can often cause conflict (Diekema et al., 2009; Haque, 2011). While a prolonged life may increase a patient's chances for recovery, it may also continue to prolong suffering.

Decision-making is especially difficult when considering the paradoxical state of UWS/VS patients' physical liveliness coupled with mental unawareness. A study by Strauss et al. (2000) that examined the perspective of medical professionals reported that patients in a UWS/VS "have been deemed to have lost personhood and be less worthy than patients who are severely impaired but who retain consciousness" (p. 315). Contrary to these results in a study about caregivers for adult patients diagnosed with UWS/VS by Cipoletta et al. (2016), a fraction of caregivers (20.8%) believed that their patient in a UWS/VS is completely aware of their condition and surroundings, but unable to express themselves due to neurological impairment, whereas the remaining caregivers believe their patient fits the medical definition of "UWS/VS" with complete unawareness or understanding of any stimuli (Cipolletta et al., 2016). The latter population of caregivers also expressed regret for the decision to pursue life-sustaining measures because it appears that the patient continues to experience suffering and pain. The study does not clarify if the 24 caregivers that participated in the study were also primary decision-makers, otherwise the caregiver's role may have affected their statement.

These findings represent a small reflection of the conflicting beliefs and experiences among professional and non-professional caregivers for people diagnosed with UWS/VS. Given these contrasting results, there is a possibility that parents experience a similar conflict through the trajectory of their child's illness and lifespan in a health state of UWS/VS.

Care for Children in UWS/VS in the Family Home Versus a SNF

Children in a UWS/VS have complex medical needs that fit four common characteristics as described by the Pediatric Complex Care Association (PCCA, 2016):

1) Chronic, severe health conditions
2) Substantial health service needs
3) Severe functional limitations
4) High health resource utilization

Children that fit the four descriptions listed above require around-the-clock medical monitoring, intensive life-sustaining technology, and multidisciplinary care (PCCA, 2016).

Once the parents or guardians of a child in a UWS/VS (or other similar type of DoC) have decided to sustain their child's life, the next decisions involve the logistics of where the complex and chronic long-term treatments should be provided. Over the past few decades, technological advances in healthcare have made it possible to reduce their child's length of hospital stay by providing the same type of medical care outside of the hospital in their family home or at lower-acuity healthcare settings like a SNF (Elias et al., 2012). Parents may provide care at home or at a SNF by choice or necessity given their financial, resource, or skill and knowledge constraints (Friedman et al., 2014). Children with medical complexities are frequently discharged home or to a SNF to continue their prescribed treatments and avoid long-term hospitalizations. The term "placement" commonly describes a decision by the guardian to choose out-of-home care for their child at a medical group home or a SNF (Mirfin-Veitch et al., 2003).

There are a variety of reasons why parents choose to place their child in a SNF rather than caring for the child at home. Some of the reasons include family and parental attitudes, the social environment, cultural practices, and availability of external assistance (Friedman et al., 2014). Other reasons that a child might be placed in a SNF is that the child requires more care and attention than the family can accommodate, community and familial resources are insufficient, and the family is unable to organize, supervise, and manage care for the child (Friedman et al., 2014). For either care setting, the care coordination for a child with complex medical needs requires multiple difficult decisions and input from multidisciplinary care teams prior to hospital discharge to a home or a SNF (Elias et al., 2012).

Few studies have explored the impact of placement on these parents' and families' psychosocial well-being. Many families who cared for their child's needs at home often reported anxiety and emotional exhaustion related to providing care (Glader & Palfrey, 2009), whereas some families believed that placement of their child in a SNF would allow their child to receive better, more attentive care. This decision has also helped them to prioritize functionality and balance for all family members in the home (Glidden et al., 2006; Kersh et al., 2006).

Parents whose disabled children have complex medical needs have also expressed how perceptions of social challenges influence their decision to place their child in a SNF. In one study by Green (2004), researchers found that parents who perceived a risk for their child being stigmatized by their community were more likely to place their child in an out-of-home care facility. Both studies also found that stress on the caregiver influenced the consideration of placement (Green, 2004).

The experiences of the total care trajectory are not well-understood due to outdated and limited research about parents and children in a UWS/VS (Fins et al., 2007). Multiple studies have examined families with children that are disabled and technologically dependent. There are two studies that examine the impact on well-being of the family before and after placement into a SNF (Baker & Blacher, 2002; Llewellyn et al., 1999); and one study examined the impact of marital quality to the well-being of fathers and mothers of children with disabilities as it applied to parenting stress and efficacy (Kersh et al., 2006). The broader literature review include studies that focus on the effects of caring for people in a UWS/VS that do not focus solely on children that are cared for at home or at a SNF (Kuehlmeyer et al., 2012; Leonardi, Giovannetti, et al., 2012; Okido et al., 2012; Pagani, Giovannetti, Covelli, Sattin, Raggi, et al., 2014; Roscigno & Swanson, 2011).

Current Knowledge Gap

An extensive review of the literature conducted by the primary investigator (PI) did not reveal any studies that focus on experiences of parent dyads through their child’s illness while the child is a resident at a SNF. Various studies have shown that mothers and fathers of severely brain-injured children focus on different aspects of their child’s illness – mothers have been reported to focus on their child’s physical needs and quality of life, whereas fathers have reported the importance of gathering as much information about their child’s health status to understand the prognosis and consequences of each decision (Hill et al., 2017; Mirfin-Veitch et al., 2003). Further research into the dyads’ caregiving experiences can provide healthcare providers with evidence of how dyadic caregiving compares to other studies that include data from primarily single mothers. Whereas caregiver studies commonly report feelings of burden, abandonment, and social isolation through providing care to their loved-one, it is possible that caregiving as a couple can influence the overall trajectory of their experiences in caring for their child at a SNF.

This study is important to nursing because decision-making conflict, depression, burden, and anxiety symptoms have been recognized in familial caregivers for adult patients with UWS/VS, but caregiving has not been widely studied in parents or guardians for the pediatric population with UWS/VS in the United States. Based upon this PI’s observations at a pediatric SNF and a pilot study performed on licensed caregivers at a pediatric SNF, there appears to be decreased visitation and participation of parents. Many times, it appears that one parent or family member will visit, while the status of the other is unknown. This observation could indicate that there has been change in the parent-child or parent-dyad relationship after diagnosis of UWS/VS and placement into a SNF.

Much of the research that has been done about children in a UWS/VS are quantitative in nature and are about children who are cared for at home by their families. This research study contributes to a growing body of qualitative work that illuminates the unique experiences shared by parents and parent dyads who care for a child in a UWS/VS and is a resident at a SNF. The findings of this research study may be useful for parents, family-caregivers, nurses, and other interdisciplinary members of the healthcare profession with planning for psychosocial support when a child is placed in a SNF.

Purpose

The purpose of this narrative study is to understand the experiences of parents and parent-dyads whose disabled child is in a UWS/VS and resides in a SNF. The study focuses on parents and parent-dyads to understand the unique relationships and experiences of parents to their dyad and/or chronically ill child in a SNF. The findings of this study may shed light on their needs so that healthcare providers can become better-prepared to assist parents and families through the complexities of planning, decision-making, and caring for a child in a UWS/VS to support well-being and improved psychosocial outcomes.

Research Question

The proposed research study aimed to answer the following question: What are the experiences of parents and parent-dyads whose disabled child is in a UWS/VS and reside in a SNF?

Specific Aims

In a sample of parents and parent-dyads ("dyads") whose disabled children are diagnosed with UWS/VS and residing at a SNF, the following specific aims include:

1. Describe how overseeing care of a disabled child in the SNF has impacted the dyad's well-being during the first year.
2. Describe the dyad's person and dyadic experiences through the first year of their disabled child's admission and residency at the SNF.
3. Specify critical points in the decisional processes undertaken by dyads through the first year of their disabled child's admission and residency at the SNF.
4. Examine the intra-personal, dyadic, social and situational characteristics that enhance or diminish the parent-dyad's engagement with their disabled child's care.

Method

This qualitative study utilized narrative inquiry methodology to collect, analyze, and understand the experiences of parents and parent-dyads whose disabled children are in a UWS/VS and reside in a SNF. Parents and caregivers in this target population share unique experiences in their roles to care for their child with highly complex medical needs. The researcher conducted in-depth interviews using a semi-structured interview guide. The interviews were recorded, transcribed verbatim, and analyzed inductively using the narrative analysis to identify themes and codes that best inform the research question.

Significance of the Study for Practice and Research

Among studies available relevant to UWS/VS or decision-making for children with chronic life-threatening conditions, little is known about how these life changes have impacted parents and parent-dyad experiences. While technological advances have improved the ability to save and sustain lives for 10 years or more, they also contribute to the growing population of children in a UWS/VS (Friedman et al., 2010; Gale & Namestnic, 2013; Giacino et al., 2018; Glader & Palfrey, 2009). The population of children in a UWS/VS is seldomly studied, and statistics regarding this specific population of children have not been published since 2000 (National Institutes of Health, 2010). Additionally, multiple studies involving parents of children in a UWS/VS reference historical publications as their point of reference for the state of knowledge and financial data (Giacino & Whyte, 2005; Ashwal, 2004; Multi-Society Task Force, 1994).

Limited literature related to UWS/VS and parent or caregivers' experiences present numerous gaps in knowledge and opportunities to perform research in this field. What is known from these studies is that the costs for children who are in a UWS/VS and technology-dependent creates a long-term strain on their parents and caregivers financially and emotionally (Ashwal, 2004; Glader & Palfrey, 2009; Multi-Society Task Force, 1994). The unique experiences of parents and parent-dyads have not been widely explored nor published in research. This study serves as a foundation that allows parent-dyads to share their experiences of caring for child in a UWS/VS at a SNF. The collection and interpretation of data may eventually lead to conceptual frameworks and interventions to support parents and children in this population (Bastianelli et al., 2016). A specific gap in literature related to this population of children and parents or caregivers is that there are not any known studies about parent-dyads whose disabled child is in a UWS/VS and residing in a SNF.

Nursing Implications

To this PI's knowledge, there are six publications that studied the parental pediatric caregiver population for children in a UWS/VS (Bastianelli et al., 2016; Cipolletta et al., 2014; Cipolletta et al., 2016; Leonardi, Giovannetti, et al., 2012; Pagani, Giovannetti, Covelli, Sattin, Raggi, et al., 2014; Roscigno & Swanson, 2011) that were performed in Italy, with no evidence of studies performed with this specific population in the United States – possibly due to its sensitive nature or cultural differences. There are also multiple U.S. caregiver (both professional and familial) studies of adults in a UWS/VS or similar DoCs that have indicated varying levels of depression, anxiety, burden, and regretful decision-making (Abbott et al., 2001; Bluebond-Langner et al., 2017; Hill et al., 2017; Honeybul et al., 2015; Kirk et al., 2015; Pearlin et al., 1990; Zaal-Schuller et al., 2016), but no studies performed on parent-dyad caregivers of children in a UWS/VS. From these research studies, one could suspect parent-dyads share some commonalities in these experiences that have not yet been documented. For practitioners, the findings from this study can direct anticipatory guidance and support measures for families who are caring for loved ones in a SNF early in the process when their experiences are better understood.

Chapter Summary

A qualitative study that focuses on parent and parent-dyad experiences and care for their disabled child will allow parents to share and discuss their unique experiences, needs, and feelings during interviews. Data collection and interpretation utilizing narrative inquiry methodology allows the PI to understand and identify commonalities among the experiences that can become useful to healthcare providers as they anticipate the dyads' needs and questions, especially in the first year of their child's residency at the SNF. This research can also lead to future conceptual frameworks and interventions for parents and caregivers that currently have a child in a UWS/VS or similar chronic conditions and disabilities.

Chapter Two
Literature Review

The PI for this study has been employed as a Registered Nurse faculty member assigned to teach undergraduate nursing students about pediatric care in three pediatric subacute nursing facilities in Southern California. At the facilities, the PI observed decreased visitation and engagement from parents whose disabled child is in a UWS/VS across the pediatric subacute nursing facilities (SNF). This observation could indicate that the child's diagnosis and placement has taken a toll on the parent-child or parent-partner (dyad) relationship.

Previous studies of familial caregivers for their loved-ones in UWS/VS indicate that this population experiences higher levels of burden, uncertainty, and even more unique to their situations – prolonged grief (PG) and emotional paradox. There are also studies that describe parental experiences of placing their child or loved-one with varying levels of intellectual and behavioral disorders at an out-of-home care facility. However, the PI is unable to locate studies that inquire about the experiences of parent-caregivers, specifically those whose disabled children have been diagnosed with UWS/VS and live in a SNF. The lack of literature in this field, especially in the nursing discipline, prevents a holistic analysis of this population of parent caregivers. It is clear in the literature that caring for patients with UWS/VS presents numerous emotional, physical, and psychological challenges. By increasing children's survival and longevity through a series of medical decisions and use of medical technology, the population of pediatric patients diagnosed with UWS/VS and their parent caregivers will continue to expand which warrants research that explores challenges that this parent population encounters when caring for and about their child in UWS/VS.

This chapter reviews the existing body of literature surrounding unresponsive wakefulness syndrome/vegetative state (UWS/VS) and parent caregiver perceptions and experiences. Research aims from Chapter One guided the selection of articles that provide a comprehensive review of the topic and to assist in identifying gaps in knowledge on the research topic. Information gained from the literature served as a foundation for deeper understandings about caregivers' unique experiences, methodological insights, and guidance for future research.

This literature review describes publications regarding the experiences and perceptions of caregivers for disabled children in a UWS/VS and neurological and/or intellectual disabilities. Studies that focused on parents' experiences of placing their child in a healthcare residency or skilled nursing facility were also included to understand the trajectories that children and their families experience through the duration of their illness. Literature that studied caregiving roles of parents and parent dyads who have children with medical needs, parent decision-making, and parent caregivers' placement decisions were also included. Lastly, limitations of studies reviewed and gaps in knowledge are presented to highlight areas for future research.

Literature Search

The following databases were searched in collaboration with a UCLA Biomedical Librarian: PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) Web of Science, and Google Scholar. Key terms included in the search were: persistent vegetative state, pediatric persistent vegetative state, parental perspectives, parent decision, lived-experience, end-of-life care, futility, terminal care, ethics, decision-making, life-sustaining measures, brain death, life expectancy, decision-making, caregiver stress, caregiver burden, developmental disabilities, and out-of-home placement.

Articles that were written or translated into English were selected. Historical articles were also included to explore changes in either UWS/VS or caregiver experiences. This search produced over 2,000 articles. A manual bibliographical search also produced related research articles for inclusion. Articles were reviewed and then limited to studies pertaining to caregivers of children in UWS/VS or similar neurological compromise. The resulting articles were screened for quality, relevance, and rigor prior to inclusion. The literature search produced a total of 11 relevant studies: two quantitative studies, seven qualitative studies, and two mixed-methods studies. No intervention studies were found. Six studies were conducted in the U.S. (Baker & Blacher, 2002; Hill et al., 2017; Kersh et al., 2006; October et al., 2014; Renjilian et al., 2013; Roscigno & Swanson, 2011), one in Italy (Giovannetti et al., 2012), one in the United Kingdom (Kirk et al., 2015), one in Belgium (Hostyn & Maes, 2007), New Zealand (Mirfin-Veitch et al., 2003), and Australia (Llewellyn et al., 1999).

All 11 studies included female caregivers, two of the selected studies were strictly focused on couples' experiences (Hill et al., 2017; Kersh et al., 2006), whereas four studies included a mixture of single and coupled parents (Hostyn & Maes, 2007; Mirfin-Veitch et al., 2003; October et al., 2014; Renjilian et al., 2013). One study focused only on the pediatric population in UWS/VS (Giovannetti et al., 2012), and 10 studies included pediatric populations (diagnoses varied from developmental disorders to severe, life-threatening illnesses other than UWS/VS). Among the selected studies, four involved patients who were cared for in a private home (Hill et al., 2017; Kersh et al., 2006; Kirk et al., 2015; Roscigno & Swanson, 2011), one study included pediatric patients who were mixed between home and a facility (Giovannetti et al., 2012), one study focused on the patient's acute-phase of the life-threatening illness or trauma while hospitalized (October et al., 2014), and four studies focused on families' decisions to place their child or patient in a residential or healthcare facility (Baker & Blacher, 2002; Hostyn & Maes, 2007; Llewellyn et al., 1999; Mirfin-Veitch et al., 2003).

Caregiving Experiences: Perceptions and Challenges

The term “emotional paradox” was formally applied in 1988 to describe a condition of grief experienced by caregivers for people in a prolonged coma (Stern et al., 1988). During an “emotional paradox,” caregivers experience a unique psychological response and form of grief for a person that is perceived as both dead and alive (Stern et al., 1988).

Roscigno and Swanson (2011) conducted a descriptive phenomenological study of parents whose child experienced a moderate-to-severe traumatic brain injury (TBI) where they found that parents in their study were experiencing an emotional paradox. The study aimed to understand their experiences and expectations of their children after the sustained injury. The study included 42 parents from 38 families across the United States that were recruited using diverse methods: personal solicitation at a children’s hospital in Northwestern U.S., national advertisement on two TBI-related websites, public posters, and mailed invitations to participants in a regional southeastern brain and spinal cord injury program and a northwestern hospital’s pediatric trauma registry (Roscigno & Swanson, 2011). Only participants from 37 families reported parent data: 29 mothers, three fathers, and five couples; all parents spoke English. The parent participants reported the following make-up of families: 11 single parents, 25 two-parent, and one non-biological parent; 17 families lived in suburban settings, 13 in rural, and seven in urban settings. The children were between 8-20 years old at the time of their injury, dependent and living with parent(s) or legal guardian(s), and characterized as having moderate-to-severe TBI as identified by their Glasgow Coma Scare (GCS) score obtained via the referring clinician (n=17), trauma registry (n=3), parents’ copies of medical reports that were voluntarily shared (n=15), or parental verbal report (n=4) (Roscigno & Swanson, 2011).

The study was conducted with two semi-structured tape-recorded interviews: first at 4-36 months post-injury, then the second interview 12-15 months later. Thirty-five parents from 33 families returned for the second interview. The transcripts were hand-coded and analyzed using the descriptive phenomenological framework, where the resulting themes demonstrated emphasis on the sociocultural factors that influenced parents' and families' experiences over time since the TBI, and how parents reconciled the responses of others regarding their situations: (a) grateful to still have my child; (b) grieving for the child I knew; (c) running on nerves; and (d) grappling to get what your child and family need.

Forty-two parent caregivers in this study from across the U.S. continued to mourn for the previously healthy child before the traumatic event that caused the UWS/VS. A common theme that arose was "grieving for the child I once knew," where parents reported feeling "stranded in time" and suspended in confusion and sadness. Most parents expressed prolonged sadness as they witnessed and struggled with the fact that their child's injury was likely permanent. Parents compared their child's current status with the child's previously active status. This was often compounded with feelings of uncertainty related to the child's future and acceptance of the current UWS/VS (Roscigno & Swanson, 2011).

An observational, cross-sectional study by Giovannetti et al. (2012) evaluated 35 parental caregivers' health condition, coping, anxiety, and depression levels in relation to their child's VS or Minimal Conscious Syndrome (MCS). Thirty-five caregivers and children with disorders of consciousness (DOC) were enrolled in the study in Italy. Standardized self-report tools that were administered included: a sociodemographic questionnaire, the Coping Orientations to Problem Experiences (COPE), Short Form-12, the Beck Depression Inventory (BDI-II) and the Spielberger State Trait Anxiety Inventory (STAI-Y). Descriptive statistics and *t*-tests were performed to analyze parent caregiver health conditions, coping, anxiety and depression levels in relation to the child's level of disability.

The children's disability rating scale (DRS) was completed by trained health professional on their objective evaluation of the child to accurately measure the level of the child's disability. The children in the study were under the age of 18 (*M*=8.9), 68.6% males, 31.4% females; 77.1% of the children were cared for at home, 22.9% lived in a post-acute rehabilitation center, and none at a long-term care center. All the caregivers that participated in the study were the child's parents, with 85.7% mothers, and 14.3% fathers. The parent participants' mean age was 38.7 years old (SD = 6.7), 82.9% were married, 5.7% were single, and 11.4% were separated or widowed; 31.4% permanently resigned from their jobs, 34.3% resigned temporarily, while 34.3% were still working. Regarding assistance, 82.9% of parent participants reported that they provided 24-hour care, 62.9% reported they did not receive social assistance, and 60% reported financial difficulties (Giovannetti et al., 2012).

The Short Form-12 (SF) was used to assess caregiver general health conditions including physical, mental, emotional, and social functioning (Giovannetti et al., 2012). These characteristics were further categorized into two factors for statistical analysis: "physical component summary (PCS)," and "mental component summary (MCS)." Results from this study revealed that on average, parent caregivers' scores for the PCS were similar to a normative sample ($t = 0.530, P = 0.600$), whereas MCS scores were significantly lower ($t = -2.119, P = .041$). This indicates that caregivers perceive themselves to have quality physical health, with poor perceived mental health (Giovannetti et al., 2012).

Data analysis demonstrated that 57.2% of parent caregivers for children with DOCs crossed the 85th percentile threshold with mild-to-severe depressive symptoms ($P<0.001$). This group also exhibits high levels of psychological burden with poor mental health status that is significantly lower than the Italian normative sample (*t* = - 2.119, *P* = 0.041), with an overall higher level of state anxiety (mean = 47.1, SD 13.1, P = 0.038 for mothers, fathers showed mean = 48.4, SD = 6.4, P = 0.013) (Giovannetti et al., 2012).

The results showed that parent caregivers reported higher levels of anxiety than a normative sample, and that problem-oriented and emotional expression strategies were used more often than potentially dysfunctional strategies when coping with a stressful situation (Giovannetti et al., 2012). The results also demonstrated that the patients' levels of disability did not significantly correlate to the caregivers' self-reported depression scores, anxiety scores, or coping strategies. More than 60% denied having psychological or social assistance (68.0% and 62.9%, respectively), and 51.45% reported they did not have family support for caregiving (Giovannetti et al., 2012).

The authors (Giovannetti et al., 2012) also found that psychological burden exists in over half of the participants, but there was no correlation between the child's level of disability and caregivers' overall burden. This could suggest patients' level of illness and functioning may not be a sufficient predictor for caregivers' burden. Other factors that may contribute to burden are the patients' place of residency. Many children lived at home with their family or caregivers, which means that they likely require more attention and 24-hour care from their familial caregiver. Parents or familiar caregivers are also likely to coordinate activities and medical appointments for their patient, largely without the assistance of social support services or nursing staff that are usually shared among healthcare professionals within a facility (Giovannetti et al., 2012).

Parent caregivers' financial conditions could also contribute to reported burden, as 65% of participants resigned (either permanently or temporarily) to dedicate more time to caregiving, though 62.9% consider themselves to have sufficient income (Giovannetti et al., 2012). Caregivers in the study also expressed feeling a lack of family, social, and psychological support which may mean the caregiver must dedicate a majority of their life solely to the care of their patient (Giovannetti et al., 2012).

A few positive aspects of caregiving were reported by caregivers, where the caregiver's commitment and responsibility to their role encouraged them to successfully cope with the difficulties that are associated with caregiving. Another positive element found in participants' data was the tendency to use problem-oriented coping strategies rather than dysfunctional strategies, however, there were no significant differences in the use of emotional expression and problem-oriented strategies compared to the normative Italian sample (Giovannetti et al., 2012).

A qualitative study by Kirk et al. (2015) examined experiences and support needs for parents following their child's TBI during initial stages of recovery in the hospital, and upon discharge to their home. The physical recovery after a child has experienced a TBI often transcends the expectations of many doctors and healthcare providers (Kirk et al., 2015). This study was included because the characteristics of the patient population and caregivers in this study share similar qualities as those children in a UWS/VS.

Ninety-four family members and caregivers of children with severe TBI who were discharged from a specialist hospital in Northern England were invited to participate in a semi-structured interview. Twenty-nine parents and caregivers from 19 families agreed to participate in the study: 9 single participants were interviewed one-on-one, and 10 joint interviews were conducted. The participants were comprised of 62.1% mothers, 37% fathers, and 6.9%

grandmothers. The ethnicities included 84.2% White-British participants, and Asian-British, Black-British, and mixed ethnicities (5.3% each). The children of the participants were 68.4% female, 31.6% male. The children' ages at the time of interview ranged from 5-6 years old (10.6%), 7-10 years old (42.1%), 13-14 years old (10.6%), 15-16 years old (15.8%), and 17-18 years old (21.0%). Ages of the caregiver participants were not reported in the article. The length of time since the children' initial hospitalization until the time of interview varied: 6-12 months (0%), 13-24 months (42.1%), 24-26 months (5.3%), 37-48 months (42.1%), and 49-72 months (10.6%), with an average of 33 months (Kirk et al., 2015).

Results from this study found that parental support needs changed throughout the different stages of the patients' recovery trajectory and transition points. The study divided its findings into five transition points: the accident and its aftermath, being in the ICU, moving to the ward (commonly known as "general pediatrics"), coming home, and returning to school (Kirk et al., 2015). Parents in the study also expressed many unmet needs while experiencing these transitions. A recurring theme in the data that was consistent throughout the stages of recovery and transitions was "uncertainty" (Kirk et al., 2015). Among the five stages of transitions identified by the parents in this study, four main areas of uncertainty that corresponded with the transitions were: (a) the impact of the TBI, (b) the child's current and future treatment and rehabilitation plans, (c) how to help their child, and (d) how to access services and support.

Findings from this study imply that healthcare providers should maintain information-sharing provisions with parents through the different points in the care trajectory to share and give information in a way that parents and lay audiences will understand. Information provisions form the study also suggest that healthcare providers should tailor information-sharing based on the parent and family's emotional state, assign a key person to follow through with information giving, and recognize the uncertainty of the child's prognosis while allowing families to retain hope (Kirk et al., 2015). To address support and unmet needs, the study also outlined provisions of support that are aimed at providing individualized support plans to parents and families of children who have had a TBI through every phase of the child's care, especially through the transition phases. This study highlights how varying degrees of uncertainty correspond with high levels of unmet needs because all members involved in the care are unable to predict the prognosis or needs of the child and family after a TBI. The findings brought forth specific areas where parents needed more support through the child's care trajectory as they were currently experiencing it.

Participants in the study by Kirk et al. (2015) reveal the need for improvement in care coordination, information giving, and support across the transitions of care. This study also outlines implications from the study for information-giving and support to fulfill unmet needs that should be integrated to hospital and community settings to meet the changing needs of the child's care (Kirk et al., 2015). This is the first study to examine the changing experiences and support needs across the trajectory of a child's care (Kirk et al., 2015).

Caregivers in these three studies claimed their friends and colleagues "disappeared" or "ran away" over time, in addition to not feeling well-supported (Giovannetti et al., 2012; Kirk et al., 2015; Roscigno & Swanson, 2011). Although it may appear that family members and friends are purposefully avoiding caregivers, Roscigno & Swanson (2011) reported that caregivers contribute to their own isolation because most of their energy is utilized to fulfill the child's needs. Subsequently, the caregiver may frequently forgo their own needs and have decreased availability to attend to other family members (Giovannetti et al., 2012; Kirk et al., 2015; Roscigno & Swanson, 2011).

Kirk et al. (2015) cites similar findings related to lack of support following the discharge of a patient with UWS/VS in Roscigno and Swanson's (2011) study. Participants in the study by Kirk et al. (2015) described the need for improved care coordination, information giving, and support across the transitions of care. This study also outlined implications from the study for information-giving and support to fulfill unmet needs that should be integrated to hospital and community settings to meet the changing needs of the child's care (Kirk et al., 2015).

The selected studies have several strengths and limitations. One strength in the study by Roscigno & Swanson (2011) is that is provides valuable insights into the experiences of families – particularly those with strong opinions or negative experiences to share. The study by Giovanetti et al. (2012) is the only study that reports information on children in VS or MCS and their caregivers. However, both studies have limited samples in terms of size and ethnic diversities, which make it difficult to generalize the results to a broader population of children with similar severe neurological deficits.

A strength in the study by Kirk et al. (2015) is that it is the first study to examine parents' experiences and support needs throughout the entire trajectory of care for their injured child – starting from the initial injury to their return to the community. A major limitation in this study is that the participants were recruited from one children's tertiary care center, which can also limit the generalizability of findings to other settings that offer different services.

Overall, these studies make important contributions, however, it is important to consider the limitations mentioned when applying these findings to a broader population or context.

Further research should aim to address these limitations to provide a more comprehensive understanding of the caregiving experiences for parents.

Decision-Making about Treatment

Seriously ill children rely on their parents or legal guardians to make life-altering treatment decisions. This requires that the parent and family explore their values and preferences related to decision-making to choose the most optimal path of care and treatment. The PI could not locate interventions or protocols established literature to improve this process. This section of the literature review provides background knowledge on the processes and experiences of decision-making for parent caregivers with severely ill children that must decide between continuing life-sustaining treatment (LST) or withdrawal of care.

A prospective cross-sectional mixed-methods study using quantitative data from the Good Parent Ranking Exercise and qualitative data from the Good Parent Tool to identify factors important to parents making decisions for their critically ill child was performed by October et al. (2014). The study was conducted at a pediatric intensive care unit (PICU) of a single urban tertiary medical center in Washington D.C. English-speaking parents who had the primary decision-making responsibilities for their child in the PICU and who had participated in a family conference to discuss clinical treatment decisions to initiate, escalate, or withdraw LST were invited to participate (October et al., 2014). Fifty-three parents of 34 children met inclusion criteria; 43 parents of 29 children submitted usable data (81%). Among the parents that participated: 58% were mothers, 70% of participants were couples, of which 73% were married.

The pediatric patient characteristics included: 55% female, average age of four years old, the median length of stay in the PICU was 29 days. Disposition from the hospital were: home (34%), chronic care facility (25%), and hospice (7%); 34% of the children died in the hospital.

Parents were enrolled until data saturation was met, and no new codes emerged after five consecutive interviews. This study included significantly higher participation from African American parents and patients (65%) than white participants (25%) and those that identified as “Asian” or “other” (5% each) (October et al., 2014).

Researchers conducted one-on-one interviews that used the Good Parent Tool-2 with open-ended questions that asked parents to describe factors important to parenting their critically ill child, and how clinicians could help the parents achieve their definition of being a “good parent.” All parents were interviewed once. The Good Parent Tool effectively elicits responses about end-of-life decision making; two open-ended survey questions were included: 1) Please share with me your definition of being a good parent for your child at this point in your child’s life. 2) Please describe for me the actions from the staff that would help you in your efforts to be a good parent to your child now (October et al., 2014). Parent responses were written and then confirmed with the participating parent by reading statements back to the parent.

The content analysis method was used to analyze the qualitative data to match pre-published codes for the Good Parent Tool with the contents of the parents’ responses. New codes were also developed for content that represented new areas of meaning. Themes that were important to parental decision-making were similar across the sample, regardless of parents’ race, socioeconomic status, or child’s clinical condition. Approximately 60% of parents described three key strategies that helped them fulfill their parental role: (a) being a “good parent” included focusing on their child’s quality of life (QoL), (b) advocating for their child with the medical team, and (c) putting the child’s needs first (October et al., 2014). The most commonly reported need was constant updates by the medical team.

The resulting themes were ranked in order of importance (according to the parents' perspective) using the Good Parent Ranking Exercise. Statistical software was used to analyze the quantitative data to provide overall rankings of parents' priorities that were identified in the completed surveys (October et al., 2014). The rankings were based on a scale of 100 points, indicating the strength of preferences. The results showed that more parents prioritized "focusing on my child's health," "putting my child's needs above my own," "making informed medical decision," and "making sure my child feels loved" as the top four most important themes. When analyzing the rankings by gender, a significant association was found between the gender of the parent and their most important theme in decision-making. Fathers ranked "making informed medical decisions" as the most important theme 75% of the time, while mothers ranked this as the most important theme 25% of the time. It is also noteworthy that this pattern was observed predominantly among mothers who were not part of a couple. Mothers that were part of a couple considered "focusing on my child's health" as the most important theme 75% of the time.

This study contributes to the existing knowledge by including a diverse group of mothers, fathers, and couples to provide a broader perspective on what it means to be a "good parent" in decision-making. Themes such as "being present," "forming a partnership with the medical team based on honesty," and "being informed" were highly valued by parents. The mixed methods design allowed the researchers to identify a gender association with the themes, where fathers were most concerned with making informed medical decisions, and mothers in a couple were more focused on the child's health and needs. The study did not report gender associations in themes for coupled fathers versus non-coupled mothers. On average, the couples identified a higher number of important themes, with minimal overlap between the themes chosen by the mother and the father. However, parents who were not part of a couple identified fewer themes, which could suggest that interviews with both parents tend to cover a wider range of important aspects in parenting and decision-making.

A prospective cross-sectional observational study of parents at the Children's Hospital of Philadelphia (CHOP) to identify and illustrate common explicit heuristics used by parents of children with life-threatening illnesses when making critical medical decisions (Renjilian et al., 2013). Eligible parents were those who legally made the medical decisions for their ill child and spoke English. Parents who were emotionally unstable (as determined by the referring physician), whose disabled child died, or was discharged or too severely ill were excluded from joining the study (Renjilian et al., 2013).

A total of 73 parents of 50 children consented to participate: 60.9% were mothers, 33.3% fathers, and 5.8% were legal guardians that reported themselves as "other." Parents' ages ranged from 21-66 years of age. Among the participants, 71% were married or partnered, 15.9% reported to be widowed, separated, or divorced, 8.7% were single, and 4.4% were not specified. Regarding race: 72.5% were White, 13% Black, 1.5% Asian, 5.8% mixed, and 7.3% not specified. In relation to financial status: 36.2% reported no financial difficulties, 49.3% reported financial difficulties, and 14.5% were not specified (Renjilian et al., 2013).

Researchers performed semi-structured interviews exploring parents' experiences and thoughts about making medical decisions for their child (Renjilian et al., 2013). Parents were asked questions about what they perceived to be the most significant elements and problems concerning their child's illness and care, and their goals of care. The parents were also asked whether a religion, spirituality, or life philosophy influenced their experiences, decisions, and how the words "trust" and "hope" applied to their decision-making process (Renjilian et al., 2013).

In total, 69 parents of 46 children were included in the analysis (four responses were unavailable due to faulty recordings). A priori data analysis was employed such that all phrases identified as explicit decisional heuristics in the interviews shared two core characteristics: 1) from the parents' point of view, the phrase expressed a *pertinent truth or important aspect* of the child or parent's situation, and 2) the phrase was used in common *everyday lay language and frequently used* across multiple interviews (Renjilian et al., 2013).

The 12 predominant explicit heuristics were extracted from the interviews, with heuristics supporting the concepts of comfort, QoL, and pain being the most commonly used. Researchers found the five primary functions of explicit heuristics were to: (1) depict or facilitate understanding of complex situations, (2) clarify and focus pertinent information and values for care and decision-making, (3) serve as a decision-making compass that identified a supreme value or philosophy in weighing and directing decisions, (4) communicate their perspectives on complex topics with others, and (5) justify a choice (Renjilian et al., 2013). These explicit heuristics have an important role in decision-making and communication between parents and healthcare providers. By recognizing explicit heuristics, healthcare providers may understand parents' perspectives and values better as they guide parents through the decision-making process.

The heuristics used to understand treatment options and guide decisions as defined in the Renjilian et al. (2017) study are similar to the values and concerns of parents who participated in the study by October et al. (2014) by placing the child's needs for physical comfort and a good QoL ahead of other hospitalization-related needs. The problems and hope identified in this study echo the same concerns for QoL and physical health/comfort in studies by October et al. (2014) and Renjilian et al. (2017). All three studies found that parents felt it was important that healthcare providers encourage parents to talk to each other about these topics and identify their values to guide their decision-making (Hill et al., 2017; October et al. 2014; Renjilian et al., 2017).

The study by Renjilian et al. (2017) utilized independent review and coding of interview transcripts by two research team members to enhance the reliability of their findings. Additionally, the prospective cohort design helped to effectively minimize recall biases by conducting interviews while parents were actively making decisions for their children. Limitations for this study include its focus on English-speaking families who were already receiving care and consults in a single children's hospital, which potentially limits the range of explicit heuristics identified.

A major strength in the study by October et al. (2014) is the inclusion of minorities and the couples in the analysis which help to provide diverse perspectives. The exclusion of Spanish-speaking patients, who represented a significant population in the PICU, raises concerns about the generalizability of the findings. Additionally, the decision of three couples to be interviewed together could have influenced each participant's responses to be more agreeable and potentially impacts the data.

Decision-Making as Dyads

A longitudinal study of 67 families with children with developmental disabilities by Kersh et al. (2006) examined the contribution of the marital relationship to the well-being of both parents (mother and father) for children with developmental disabilities. Although this study does not include children who have been placed, it adds unique knowledge about the experiences and perceptions that dyads have when raising children who have disabilities. The participating families (N=67) were already participating in a community-based longitudinal study about adaptation of families with children who are disabled. Only data from biological parents that have been married at least one year were involved in this study on the contribution of the marital relationship to parental well-being. The characteristics of the participants were: mothers (n=67; mean age of 40.1 years old [SD = 4.6 years]) and fathers (n=67; mean age of 42.4 years old [SD = 5.6 years]); 94% of parents reported employment; and 95.5% of families were Euro-American. The children in placement consisted of 50.7% males (all 10 years old at the time of data collection), and 14.9% of children qualified for free lunch programs, which indicates likelihood of financial hardship (Kersh et al., 2006).

Within one month of the child's 10th birthday, two field staff members visited the participating families to collect demographic data and to assess the cognitive status of the child. Researchers also administered questionnaires to collect data regarding parents' depressive symptoms, parenting stress, parenting efficacy, strains, child functioning, child behavioral problems, social support helpfulness, and marital quality. Mothers and fathers completed the demographic questionnaires independently (Kersh et al., 2006). Statistical software was used to analyze the quantitative data to provide overall rankings of parents' priorities that were identified in the completed surveys.

The data analysis revealed that overall greater marital quality was a better predictor for decreased reports of parenting stress and depressive symptoms as compared to socioeconomic stress (Kersh et al., 2006). For mothers, higher marital quality significantly contributed to greater parenting efficacy, lower depressive symptomology, and lower parenting stress. This finding differed slightly for fathers. For example, higher levels of marital quality predicted lower levels of depressive symptomology and parenting stress for fathers, whereas greater social support predicted increased parenting efficacy (Kersh et al., 2006). Overall, the findings of this study support the importance of a strong positive marital relationship as critical components to parents' well-being for families with children who have disabilities.

This study has several limitations. First, the small sample size limits the statistical power and predictors that could be examined. A larger sample size would have allowed for more exploration of the effects of different behavior problems on parental well-being. Second, generalization is difficult due to the homogeneity and self-reported measures of the sample. This makes the results difficult to extend the findings to families from other ethnic backgrounds.

A mixed-methods prospective cohort study of parental dyads (n=84 individuals) of children (n=42) who were seriously ill was performed to describe the major hopes and problems that parents perceived for their child (Hill et al., 2017). This study also examined the patterns and degree of concordance between the parents, and how the concordance changed over time. This was the first study that systematically examined parental concordance over time (Hill et al., 2017). Parents that had the primary decision-making responsibility for their child (who was admitted to the PICU or Neonatal Intensive Care Unit [NICU], Cardiac Intensive Care Unit [CICU] at CHOP, or identified as requiring palliative care services or major medical decisions in the next 12-24 months), and spoke English were invited to participate in the study.

A majority of the selected parent dyads included a mother and a father, one dyad included two mothers, another included a mother and a maternal grandmother, and another had a mother and stepmother. The participant sample included mothers (n=42), fathers/others (n=42); ages ranged between 21-55 years old; 93% of mothers were married, 90% of fathers/others were married; 41% of mothers and fathers/other reported financial hardship. In relation to race, more than 80% of the participants were white, no African American mothers, with 12% of fathers/others African American, and 2% other fathers/other were Asian American (Hill et al., 2017).

Parents in the study reported demographic data; information regarding their child's complex chronic conditions were obtained from medical records. A baseline interview was performed, followed by another interview at 24 months. The interviewers asked the parents individually to answer two open-ended questions: "Please think of 3 major problems that bother your child," and "Please think of 3 major goals or hopes you have for your child" (Hill et al., 2017).

Data analysis was performed using an emergent codebook approach to code the parents' responses. To measure the concordance between parent-dyads regarding their responses of "problems" and "hopes," the researchers identified if both parents in the dyad endorsed the same domain and responses were calculated as percentages. At baseline, concordance was identified at a higher rate for "problems" related to the child's physical condition (69%) than "hopes" for a good QoL (61%). At the follow-up interview after 24 months, 32 parents participated in the study (those parents whose child died within 24 months could not participate in the follow-up interview). Parents reported different kinds of problems and hopes related to their child, but maintained similar rates of concordance for problems (68%) and hope (70%) in the areas of their child's physical health condition and QoL, respectively (Hill et al., 2017). The other most commonly reported domains included "future health (status)," "well-being", and "medical care," where only a few parents mentioned concerns related to having medical knowledge about their child's condition, suffering, or finding a cure (Hill et al., 2017). The data analysis overall suggests that parents were more likely to reach higher levels of concordance and consensus over time in those common domains (Hill et al., 2017).

The study by Hill et al. (2017) had an exclusive focus on dyads, however, the research primarily studied white children and parent dyads, which also limits the generalizability of the findings to more diverse populations. The findings from these studies offer crucial insights into parental decision-making during severe stages in child illnesses. However, it is important to also acknowledge that the limitations related to the lack of diversity among participants or the specific study location can restrict the generalizability of these findings.

Experiences of Parents Making Decisions about Placement

Government policies, professional opinion, and advancement of medical technology have greatly shaped the opinions of out-of-home placement (referred to as "placement" in this paper) for children with disabilities over the last 30 years (Llewellyn et al., 1999).The following section will review and discuss prominent studies related to experience and perspectives of placement for children and family members with special needs and disabilities.

Llewellyn et al. (1999) explored factors which influence families to decide to care for their children at home, or to place them at an out-of-home facility for continued care. Children with high support needs were those who require continuous and daily assistance, and whose support needs are significantly greater than children without disabilities and identified as severely disabled by the State of Developmental Disability Centres or other state service agencies in Australia. More than 200 families were referred to the study over a three-month period; 167 families of young children with disabilities and high support needs volunteered to participate. The families broadly represented the demographics of Australian families – 65% came from metropolis and urban areas, 35% from rural areas; 84.2% were two-parent families. The average age of mothers in the sample was 35.6 years, and fathers 37.7 years; approximately 60% of mothers described themselves as homemakers, 82.8% of fathers reported full-time employment (Llewellyn et al., 1999). The children in the selected families were between the ages of 15 months to 6 years old (with one child at 9 years of age, *M*= 5.4 years); 64% were male, 57% had multiple disabilities. Nearly all the children were living at home (96%), one lived in a foster home, and six lived in permanent residential care (Llewellyn et al., 1999).

The selected parent (identified as the primary caregiver) completed a modified Ecocultural Scale Short Form questionnaire (adapted for Australian conditions) to gather demographic data, as well as data about family, daily routines, financial resources, and children and family services. Upon completion of the questionnaire, parent caregivers were interviewed in their home using an open-ended, semi-structured interview across 10 domains of everyday family life, with two primary areas of interest: family accommodation activity in family life, and the family's views about caring for their child at home or seeking placement (Llewellyn et al., 1999). All interviews were recorded, transcribed verbatim, and coded by two coders.

The quantitative and qualitative data were analyzed and reduced to three groups: placement not wanted (75%), undecided about placement (19%), and placed or actively seeking placement (6%). Constant comparative analysis procedures were applied to the interview data regarding family responses to out of home placement to identify emerging themes until mutually exclusive thematic categories were identified. The themes were: values and beliefs about caring for their child, changes in the family circumstances, and messages received about placement (Llewellyn et al., 1999).

A majority of the sample did not want placement for their child. The factors which influenced families to seek placement were: (a) lack of congruence in everyday family life with regard to their child ("coherence"), (b) lack of integration with the child into everyday family life (integration and quality future"), and (c) concern about the effect of the child on? the siblings now and in the future ("sibling involvement and concern") (Llewellyn et al., 1999). The strongest influencing factor reported by families who were categorized as "undecided" were the predicted changes in the current family circumstances, such as cancellation of services, child behaviors, and disrupted marital relationships. To the researcher's surprise, a cumulative increased burden of care was not present in the families' explanations. Given that the children were very young at the time of the interview, their age and size may contribute to how families perceive the role challenges that lie ahead and how they imagine their child's future needs (Llewellyn et al., 1999).

A descriptive cross-sectional quantitative study by Baker and Blacher (2002) directly assessed postplacement adjustment of families to understand if they now viewed their decision for their child's placement as a better or worse alternative (Baker & Blacher, 2002). This study was included because although the residents at the facility were not children at the time of data collection, however, parents were asked to reflect back on their experience of placing their child in a facility. Family members of residents at three large centers in California, Arizona, and Florida were invited to participate in this study – 153 families indicated willingness to participate, 106 families returned their surveys with complete, usable data, and 106 adult primary caregivers were identified as participants for this study. Among the participants, 68.9% were mothers (*m* = 49.9 years of age, [SD = 11.1]), 22.6% were fathers (*m* = 52.4 years of age, [SD = 12.3]), 6.6% were siblings (age not listed), and 1.9% were grandparents (ages not listed). The residents (n = 106) had the following characteristics: mean age was 23.8 years old (SD = 12.7 years), and average years in placement was 2.4 years (SD = 1.9 years, range 1-10 years) (Baker & Blacher, 2002).

Participant demographics and family involvement characteristics of the child and family member were collected using a client data sheet. Staff members of the facility who were also familiar with the resident and had access to patient data logs also completed the client data sheet to validate the participants' reports. Family members also completed a survey (Family Involvement Survey) to collect data that supplemented their client data sheet related to their resident's placement and the family's involvement in their care (Baker & Blacher, 2002).

The well-being of the family was measured using the Family Well-Being Survey that addressed the respondents' health and marital adjustment. Subjective caregiver burden, resource availability, and family stress were measured along with an open-ended survey that asked family caregivers to list their ideas of advantages and disadvantages of their resident living out of the home, followed by a section with a six-point Likert Scale that required caregivers to rate the advantages and disadvantages of their resident's placement as it related to each family member in the home (Baker & Blacher, 2002).

Overall, caregivers demonstrated good post-placement adjustments, reported that they remained involved with their family member who has been placed, maintain good health, and positive marital adjustments (Baker & Blacher, 2002). Over 90% of participants concluded that placement of their child provided advantages in the areas of balance and a better living arrangement for all family members in the house. The researchers also noted that in families with children under 15 years old that are in placement, in contrast to families with an adult in placement, visited their patient more often, reported higher scores of stress and caregiver burden, and overall lower scores of marital adjustment and fewer advantages for placement (Baker & Blacher, 2002).

A qualitative retrospective study by Mirfin-Veitch, Bray, and Ross (2003) recounted family members' experiences and critical elements of decision-making related to seeking placement for their child with intellectual disabilities (ID) and special needs (Mirfin-Veitch et al., 2003). All families (or next of kin) at Templeton Centre (a former residential housing for people with disabilities) were invited to participate to complete a survey to collect basic demographic information about themselves and their family member at the facility. Researchers selected a maximum variation sampling method – 65 families wished to participate in the study, and 35 participants were selected for 36 patients (two patients were siblings). The patients' characteristics were described by the following: 23 males, 13 females; five were admitted between the ages of 0-4 years old, 16 were admitted between the ages of 5-9, six were admitted between ages 10-14, seven were admitted between 15-19 years old, and two were admitted after the age of 20. Among the study's participants, the participants included combinations of parents, parents and siblings, siblings only, mother and aunt, grandmother, and sibling and niece.

Unstructured interviews assisted by the "aide-memoire" method was used to discover participants' perceptions of their past decisions for seeking placement. The data were analyzed to develop codes and identify emerging themes. All parents involved in the study expressed the importance and desire of keeping their family together in the same home for as long as possible, but also expressed difficulties in caring for their child overtime, which eventually led to institution placement (Mirfin-Veitch et al., 2003).

A contributing factor that made coping difficult for parents was the increased demands of the growing child with ID. Parents reported difficulty and overall physical exhaustion in meeting the child's physical needs as the child grew bigger (Mirfin-Veitch et al., 2003). This finding is similar to parental responses from an earlier study Llewellyn et al. (1999). As coping difficulties increased, parents also recognized their inability to continue care for the other siblings (Mirfin-Veitch et al., 2003). Poor coping was also noted in the mothers' declining mental health and how it adversely altered the balance of caring for the child's special needs and family life (Mirfin-Veitch et al., 2003).

The study also identified mothers in the families as the bearers of responsibility for making the final decisions regarding the child's placement at an institution. Their final decision often included the responsibility of coping with the guilt of their choice and defending themselves against outside accusation that they "abandoned" their child, or are unable to fulfill their parental obligation to provide care (Mirfin-Veitch et al., 2003). In situations where fathers were parenting alone, they reported similar responsibilities and guilt as the mothers in the study. A (undisclosed) number of participants reported that fathers began to work longer hours as a way to cope with the tasks associated with caring for their child with disabilities – and that some fathers went as far as rejecting their child with a disability (Mirfin-Veitch et al., 2003). To assist parents with considering placement where cultural and social perspectives may find it unacceptable, parents recalled being given "permission" to think about placement by their healthcare provider who knew their child and the family. This implies that the statements from their healthcare provider served as a justification that allowed parents to be realistic with their needs for coping and caring for the whole family.

A study by Hostyn & Maes (2007) focused on 15 parents' perspectives on out-of-home placement for their young child with intellectual disorders or severe developmental delays (Hostyn & Maes, 2007). The families for this study were selected from The Flemish Fund for Social Integration for Persons with a Disability – a resource that provides services to families whose child have a disability and are placed out-of-home to meet their needs. The children were between the ages of 1-5 years old at the time of the study.

The researchers used a maximum variation sampling method to purposefully select a wide range of variety of children between the ages of 0-6 years old with disabilities in residential care in the Flemish region of Belgium. The children included six females, nine males; 10 had multiple disabilities with a combination of sensory, physical, and intellectual disabilities, and were living at their facility between three months to three years. The family members that participated consist of nine parents (all married, no indication if any participants in this group were couples), four divorced mothers, one single mother, and one newly composed family (Hostyn & Maes, 2007). Additional demographic information related to the participants were not included.

The researchers utilized a qualitative approach to explore parents' personal views, experiences, thought, and feelings about the placement of their child using a flexible interview question guide. The interviews were recorded, transcribed, and coded independently by two researchers according to a coding schedule. Data were analyzed for thematic content starting with a within-case analysis to develop a coding schedule with several categories. Lastly, a cross-code analysis was performed to uncover similarities and differences between data (Hostyn & Maes, 2007).

The data revealed factors and reasons associated with residential placement. One major result was that parents expressed difficulties in caring for a child with disabilities at home, and found it hard to find emotional support – though they received a lot of information from healthcare professionals, they reported have little space to share their emotions, and family and friends could not understand their experiences (Hostyn & Maes, 2007). Parents also expressed the difficulties of handling multiple tasks and roles for their personal life, their child with special needs, and the siblings. Participants also described how care for a child with disabilities had negatively affected their relationship with their partner or spouse, along with their inability to meet the needs of other family members with much of their efforts and time focused on the child with disabilities (Hostyn & Maes, 2007)

The results classified families' reasoning for placement into four prototype categories according to the parents' and child's needs: type 1 (highly dependent for needs, five families), type 2 (child has a developmental disorder and behavioral disorder, four families), type 3 (the child has varying levels of mental health and intellectual disorders, parents who also have mental health or intellectual problems, three families), and type 4 (child has auditory, physical, or communicative disorder, in combination with mild intellectual disability, three families) (Hostyn & Maes, 2007).

The researchers shared an interesting finding that families with children in placement were likely to visit their child more often and report being more involved in their care yet adjusted more poorly to post-placement. This can possibly be due to guilt or negative feelings of giving up, as seen and expressed in caregivers from the studies by Llewellyn et al. (1999) and Hostyn and Maes (2007). Possible guilt could stem from parents' or families' realization of advantages and improved relationships after placement of their child away from the family. The results also demonstrated that burden scores decreased with the increasing age of the child (into adulthood) within the sample, likely reflecting that acts of caregiving naturally decrease as non-disabled children age and spend greater lengths of times out of the home (Baker & Blacher, 2002).

The findings in the study by Hostyn & Maes (2007) were related to larger residential institutions, these findings cannot be generalized to smaller institutions or other living arrangements for families with members who are disabled and placed. The sample of volunteers are also mostly Euro-American with higher socioeconomic status who were more involved with placement and care. Their socioeconomic status may allow them to identify and utilize more resources than families from low socioeconomic backgrounds. Overall, it is difficult to gather volunteers and data from families who are less involved with their resident. The sample also predominantly reflects findings from parents, and researchers cannot say to what extent this experience would be like for other relatives who are also caregivers. Due to specific inclusion factors, participants' recollection bias and the number of years since placement can affect the validity of the statements shared in the interview.

The study by Llewellyn et al. (1999) is limited by the small number of families who participated. Additionally, the retrospective nature of the study may lead participants to provide new justifications for their decisions, potentially influencing the reported findings. This study also lacked diversity in the sample, which limits the generalizability of the findings to other families in similar situations.

Major limitations in the study by Baker & Blacher (2002) include the characteristics of the sample. The families who returned their surveys were more likely to be European American with higher socioeconomic status. Additionally, Baker & Blacher (2002) mentions the possibility of cognitive dissonance, where respondents may alter their beliefs or even emphasize benefits they have experiences to reduce the discomfort they may experience from their conflicting attitudes and actions.

Mirfin-Veitch et al.'s study (2003) also presented with the limitation of relying on retrospective accounts, which can influence the accuracy of the reported memory, and the potential for parents to justify their decision-making processes. Despite retrospective nature of the data, the researchers found that reports across the families were remarkably consistent, aligning with other studies that also explored factors influencing out-of-home placement.

Similarly, Hostyn & Maes (2007) utilized a retrospective design for their study, which can distort the accuracy of parents' memories. Additionally, the sample size was small, and the focus was on very young children, which makes it difficult to generalize these results to older children or adolescents. Hostyn & Maes (2007) also cite the study could have benefited from inclusion of questionnaires and perspectives from professional workers to enhance data triangulation to provide a more comprehensive understanding.

Discussion

A clinical report by the American Academy of Pediatrics (AAP) addresses the difficulties associated with discharging a child with complex medical healthcare needs and technological dependencies to home which includes those disabled children in a UWS/VS (Elias et al., 2012). The report also offers guidance for healthcare providers as they support families in the transition from the hospital to home, and how to ensure the child and family's needs will be met. The AAP presents the guidelines using a systematic approach that should be easy to follow for caregivers and parents of children with special needs (Elias et al., 2012). Accounts of parent caregiver experiences in multiple studies included in this literature review demonstrate the challenges associated with the parent caregiving role for children both in-home or at a facility. Despite the guidance offered by the AAP, the studies in this review suggest that gaps in care for parent caregivers persist and need much more attention from researchers and clinicians alike.

Multiple studies identified that parent caregivers reported stress, depression, lack of support, and isolation (Giovanetti et al., 2012; Kirk et al., 2015; Mirfin-Veitch et al., 2003; Roscigno & Swanson, 2011). A common suggestion and identified need from these studies indicated that more efforts should be used to develop effective family support services for families and young children who have disabilities.

Multiple studies have also identified that families strived to pursue convergence between the needs of all family members. Families in the studies that included an element of “placement” reported feeling of guilt and varying levels of dissonance when attempting to create a balance of care for all family members, but overall experienced improved QoL for themselves and the remainder of their family members after placement (Hostyn & Maes, 2007; Llewellyn et al., 1999; Mirfin-Veitch et al., 2003). Across the studies, the decision to “place” their family member with disabilities was a difficult decision, but placement did not remove all the negative emotions and experiences from parent caregivers. The study about post-placement adjustment by Hostyn and Maes (2007) identified that psychosocial and environmental factors should be considered when developing services, resources, and practical support for families before and after placement of a child with disabilities to maintain meaningful routines and positive relationships between members and to improve the overall family wellbeing.

Limited research has examined the burden experienced by parental caregivers. In one study, Baker & Blacher (2002) explored caregiver burden among their sample of parent caregivers. Meanwhile, a broader literature review identified multiple Italian studies that investigated the burden levels of caregivers for adults in a UWS/VS, but were not included in the present study due to not meeting the literature review criteria focus on the pediatric population (Bastianelli et al., 2016; Chiambretto et al., 2001; Cipolletta et al., 2014; Giovannetti et al., 2013;

Giovannetti et al., 2012; Leonardi, Giovannetti, et al., 2012). An interesting finding in relation to caregiver stress and burden was that caregivers commonly reported they maintained good health post-placement in Baker & Blacher's study (2002), whereas caregivers in many of the Italian studies reported poor health maintenance post-placement (Cipolletta et al., 2014; Leonardi, Giovannetti, et al., 2012). The type of population that the caregiver is caring for may account for these differences, where many of the Italian studies focus on caregivers with adult and pediatric patients in a UWS/VS, whereas the patients in Baker and Blacher's study (2002) were children with multiple disabilities, but not UWS/VS. This difference could be explained by the location of the patient – the studies conducted in Italy do not solely focus on caregivers whose patients are at home, or in a facility. The roles and responsibilities of caregivers in Italy may also be significantly different than those in the facilities chosen by Baker and Blacher (2002), in addition to cultural differences and expectations of the type and amount of work that family caregivers should provide. The caregivers in Italian studies are also on average older than those listed in US studies, so it is likely that participants rate their physical and mental abilities without considering their natural aging process.

While persistent grief is widely studied in Italian studies surrounding caregivers of adult patients with UWS/VS or DOCs (Bastianelli et al. 2016; Chaimbretto et al., 2001; Cipolletta et al., 2014; Giovannetti et al., 2012), only one study in this literature review described PG being apparent in their studied caregiver population (Roscigno & Swanson, 2011). This could be an area for future studies in parent caregivers, unless the families are so well-adjust~~ed~~ after placement that PGD (or similar concepts) are not a large issue. Another possible explanation for the lack of studies focusing PGD outside of Italy may be that the sensitivity of the UWS/VS topic (or illnesses similar to UWS/VS) is difficult to measure or distinguish from low-level depression. Cultural differences among caregivers and the role of caregiving may also influence how caregivers view their patients.

With an evolving healthcare system and drastic changes in medical technology that has nearly doubled the lifespan of a person with complex medical needs, it is necessary to understand how a parent-dyads maneuver through their decisions for their critically ill child, and how it has impacted their lives. It is possible that caregiving as a parent-dyad can influence the overall trajectory of their experiences in caring for their child's health status and care as the child resides in a SNF, where many of the studies included in this literature review focus on one single parent or caregiver to share their experiences. The study by Kersh et al. (2006) utilizes the Family Experiences Questionnaire to study parenting efficacy for decision-making. This area is not well-informed in research studies related to child illnesses and decision-making. The findings from Kersh et al. (2006) study indicate that better marital quality is more highly associated with decreased levels of stress and depression than SES. This implies that emotional and psychological support of caregivers and family members are key interventions to promote the overall well-being of families with a member that is disabled.

Decision-making conflict, depression, burden, and anxiety symptoms have been recognized in familial adult caregivers, but have not been widely studied in parents or guardians for the pediatric population in the United States, especially for the population in this proposed dissertation – disabled children in a UWS/VS. The proposed study about parent-dyads' experience through the trajectory of their disabled child's illness can cue healthcare into ways to be more supportive and prepared for parents who are required to make difficult decisions about life-threatening illnesses and caring for their child at a SNF afterward.

Limitations and Gaps in Literature

A common limitation identified in the literature was sample size. Due to the nature of qualitative methodologies, a sample size of 12 participants will suffice in most cases, but the results are not easily transferable to other caregiver populations. Samples in the selected studies must also fit a strict, yet limited and unique set of criteria to participate. This does not allow randomization, thereby increasing possibility for researcher biases in the findings and publications. Considering that the population of UWS/VS patients is only a small, unique, percentage of the U.S. population, it is understandable that studies have low numbers of recruited subjects. Many of the studies available for this review were qualitative which also limits the number of participants. Much of the data that were collected in qualitative and quantitative studies are also subject to recollection biases as participants attempt to rationalize their decisions and behaviors from the past – sometimes years ago. Additionally, governmental policies and cultural attitudes about placement of family members may have changed throughout the decades and could influence the experiences that were shared at that time of collection. Even with an extensive literature search, no intervention studies were found for this literature review. To build on current knowledge, it is suggested that researchers focus on conducting quantitative and intervention studies to understand and improve the overall role experiences of caregivers whose patient in diagnosed with UWS/VS, or a similar DOC.

Other biases that create limitations on these findings are that only caregivers who chose to volunteer and participate shared their experiences. It is possible that they had mostly positive experiences to share, whereas caregivers that chose not to share may harbor more negative feelings and experiences.

Publications related to caregivers and UWS/VS are very limited, with only six of the 11 studies conducted in the U.S. were related to caregiving for children who have intellectual disabilities or neurological compromise, and one study from Italy (Giovannetti et al., 2012) that specifically explored UWS/VS in children . While it is important to have an international perspective about this topic, differences in medical care, legal frameworks, social expectations of the caregiving role, and advancements in healthcare technology make these findings difficult to generalize to caregivers and UWS/VS patients in other parts of the world. Additionally, not all the selected studies included parental dyads who were acting as the caregiver for the patient. It is difficult to formulate a valid, specific hypothesis due to potential differences in relationship, treatment, and beliefs about patients in a UWS/VS.

Lastly, the selected publications in this literature review did not include UWS/VS populations that either only lived at home, or permanently resided at a SNF. This is likely due to difficulties in recruitment to participate in the study, which thereby affects the data and theoretical saturation claimed by researchers. To contribute to this gap in knowledge, this current study explored the experiences of parents and parent-dyads whose disabled children are diagnosed with UWS/VS or similar severe neurological compromise and permanently residing in a SNF.

Chapter Three

Theoretical Framework

This chapter will introduce the philosophical assumptions and theoretical framework that will guide data collection, interpretation, explanation, and the application of study findings. This will be a qualitative study that utilizes the narrative inquiry approach. The aim is to develop deeper understandings about the meanings that people create regarding their dynamic world and realities related to this particular phenomenon (Cypress, 2017; Hesse-Biber, 2017). A qualitative design is flexible and adapts a wide array of techniques from other qualitative methodologies to allow for normal and necessary variations in the research process to suit the needs of the research question as the study unfolds (Polit & Beck, 2017). The narrative inquiry methodology will guide data collection, and narrative analysis will be utilized to analyze themes and patterns that arise from the data. The outcome of the study will include a complex description and interpretation of the phenomenon from the participants' perspectives, as well as the reflexivity of the PI (Cypress, 2017).

Philosophical Assumptions and Theoretical Framework

The use of theoretical frameworks in a narrative inquiry study is different from quantitative studies in that the overall theoretical framework may adapt from multiple theories and philosophies to explain how ideas and beliefs are formed. Philosophical orientations that influence this narrative inquiry study include the constructivist paradigm, and pragmatism. The qualitative nature of this study also adapts some analytical methods and philosophical underpinnings from constructivist grounded theory (CGT) and symbolic interactionism (SI) to allow the PI to get an in-depth sense of the participant's whole narrative experience by reducing their stories into meaningful units, codes, and themes that capture and interpret human complexities which cannot be quantified for numerical data (Hesse-Biber, 2017).

Philosophical Assumptions

Constructivism Paradigm

A paradigm is a general perspective on the complexities of the world and human nature that describes the nature of reality, and the relationships between the inquirer and those populations that are being studied (Polit & Beck, 2017). The constructivist paradigm ("constructivism"), which was originally termed the "naturalistic inquiry," is rooted in the cultural transformation of postmodernism to deconstruct old ideas to put them together in new ways (Polit & Beck, 2017). Constructivism recognizes that reality is not fixed – instead it is fluid and can be interpreted differently in any individual's mind. The foundation of constructivism lays a heavy emphasis on how and why individuals (or research participants) create meanings as they experience specific situations within their own world (Charmaz, 2014; Gergen, 2009). This research paradigm and approach attempts to capture the dynamic and holistic aspects of human life or a phenomenon in its entirety through flexible data collection methods and analysis to gain further insights (Polit & Beck, 2017).

Social constructivism, another branch of the constructivist paradigm, identifies how individuals create meaning and sense of their realities according to outcomes of relationships (Gergen, 2009). The social constructivism approach acknowledges how the research participant's experiences are embedded in other larger networks, discourses, and relationships as each factor contributes to a participant's sense-making (Charmaz, 2014).

The analysis process of social constructivism requires the PI to become alert to how changes in structures and conditions within a participant's situation influence the way meanings are created within the individual's mind (Charmaz, 2014; Gergen, 2009). The result of the analysis are interpretations of how the participant views their world, but through the PI's descriptions and interpretations. The research question for this study emphasizes how parent-dyads of chronically, critically ill children in a UWS/VS describe changes in their child's living structures and conditions over time, and how those changes influence their realities and meanings they create within their relationships and roles.

Pragmatism

The pragmatic philosophical approach is appropriate for this research study because it acknowledges the existence and value of multiple forms of knowledge and interests (Cornish & Gillespie, 2009). Pragmatism provides a critical approach to data collection and analysis that focuses on the interests of specific populations, has a non-relativist foundation where knowledge is evaluated by its ability to facilitate successful actions, and has an action-oriented view where daily problems and actions are considered the primary reality (Cornish & Gillespie, 2009). Pragmatism does not confirm nor deny knowledge gained from narratives – instead, it offers solutions that may have worked for some people in the past or create new strategies and solutions that better reflect the needs of other people with similar findings (Cornish & Gillespie, 2009). The main emphasis of pragmatism is on the practical usefulness and consequences of ideas and actions (Nowell, 2015). Three major philosophers have contributed to the development of pragmatism: Charles Peirce, William James, and John Dewey (Nowell, 2015).

Charles Peirce (1878) is commonly known as one of the founders of pragmatism. Pierce used a problem-solving approach that includes scientific logic to understand and clarify the meaning of concepts as they potentially related to the real world (Rodgers, 2005; Nowell, 2015).

According to Peirce, pragmatism was used to analyze concepts and beliefs, their conditional statements, and the expected outcomes for each possible action (Rodgers, 2005; Nowell, 2015).

Peirce's original application of pragmatism will be apparent throughout participant narratives in this study. The research will utilize a semi-structured interview guide and probing questions to collect a rich narrative about the various options and consequences that the participants considered throughout the care processes of their child, and which factors motivated their actions.

Understanding the human experience through narrative inquiry is deeply rooted in John Dewey's (1938) application of pragmatism to William James' original philosophical method of pragmatism (Nowell, 2015). William James (1907) is often credited with being the founder of the "pragmatic method," which he defined as "a method of settling metaphysical disputes that otherwise might be interminable" to interpret actions and behaviors by tracing their practical consequences (Rodgers, 2005, p. 176). Application of James' pragmatism focuses on the practical consequences and beliefs of each possible choice in a situation. According to James, ideas and beliefs become true when the consequences help to satisfy the preceding parts of a person's experience. James argued that if there are no practical differences in the consequences, then all dispute is idle and the alternative would not make sense (Rodgers, 2005; Nowell, 2015).

James' development of pragmatism will be apparent in the way that participants of this study share their narratives of their actions and behaviors that were linked to practical and desirable consequences in relation to the care for their child in a skilled-nursing facility (SNF). Through data collection and analysis, the PI may learn that participants' actions and behaviors change over time as the participants become more acquainted and knowledgeable about how to manage the needs of their child, in addition to changes in the participants' personal needs.

John Dewey (1938) promoted pragmatic philosophy as a basis for practical problem-solving – where similar to William James, there was a focus on consequences and the possibilities of actions. However, unlike his predecessor in pragmatism, Dewey argued that pragmatic choices and ideas did not depend solely on antecedent phenomenon and instead, the ideas should be at the base of organizing future observations and experiences (Nowell, 2015).

John Dewey (1938) expanded on pragmatic philosophy in ways that helped to develop a narrative view of the human experience. Dewey identified two criteria of human experience in pragmatic philosophy from which contemporary researchers draw upon as the basis for narrative inquiry: 1) interaction, and 2) continuity (Clandinin & Connell, 1990). The first criterion of Dewey's pragmatic philosophy, "interaction," requires that people are understood individually, and in a social context as they are always in relations with other people. The second criterion, "continuity," assumes that current experiences grow from past experiential bases, which ultimately lead a person to create their experiential future (Clandinin & Connell, 1990).

Dewey's application of criteria in his pragmatic philosophy allows for a way to understand human experiences through stories of experience that made up people's individual and social lives (Clandinin & Connell, 1990). Participants in the study will have an opportunity to narrate their experiences as individuals, in the social context of their child's healthcare team, and how their actions and experiences motivated their future decisions and ideas (Clandinin & Connell, 1990).

Adopting a pragmatic approach in nursing promotes knowledge development from multiple viewpoints to gain a greater understanding of patient populations and their identified problems, while considering a variety of approaches for problem-solving to find workable solutions and actions (Cornish & Gillespie, 2009; Rodgers, 2005; Nowell, 2015). The basic principle of pragmatism is that human values, beliefs, and interactions precede and determine the application of actions and their successes. This philosophy encompasses the reality of the past and the possibilities of the future (Nowell, 2015).

Symbolic Interactionism

Symbolic interactionism (SI) is a sociological theory that was primarily developed by George Mead that is used to study and analyze human life and their actions (Blumer, 1969; Charmaz, 2014). SI rests its views of people and their and actions upon three premises outlined by his student Herbert Blumer (1969), and further explained by Charmaz (2014).

The first premise states that individuals place value and meaning on entities and elements which they engage in. These entities can include physical objects, personal beliefs, and social relationships. The theory of SI further states that behaviors are dictated according to the amount of value that people have placed on each entity (Blumer, 1969; Charmaz, 2014). The first premise of SI may be seen in how participants in this study list people or things as entities that were helpful and valuable to them while they provided care for their child in a SNF.

The second premise states that value and meanings of entities are derived from how social environments view these entities (Blumer, 1969; Charmaz, 2014). Persons can change how they value or make meaning of entities through social communication – therefore, entities may be viewed as having high values, or viewed as unimportant depending on social group interactions and individual values (Charmaz, 2014). In this study, participants may identify members of the healthcare team, family members, or other support systems as the primary social group interactions that have been influential in how they create and perceive the value of things, actions, or decision relative to their situations.

The third premise uses pragmatic philosophical foundations to explain the reasons behind actions and interactions. This premise states that people undergo an internal interpretive process with the values they have placed on entities to handle various daily-life situations (Blumer, 1969; Charmaz, 2014). Charmaz (2014) extends Blumer's third premise by claiming that a person's interpretive process becomes explicit when a person must engage and communicate intra-personally (i.e., within their own being) to negotiate values and meaning on social and interpersonal levels as a process to decide on an action in problematic situations. It is through this last premise from which Blumer defines people as "acting organisms" in their environment that manage meaning and interpretations within their personal and social situations. The person's interpretations influence her or his responses in a way that is sensible to that individual -- usually as a mechanism for survival. For this study, participants are the "acting organisms" who will narrate how their intrapersonal and social interactions impacted their internal interpretive processes to choose an action that was the most sensible for them.

SI is a useful theoretical perspective that allows the PI to analyze data and develop hunches of how decision-making and caregiving influence caregivers' experiences. For this dissertation, the PI will use the premises from SI as a lens to understand meanings within participant responses to develop codes and themes through the methods of narrative inquiry and narrative analysis.

Theoretical Framework: Narrative Inquiry

Narrative inquiry arose in research as a response to the decline of the positivist paradigm for social sciences to describe and understand human experiences. A narrative study explores how humans construct and reconstruct their personal and social experiences of the world (Connelly & Clandinin, 1990). Narrative inquiry is considered both a phenomenon and a method

– where the “narrative” is the experience to be studied, and the “inquiry” is the pattern and methodological response the PI will use to study the narrative (Connelly & Clandinin, 1990).

Narrative inquiry (NI) has a fundamental structure in the human experience with a holistic quality that originated in studying quality of life and education (Connelly & Clandinin, 1990). With its intellectual roots in the humanities, this methodology is applicable to a variety of social science fields to tell personal, meaningful stories (Connelly & Clandinin, 1990; Clandinin, 2006).

Narratives are not meant to be written or presented as a “cause and effect” story, but rather as an explanation of the experience extracted from the overall narrative. When written and analyzed properly, the PI will have an overall sense of the whole experience (Polkinghorne, 1988). There are four elements of NI: construction of a story, temporality, sociality, and place (Connelly & Clandinin, 2006; Green, 2013).

Construction: The construction of the “narrative” is a process of creating a story that includes a plot, theme, and resolution through collaboration of mutual storytelling between the participant and researcher to allow the participant to feel cared for with an important voice. NI is how the PI understands the participant’s experience as their story emerges from rebuilding and retelling the experiences that have taken place over time, through a series of places, and through various social interactions (Connelly & Clandinin, 2006; Green, 2013).

Temporality: Connelly and Clandinin (2006) identified dimensions of an inquiry as the temporality, sociality, and places of the story as reference points to help direct the PI’s attention (Connelly & Clandinin, 2006; Green, 2013). Temporality is concerned with the past, present, and future events. Through storytelling, the participant is constantly in transition across these time fields (Connelly & Clandinin, 2006; Green, 2013). As participants share their experience, it is important to note that what they view as truth in the present time of the storytelling, may not have been perceived as true at the time of the experience, which means that the meaning of the experience may have transformed for the participant over time (Green, 2013).

Sociality and Place: “Sociality” and “place” are often explored simultaneously. Social conditions highlight environmental factors, forces, people, and relationships that help to shape the participant context as they build a relationship with the PI (Connelly & Clandinin, 2006; Green, 2013). “Place” refers to the physical place where the inquiry and events of the story occur. It is important for the PI to understand the impact of the participant’s situation (i.e., context and relationships) and the geographic and personal space (i.e., place) in the participant’s story and during the time of inquiry (Connelly & Clandinin, 2006; Green, 2013).

Narrative inquiry will be used as a collaborative method between the PI and the parent who will convey their experiences of having a child that has been diagnosed with UWS/VS and living in a SNF. The assumption in narrative inquiry is that people who have lives specific to the phenomena can provide powerful insights to further offer new perspectives about how their experiences sustain and influence social and health dynamics for this population (Green, 2013). The elements and process of narrative inquiry will be discussed in chapter 4.

Narrative Analysis

Narrative analysis is a method where the PI may subjectively interpret the content of text data (often in the form of stories or descriptions of participants’ experiences) to analyze the themes and patterns that emerge. Using narrative analysis, researchers systematically code textual data from a participant’s narrative content, arrange similar codes into more abstract categories that are sorted into meaningful themes that represent participants’ experiences and perspectives (Polit & Beck, 2017). This study will apply inductive coding, systematic sorting, and holistic analysis to describe the experiences of parent-dyads caring for a chronically, critically ill child in a UWS/VS that resides in a SNF and to identify meaningful concepts that regularly appear in the data without pre-existing frameworks (Polit & Beck, 2017). The aim of the analytic process is to describe and interpret the meanings that underpin the phenomenon within the participant's social context (Polit & Beck, 2017). The final product will be the meaningful patterns from the data in the format of themes.

Chapter Summary

This chapter discussed how the theoretical framework of NI will guide data collection to elicit ”thick” descriptions from participants about their caregiving experiences within their specific culture and context. Narrative inquiry will also guide data analysis with the philosophical paradigms of social constructivism, pragmatism, and symbolic interactionism to systematically code narrations into small, meaningful elements that are sorted and reconstructed into meaningful and more abstract themes. The following chapter will describe the methodology that will be used to conduct this study.

Chapter 4
Methodology

This is a qualitative narrative inquiry study that used a narrative analysis approach to collect, analyze, and understand the experiences of parents and couples whose biological child resides in a skilled nursing facility (SNF) with a diagnosis of being in an unresponsive wakeful state/vegetative state (UWS/VS). The study results were influenced by the constructivist, pragmatic, and symbolic interactionism perspectives. The qualitative study method is appropriate because the goal of this research was to explain a person's experiences in this given phenomenon. This approach aimed to understand subjective meanings that people give to their multiple social worlds, and how they understand their realities (Hesse-Biber, 2017). The qualitative study is a dynamic process that allows the primary investigator (PI) to move back and forth in the steps of research for exploratory and descriptive research questions while utilizing an inductive, systematic approach to analyze data. In this chapter, the research methodology and design for this study will be discussed.

Research Approach

Narrative inquiry (NI) is a research methodology based on the premise that humans experience the world and give meaning to their lives through the construction and reconstruction of their personal and social storytelling (Connelly & Clandinin, 2006; Green, 2013). This methodology is historically popular for its use in educational research, where the "narrative" from the storyteller is the structured quality of the experiences to be studied and largely focuses on the human experience (Connelly & Clandinin, 1990). With its holistic quality, this methodology is also appropriate for other social science fields including health care (Connelly & Clandinin, 1990). When applied to nursing research, NI helps to highlight the intricate experiences of very specific phenomena, along with the interconnected paradigms that categorize and identify people as they express and articulate the meaning of the phenomenon in their lives (Green, 2013). Through the use of an NI approach, parents that fit this description are expected to share very unique experiences that involve the complexities of parenting a chronically ill and technologically dependent child living in a SNF.

Sample

This study used a narrative inquiry approach to interview parent couples/dyads whose biological child (under the age of 18 years old) is diagnosed with UWS/VS (or similar severity of neurological devastation – terminology described in chapter 1) and residing at a SNF. At least one parent must be biological because this study is targeted at understanding the unique relationship and experiences of parents to their chronically ill child in this particular phenomenon, rather than studying the experience of a professional caregiver or non-biological caregiver. The other partner of the dyad can either be a biological parent, or a person that is in a committed adult partnership with the biological parent stated above. Each couple will be referred to as a “dyad.”

Purposeful sampling

Narrative inquiry is concerned with creating an in-depth understanding of the participant’s experiences in their given social situation and achieving transferability (as opposed to generalizability), so small samples are generally acceptable (Hesse-Biber, 2017). Purposive sampling methods allowed the PI to be more closely involved in the selection process to ensure that participants fit the inclusion criteria to best inform the research question. Due to the sensitive nature of the research question and limited selection of SNF affiliations and informants for this population, the PI also applied convenience sampling and snowball sampling within the participants’ personal networks to recruit participants for the study. These networks included other families whose disabled child resides within the same SNF, people that participants reach out to for support who also have a child in a SNF, or internet-based support groups that pertain to this population.

Sample Size

The PI aimed to collect at least 14-20 people (7-10 dyads) for the study, or until a point of saturation is met, where no new information appears by sampling again from the population (Hesse-Biber, 2017). The final sample size resulted in 10 individual participants, and 4 dyads. To ensure the most accurate results and increase transferability for the target population, the selected sample must be representative of the research question and the population by meeting the eligibility criteria. Upon analysis and dissemination of the data, the PI has identified and acknowledged limitations of the sample and transferability to the overall target population (Hesse-Biber, 2017).

Eligibility Criteria

Eligibility criteria for individual participants and dyads include the following: a) the participant must be a biological parent of a child who has been diagnosed with UWS/VS (or similar severity of neurological devastation – terminology described in Chapter 1) and residing at a SNF for at least one year; parents and supportive partners who interviewed as a dyad was defined as a ‘committed adult partnership’ with at least one person in the partnership being the biological parent of a child being discussed in this study; b) participants must consider themselves to speak English fluently enough for conversation; c) participants must have an active and reliable phone number or email address for communication with the PI; d) must own (or have access to) a mobile electronic device, computer, or laptop with video call capability and adequate and reliable internet connection to participate in video call interviews. Their child has been diagnosed with UWS/VS or in a similar neurologically devastated state and resided in the SNF for at least one year to ensure that parents have fuller ideas and richer experiences of how this situation impacts their daily lives. Participants must speak English so that the PI can conduct the study without the need of a medical translator or language interpreter. The participants' feelings and thoughts can be communicated and understood more readily, without the influence of a third party to translate their responses. Lastly, participants owned, or had access to, an electronic device with video call capabilities because the PI will conduct interviews via video chat.

Exclusion criteria were applied to those parents who do not fit the descriptions listed above, and parents who are prohibited from visiting their child or require monitored visits with a member from the Department of Child and Family Services (DCFS) due to a history of abuse or neglect. Parents who fit the exclusion criteria were not included to avoid illegal actions influencing their experiences and interview responses.

Setting

Approval to conduct this study and for all materials involved in this study has been obtained from the Institutional Review Board (IRB) of the University of California Los Angeles (UCLA). Following IRB approval from UCLA, the PI called and emailed the administrative staff and directors of nursing (DON) at the SNFs to contact their IRB for permission to contact or approach prospective participants from their facilities for this study (see appendix A for invitational letter). The PI for this study has academic affiliations as a clinical instructor for nursing students at two Associate Degree Nursing programs with three pediatric SNFs in Southern California: Whittier, Sun Valley, and Foothill. The PI is not a direct care provider at any of the facilities. To broaden the sample pool, the PI also contacted a member of an online support group and blog for permission to recruit participants from their privately shared group by sharing the flyer in an online post or on their announcement page. A sample of this flyer is located in appendix B.

Recruitment Procedures

Upon approval from the SNF administrative staff, DON, and IRB from UCLA and the SNF, the PI began recruitment by inquiring with the nursing and medical administration and management at all 12 SNFs in California for permission to recruit participants from their SNFs. The PI was able to establish initial communication with administrators from five SNFs, follow-up communication ceased when four contacts discontinued their communication for unknown reasons, and one SNF nurse manage declined participation over the phone, stating the patient population at that particular SNF were ineligible. The PI did not receive a response to the PI's attempts for contact.

To continue the recruitment process, the PI contacted a participant on their publicly shared online blog. After their interview, this participant volunteered to share information about the study by posting the IRB-approved flyer on a private Facebook support group.

Prospective participants were directed to email the PI using the information on the flyer: 172 people responded, 97 people were screened for eligibility, 29 met the final eligibility criteria and were contacted to schedule an interview. Common reasons for ineligibility included: the child did not have a diagnosis of UWS/VS or a neurological illness, the child is receiving care at home, the parent was restricted from visiting their child in the SNF, or the SNF was located in another state other than California. If the prospective participant did not meet eligibility criteria, the PI explained the reason for ineligibility to join the study and thanked them for their interest.

This resulted in 20 participants who were invited for an interview, with the final sample at 18 participants (10 individual interviews, 4 coupled interviews – 2 individual interviews were not included in the analysis after the PI determined they did not meet the eligibility criteria during the interview). Upon consulting with the co-chairs of this study following the 16th interview, the PI received guidance to conclude data collection due to the large sample size involved for this dissertation study and the limited time available for a comprehensive data analysis.

Eligible participants received a study brochure in paper or electronic format to be informed of the study purpose and procedures, risks and benefits of participation, and the voluntary nature of the study. Eligible participants were presented with the option to participate in a joint interview, or separate interviews. The purpose of providing these options was to make the process more convenient for the dyads, respect their preferences, and to maximize participation. Some dyads might have preferred to be interviewed separately for various reasons: one (or both) members of the dyad may feel they would have to censor themselves significantly if they were interviewed together, members may feel uncomfortable sharing highly sensitive information about their experiences to their partner, or it is simply inconvenient and difficult for both members of the dyad to be present for a joint interview (Braybrook et al., 2017). A diagram that describes the recruitment process is located in appendix D.

Out of the 20 eligible participants, four people invited their support person, 13 people claimed to have a support person but they were interviewed individually (their reasons were unknown), and 1 person claimed to have a support person who died five years ago. There were two participants who interviewed individually, and upon interviewing, the PI determined that they were ineligible because it did not appear that their child had a UWS/VS diagnosis or severe neurological impairment. The final sample size for this study was 18 participants (10 individual participants, 4 dyads).

Interview Arrangements

The PI arranged an interview time that was convenient for the participants based on their interview-style selections (joint or separate). Upon date and time confirmation, the PI sent a "confirmation" message to the participant via text or email, and a "reminder" message 24 hours before their scheduled interview (see appendix E for confirmation and reminder messages).

The link for the video call was provided to each participant in their reminder message. Communication with the participant regarding questions or logistics related to the interview procedure occurred via email, phone calls or text messages using the PI's encrypted web-based phone number that is separate from the PI's personal phone number. Interviews were conducted by an encrypted video call to adhere to safety protocols for social-distancing set forth by the Center of Disease Control (CDC) during the COVID-19 pandemic. The video call took place at any location the participant chose to be in during the call – however, the PI strongly suggested that the participant selected a time frame and private location where they could speak freely about their experiences with very few distractions and participant's privacy can be protected. The PI conducted interview calls from her private office to have all necessary resources available, and to avoid distractions.

Video calls were audio-taped using two methods: the "record" function from the encrypted web-based phone service, and a second audio-recording device placed in the PI's office. Two methods were utilized in case either electronic device experiences a malfunction during the interviews. All interviews occurred over a single session that took place over approximately 1-2 hours. All interviews were audio-recorded and stored in the PI's password-protected online cloud.

During each interview, the PI remained "on camera" for the entire duration of the session. All participants were invited to also be "on camera" during the interview. Only five participants chose to turn their camera "on" during the interview, one participant stated he was at his workplace and did not want to turn his camera "on," the remaining participants declined to turn "on" their cameras for unknown reasons.

Payment

The PI offered each participant a $25 Visa e-gift card honorarium upon completion of the interview as an incentive to generate interest and payment for their time. This form of monetary incentive is versatile and can be applied at most local and online merchants that accept Visa as a form of payment. All payments were sent to the contact email address provided by the participant. At the conclusion of each interview, the participant was asked to check their provided email address to confirm they have received their $25 e-gift card.

Human Protection

Human subjects' approval was obtained from the University of California, Los Angeles Institutional Review Board prior to all recruitment procedures and data collection. The topic for this research study could present some ethical and moral challenges to the PI and participants. To protect the participants, two mechanisms were established and implemented through the duration of the study: 1) each parent or family received a brochure that contains pertinent information about the study, and must have provided verbal consent prior to participation – all prospective participants were given sufficient time to understand the consent form and have an opportunity to ask questions about the study and 3) all participants had the right to refuse participation or withdraw from the study at any time without penalty.

The topic of UWS/VS is often sensitive and complex. Participants that were interviewed may have experienced phases of sadness, anxiety, emotional discomfort, hurt, or anger when speaking about their care for a child in a UWS/VS. To minimize these risks, participants were not overly encouraged to share details of their experiences if they choose not to and had the right to "skip" a question or dismiss themselves from the study at any time. The PI was also able to provide resources for emotional support and situational distress so that participants may contact the resources to receive support immediately (see appendix F). The PI also had access to these resources in their personal office in the event that a participant demonstrated or verbalized immediate distress.

Consent

This study presented no more than minimal risk of harm to participants and involved no procedures for which written consent is normally required outside of the research context ("Request IRB Waivers," 2019). Each participant was emailed a copy of the Study Information Form with time to consider whether they wanted to volunteer for the study (see appendix K). For those who agreed to participate in the study, verbal consent to be interviewed was obtained immediately before the interview. The PI read the verbal consent form from a script (see appendix G). Each participant was be given ample time to ask questions through the consenting process. Verbal consent from the participant granted the PI permission to record, transcribe, and analyze their interview data. The participant's verbal response "yes" indicated that the participant has received information about the study and was consenting to participate with the option to withdraw at any time. The PI was unable to obtain consent and assent from the participant's child due to their minority age and poor cognitive status.

Confidentiality

To maintain confidentiality, the PI assigned a unique alias to each participant as their alternative identity. All identifying information of other person's names or places that were transcribed from the interview also received pseudonyms to protect the participants' identities and associations. The list of alternative identities is kept in a file on a password-protected laptop in the PI's office. All audio recordings from participants' interviews were stored on the PI's personal online storage cloud and downloaded onto a personal, password-protected laptop in the PI's personal office. Visual data from the video calls were not recorded to enhance participant confidentiality. Only the PI and her dissertation committee and BSN-transcription team (description below under "data preparation") had access to the audio recordings and transcripts. Upon completion of the study, all identifying information will be destroyed.

If the participant revealed that he/she or the patient is being harmed or neglected, the PI had the contact phone number for counseling or support and could have encouraged them to report this to legal authorities for their safety. Dr. Lee and Dr. Pavlish (chairpersons) were also available for advice on appropriate action to take regarding the participants' situations if this arose.

Ethical Conduct of Study

All participants were verbally consented to participation in the study prior to the start of the interview. Participants had adequate time to ask questions about participation in the study and may select an interview-style (joint or separate) that suits them best. Participation was strictly voluntary, and participants were able to withdraw from the study at any time without penalty.

Voluntary participation of this study posed no physical risk or pain; however, some participants may have experienced sadness, embarrassment, anxiety, or emotional distress due to the sensitive nature of this topic. In these events the PI could provide the participant with referrals for support and counseling.

Any information that was collected in connection with this study was obtained and stored confidentially. This includes questionnaires, audio-recorded interviews and their transcriptions, and all contact between the participant and the PI. Each interview was transcribed within one week of completion and any identifiable information such as people, medical facilities, cities, and schools were replaced with pseudonyms. All confidential study data is stored on a password-protected laptop in the PI' personal office and will only be accessible to the PI.

Data Collection

The PI conducted individual in-depth interviews using a semi-structured interview guide (SSIG) to collect exploratory and descriptive data about participant experiences. In-depth interviews are useful in qualitative studies because it encourages individuals to share their unique knowledge and experiences in their world that can be shared through verbal communication (Hesse-Biber, 2017). The SSIG provides a consistent yet flexible structure throughout the interview process. Using this approach, the PI was able to ask the participant preset open-ended questions that solicit a narrative related to the research topic, while allowing the participant freedom to talk about what is important to them in relation to the main research topic (Butina, 2015); Hesse-Biber, 2017). The open-ended nature of the questions allows the participants to respond more comprehensively, while the semi-structured interview guide keeps the interview focused on the initial research question. The PI asked more probing questions to encourage participants to clarify meaning and provide rich descriptions of their experiences (Butina, 2015).

Each interview concluded with allowing the participants to discuss other experiences related to the topic that were not described earlier in their interview (Hesse-Biber, 2017). The SSIG can be located in appendix H.

Socio-demographic Data Collection

The socio-demographic data pertinent to this study was collected through a short questionnaire that took less than five minutes to complete (see appendix I). At the completion of each interview, the PI completed the demographic survey verbally to collect participant data that included: current age, gender, relationship to their partner, ethnicity, current living location, location of their child's SNF, number of years their child has lived at the SNF, highest level of education, employment status, marital status, and family situation.

Data Preparation

Each interview recording was downloaded and transcribed by an online professional transcription service that handles personal data securely. The professional transcription service did not transcribe participants' responses accurately if the participant spoke English with a non-U.S. accent. To improve accuracy of the transcribed data, the PI obtained approval from the IRB to share an opportunity for UCLA-BSN Undergraduate students to gain experience in research by transcribing audio data. Twelve students volunteered to transcribe audio data and completed the required CITI Training for HIPAA and Human Subjects prior to gaining access to the audio data and transcripts to protect the privacy of the participants. Upon receiving proof of their CITI Training certificates and IRB approval, each student received one transcript (automated from the transcription service with personal names already replaced by an alias), and the corresponding audio file. All the files were shared in private folders in the HIPAA-compliant file storage system: UCLA BOX. Once the student uploaded their transcription of the audio, they were asked to delete all files related to this study from their personal computers. To ensure accuracy, the PI listened to the audio and read along with the transcript. Additional corrections to the transcript were made during this time.

All the participants of the study were contacted via email to inform them that the research team has expanded to include additional selected and trained people that will have access to their data. Each participant received an updated copy of the IRB approved Research Study Brochure (see appendix K0. Participants were asked to contact the PI if they wanted to withdraw their consent to continue participation in the study. After three days, the PI did not receive any emails from the participants.

The corresponding analysis for this NI research is a narrative thematic approach to deeply study the content and meaning of the participants' experiences within the context of their unique and complex phenomena (Butina, 2015; Riessman, 2005). Interview transcriptions were formatted line-by-line and numerically to aid the PI to organize the datasets. The PI manually searched each transcript to replace any actual or potentially identifying information with alternative names to protect the privacy of the participant and their child. The header and footer of each transcript was noted with the participant's unique alias. These identifying names and aliases are kept on the Primary Investigator's (PI) password-protected computer.

Data from NI comes in the form of interview transcripts, field notes of the shared interview experience, and observations. Through the data collection and analytical processes, the PI developed deeper understandings of patterns that are set in recurring descriptions across all participants while also focusing on the concrete particularities of each participant's life experiences in relation to the phenomenon (Connelly & Clandinin, 1990).

Narrative Data Analysis

Narrative Analysis (NA) is a contemporary approach that is grounded in interpretive constructionist epistemology. The goal of NA is to address questions of meaning and experience in a specific context (Josselson & Hammack, 2021). NA is appropriate for exploring personal narratives that focus on how meaning is constructed from internal processes as well as external (interpersonal and situational) experiences (Josselson & Hammack, 2021; Riessman, 2005). As noted in Chapter 3, there are four elements of NI that impact the participants' oral narrative: construction of a story, temporality, sociality, and place (Connelly & Clandinin, 2006; Green, 2013). By understanding these elements, the PI views participant narratives as refractions and recollections of their past, rather than direct mirrors of their past (Riessman, 2005).

The four major approaches to NA are (1) narrative thematic analysis which primarily focuses on the narrated content within the text, (2) structural analysis, where the analytic focus is on the way a story is told or put together by the narrator, (3) dialogic/performative analysis that focuses on the dialogic processes between the narrator and the listener, and (4) visual narrative analysis which encompasses words and images alongside written text during data analysis (Butina, 2015). This research study used narrative thematic analysis to focus and analyze the content of the participants' transcribed narrations (Butina, 2015). The narratives were organized by theme, with vignettes of the narratives to provide an illustration of the personal experience (Riessman, 2005)

Narrative Thematic Analysis

The narrative thematic analysis approach requires the PI to find common thematic elements across the participants and the experiences that they report (Riessman, 2005). This method allows the PI to reduce textual data from the transcripts into codes and categories that identify recurring themes and patterns through subjective interpretation of the data.

Throughout the data collection and transcription process, the PI interpreted what each participant said by focusing on the meaning of their narrative to inductively create codes, themes, and conceptual categories as a condensed representation of the data (Riessman, 2005). Findings from analysis of early interviews helped to inform subsequent data collection and analysis. Through simultaneous data collection and analytical processes, the PI developed deeper understandings of patterns that are set in recurring descriptions across all participants while also focusing on the concrete particularities of each participant's life experiences in relation to the phenomenon (Connelly & Clandinin, 1990).

Narrative thematic analysis is a circular process that requires careful reading; line-by-line coding; code comparing, clustering, and sorting into categories (which may include sub-categories); re-reading; and developing conceptual categories into more abstract themes to truly develop a deeper understanding about the participants' contextual realities (Pavlish & Ceronsky, 2009). A "code" is a brief word label or phrase that captures the essence of a meaningful unit of data. Initially, the PI performed inductive line-by-line coding to identify topics or action words that represent the meaning of participants' descriptions. The PI coded each transcript in its entirety to identify the most relevant sections of how participants' thought patterns and assumptions may be influenced by the patterns of meanings that commonly occur in their responses (Hesse-Biber, 2017). The coding process was not aided with the use of computer data management software to assist in organizing and sorting initial codes because it was not feasible to obtain the software for the co-chairs to also complete independent coding. Instead, initial codes were sorted manually by the PI and the co-chairs. The development of categories derived from code clusters allowed the PI to set boundaries on the areas to be more narrowly explored (Hesse-Biber, 2017). To gather patterns in participant responses, the PI used a constant comparative analytical process to identify correlations and trends in the data within each individual transcript, and among participants' transcripts. Additionally, the PI's field notes helped the PI identify potential hunches on what is occurring in the data (Polit & Beck, 2017). Each step is described further.

Initial Coding Procedure

Data analysis began by reading the data and listening to the corresponding audio recordings of each interview repeatedly to obtain a general sense of the whole (Butina, 2015). Then, each transcript was read word by word from beginning to end to highlight passages or words that appear to capture key thoughts and phrases upon the first impression (Hsieh & Shannon, 2005; Saldaña, 2016). After coding for the first impression, the PI made notes of initial thoughts, emerging insights, or hunches related to the data in the margins of the transcript (Butina, 2015)

As the number of codes quickly accumulate in this process, a codebook was created manually. The codebook contains a compilation of codes, content description, segments of interview transcriptions, and the corresponding page numbers (Saldaña, 2016).

Focused Coding

The data required several processes of coding and recoding to make the codes and categories/sub-categories more refined (Lincoln & Guba, 1985). Using the initial set of codes that were identified in the first cycle, the PI synthesized the data to create a new, more accurate set of focused codes based on those that are most frequently occurring and significant. The focused codes help the PI to identify and organize similarly coded data that share common characteristics and “make the most analytic sense” into categories and, if indicated, sub-categories (Charmaz, 2014; Saldaña, 2016).

Diagramming

As codes were sorted into categories (and potentially sub-categories), it was helpful to create a diagram or map of the codes. The PI utilized timelines and a tree diagram to organize focused codes, categories, and sub-categories into a hierarchical structure (Lincoln & Guba, 1985). A visual depiction of these data elements and their relationships contributed to the development of more abstract themes. Diagramming was dynamic as the PI interacted with the data throughout the analytic process.

Axial Coding

As analysis progresses, the PI used axial coding to further synthesize and organize earlier codes and categories, describe relationships between codes, and identify central categories and emerging themes (Allen, 2017; Saldaña, 2016). This process of integrating categories revealed new categories or emerging subcategories (Allen, 2017). The themes that were revealed through axial coding came to light through the constant comparative method that required the PI to explore and re-read data to ensure that the categories and subcategories truly reflect the participants’ voices and any relationships across the data (Allen, 2017). To report the findings from the data analysis, the PI has provided exemplars from the data to represent the categories and themes (Saldaña, 2016).

Field Notes, Reflexive Memoing

Field notes were written down about each interview where the PI has entered notes that reflect the events that took place during the interview, specific observations about participants and the environment, and how their physical space and presence may have impacted the interview (if their camera was turned “on” during the interview) (Hesse-Biber, 2017). Due to social-distancing suggestions by the CDC, interviews were conducted via video calls from the PI’s personal office. The PI’s consistent environment was unlikely a large influence on the data collection process. The PI has adapted a template from the UCLA SON qualitative research courses (see appendix J) to take field notes before and after each interview to allow the PI to recall specific details about individual encounters.

As a technique to ensure trustworthiness of the data and enrich the analysis process, reflexive memoing was an important aspect that helped the PI to identify personal biases, assumptions, and ethical standpoint while collecting data from a vulnerable population. (Hesse-Biber, 2017). After each interview, the PI recorded any initial thoughts and reactions about the responses. Reflexive memos also help to construct a map of the PI’s impressions, thoughts, considerations, and explorations while immersed in the data that can be revisited throughout the axial coding process (Allen, 2017). As more participants are interviewed, the PI became more aware of trends in the data. Revisiting previous memos help to heighten the PI’s theoretical sensitivity and sense-making (Allen, 2017). In reflexive memos, the PI also identified areas where personal biases can compromise the analysis (Hesse-Biber, 2017).

Socio-demographic Data Analysis Plan

Data that were collected from the socio-demographic questionnaires was entered into a Microsoft Word Excel spreadsheet. Descriptive statistics were calculated to describe the characteristics of participants in this study.

Ensuring a Rigorous Study

Currently, there are no specific strategies designated to ensure a valid study for NI and NA, however, researchers may select strategies that are commonly used in other qualitative methodologies (Butina, 2015). For this study, several interventions were implemented throughout the study to enhance trustworthiness and maintain rigor. To ensure rigor, the qualitative, NI methodology directed the design, data collection, and analysis of the study. This required the PI to adhere to the method's design when selecting samples and performing data collection and analysis (Cypress, 2017a). Lincoln and Guba (1985) have identified five important criteria required for trustworthy qualitative studies: credibility, transferability, dependability, confirmability, and validity.

Credibility

Credibility is an accurate depiction of the participants' experiences (Cypress, 2017b). To establish credibility, the PI must have prolonged engagement in the selected environment with persistent observations (Lincoln & Guba, 1985). To establish credibility, the PI for this study is a registered nurse (RN) with 10 years of bedside experience in a PICU with experience in caring for children who have experienced severe illness or traumatic injuries and are discharged to subacute facilities due to their complex medical needs for 24-hour observation and care. Additionally, the PI has nine years of bedside teaching-experience at three pediatric subacute facilities and has interacted with the staff, patients, and parents on a weekly basis during the nursing school clinical rotations.

Additional strategies to establish credibility through prolonged engagement included listening to the audiotapes of each interview at least twice to obtain a sense of each interview before viewing the verbatim transcripts for coding. The PI also listened to the audiotapes for a third time to check for transcription errors.

The PI also used collaborative groups for interdisciplinary review and feedback to ensure that the PI is performing the study and analysis honestly to reduce biases and clarify interpretations of the data (Lincoln & Guba, 1985). The PI has met with her dissertation committee, which includes four experienced-researcher faculty members from the UCLA School of Nursing: two are experienced researchers in methodology, the other two are knowledgeable in the area of inquiry. Codes that are identified in the data were discussed and refined with their guidance. Decisions that are made in the data analysis was checked by the co-chairs of the dissertation, and areas of conflict will be resolved with the guidance of the co-chairs.

Transferability

Through individual, in-depth interviews, the PI has collected a thick description of the participants' experiences as they relate to the research question. Verbatim quotes from the participants are presented in the findings. Transferability of the study is further enhanced by purposive sampling methods during the data collection process (Cypress, 2017b). A diverse amount of perspectives are possible with an adequate sample size of study participants that resemble the eligibility criteria (Hsieh & Shannon, 2005). The PI has also provided a comprehensive description of the setting(s), so readers can assess similarity to their own setting. This explanation enhances transferability of the findings to new settings. The emerging codes and themes would be applicable and transferable to other people who are also parents or family-caregivers to a person in a UWS/VS.

Dependability

To establish dependability, members of the committee will have the opportunity to perform external audits or appoint another outside individual with experience and credentials in research to this task as a method to "challenge the process and findings" of the study (Lincoln & Guba, 1985). At least two qualitative experts on the dissertation committee, Dr. Lee and Dr.

Pavlish, have also assisted to validate the findings by reviewing the transcriptions and endorsing the themes that emerged from several cycles of coding (Cypress, 2017b).

Confirmability

Confirmability has been established through additional inquiry audits in the preliminary stages of research. The audit trail has been developed through the collection of raw data, reflexive journaling with introspective documentation in a personal reflexive journal, and multiple coding and analysis trails (Lincoln & Guba, 1985). The purpose of these audits is to provide proof of data collection and the PI's attempts to minimize errors and bias through the data collection and analysis phases. Through the duration of the study, the data has gone through various cycles of analyst triangulation with the chairperson(s) to ensure that the research methods and data are robust and well-developed (Lincoln & Guba, 1985). During reflexive journaling, the PI has made note of hunches, thoughts, intuition, and insights during data analysis. The process of reflexivity encourages the investigator to consciously examine her own response to the data and become part of a reflexive dialogue of through the study's research process (Hsieh & Shannon, 2005).

Validity

The PI's findings must be received as a credible explanation of the phenomena to be studied to gain the confidence of readers (Hesse-Biber, 2017). Common threats to validity in qualitative studies come from researcher and measurement biases. The PI's biases were identified and acknowledged in reflexive journaling to avoid their influences on the data analysis. The PI was made aware of the ways in which she is similar or different to the research population in relation to culture, ethnicity, gender, class, age, and ability – these characteristics are sources for researcher biases (Burck, 2005). Application of rigorous sampling methods to participant selection was also used to enhance validity of measurement by ensuring the participants are best fit and most eligible to inform the research question to capture an in-depth understanding of the participants' social realities (Hesse-Biber, 2017).

Chapter Summary

This chapter described how NI methodology guided this research study, followed by narrative analysis to extract rich descriptions of parent-dyad experiences of caring for child who lives at a SNF with UWS/VS. NI helped highlight the unique experiences of the human experience of people in this population through their storytelling. This study has given participants a platform to articulate their experiences that are considered relationally or emotionally sensitive and to share problematic aspects of their unique situations. Clinicians and other healthcare providers may learn that the focus of support, treatment, and care may reside heavier with one partner. Through narrative analysis, the storytelling of parent-dyads whose disabled children are diagnosed with UWS/VS and living at a SNF revealed meaningful themes that illuminated these parents' unique experiences. This information may encourage healthcare providers and systems to enhance their care and support approaches, as well as anticipate and fulfill needs for these families more effectively.

Chapter Five
Results

This chapter presents the findings of a narrative inquiry study that explored the experiences of 18 parents whose disabled children with severe neurological disabilities resulting in an Unresponsive Wakefulness Syndrome/Vegetative State (UWS/VS) or similar neurological disability reside in a skilled nursing facility (SNF). Whatever the cause of a child's neurological injury, the prevention of secondary health complications and further health status deterioration depends upon total care and medical technological devices (including nasogastric or gastrostomy tubes with feeding pumps and respiratory support through oxygen delivery tanks and ventilators) (Kirk et al., 2015; Roscigno & Swanson, 2011). Notably, sixteen participants were not able to provide a clear name or diagnosis for their child's medical condition, and instead, described their child's medical condition and needs and what they could remember from their conversations with their doctor. At least four parents voluntarily and spontaneously shared pictures of their child (the parent or family hugging and smiling with their child, or the child alone in their wheelchair or bed in the SNF) at the beginning of the interview as a way to help describe the child's current health condition and technology-dependence at the SNF.

Participant Characteristics

Ten participants were interviewed individually, and eight participants were interviewed as couples. All participants who met the inclusion criteria were biological parents of a disabled child who resided in a SNF for at least one year (Table 1). Seventeen participants (94%) reported the child's other biological parent to also be their "supportive partner" through the care of their child. One participant, Toni, a single parent, described that her "supportive partner" was her father who died five years ago; she did not identify a current "supportive partner." Among the participants, eight were female, and ten were male. This is significant because it counters the prevailing trend in the literature, which often tends to have predominantly female participants. Thirteen participants (72%) were married, while four (22%) were single and co-parenting, and one participant (6%) reported being single and parenting alone. The participants' ethnicities were reported as follows: 10 identified as Black (55%), three as Latinx (17%), three as White (17%), and two as Caribbean (11%). Numerous participants had a distinct non-English accent while speaking. The participants' ages ranged from 26-50 (mean age = 35.8 years). All participants reported having a college education and being employed; four worked part-time (Alice, David, Lisa, and Mitchell) and the remaining participants worked full-time. Over half of the participants (56%) reported this being their only child.

Table 1: Demographic Characteristics of Parents (Self-Reported) (n=18)

Name (Alias)	Gender	Ethnicity	Marital Status	Age	Number of Other Children	Ages of Other Children
Individual Interviews (n=10)						
Amy	Female	Latinx	Married	32	0	
Brandon	Male	Black	Married	31	0	
David	Male	White	Single	39	0	
Dean	Male	Black	Married	50	2	5,18
Lucy	Female	Latinx	Single	27	0	
Matt	Male	White	Married	37	3	5, 9, 13
Mauricio	Male	Black	Married	36	1	5
Mitchell	Male	Black	Married	47	1	11
Toni	Female	White	Single	41	0	
Zara	Female	Black	Married	28	0	
Couples Interviews (n=8)						
Alice and SJ	Female/Male	Caribbean/ Caribbean	Married	26/35	0	
Essie and BJ	Female/Male	Black/Black	Married	27/36	2	3, 10
Lisa and Michael	Female/Male	Black/Latinx	Single	30/35	0	
Maggie and James	Female/Male	Black/Black	Married	35/39	1	8

Characteristics of Participants' Disabled Children Residing in a SNF

Table 2 provides demographic characteristics of the participants' disabled children (n=14) that reside in a SNF, along with the diagnosis and medical condition as reported by the parent. All children reside in a SNF in Southern California. The children's current ages ranged from 2-16 years old (mean age = 7.4 years old), and the number of years spent residing in the SNF range from 1.5 years to 5 years (mean= 2.5 years). The most common medical conditions reported were neuromuscular (29%) and brain infection (29%).

Table 2: Description of Children Residing in a SNF (n=14)

Parent Name (Alias)	**Child's Age**	**Years in SNF**	**Transition Time to SNF**	**Medical Condition***	**Description of Medical Needs**
Amy	6	1.5	few weeks	Progressive neuromuscular illness	Nonverbal, feeding tube
Brandon	2	1	immediately after hospitalization	Neuromuscular illness	Ventilator and feeding tube
David	9	3	few months	"brain sickness," unknown degenerative neuromuscular disease	Ventilator and feeding tube
Dean	16	2	5 weeks (prolonged hospitalization)	"sudden brain infection"	previously ventilator dependent, currently feeding tube dependent
Lucy	8	4	2 years (previously cared for at home)	Severe cognitive and physical disabilities, chronic epilepsy	Nonverbal, feeding tube dependent
Matt	2	2	Immediately after hospitalization	Cognitive and developmental disabilities due to fetal alcohol exposure	Ventilator and feeding tube
Mauricio	7	1 year 9 months	2 months	Sudden "infection in his brain"	Ventilator and feeding tube

Parent Name (Alias)	**Child's Age**	**Years in SNF**	**Transition Time to SNF**	**Medical Condition***	**Description of Medical Needs**
Mitchell	9	4	2 months in hospital, then immediately after	Arteriovenous Malformation	Ventilator and feeding tube
Toni	7	5	2 weeks	Traumatic Injury - near drown	Ventilator and feeding tube
Zara	7	3	4 years	Severe brain infection, became progressively ill	Ventilator and feeding tube
Alice and SJ	10	2	2 months	diagnosed at 3 years old with brain and muscle wasting disorder	Feeding tube
Essie and BJ	6	3	2 months from hospitalization	"brain disabilities…loss of brain functions"	Feeding tube
Lisa and Michael	9	1 year 8 months	5 days	diagnosed with intellectual disability at 5 years old, then "infection in his brain" at 7 years old	Feeding tube
Maggie and James	5	1.5	2-3 months	Unknown diagnosis, previous diagnoses included: epilepsy, brain cancer	Ventilator and feeding tube

*Medical condition reported by parent(s); medical diagnosis not substantiated via medical records

Description of Study Themes

Data analysis for this study focused on identifying themes that were shaped by the narratives through the in-depth interviews (Table 3). Participant narratives revealed the varying journeys and experiences they continue to live through, starting from the moment they learned about their child's medical condition. The analysis resulted in four primary themes with 2-3 sub-themes describing each theme.

- The first theme to emerge from the narratives was how participants found themselves "Enduring the Unexpected" upon learning about their child's severe health condition. Their experiences were further described by three subthemes including: a) Feeling Lost, b) Questioning "Why?", and (c) "Grappling With Reality" as they faced the state of their child's condition.
- Secondly, the next theme to emerge described how participants continued on "Navigating the Unknown," where they described their emotional struggles of (a) Holding On and eventually, and (b) Moving On despite the uncertainties that surround their child's prognosis.
- Thirdly, the theme "Prioritizing Values for Decision-Making" emerged as participants faced the difficult task of eventually placing their child at a SNF. Their narratives were further illustrated by their moral commitments of (a) Preventing (Further) Harm, and (b) Promoting the Well-Being of their child while, and (c) Living With Their Decision.
- Lastly, the fourth theme "Changing Relationships" emerged as participants experienced a sense of (a) Distancing, and (b) Connecting and Reconnecting with social networks during their complex and unique journeys.

The themes presented organically developed from the participants' narratives to form a coherent and interconnected storyline that depicted a very subtle chronology of events and experiences. The participants' narratives commenced with the shock of learning about their child's condition, which turned their worlds upside down, followed by their grappling to understand the significance and meaning of these events in their lives as the shock began to subside. Subsequently, the participants began a new journey of adjusting to a new reality and seeking assistance and support to navigate their unexpected circumstances, all the while encountering shifts in their interpersonal connections. Table 3 (below) illustrates the specific aims that guided our research, along with the corresponding themes and subthemes that emerged from the findings.

Table 3. Specific Aims, Themes and Sub-themes

Specific Aims (SA)	**Themes**	**Sub-themes**
1: In exploring SA 1, we learned that participants described enduring the unexpected realities of their child's illness of chronic critical illness and SNF placement as "feeling lost" and questioning "why is this happening [to me]?" These experiences significantly impacted their emotional and psychological well-being.	Enduring the Unexpected	• Feeling Lost • Questioning why • Grappling with reality
1 & 2: The emerging theme "Navigating the Unknown" described how participants adapted to their own well-being and their child's health needs after the shock of their child's health status had subsided. Participants shared their coping mechanisms and adjustments they made in their lives during the first year and beyond.	Navigating the Unknown	• Holding On • Moving On
3: Participants highlighted the significant role of their personal values in guiding their decision-making for placement at a SNF. Among these values, "preventing further harm" and "promoting the child's well-being" emerged as the most frequently mentioned influences.	Prioritizing Values for Decision-Making	• Preventing Further Harm • Promoting the Child's Well-Being • Living With the Decision
1 & 4: In exploring SA 4, we gained insight into the changing relationships experiences by participants with their child in the SNF, as well as their interactions within their social networks. Participants frequently described different forms of distance that emerged within their social circles, along with the ways they connected and reconnected through their shared experiences of having a child in a SNF.	Changing Relationships	• Distancing • Connecting and Reconnecting

Theme 1: Enduring the Unexpected

The first theme describes the initial impacts that parents endured upon learning about their child's condition. Throughout the study, participants displayed "endurance" as they navigated the extraordinary psychological challenges that came with this revelation (Morse & Penrod, 1999). A major underpinning theme to the participants' narratives is that their child's illness or injury was unexpected, and their worlds were shaken by the onset of the illness. Their child's condition and consequential life-altering decisions parents faced reshaped the course of their lives in ways they could not have anticipated. The narratives also revealed that participants experienced profound shifts in their own sense of self through feelings of being lost in the initial shock, disbelief, and attempts to come to terms with their new realities. Throughout the interviews, participants shared stories of existential questioning and grappling with realities of their unknown future which highlighted the transformative nature of their experiences as they worked to understand and redefine their sense of identity**.**

1.1 Feeling Lost

"There's a lot of fog around that time of just shock, trauma, and just that acute 'Oh my God!'"

Toni (quoted above) described her initial thoughts and emotions when learning about the severity of her child's brain injury from a near-drowning incident. Her two-year-old child, Eric, was under the care of his father and grandfather when he walked out the back gate unsupervised, fell into the pool and was found unconscious moments later. The child was revived multiple times in the ambulance and in the emergency department, and has been comatose requiring feeding and ventilatory support for the last five years. The abrupt and unexpected nature of these events resulted in profound transformation in her life, leading Toni to label her life as two distinct phases: "before" and "after" her son's traumatic accident. Toni explained:

> I don’t know, my life completely changed. It was like literally, I call it “the before and after.” I mean, everything, everything changed. I had a medical practice that I closed literally when Eric was in the PICU. I called a colleague and was like, “Here's my charts.” We're waiting on labs for this patient. Just take it. I can't. Can't do it…So my career stopped and everything changed, and I also didn't have the tools really to deal with it. I didn't know how, so I struggled on that level. I also had everything going on with his father and a lot of mental and emotional abuse from him to me and my family. And that added a whole level of trauma. It was like he didn't have much remorse, or he had so much that he couldn't deal with it and turned it on me. I mean, he tried to blame me on being late. I was running like 15 minutes late to pick up Eric. So he was like, “well you were running late.” OK. “So that forced you to leave him alone?” And he actually tried to do that…I mean, I don't even know how to describe it. I don't wish it upon my worst enemy.

The transformation that Toni underwent from her “before” to “after” life, along with the difficult decisions and emotional struggles, represents a significant moment that forever changed the course of Toni’s life, leaving her with a profound sense of feeling lost.

Another mother, Alice, whose child was diagnosed with an unknown brain and muscle-wasting disorder at the age of three years old, described feeling such a tremendous shock that she felt at a loss for words to fully describe her experience at that moment in time:

> That was when they diagnosed him and it was a very tough stage, tough period for the family, and what we were going through was…like [there are] no exact words to experience how we felt at that point, or the doctor.

Alice’s husband SJ noted that the physician had warned both parents during their pregnancy that the ultrasound test results were concerning and that their child would begin to develop neuromuscular weakness when 3 or 4 years old. However, when the neuromuscular weakness worsened, and the child needed life sustaining treatment like an enteral feeding tube, it was still a shock for both parents.

Participants often expressed that the initial shock of their child’s condition rendered them speechless, apprehensive, sad, and uncertain of what the immediate future held for them. James and Maggie were interviewed together; James described his feelings when learning about his daughter’s medical condition:

> It's not something any parent wants to go through, it’s very painful and to sum it all up...This is something that has really, really affected me negatively, and it's something that has made me have difficulties in concentrating with my normal daily life. Why? Because that's my first fruit; she is the first child I ever had. Having this mindset that my child has a medical condition, that she's unable to be her normal self. This is…[an] unexpected painful experience with negative effects that disrupt daily thoughts. This new reality comparing before and after illness has affected I and my partner and I'm just always trying to be the man. My partner is really, really down and I’m also down. I always want to be the shoulder that she leans on.

Maggie concurred with James and acknowledged:

> Most times, I feel really scared. I think, ‘what if she's not able to make it out?’ I mean, ‘what if she's not able to survive this?’ She's going through a lot at her age, and I feel like she's too small for that and that makes me feel very sad most of the time. We kind of learned about a diagnosis, and until today, I haven't really been able to get what exactly is

> wrong. First of all, the doctor told me that she had epilepsy…and then I was told that she was diagnosed with cancer. So I really don't know what exactly is wrong. I am very scared. I mean, I just want the doctors to make sure that they're able to save my daughter.

The abrupt nature of these life-altering events left the parents engulfed in a fog of shock and disbelief. For some parents, this experience marked a clear division between their lives "before" and "after" their child's diagnosis. The emotional impact was so immense that many parents found themselves unable to articulate the depth of their feelings at that critical moment. One parent (Toni) even remarked that she would never wish such a painful experience on her worst enemy, highlighting the immense anguish she endured at that time.

1.2 Questioning "Why?"

"And sometimes I ask God: Is this really kind of your fate for me?"

In the quote above and throughout the interview, Mauricio questioned God about the unexpected nature of the events leading to the chronic condition created difficult feelings of uncertainty and profound existential questioning of his own sense of being. Participants often reported calling out to a higher being to seek an explanation or causative factors for their situations. James whose five-year-old child has been in a SNF for 1 ½ years with an unknown diagnosis stated: "At first, I asked myself the question: 'Why should this be happening to my daughter?... Is that…just how she was meant to be? Zara whose seven-year-old child suffers from complications of a brain infection asked: "How can my first kid be like this, was this some kind of punishment or something? I felt really bad." During the participants' existential questioning process, certain participants embraced the notion that their child's condition was a part of fate and destiny in their lives. Lucy, whose eight-year-old son has been residing in a SNF for four years due to severe physical and cognitive disabilities, alongside chronic epilepsy, shared her contemplation about of her child’s existence with such challenging health circumstances:

> I had so many thoughts on my mind. I won’t lie about this but, at one point I thought about leaving him in the hospital…or putting him up for adoption or something else…[Then] I felt like it wasn’t his fault for whatever he’s enduring at the moment, it’s not his fault…So I…I decided to accept it as fate.

These statements reflected the deep contemplation and search for their life’s meaning that the participants endure in the face of uncertainty and limited answers from their trusted medical professionals.

1.3 Grappling with Reality

"And I came to hospital to the emergency room…and honestly, it didn’t look good at all. I thought we were going to lose him…No parent would actually want something like that for their child…I was heartbroken, but…all we worried about is if there is actually a solution, if there was a way out…how he’s gonna get better.”

Mitchell (quoted above), whose nine-year-old son suffered from complications of an arteriovenous malformation at the age of five, has been residing in a SNF for the past four years. Mitchell recalled his initial thoughts as the doctor discussed their child’s condition with him and his wife. Many other narratives capture the immense emotional toll and devastating loss experienced by parents as they grappled with the intense shifts of their new realities. Toni, whose son experienced a near-drowning event vividly described the crushed realization she had when her envisioned future of parenting a family completely changed. Toni stated:

> And I just right then and there, [a strong force within] was just gone. Something just died in me, and it's still gone…Hope didn’t die…who I was ‘before’ died, you know? And it

> was like the dream, too…like the dream of having a healthy child, having grandchildren, raising a son…Like I don't, I don't, I won't ever have that experience…

Multiple participants echoed these sentiments and described their lives as grappling with loss, grief, and mourning for the future they once imagined. Brandon, a married father whose son was placed in a SNF at the age of one, described the anguish he experienced when confronted with the nursery and baby-care items he and his wife had arranged, followed by the painful reality that his son resides in a SNF: "I always…fancy [of] having a boy…we prepared the room for the baby…I never expected he was going to spend his early childhood in special care…So sometimes I come back [to his room]…it breaks my heart." Zara expressed her evolving feelings towards her child whose illness progressed over a course of four years. She acknowledged that at first, the disability was overwhelming, but over time as she struggled through her challenging emotions, she came to love and accept her child unconditionally: "Growing to know the kid, and seeing that my kid just…have this major disability. I could love him, but at first, I was devastated." For Matt, grappling with reality seemed to mean coming to terms with his wife's alcohol consumption during pregnancy, and the negative effects on their child from this decision. Matt talked openly about the pain of watching his son experience the consequence of his and his wife's "mistakes." He stated:

> I don't feel happy because I'm always thinking about why it happened to me? Why is it my child [is] like this? From mistakes my wife and I made while she was pregnant with the child? The doctor said that [alcohol] is what caused the condition, that is what affected the baby according to the doctor. And I knew she [wife] used to take it excessively…I thought she had stopped. I didn't know she was still doing it…and that was really affecting the baby and we did everything we could after the baby was born. It

> happened [and] we get through. As a man you need to look at the next available solution to solve the problem. I just need to understand the fact that it has happened, and there is a solution…In Africa, where I come from, we value the male child a lot and it is not so easy to lose a child so that is why I felt so devasted at the time.

Mauricio expressed the overwhelming despair and psychological distress his wife experienced by briefly describing how his wife contemplated suicide from the immense grief about the potential reality of living a life without their child when he shared: “my wife nearly wanted to kill herself like…living the life without the kid she was like ‘God, why?’ And…not getting to see our son…that was a first fruit…and just being taken out due to some disease condition, [this] was going to be our fate.”

Participants candidly shared the emotional and psychological toll caused by this unexpected and life-altering event. Their narratives revealed a transformative journey marked by a sense of being lost, grappling to navigate the uncertainty of the future, and a profound shift in their sense of self.

Theme 2: Navigating the Unknown

Throughout the narratives, participants described the nature of a very complex journey characterized by continually navigating the unknown and uncertainties of their child’s illness while also acclimating to unfamiliarity of deciding what is best for their child and their family. The narratives highlight a mix of emotions conveyed by the participants, as well as the strategies they employ to manage the uncertainty of each day by holding onto optimism and hope. Participant narratives demonstrate how they cling to the potential for a positive outcome for their child, while simultaneously engaging in adaptability to allow their lives to move on while navigating the challenges of their child’s condition and best course of action.

2.1 Holding On

"…and if she is destined to make it, I believe she will. I strongly believe she will pull through."

James' narrative was one expression of optimism, unwavering faith, and enduring hope that participants also hold on to as they navigate the challenges of their child's situation. Fueled by this narrative, they hold onto the belief that recovery from the chronic illness is possible and hope that their child will eventually come home. Toni decided to relocate to a new apartment located conveniently near the SNF where her son was placed. Despite the circumstances, she held on to the hope that her son would eventually come back home as she was reluctant to make immediate changes to her son's room following his placement at the SNF:

> So I moved to an apartment that was like literally half a mile from him. I never unpacked. I lived around boxes like I couldn't settle. I couldn't be like, 'This is my new life.'…it took me a while to like, unpack it. I literally moved his crib. Still, with the same sheets on it made the same way I had his clothes. Still, it was ready for him to come back [home]. So every time I would go home and sleep in the one bedroom apartment…there was his crib with his animals lined up waiting for him to come home. So, I was waiting, but it was hard.

Alice, Lucy, and Zara, along with others, described similar sentiments of holding onto hope in the initial moments after placement as they continued their usual home routines and were drawn to go back into their child's room to "check on", only to be painfully reminded that their child has was no longer home. Zara, whose son has resided in a SNF for three years, describes the emotional challenges she faces when returning home from work, finding herself subconsciously walking back into her son's room, longing for his presence:

> …it has been difficult because coming home to a house, coming back from work or wherever, and staying in a house that normally a kid is around, and now there is no kid around. We come back everyday and [it] feels kind of lonely…Like sometimes I go to his room thinking that I was supposed to look at him or check on him or ask questions…So I would find myself still going back to his room.

Despite the difficult circumstances, the narratives illustrate the parents' deep commitment to holding on to the possibility of their child's recovery and eagerly anticipate the day when their child would come back home. For many parents, the act of holding on takes on a poignant expression as parents continue their daily routines and maintain their child's bedroom as a hopeful reminder of their eventual return.

2.2 Moving On

"...I just have to do it. You know, there's some things we do with no choice, I had no choice [but] to adjust to the situation."

Matt, whose two-year-old son spent an extended amount of time in the neonatal intensive care unit (NICU) due to alleged maternal alcohol consumption described how he, along with many other participants, were navigating the unknown and unfamiliar by adopting a perspective of acceptance toward their current reality. By choosing to adjust to their situations, this allowed them to move forward. Participants acknowledged that their options for their child's care were limited by their level of medical knowledge and skills, time, and resources.

To progress in their lives, participants recognized that the most useful course of action for them was to accept and adjust to the necessity of their child's medical needs that were best met with placement at a SNF. These adjustments involved reorganizing their personal time for visitation at the SNF, family finances, and seeking out useful social support networks that provide valuable assistance and methods for coping through the challenges. Michael described the mindset that he embraced to come to terms with his family's reality when he stated: "I just have to understand that it's a part of life….So I need to adapt to move on [to] this new one because it's life, [it] still moves on." Mitchell also described the adjustments he and his wife have made over the years to ensure the proper healthcare for their son when he shared:

> At a point we [have been]…wanting to buying a house, but we had to hold that up just to be able to focus on the bills and everything, so we made a lot of sacrifice just to make sure everything works out the way it should be.

BJ and his wife Essie both have full-time job commitments, as well as two other children in their home, ages three and 10. When reflecting on the resources he and his wife were going to use to move forward after the initial shock began to wear off from learning about their child's condition, BJ shared the resources and solution that felt helpful for them when he stated: "Because I'm a full-time worker, [I] don't really have much time at home, and I don't have the medical knowledge, and also…I have some health insurance which would really naturally provide."

Throughout their narratives, participants shared how they navigated the unfamiliar territory of their child's health status as they simultaneously held onto the potential for a positive outcome, while adapting to the changes to allow their lives to move forward.

Theme 3: Prioritizing Values in Decision-Making

The third theme that emerged from participant narratives was the difficult decision-making process of where and how to best meet the needs of their chronically ill child. Participants shared the emotional toll the decision-making process has extracted, especially as they weighed their desire of keeping the child at home and provide care on their own (or with the assistance of a home-health nurse), versus the realities of their child's complex healthcare needs and resources required to adequately meet those needs. During each interview, participants expressed ambivalence toward making this difficult decision, and highlighted two key factors that were at the foundation of their choices: to prevent further harm (to self or others), and to promote the child's well-being.

3.1 Preventing Further Harm: *"And I'm actually no good when it comes to the medical field. So if anything [harmful] happens at home, I won't be able to take care of that."*

Maggie (quoted above) and other participants often acknowledged their level of knowledge and skill in the medical field, and how it led them to rely on the recommendation of doctors and other medical professionals to make the difficult decision of placement. They acknowledged that the care provided in their homes could not match the level of care available at a SNF. Participants also frequently expressed a trust in their medical professionals' expertise and believed that their recommendations were also aligned with their own values and desires of the child's safety, consistent medical care, and prevention of further harm or deterioration. BJ expressed his fear of his son accidentally hurting himself if he was not under constant supervision and care in their home: "…he [might] think of something funny within himself, and get himself hurt or harm before someone get home to…maybe any rescue…so we thought of these…to see reasons that …[in] the nursing home…he will always have these [supervisions]." Mitchell similarly described his-decision-making process to prevent further harm to his son's condition by placing his trust in medical professionals when he stated:

> Well personally, I would say…we know less about the treatment…we don't make decisions [about treatment] because we know less about what needs to be done. And I guess that's more reason why we move him there because they know more, and we don't.

The parents' awareness of their limitations in the medical field and their recognition of the expertise of the healthcare professionals led them to prioritize the safety and well-being of their children. By choosing a SNF for their child's care, they believed that that constant supervision and specialized medical attention would help to prevent further harm to their child.

3.2 Promoting Child Well-Being:

"…I have to check the environment and know the kind of place my child is coming to…the medical services provided there…programs the child can enroll in to make the child active…engage into different things"

Lucy, along with several other participants, described particular attributes of the SNF that were significant to them. The narratives show how participants prioritized their child's well-being over their personal wishes to keep their child at home by ensuring that the SNF was able to meet their child's medical needs as well as developmental needs. Participants expressed the importance of schooling and interaction throughout the day with other children "like them" who share similar medical conditions to promote their child's psychosocial development. Zara described how she believed a SNF would best promote her child's well-being when she stated:

> I do believe that at a nursing facility, he will receive all the care he needs, and to also meet all the children who have disabilities like him…he'll get to interact…with other kids…him staying just at home…it told me that this isn't right. Yeah, I love my kid, but this [staying home] is not right.

Amy, whose six-year-old daughter has resided at a SNF for 1 ½ years due to a progressive neuromuscular illness, shared how her daughter faced constant bullying from the neighbor's kids when she was living at home, likely due to her physical and developmental differences, which worsened over time. She expressed her belief that the SNF provided a safer environment for her daughter "because [she's] seeing other people with the same condition [as hers]," which offered much-needed support and understanding for both Amy and her daughter.

3.3 Living with the Decision

"Before, it was so draining to me leaving my child in the nursing facility…and then after some time, I was like…'okay, I think I see now, I kinda prefer it."

Amy conveyed her current feelings and thoughts regarding the placement decision she made for her six-year-old daughter, who has been living with a progressive neuromuscular disease since the age of four. Amy's daughter is nonverbal, reliant on a feeding tube, and requires total assistance for daily care in a SNF for the past 1 ½ years. Following the participants' decision to place their child in a SNF, the majority of participants expressed an unexpected sense of satisfaction and internal validation for this decision which stemmed from witnessing small improvements in their child's health. One participant, Mauricio, described the positive physical changes he saw in his son after placement as "magic." Another participant, Zara, expressed relief even through her loneliness in knowing that her child's needs are being met and that he is in safe hands at the SNF. Dean's 16-year-old daughter has been living in a SNF for the past two years after a sudden brain infection that rendered her dependent on a ventilator and feeding tube. Dean stated that he gained comfort and happiness from this decision for placement because he is able to witness more improvement in his daughter's health condition as he stated:

> …seeing the difference on the health, knowing that there was a lot of improvement. I feel more comfortable and I felt more happy, and I feel [she] had a purpose of going there. Every moment you are going there, you are seeing more improvement…She as opening

> her eyes more, she was able to eat more through her stomach. [And] had better breathing than before.

While the decision for placement in a SNF brought about apprehension and ambivalence regarding their child's safety, care, and future, participants found solace in seeing their child's needs are being met. Essie went to the extent of describing the SNF as "not [like] the traditional [nursing home]…it's actually comfortable there." Other participants shared similar expressions of acceptance and joy in their difficult situations by stating "above all I'm always happy he's alive and he's improving" (Brandon).

One participant, Toni, described how her experiences at the SNF were very different compared to the other participants who expressed appreciation for the nurses and medical care their child was receiving at the SNF. Throughout the years her son was residing in the SNF, Toni used her background in medical knowledge as a physician and insights to question the quality of care that her child was receiving, as well as act as an advocate for his care by identifying areas of alleged nursing and medical mistakes that caused her to lose trust in SNFs as she stated:

> …realizing, wait, they're not taking care of him as well as they should…why aren't you doing this? Why are you doing that?… [I was] starting to see the reality of these facilities…starting to…tell doctors they're wrong, because they were, and not all of them, but the ones that were, were.

Toni, unlike the other participants, felt frustration and anger from feeling ignored by medical professionals that were caring for her son.

By choosing placement in a SNF, the participants believed they were able to prioritize their values of ensuring their child's safety and promoting their development. Despite the pain and ambivalence surrounding this choice, the majority of narratives conveyed a sense of relief, as participants found comfort in knowing that their child is receiving the essential care they require.

Theme 4: Changing Relationships

Participants described significant changes to their social relationships and intrapersonal relations through the entirety of their experience. Their narratives reveal evolving dynamics and relationships characterized by fluctuating levels of distance, connections, and reconnection as participants navigated their journeys.

4.1 Distancing

"My relationship was a little bit withdrawn because I didn't really pay attention to them at any time because my child wasn't there…at the time I was just really concentrating in jobs, in my work...connection at that time was, was not that strong with my…relations"

David (quoted above) and other participants reported choosing to distance themselves from their social networks during the process of learning about their child's illness and deciding on SNF placement. Common reasons for distancing themselves from others included turning inward to cope with emotions, wanting to focus on their career to support their increased financial demands, and caring for their immediate family. Participants like Lucy, James, and Zara also chose to distance themselves from their social networks and dedicate more time to their work and avoid the feelings of sadness associated with their child being at the SNF. Multiple participants, such as the couple Lisa and Michael (co-parenting), perceived their social networks as potential distractions that diverted their focus and hindered their ability to prioritize the needs of their family and child. Lisa distanced herself from her friends when she was not feeling supported in her decisions by her social network:

> At some point I always distance some of my relationship with friends because I think I do feel some discomfort from them. Like, I’m there, [they] aren’t giving me positive vibes like I would want. So I think I limited my interaction with them, so I don’t get distracted.

In addition to managing the distance and detachment within their social networks, some participants also experienced a sense of disconnection from their child in the SNF. David, a single father who is co-parenting with his supportive partner and child’s biological mother, expresses challenges he experiences in maintaining his parent-child connection due to his child’s separation from home to reside in the SNF; he stated: “…you know, it's something that, makes you feel, umm, sometimes as a parent, you feel that slight disconnection.” Lisa also described the emotional strain and detachment she feels when she is only able to spend time with her child in her spare moments amidst her work and home related duties. This distance is intensified when she is limited to visit her child within designated visitation hours set by the SNF: “I would say it was quite emotional for me, like going there, I just feel like I visit my child in jail.”

For some participants, the emotional intensity of their experiences became so overpowering that it changed them in profound ways. The intrapersonal change was significant enough that their usual social networks could no longer recognize or effectively handle the person. As a result of these intrapersonal changes, people within the participants’ personal support networks distanced themselves. Toni described a good friend who could not handle the changes in Toni’s personality and simply walked away from her during this crisis; Toni noted that they have never reestablished their relationship. Similarly, Lucy reflected on her intrapersonal changes as she described how her husband, the biological father of their child who resides in the SNF, distanced himself from her:

> …My husband started withdrawing…looking at it now, I feel like maybe…then, I was no more my jovial and happy self. I was always under my shell like I was either stressed or, um, giving my attention to my child. Like I wasn't the bubbly type I was before. Like everything about me started changing…looking at it now, [back] then, I didn't know distance was happening. And a lot of things, I stopped doing. Everyone going out, I stopped trying to give myself a makeover or something…I was always indoors, like…a lot of things stopped at that moment. And so maybe that was why he started withdrawing. I don't know.

Common experiences parents shared throughout the interviews included withdrawing from social networks to focus on their jobs, detaching from their child in the SNF due to physical separation, or intrapersonal changes that lead to a disconnection with their usual selves as they grappled with the emotional strain of their circumstances. The profound impact of these experiences sometimes resulted in changes in relationships with others as some parents struggled to understand or cope with the changes in their lives, resulting in distance and disconnections.

4.2 Connecting and Reconnecting: *"[I felt] able to…express my feelings…'cause I was able to pour out things that were actually bothering me and also get a lot of advice…"*

Mitchell (quoted above) described how he found connection and support through his religious group to adjust to the changes he was experiencing with his child's transition to the SNF. Mitchell greatly appreciated the support he received from his church, as he described feeling excluded and unhappy due to having limited social interaction with his friends. This was a result of him taking up extra jobs and his friends not fully understanding the challenges he was facing during this time. Alice, along with other participants, shared how they reached out to social networks and social media on the internet to build connections with people who could understand their challenges because they also have a child in a SNF:

> …I actually joined the [online] support group that was very helpful for me…Most of them were in the same condition with me or similar conditions…and we had time to talk about emotions, talk to each other about how we actually felt, how the process was going.

Despite feeling disconnected and distanced from others, numerous narratives demonstrated ways in which the participants established new forms of connectedness with others. These narratives highlight the desire for more bonding experiences with supports that understood and helped participants navigate the various challenges that are very unique to their situations.

One participant, Brandon, described how going through this experience with his wife has increased their sense of connectedness as they share these difficult experiences together:

> I think [that] it's created this bond and love. I think it does, I don't know, in some ways makes us a bit closer?... Also maybe I pay more attention to my wife in some ways I just don't know how it happens. Yeah, I feel it as…though he has been able to bring this unity among us and bring this love and attention among the family. Even though he's done this without being at home.

Some female participants who were married also expressed ways their husbands provided emotional support and increased closeness to relieve their feelings of loneliness or emptiness after their child was placed at a SNF: "So in some of those things, my husband tried his best to take me to dinners or some other locations that I don't normally go to just to relieve me from all the loneliness" (Zara). Similar experiences and examples of positive social support were described in multiple narratives and appeared to help participants establish a sense of connectedness with family members and friends.

Participants also shared how the challenges stemming from their child's health condition caused strain in their relationship with their partners, resulting in a temporary disconnect. However, over time, this led to a reconnection within their partnership, as they found ways to support each other and their child together. Alice described how this experience has impacted her relationship with her partner, SJ, below:

> …initially…we invested some time in child care…But because the child is in the facility, now we have that time free…at first, we didn't know what to do with the time…We were separated at first, like, the time we would have invested in the child, we initially didn't know what to do…So recently, we've gotten to a point where the time we would have spent with the child, [is now] the free time we spend together. We talk about ourselves. We talk about his health…So we've gotten more time to reassess ourselves and help support him in any way that we can.

Her husband, SJ, described how they became reconnected after their temporary separation:

> We are together to give the child hope…We [were] divided, at the point when we are supposed to be together for him to be healthy. So we actually…do everything together [now], and the time we have now, [we] create more time for ourselves and for the child to understand that we are still together for him.

Another participant, Matt, described how his intense emotions concerning his wife's alcohol intake and their son's condition nearly led to a divorce. The support and advice from his friends, helped Matt to forgive his wife to focus on their son's health:

> After a few counsels from my friends, they advised me in many ways not to go so crazy to my wife and take it into my [own] hands, and [to] take the high [road] because I tried to divorce [her] for what she did, and get divorce papers. But they told me not to do that. After I evaluated what they said, I said I should leave it, and let it go, and then face what is the case [at hand]…So I am okay [now] and thought [of a] better solution to what has happened [to our son] than to destroy the relationship I have built over the years.

The support and advice from social networks and partnerships served as a crucial realization for participants, highlighting the importance of preserving their relationships. This understanding led them to find better solutions for addressing their child's health situation without putting their relationship at risk.

Chapter Summary

This study was comprised of 18 participants who generously shared their candid narratives and provided profound insights into the experiences of having a disabled child with UWS/VS residing in SNF. The narratives highlighted the immense emotional toll and challenges they faced as they grappled with the ongoing uncertainties of their reality from enduring the unexpected when their children's condition changed, to navigating the unknown and deciding for SNF placement which made the participants experience changing relationships in themselves and others. The participants also emphasized the importance of professional support and sense of social solidarity as they navigated the challenging and complex dynamics in their journey. Their contributions have greatly enriched this study and shed light and invaluable insights into the intricate realities and emotions of this unique experience.

Chapter Six
Discussion

To the best of our knowledge, this is the first study that described parents' experiences in the context of having a disabled child that resides in a SNF while being in a UWS/VS or similar neurological compromise and the moral dilemma associated with the decision-making process. The in-depth narratives from this study revealed a comprehensive view of the participants' experiences throughout their unexpected journeys involving their child's severe medical condition and subsequent placements in a SNF. The rich narratives shared by the participants unfolded as a subtle and nuanced chronology, rendering their holistic experiences more comprehensible, which shed light on the profound emotional, psychological, and relational aspects inherent in the unique role of parenting in this context.

Previous qualitative research has explored the connections between enduring, uncertainty, suffering, and hope to develop a model that illustrates their theoretical relationships (Morse & Penrod, 1999). In their study, Morse & Penrod (1999) identified attributes to describe how individuals cognitively process a catastrophic event and attempt to understand the situation to identify linkages between the four concepts. Upon completion of our data analysis, it is evident that the themes in our study are also aligned with Morse & Penrod's (1999) model as the identified themes reflect how participants in our study processed their overwhelming emotions and incomprehensible situation.

Enduring the Unexpected

The concept of "enduring" relates to how individuals navigate through extraordinary physiological or psychological challenges during a crisis (Morse & Penrod, 1999). In Morse & Penrod's (1999) model, enduring was characterized by suppressing emotions to remain composed and focused on getting through the crisis. Similarly, in a grounded theory analysis of pain in elderly hospice patients, enduring was described as a conscious and active process, requiring strength, willpower, and effort to "live with" and "bear" the pain, while also "holding up" and not "giving into" it (Duggleby, 2000).

The participants' narratives in our study began with rich descriptions of how they endured an unexpected upheaval that propelled them into an emotional crisis and entirely new trajectory, initiated by their child's medical condition. In the midst of their crises, the participants expressed a sense of being lost as they experienced an overwhelming shock of their child's unexpected and severe medical condition. This left many of them with a profound sense of grief and at loss for words, yet they felt a strong desire and moral obligation as a parent to do everything they could to support and help their child.

The narratives revealed that participants were actively seeking meaning for their disabled child's condition and navigating a new reality that differed than the life they had imagined for their family. Throughout their existential crises, parents often questioned "why me?" or "why did this happen to me?" when describing their reactions to their child's illness. Their attempts to identify a causative factor for their child's illness also reflected the way that some parents, although not experiencing the illness themselves, took ownership of the illness-related suffering their child endured and compared it to a form of punishment from a higher being. Through this questioning, some parents appeared to prioritize their own sense of suffering and emotional challenges over their child's health status and well-being during this crucial moment. This finding demonstrated similar behavioral aspects of "owning identities" in "sense-making" from a grounded theory study that described the processes of sense-making after the Down syndrome diagnosis of a child (Clark et al., 2020). Participants in the study conveyed that they owned their identity as the parent of a child with Down syndrome, and began to recognize similarities and differences in their child as part of both their child’s identity and their own (Clark et al., 2020).

Through the existential questioning, parents clung to hope and optimism for their child’s return to their “normal life” as they grappled with the ideas of their new reality. In James’ narrative, he expressed concern that his daughter may never return to her “normal self,” and similarly, other parents’ narratives echoed this sentiment as they strived for normalization of their child through ensuring the SNF provided development and education for their child, as well as a place to “meet other kids like them.” Their desires to return to their “normal selves” or preserving their child’s participation in normal activities after moving to a SNF appears to overlook and devalue the child’s actual health status, reducing their overall well-being to the attainment of developmental milestones and interaction with other children who are also not functioning as other “normal” children do.

Navigating the Unknown

The concept of “uncertainty” according to Morse & Penrod’s (1999) model involves recognizing what has happened and having a goal to change the present or move forward, while not knowing how to achieve that goal. While there are multiple pathways to reach the desired outcome, the person is unsure which route to choose. In this state of uncertainty, individuals know where they want to go, but lack the information or ability to evaluate or compare their available choices.

The qualitative study conducted by Kirk et al. (2015) also identified a sense of uncertainty experienced by parents following their child’s traumatic brain injury (TBI) and the immediate aftermath. This sense of uncertainty centered around treatment options, expectations for the child’s recovery, and transition of care within healthcare facilities. Similarly, participants in our study endured through their crisis as they grappled with shock, confusion, and uncertainty for their child's life or unknown future. Many participants expressed their determination to "save" and help their child but were unsure of their options. Frequently, they depended on advice and recommendations from their healthcare professionals to determine their next course of action.

Participants in our study shared how moving forward in their lives was lined with a sense of uncertainty that evoked a phase of moral injury to their values in parenting and distress as they grappled with a pivotal and challenging decision regarding the placement of their child in a SNF. They were compelled to weigh and prioritize their values centered on meeting their child's needs, which also shed light on how participants are left with the ongoing emotional and psychological impacts arising from their decisions. Findings from this study illuminates the profound moral injury experienced by parents when faced with decisions regarding their desire to care for their child at home while wanting to also promote the safety, well-being, and development of their child and their medical condition.

The qualitative study by Mirfin-Veitch & Ross (2003) focused on families' past experiences of seeking out-of-home placement for children with intellectual disabilities in an institutional facility. The study revealed that these families held a strong desire to have their children live within the family home and be cared for by them for as long as possible. Parents additionally made efforts to keep their child at home, attempting various options before realizing that placement became inevitable due to the community-based service system's inability to meet their child's needs. Gradually, they came to terms with the idea of their child living away on a permanent basis, though making this decision was described by every parent as "the hardest and most painful" one in their lives (Mirfin-Veitch & Ross, 2003).

The findings from this study resonate with the experiences of participants in our research. Similar to the parents in the earlier study, the parents in our study expressed the same desire to care for their disabled children at home if it was feasible. However, for most parents, it is uncertain whether the option to remain at home was even presented to them by their doctors, nurses, social workers, patient advocates, disability advocates, or insurers. Consequently, the parents in our study placed full trust in their doctor's recommendations for placement, often citing their lack of medical knowledge and their inability to provide continuous care and safety at home.

As time passed, parents in our study also gradually accepted their realities, and many witnessed improvements in their child's health status which established and reinforced their hopes for their child. Morse & Penrod's (1999) model describes the concept of "hope" as an expectation that allows people to move forward into becoming future oriented as they identify a goal and path to a desired goal. The positive progress that parents in our study witnessed helped to validate their decision for placement which eventually brought a sense of contentment with this decision.

While some parents may find comfort in attributing their decisions to a lack of medical knowledge, it is essential to consider that they may have constructed this narrative as a way to justify their choices. By convincing themselves that their decision prioritizes the child's safety and growth, it could also aid in alleviating feelings of guilt and doubt about the decisions they made.

Prioritizing Values in Decision-Making

While existing literature often focuses on the moral and ethical dilemmas healthcare professionals encounter in similar situations, the difficulty of parental decision-making from a moral standpoint is often overlooked. By recognizing the moral dimensions inherent in these types of decisions, healthcare providers can become better advocates and resources for parents who are confronted with similar circumstances in the future. This is the first study that expands on the moral injury that parents grappled with through the decision-making process for placement. It reveals that personal core values and considerations in decision-making extend beyond the clinical realm and are also profoundly experienced by parents caring for critically ill children. Ultimately, viewing these situations through a moral decision-making lens can enhance the support provided to parents to foster a more compassionate and informed approach to decision-making concerning their child's welfare.

In a quantitative study exploring family adjustment post-placement in a behavioral care facility, participants reported to perceive a better home balance and considered placement as a better arrangement for their child with behavioral needs (Baker & Blacher, 2002). However, parents also expressed negative feelings related to adjusting to the placement. The authors investigated family views on placement and found that families with young children at the time of placement struggled to imagine their child's future needs, which influenced their challenges in adjusting to the placement. Similarly, in our study, participants expressed negative emotions and battling with their personal and family core values when faced with decision-making for placement and living with that decision for an uncertain duration of time. Some participants were hesitant about considering placement at a SNF due to uncertainties about the level of care and development in such facilities. However, as they carefully evaluated their priorities for their child's safety and development, many participants eventually recognized the value and benefits of placement in a SNF. It is worth noting that the children in our study have been diagnosed with a more severe neurological illness, and the average age at the time of placement is seven years old, whereas the children mentioned in Baker & Blacher's study (2002) had an average age of 13 years old at the time of placement and included children who were adolescents up to young adulthood.

Changing Relationships

Roscigno and Swanson (2011) also highlighted the challenges faced by parents in their relationships, particularly the sense of isolation. Parents in the study by Roscigno and Swanson (2011) described their dedication meeting the needs of their child and family that potentially lead to a sense of isolation from their social networks. Unlike our study, participants in Roscigno and Swanson's study (2011) cared for their children with differing levels of brain injuries in their home, rather than a facility. Their sense of isolation the parents experienced may be heightened by the fact that their child with a brain injury is living at home and likely requires more attention than those parents in our study. The parents in our study also described a type of self-induced isolation which stemmed from their intense focus on their child and family. Furthermore, they viewed this isolation as a means to shield themselves from the negative opinions of their social networks, which they believed did not alight with their hopes and values for their child.

In various studies, additional family members or parents expressed how they perceived their friends and colleagues to "run away" or "disappear" as they assumed the responsibilities of caring for their critically ill child (Giovannetti et al., 2012; Kirk et al., 2015; Roscigno & Swanson, 2011). In our study, the theme "distancing" was identified as participants encountered a similar mechanism of isolation which resulted in feelings of abandonment and a lack of support by their social networks. This type of isolation was extensively discussed in a similar study of familial caregivers who were caring for adults in a facility (Giovannetti et al., 2013). The impact of isolation and need for support were identified in other studies of parents facing similar circumstances. These findings highlight the need for further exploration and interventions to mitigate isolation and bolster supportive services.

Baker & Blacher's (2002) quantitative study about postplacement adjustments of families whose child was diagnosed with intellectual disabilities revealed that 86% of respondents experienced increased peace of mind and reduction of negative feelings, such as stress, burden, or guilt. Additionally, among married participants, 84% of married respondents rated their marriages as "happy" or "better" postplacement.

Their study also shed light on a significant aspect, as 75.5% of respondents expressed a lingering feeling of uneasiness about not being able to fulfill their role as a parent to provide care and guidance in daily activities. These positive findings are also resonated with participants in our qualitative study as well. Several participants shared their initial struggles and uneasiness in placing their child in a SNF. However, they also expressed that this substantial decision brought them peace of mind, knowing their child is receiving essential medical and developmental care. Surprisingly, some participants even reported an increase in marital closeness, as they found ways to adapt, cope, and distract themselves from the emptiness caused by their child's absence at home. Participants shared that they started to attain additional marital closeness by filling the time they would normally spend with their child at home with social distractions, such as going to dinner at a restaurant, watching movies, or trying a new outdoor activity together.

The parents in our study have undoubtedly faced the challenge of making crucial decisions while not feeling well-informed or supported. Although decision-making regarding life-sustaining medical treatments did not emerge as a prominent theme, it is important to note that parents had to make those decisions at some time during the acute care moments, which ultimately led to their child being placed in a SNF. While parents had to navigate numerous critical decisions throughout their child's illness journey, including the use of life-sustaining treatments, the primary focus of this study was on the decisions they made regarding placement in a SNF.

With current medical technologies in life-sustaining treatment, young children with UWS/VS have the potential to live well into their teenage years, and in some cases, even into their early adulthood, and people with intellectual or developmental disabilities are able to live longer and more independently outside of institutions (Bastianelli et al., 2016; Cipolletta et al., 2014; McLean et al, 2021). Despite having full-time employment, over half of the participants mentioned facing financial difficulties during their experiences. Many discussed the need to reprioritize family finances and obligations, some participants took on more work to meet their increased financial needs, while only a few mentioned having insurance to assist with the costs of the SNF. It was concerning to find that many participants in the study did not mention the use of Medicaid insurance to access home and community-based services (HCBS). In contrast, the cost of state institutions remains significantly higher compared to Medicaid-funded HCBS ($188, 318, compared to an average of $42,486, respectively), indicating a policy problem related to transitioning care to family homes with adequate education and support. Instead, based on these findings in the narratives, healthcare providers seem to favor recommending placement of children in Medicaid-funded SNFs rather than integrating them into community life. These actions further perpetuate isolation and segregation of people with disabilities, as observed in the experiences of the children in our study (McLean et al., 2021).

Moreover, 56% of participants shared that they had only one child (who was residing in the SNF). The presence of an only child requiring care in a SNF potentially influenced participants' decisions about having more children. Some participants with a single child expressed fear and apprehension about having another child due to concerns of a similar health condition occurring in their future child.

Besides the identified themes of our study which introduced new information about caregiving in this context, it also presents various unique aspects that enhance the existing body of literature on caregiving. First of all, the focus of this study is distinctive in comparison to the context of studies in previous literature. Previous studies have examined caregivers of children with varying levels of special needs and/or traumatic brain injuries (TBI) in different care settings, including home care or placement in medical residential care, rehabilitation facilities, and SNFs (Baker & Blacher, 2002; Giovanetti et al., 2012; Hill et al., 2017; Hostyn & Maes, 2007; Kersh et al., 2006; Kirk et al., 2015;Llewellyn et al., 1999; Mirfin-Veitch et al., 2013; October et al., 2014; Renjilian et al., 2013; Roscigno & Swanson, 2011). Furthermore, there were no studies concerning specifically children in a UWS/VS and placement in a SNF in the United States. Thus, this study makes a substantial contribution to the literature by providing valuable insights into the unique challenges and experiences faced by parents of children with this condition in the U.S.

Secondly, another notable aspect of this study is that its focus captures the retrospective experiences of parents from the time when they learn of their child's diagnosis, through the first year of adjusting to their child residing in a SNF and beyond. Existing research lacks an in-depth exploration of the entire trajectory of parents' experiences in this context. This narrative delves into the unique circumstances that parents face during this time frame. By doing so, it offers unique insights into the initial shock and adjustment periods following the diagnosis, the evolving dynamics of parental caregiving while navigating unknown medical territory, decision-making, and relationships.

Thirdly, this study also expands the traditional emphasis on the caregiving experience as an individual experience by exploring support and relationships that parents engage with to promote well-being and coping by including narratives of parents who reported having a supportive person to examine support and relationships. Initially, this study aimed to explore parental-dyad engagements – all participants that were interviewed were encouraged to invite their supportive person, however, only four participants chose to bring their supportive person. Consequently, it was not feasible to draw implications or conclusions regarding their dynamic relational interactions. Instead, the researcher was able to examine the dyads' perception of support received from their partners. However, due to the limited sample which included 4 couples, the ability to thoroughly examine dyadic dynamics was constrained.

Lastly, the uniqueness of this study lies in the sampling inclusion of parents who have a child in a UWS/VS or similar neurological disability from six SNFs in California. Initially, recruitment for this study posed numerous challenges. SNF administrators and parents often acted as gatekeepers, which presented obstacles in accessing the target population. However, the PI managed to gain entry by utilizing a social media network and personal blogs frequented by parents in this population. As the first participants agreed to share the study flyer in a private social media venue, an overwhelming response ensued, with over 100 inquiries from across the U.S. between December 2022 to February 2023. As the participant narratives encompass multiple SNFs rather than one SNF, this study provides a comprehensive and robust depiction of parental experiences across various SNFs in California.

Suggestions for Future Research

While this study aligns with other themes from the existing literature, several distinctive aspects should be considered. This study could not capture the long-term challenges of caring for children as they grew older and larger with their medical conditions as captured by previous studies (Baker & Blacher, 2002; Llewellyn et al., 1999; Mirfin-Veitch et al. 2003), nor could it capture the potential transition period to an adult SNF at the age of 18. The average age of children discussed in this study was seven years old, in contrast to other studies that included children ranging from infancy to adolescence. Therefore, longitudinal studies that explore the experiences of parents whose disabled children are in a UWS/VS and resided in SNFs for longer periods of time from school-age into adolescence are recommended.

Furthermore, the overall burden and strain experienced by parents could not be quantitatively measured, highlighting the need for future quantitative research utilizing reliable and validated tools to comprehensively assess the struggle of moral reasoning in decision making about treatment and placement as well as the emotional, psychological, and spiritual/existential impacts on this population. Future research should also quantitatively assess how parents' race/ethnicity, socioeconomic status, and social determinants of health impact their overall experience.

Implications

Narratives from 18 participants about their experience of having a child with an unexpected, serious chronic illness has shown this experience to be a persistent cycle of moral, emotional, and psychological challenges for parents. An important aspect of improving the overall well-being of families who have a disabled child that is in a UWS/VS and residing in a SNF is to address their unique needs with comprehensive and sensitive care. The identified themes highlight the emotional, relational, and decision-making challenges parents encounter when faced with these circumstances, and the findings demonstrate important implications for healthcare professionals and policymakers to inform, educate, and support these populations.

There has been a notable increase in some forms of intracranial infections in children under 18 years old living the in the U.S. during March 2020 – March 2022, coinciding with the first two years of the COVID-19 pandemic (Khuon et al., 2022). A significant number of intracranial infections were diagnosed either during or shortly after an infection with SARS-CoV2 (COVID-19), with the majority being identified in infants and children under the age of two (Khuon et al., 2022). This awareness of the rise in intracranial infections has the potential to impact more families and children, leading to an increased demand for SNFs and additional resources to aid in decision-making processes.

The potential for this population that requires medical technology to grow is significant, driven not only by the rise in brain infections, but also by increasing prenatal and maternal substance use (alcohol, methamphetamines, opioids), the legalization of cannabis, and restrictive access to abortion rights in certain states. As a result, we can anticipate an increase in younger-aged children requiring medical technology support in SNFs due to the harm caused to the developing fetus and the lifelong devastating consequences, alongside maternal mental health implications.

Healthcare professionals in the acute care setting, as well as the long-term care setting (SNFs), should strive to identify and address the emotional and psychological needs of parents through the duration of their child's care. This can be achieved by creating a compassionate and supportive environment with less judgement where healthcare providers (namely doctors and nurses that manage most of the care in both acute and chronic areas) actively listen to parents' concerns, offer counseling or psychological support services, and include interdisciplinary services, such as social work, chaplain visits, and case management. Integration of interdisciplinary services are necessary for this type of care because it provides long-term support both inside and outside the care facility. This is particularly important for parents that present with “high-risk” factors including lack of oversight, maternal substance use or abuse, of child abuse/abusive head traumas. These services can help parents navigate the complexities of the health care system by coordinating care, connecting parents with resources, and offer ongoing assistance beyond the acute phases of their child’s illness.

Healthcare professionals should also strive to provide parents with a better understanding of their child’s illness and medical needs while also acknowledging with sensitivity the challenges of facing an uncertain future. In our study, it was evident that a significant number of participants were unable to clearly articulate their child’s diagnosis. This underscores the importance of providing education that is comprehensive and accessible to describe UWS/VS, the treatment options, potential prognoses, and care options while meeting the parents’ level of understanding. By tailoring this education, healthcare professionals can empower them to actively participants in their child’s care and make well-informed decisions. Additionally, a better understanding of the child’s illness could potentially ease some of the psychological distress that parents experience simply by reducing confusion of details about their child’s illness and plans for care.

Another way that healthcare professionals can provide more sensitive care to parents in the acute phases of children’s care in these situations is to consider adopting treatment and care patterns and policies that are observed in specialized pediatric hospitals during the acute phase of illness. Pediatric hospitals are well-known to prioritize family-centered care models and provide child-friendly environments that will likely create a more supportive environment for parents to help them better understand their child’s illness through moments of shock, especially when they are faced with an unexpected illness that has a severe prognosis and implications, such as UWS/VS.

Pediatric hospitals also offer a range of other services, including early inpatient and outpatient palliative care consultations and rehabilitative services aimed at restoring aspects of their child’s well-being. The field of palliative care has nearly tripled over the last two decades as health care institutions, health plans, and policymakers implemented this as a means to enhance care quality and diminish costs (Center to Advance Palliative Care, 2022). The provision of outpatient pediatric palliative care helps to facilitate the enhancement of care coordination, symptom management, and conversations about care objectives throughout the entire illness course, rather than solely during acute episodes of crisis (Autrey et al., 2023). Despite this impressive growth, barriers to accessing palliative care persist due to considerable variabilities in funding, operational framework, culture, and structure, specifically in pediatric palliative care programs (Rogers et al., 2021). According to a studies about the prevalence of pediatric palliative care programs in the United States, pediatric palliative care remains largely unrealized, underutilized, and inconsistent across healthcare settings (Autrey et al., 2023; Weaver et al., 2022). The accessibility and availability of specialized pediatric palliative care programs, in addition to the absence of a universal standard for pediatric palliative care leaves many families without the comprehensive support needed during the challenging journey of caring for a child with disabilities (Weaver et al., 2022).

As disabled children transition from the acute care settings to their homes or a SNF, the importance of continuity and holistic care and support cannot be emphasized enough. Referring palliative care services upon discharge from acute care could ensure a well-coordinated transition that considers the child’s medical needs while also addressing the emotional, social, and psychological well-being of both the child and their family. Palliative care experts have the skills to customize care plans according to the child's distinct needs and wishes of each family, which will ultimately enable open dialogues about treatment choices, symptom control, and considerations of quality of life ("Palliative care: Conversations matter," n.d.).

A systematic review by the American Academy of Neurology identified that there are no established therapies specific to pediatric care practice guidelines for disorders of consciousness (Giacino et al., 2018). However, practice guidelines have outlined specific recommendations to optimize assessment and symptom management through the expertise of specialized neuro-palliative care providers. Providers with this specialty encompass skilled communication with patients and their caregivers to enhance medical choices and deliver family support (Giacino et al., 2018). These referrals and interventions are especially significant in the acute stages of the disorder of consciousness, just as neurorehabilitation is essential following the acute phase of the diagnosis (Fins & Bernat, 2018; Giacino et al., 2018).

Skilled nursing facilities should consider establishing protected visitation periods to prioritize family time by limiting medical procedures and treatments during these time windows. This will allow parents and families to focus on bonding with their child, provide emotional support, and promote a sense of normalcy while the parent is able to be with their child at the SNF. SNFs should also actively facilitate connections among parents who express interest, both within the facility and through online platforms. Participants within this study have shared how peer-to-peer networks and online forums (not sponsored by the SNF) have been helpful in providing support and coping practices. By establishing this form of connection within the SNF, this can more easily and effectively provide parents with the opportunity to exchange information and provide mutual support without having to reach outside of their personal network.

While this study sheds light on the direct impact of a child's severe medical condition on the emotional and psychological well-being of parents and caregivers, it does not delve into the broader socio-political ramifications, as it lies beyond this study's scope. Still, it is crucial to acknowledge that these impacts can significantly contribute to disparities in health and healthcare outcomes for the parent (or caregiver) and child over time. As healthcare providers, it is important to recognize that even though parents and caregivers are able-bodied, they bear the responsibility of caring for a child with high medical needs and very little capacity to advocate for themselves. This burden becomes even more challenging when access to quality healthcare, resources, and social support is limited. Addressing political barriers that marginalize this population by implementing a more responsive HCBS that meets parents' needs is therefore necessary for improving holistic health outcomes.

Ableism

In this study, "ableism" stands as the pressing issue that must be addressed and tackled in healthcare. The National Center on Disability and Journalism (2021) defines "ableism" as the discrimination or social prejudice against people with disabilities. This stance often assumes that they are inferior or less capable. A disability justice framework proposes that a person's disability should not become a marker of health inequities alone. Instead, disabilities should be recognized as a vital demographic that helps parents to understand and measure the adversities that they encounter within the context of other identity categories (such as race, gender, or SES), rather than placing focus the inequitable outcomes compounded by their status as a "disabled person" (Harris, 2022).

Some parents may implicitly accept the notion that their child's condition makes them less valuable or unable to thrive in a home environment, leading them to believe that a SNF is the only viable option for their child's care. The parents in this study, though well-intentioned, unknowingly harbor ableist perspectives themselves, and are not well-equipped to become disability advocates for their children nor view their child's situation through a perspective that promotes disability justice.

This ableist undertone can be attributed to a lack of comprehensive information and education provided to parents about the range of resources and choices available for their child's care. When parents are not adequately informed about their options, they may default to trusting their doctors completely and assume that medical professional possess all the knowledge and authority in making decisions for their child's well-being, even if these choices do not alight with their own values or preferences.

Consequently, their ability to be effective champions in combating ableism in their child's care and reshaping their relationship to disability, dignity, and humanity of people with disabilities remains compromised. As healthcare providers, it is our duty to reframe information for families and to facilitate their sense-making processes to construct a meaningful understanding of their child's disability.

By actively involving parents in this type of decision-making process and respecting their insights and concerns, healthcare providers can aid in breaking down ableist undertones that are present in the narratives. Instead of perpetuating the believe that institutional care is the only solution for children with UWS/VS and severe neurological disabilities, parents can feel supported in exploring various care arrangements through HCBS that prioritize their child's individual needs and goals. This including and collaborative approach not only ensures better outcomes for the child, but also fosters a more compassionate and equitable healthcare environment that values the perspectives and agency of parents and families.

Limitations

Sample and Geographic Area

The experiences and perspectives of parents in other regions or cultural contexts may differ substantially; consequently, the findings cannot be extended beyond the sample of participants that were studied in California. In California, the Lanterman Developmental Disabilities Services Act “entitles people with developmental disabilities to a wide range of services and supports” which are coordinated by a system of Regional Centers (Regional Centers and the Lanterman Act, 2018). It is important to acknowledge that the unique characteristics and resources available to California residents through regional centers may have influenced the experiences reported by the participants, and there should be caution when applying these findings to other contexts.

Furthermore, the PI made efforts to recruit participants directly from the 12 SNFs in California by reaching out to the nurse administrators from each facility. Although initial communication was established with five SNFs, follow-up communication ceased when four contacts discontinued their communication, and one SNF declined participation over the phone, stating ineligibility based on the patient criteria. The remaining SNFs (7) did not provide a response to the PI’s outreach attempts. In order to continue the recruitment process, the PI continued to search for publicly shared personal blogs and online support groups. Through this approach, the first participant, Toni, graciously volunteered to share information about the study by posting the PI’s flyer on a private Facebook support group she had previously been involved in. The eligible sample in our study displayed sociodemographic biases, as all participants reported, having a supportive person, being employed either full-time or part-time, possessed higher education, and had access to the information posted on the online support group page. Additional limitations to this sample were the level and knowledge of technology that participants had access to (including internet access, an electronic device with video-call capability), which may also speak to the participants' sociodemographic status and ability to own and utilize current technology. The sample was also limited to people who were fluent in speaking English.

Recruitment

The interviews were not always conducted with a parent and their designated support person, as initially proposed by the PI. Conducting solely dyadic interviews could have provided a more comprehensive understanding of the dynamics and interactions between the parent and their support person. The lack of dyadic interviews for this study may have limited the full exploration of a support person's role and influences in parental experiences, and the ways in which they aid with coping through the challenges associated with having a child in a UWS/VS.

Initially, the PI anticipated challenges in recruiting couples who were willing to participate as a dyad. As a result, the study protocol was adjusted to include participants who were interested in participating individually, but also claimed to have a support person. Throughout the recruitment process, the PI informed all eligible participants that the study was designed to include dyads, and all eligible participants were given the option and encouraged to share the study's information with their supportive person.

Among the eligible participants, nine participants interviewed as individuals and did not state a reason for not including their supportive person, and Toni, this study's first participant, indicated that her supportive person died from an unexpected illness five years ago and has not identified another support person since. The remaining eight participants agreed to participate in the interview as a dyad. All dyad participants were biological parents to the child in the SNF.

Surprisingly, the sample consisted of 44% female participants, and 56% male participants, with 60% of the sample consisting of males who interviewed individually. This higher percentage of male participants in a qualitative study is not commonly observed in the literature. The gender imbalance could potentially lead to gender-specific findings that are more relevant to males than females, leaving important female perspectives underexplored.

Additionally, the skewed gender distribution may inadvertently reinforce and represent cultural biases in the data that are more aligned and applicable to males than females. This could result in a partial representation of the broader population.

Methodology

This study initially aimed to conduct video call interviews with dyads. Each participant who was invited for an interview was given the option to invite a partner who they considered "supportive" for them. Each participant that interviewed individually was also asked if they would like to invite their supportive partner to participate in the study. However, participant preferences, which were oftentimes not explicitly explained, the PI was only able to recruit four dyads who participated in interviews towards the later stage of data collection. Furthermore, the majority of participants opted not to turn their video camera "on" during the interviews when asked. These limitations present challenges for the PI in conducting a comprehensive analysis of dyadic dynamics in caregiving and decision-making.

Long-term Effects

A further limitation of this study is the child's relatively brief residency in a SNF. Children whose parents participated in this study have resided in a SNF for less than five years (average length of residency is 2.5 years). Additionally, the majority of the children mentioned in the study were of school age. This limited timeframe and age range may not adequately capture the long-term effects on parents and families, as parents' experiences and difficulties may change over time.

Child Diagnosis

A potential limitation is that several parents were unable to provide the exact diagnosis of their child's condition and it was not substantiated via medical records. Without accurate diagnosis information, it is challenging to ensure that participants represent a homogenous group with comparable experiences. The inclusion of participants with varying diagnoses may have contributed to diverse experiences and perspectives. To reduce the effects of this limitation, the PI spent time during the introductory portion of each interview to ask participants to describe their child's illness and medical needs to the best of their ability to determine their eligibility to participate in the study. Five participants voluntarily shared pictures of their child in the SNF to aid in their description of their child.

Additionally, some of the conditions described by parents were acute onset, while others were chronic and progressive in nature. The difference in onset of illness could have also allowed parents and families more time to ask questions, seek out alternative ways to provide care, and to investigate SNF placement.

The absence of precise diagnosis information from parents in this study contradicts the notion of "flashbulb memories" associated with medical diagnoses. Existing research suggests that individuals often develop vivid and impactful memories of the moment they learn about a loved one's medical diagnosis (May et al., 2019). Various factors might explain why parents in our study did not exhibit characteristics of flashbulb memories regarding their child's diagnosis.

It is possible that their child's health condition was very complicated, or the information provided to them might not have been conveyed in a manner that allowed for clear comprehension and articulation. In certain cases, such as with the couple James and Maggie, the uncertainty about their child's diagnosis persists due to conflicting information provided by different doctors.

Self-reported Narratives

Lastly, this study relied on self-reported narratives provided by parents and their support persons, which are susceptible to recall biases and social desirability. Participants' memories of events and experiences may have been influenced by various factors, including passage of time, emotional biases, and personal interpretations of events, among other variables. Furthermore, participants may have been more inclined to present their experiences in a socially desirable manner that may have limited the objectivity and accuracy of the findings. As an effort to minimize these effects, the PI attempted to establish rapport and a supportive environment with the participants during the introductory phase of the interview. The PI spent at least 7-10 minutes conversing with the participants prior to initiating the consent process to ease their nerves or tension and offered multiple opportunities for participants to ask questions. The PI also reiterated that all participants' personal information will be protected and will be replaced with an alias, and that they are able to withdraw from the study at any time without any penalties. Apart from conducting the interviews, the PI took measures to control for personal biases. This involved writing field notes both before and after each interview, as well as writing reflexive memos throughout the data analysis process. The PI held regular meetings with the co-chairs of this study to ensure coding consistency and reliability. Additionally, member checking amongst the PI and co-chairs was adopted to facilitate the analysis process and establish reliability and validity, and an audit trail was updated on a weekly basis. These steps were taken to ensure the PI could set aside her personal biases and assumptions while analyzing the data.

Conclusion

This study provided a profound overview of the participants' comprehensive experiences, weaving together a narrative tapestry that illuminated the emotional, psychological, moral, and relational dimensions of their parenting journey. Participants in this study have made clear the challenges they face in a journey through unknown territories in dealing with the crisis of their child's medical condition, as they continue to face a variety of setbacks, emotional challenges, and uncertainties while they navigate their realities.

One notable aspect from this study is the emergence of four main themes, interwoven to form a coherent and connected narrative that chronicled a subtle progression of events and experiences: (1) Enduring the Unexpected, (2) Navigating the Unknown, (3) Using Values-based Decision-Making, and (4) Changing Relationships. This study contributes to the limited research conducted in the U.S. on parents and caregivers of disabled children with UWS/PVS. It is concerning that this problem and this specific population have received less attention in the U.S. compared to studies conducted in Europe, which primarily focused on adult populations with UWS/VS or other disorders of consciousness. This lack of research may contribute to the invisibility of this population, resulting in a further injustice to the disabled child and their family, lack of public awareness, advocacy, and support which will ultimately exacerbate the invisibility and underserved nature of this population.

Consequently, parents and caregivers of this population are more at risk to face harm and injustices when healthcare providers and policymakers fail to recognize how these distinct experiences profoundly impact their lives. As a comprehensive healthcare system, it is crucial that we address this gap and look to invest more resources into understanding and meeting the needs of these children and their parents and caregivers. By prioritizing research, awareness, support, and policymaking through the lens of disability for parents and caregivers in the UWS/PVS context within the U.S., we can work towards a more compassionate and inclusive healthcare system that meets the needs of all individuals.

Appendix A

Invitational Letter to Administrative Staff and DON at Selected SNFs

Nursing Research: Experiences of Parent-Support Dyads Whose Disabled Child Resides in a Subacute Skilled-Nursing Facility
Dear DON(s) and Administrative Staff at ________,
My name is Victoria Abatay, RN, MSN-Ed, PhD (c). I am a pediatric registered nurse (RN) with 11 years of Pediatric Intensive Care bedside experience, and a doctoral candidate at UCLA. I am conducting a qualitative research study to learn more about parents and their supportive-person's experiences of overseeing care for their child who resides at a pediatric subacute-nursing facility. I am interested in learning more about how parents have adjusted to their child's healthcare needs and what it is like for them to oversee or provide care for their child who has been living outside of their family home and at a subacute facility for at least one year.

To conduct this research, I would like to interview parents and their identified support person over a video-call app of their choice (Zoom, What's App, Facetime, etc.) or in-person to ask questions such as "can you tell me what a usual visit-day looked like for you during the first year?" and "in what ways did you and your support person adjust life during this period?" This study is completely voluntary, all potential participants will be screened for eligibility, and I will obtain verbal consent if they choose to participate. Any personal identifiers will be kept confidential and receive an alias for the analysis and write-up of findings. By participating in this study, each parent and their support person will each receive a $25 Visa Gift Card as a token of my gratitude for their time.

This study is important because the findings of this study can help to identify ways to enhance the support and care for parents and families that are or will be experiencing situations like this. Additionally, there are no publications to date that look specifically at this population of parents and their support person.

My study has been approved by my PhD Dissertation Committee and the Institutional Review Boards (IRB) at UCLA. I am reaching out to ask for permission to recruit potential participants from your site (these will be parents of children at your site). I hope you will take a few moments to consider this request, and I am happy to discuss with you more details about this very important study!

Thank you for your time and consideration, I am looking forward to hearing from you!

Sincerely,
Victoria K. Abatay, RN, MSN-Ed, PhD (c)
University of California, Los Angeles | School of Nursing
5th Year PhD Student
Phone: 562-XXX-XXXX

Appendix B

You could help us learn more about parents’ experiences and well-being!

A researcher from the UCLA School of Nursing wants to learn more about the experience and well-being of parents whose child resides at this facility! This study also allows parents to invite a person who has been supportive for them to participate.

Research participation is always voluntary!

Would the study be a good fit for me?
This study might be a good fit for you if:

- Your child has been a resident of this facility for at least one (1) year.
- You can identify another person (friend, family member, etc.) who you feel has been supportive for you in any way.
- You and your support person can both participate at the same time!

What would happen if I took part in the study?
If you decide to participate in the study

- Complete a short screening form to check if you are eligible to participate in the study.
- Complete an interview along with your support person (this will take about 1 hour)

Parents and their support person who take part will receive a $25 Visa E-Gift Card to thank them for their time.

To take part in this research study or for more information,
please contact Victoria Abatay, RN at
(XXX) XXX-XXXX
VAbatay2@ucla.edu

The principal researcher for this study is Victoria Abatay, RN, MSN-Ed

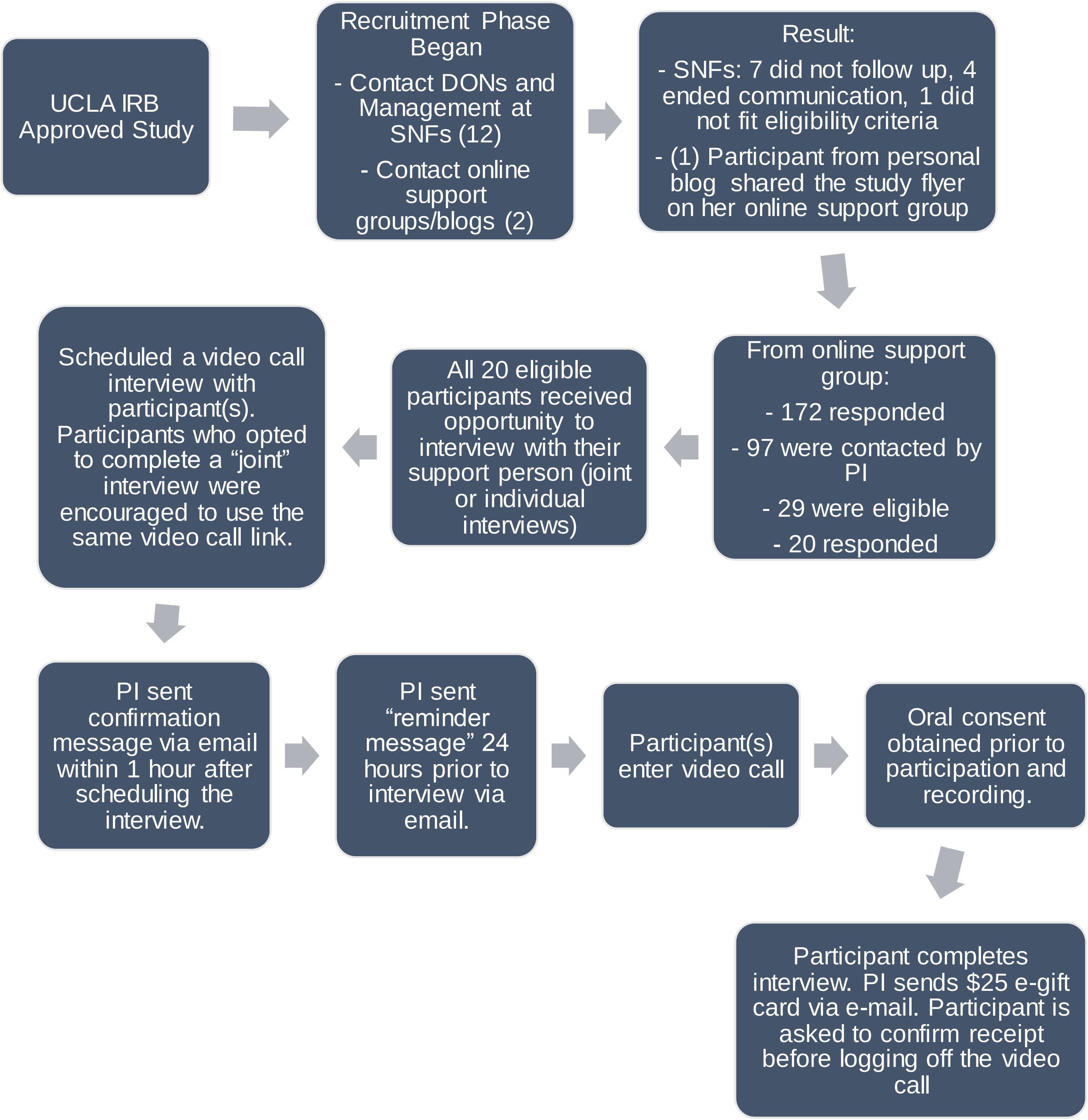
Appendix C
Pre-Eligibility Screening Guide for Participants

*To be completed in person, over the phone, or email, dependent upon how the participant is recruited.

- **[I will state]**: I understand that you are intersted in this research study about experiences of couples who have a child that is in a unresponsive wakefulness state or vegetative state (UWS/VS) that is currently living in a subacute skilled-nursing facility (SNF). Couples who participate will receive a $25 Visa gift card payment for each person in the couple that interviews – this will be sent electronically via email or text message using the contact information you have provided.
- **[I will ask]**: Are you still interested in participating in the study?
- **Participant response**: Yes/No
- **[I will proceed to state the following]:** To assess if you are eligibile to participate, I will need to ask you a few questions:
- **[I will ask the following eligibility questions]:**
    1. Are you, or your partner, a biological parent of a child who has been diagnosed with UWS/VS?
    2. How old is you/your partner's child?
    3. Does this child currently live in a SNF?
    4. Has this child lived there for at least one year?
    5. Do you speak English comfortably to express yourself in conversation?
    6. Do you think your partner is also willing to participate in this study?
        - If participants responds "yes/maybe":
            - Could you please share this flyer with your partner? This study is looking for both partners to participate in an interview.
            - Are you able to share contact information for your partner so that I can ask if he/she is interested in participating in this study?
        - If participant responds "no":
            - Ok, I understand. For this study, I would prefer that you both participate in an interview. You do have the option to interview separately if that is more convenient for the both of you. In case your partner changes his/her mind and would like to participate, please share this brochure and my contact information with him/her so that I can schedule an interview.
    7. This interview will be conducted over a video call. Do you have a personal cell phone, mobile device, or computer wth video capabilities to participate in the study?
    8. Would you have a way to find adquate internet connection during our video call?
    9. What is your understanding about this study? [If participant answers correctly, proceed. If participant answers incorrectly, researcher will review purpose of study, and ask if the participant is still interested in participating in the study]
- **[If the participant is ineligible, I will state]:** Thank you for your time, however, based on the questions I asked, you are not eligible for the following reasons (state reasoning based on questions 1-8].
- **[If the participant is eligible, I will proceed to ask]:**

    - For this research study, I prefer to interview both you and your partner at the same time. However, to make it convenient for both of you, there is an option to interview separately. Neither option would affect your eligibility for this study. Would you prefer to be interviewed together, or separately?
- [**I will note the participant's preference and proceed to ask]:**
    - This interview will be about 1 hour, to 1.5 hours. What day(s) and time(s) are convenient for you to interview over a video call?
    - Will you have a private and quiet place where you will be comfortable to do your interview over a video call without interruptions?
        - If the participant states "yes," I will proceed.
        - If the participant states "no," I will recommend private and accessible places to do the interview, such as their car, room in their home, or outside areas.
    - Since this interview is done over a video call, do you have access to Zoom?
        - If the participant says "no," I will ask which video call app the participant prefers: What's App, Duo, Facetime
    - **[I will take note of the time and date that is most convenient for the participant. Then I will proceed to state]:** I am confirming that we will have a video call interview at _____ (time and date). I will send you a reminder via email or text message 24 hours before our interview. This message will contain a private link that you can click on to enter our scheduled interview. Before we start the interview, I will also do verbal consent and give you time to ask any questions related to the study. In case you have any questions before our interview, you can contact me by phone call, text message, or email.
- **[I will state]:** Do you have any other questions for me at this time?
- **[I will ask]:** Can you please share with me the phone number that I can contact you at for our interview?
    - Can I call and send text messages to this phone number? I will send you a reminder about our interview via text message or email the day before.
- **[I will state]:** Thank you! I look forward to your participation in the study! I will see you on video call on ______ (the time and date given). If you have any questions before our video call, please use the contact information in this flyer (hands over/electronically sends) to call or text me with your questions.

Appendix D
Sampling Diagram/Recruitment diagram



UCLA IRB Approved Study

Recruitment Phase Began

- Contact DONs and Management at SNFs (12)

- Contact online support groups/blogs (2)

Result:

- SNFs: 7 did not follow up, 4 ended communication, 1 did not fit eligibility criteria

- (1) Participant from personal blog shared the study flyer on her online support group

From online support group:

- 172 responded

- 97 were contacted by PI

- 29 were eligible

- 20 responded

All 20 eligible participants received opportunity to interview with their support person (joint or individual interviews)

Scheduled a video call interview with participant(s). Participants who opted to complete a "joint" interview were encouraged to use the same video call link.

PI sent confirmation message via email within 1 hour after scheduling the interview.

PI sent "reminder message" 24 hours prior to interview via email.

Participant(s) enter video call

Oral consent obtained prior to participation and recording.

Participant completes interview. PI sends $25 e-gift card via e-mail. Participant is asked to confirm receipt before logging off the video call

Appendix E
Confirmation and Reminder Messages

Confirmation:

Subject line: Research Study -- Video Call Interview Confirmation

Hello! This message is confirming your video call interview on (day, date, time) with Victoria, the researcher from UCLA. The day before your interview, you will receive a reminder message that includes your interview date, time, and the link you will use to enter the video call.

Your participation in this research study is strictly voluntary. Attached to this message is the "Research Study Information Brochure" for more information. If you have additional questions before your interview, please call or text me at (###) ###-####.

Thank you for participating in this important research. As a token of my gratitude for your time, you will receive a $25 Visa e-gift card upon completion of your interview sent via email or text. I look forward to seeing you on video call on (insert interview day, date, and time).

Sincerely,
Victoria

Reminder:

Individual interviews: Hello! This is Victoria, the researcher from UCLA. This is a reminder that your video call interview is scheduled for (day, date, time). You have chosen to use (insert app choice: Zoom, What's App, Duo, Facetime) for your video call. The link to enter the video call is:

INSERT LINK HERE

Simply click on this link to go directly to our video call. If the link does not work, copy and paste the link into the address bar of your internet browser.

Your participation in this research study is strictly voluntary. Attached to this message is the "Research Study Information Brochure" for more information. If you have additional questions before your interview, please call or text me at (###) ###-####.

Thank you for participating in this important research. As a token of my gratitude for your time, you will receive a $25 Visa e-gift card sent via email or text upon completion of your interview. I look forward to seeing you on video call on (insert interview day, date, and time).

Sincerely,
Victoria

Joint Interviews: Hello! This is Victoria, the researcher from UCLA. This is a reminder that you and your partner have a video call interview is scheduled for (day, date, time). You have chosen to use (insert app choice: Zoom, What's App, Duo, Facetime) for your video call. The link to enter the video call is:

INSERT LINK HERE

Simply click on this link to go directly to our video call. If the link does not work, copy and paste the link into the address bar of your internet browser.

Your participation in this research study is strictly voluntary. Attached to this message is the "Research Study Information Brochure" for more information. If you have additional questions before your interview, please call or text me at (###) ###-####.

Thank you for participating in this important research. As a token of my gratitude for your time, you will each receive a $25 Visa e-gift card sent via email or text upon completion of your interview. I look forward to seeing you on video call on (insert interview day, date, and time).
Sincerely,
Victoria

Appendix F
Emergency Contacts

- Immediate physical distress or requiring medical attention: 911
- National Suicide Prevention Hotline: (800) 273-8255
- CalHope for crisis management: (833) 317 – HOPE (4673)

Appendix G
Consent Script

University of California, Los Angeles

CONSENT TO PARTICIPATE IN RESEARCH PROJECT
EXPERIENCES OF PARENTS-DYADS CARING FOR CHILDREN DIAGNOSED WITH UWS/VS AND RESIDING IN A SNF

Hello, my name is Victoria. I am a PhD student from UCLA that is conducting research about parents' and their partners' experiences of caring for their child in a skilled-nursing facility. You were selected as a possible participant in this project because you are a parent or a partner of a child that is in an unresponsive wakeful state/vegetative state (UWS/VS) at a skilled-nursing facility (SNF).

Your participation is strictly voluntary. This means that you do not have to participate in this research unless you want to. Would you and your partner be willing to answer some questions about your experiences in caring for your child at a SNF? (If yes, continue. If no, thank them for their time and end the call).

The interview will last about 1 to 1.5 hours, followed by a brief demographic survey that should take about five more minutes to complete.

I hope that you will do your best to answer all the questions. It is helpful to have the most complete interview possible. This interview might bring back some uncomfortable feelings, so if you find some of the questions difficult or sensitive in nature and do not wish to answer a question, just tell me and we will skip it, and go on to the next one. You also have the right to withdraw from this study or stop your interview at any time without any penalties. I appreciate any time you give me.

The purpose of this research study is to explore and describe the unique experiences of parents Whose Disabled Children are in an unresponsive wakefulness state/vegetative state (UWS/VS) and living at a long-term skilled-nursing facility (SNF).

I estimate that approximately 10-14 people will participate in this study.

If you agree to be part of this study, I will ask you to participate in an interview using the video call we are on right now. I will be asking you to tell me what it's like for you to care for your child that is in a UWS/VS and living at a subacute skilled-nursing facility, and to describe the impact that this experience has had on you and your partner's lives and well-being.

The interview will be audio recorded and transcribed verbatim for data collection and analysis purposes. All names, places, and other identifiable information will be replaced on the transcript with an alias to protect your privacy. If it is okay with you, I might want to use direct quotes from you, but these would only be cited using the aliases so that nobody will know if you said that quote. There is no expected risk to you for helping me with this study. When I get back all the interview data of everyone who has agreed to participate, I will group all the responses together in my analysis to write up and report the information that I gained from this study.

There will be no way to identify individual participants. Any data collected in this research study will remain confidential and I will be the only person to have access to this data.

Do you still want to talk with me? Remember, your participation is voluntary; you do not have to complete these questions.

If after the interview you still have questions about the research or your rights as a participant, please use the contact information that is listed on your Research Study Brochure to contact me, or the Office of the Human Research Protection Program (OHRPP) at UCLA.

If you change your mind later and do not want me to collect or share your data from your interview, you need to contact me and say that you have changed your mind and do not want me to collect and share your information from your interview.

Before we move forward, do you have any questions?

A verbal "yes" indicates that you are consenting to participate in this research study.
Do I have your permission to begin asking you questions?
[If yes, begin audio recording and start interview]

Appendix H
Focus Areas of The SSIG and Probes

1. **Parents learning about their child's UWS/VS health status.**
    a. "In general, how has this whole experience been for you?"
        i. "How do you think this experience has impacted your overall well-being?"
            1. "Your physical or mental health?"
    b. "Can you take me back to where this may have started for you and your child? Think back to the time when the doctors told you about your child's condition… Do you remember what the doctors said?"
        i. "What do you remember thinking?
            1. "How did this moment/time feel for you?"
        ii. "What was helpful for you at this time?"
        iii. "What was particularly challenging for you?"
2. **Decision factors considered when choosing to care for the child at a SNF or at home.**
    a. "How long after you found out about your child's condition did you decide to move him/her to this facility?"
        i. "What kind of decisions did you have to make in this process?"
        ii. "Can you remember what factors you considered when transferring him/her to this facility?"
        iii. "Did anyone or anything in particular influence your decision to transfer your child here?"
            1. "In what ways was this person/thing most influential to you during this decision?"
        iv. "What kind of support did you receive while making this decision?"

            1. “What was helpful?”
            2. “What was missing?”
        v. “How has this decision affected your well-being?”

3. **Description of experiences of SNF care and home life during the first 1 year of residency at a SNF.**
    a. “Let’s go back to that first year that ____(child’s name) was at the SNF. During that first year, what was it like for you when you visited ___ (child’s name) at the SNF?”
        i. “Can you tell me what a usual visit-day looked like for you during the first year?”
        ii. “Did anyone come with you? What role did this person have during your visits?”
    b. “Tell me, what was it like for you at home after your child was transferred to this facility?”
        i. “What ways did you adjust your life during this period?”
        ii. “How about other members in your home – can you tell me how this change impacted their daily lives during this first year?”
        iii. “Outside of your home, what were your relationships like with your other friends or family while you were going through this in the first year?”
4. **The communication and decision-making processes between dyads.**
    a. “In what ways is your partner involved in ___ (child’s name) life?”
    b. “Over time, what kind of decisions have you had to make about ___(child’s name) care?”

        i. “In what ways have you or your partner been helpful with these decisions?”
        ii. “What were the biggest challenges that you recall when you had to make decisions?”
            1. “As a couple/partnership, how did you overcome these challenges to make a decision?”
        iii. “How would you say this experience of your child living at the facility affected your relationship with/to your partner?”
            1. “Can you explain…?”

5. **Other factors that assisted with the adjustment to their child living in a SNF.**
    a. “What type of social-support networks or systems did you find most helpful while you were adjusting to your child living in a SNF?”
        i. “In what ways was this network/system helpful for your adjustment?”
6. **Factors that affect the parent-dyad’s participation in care for their child.**
    a. “How has ___(child’s name) needs impacted your relationship to ___ (partner)?”
    b. “Could you describe your roles vs. your partner’s roles in providing care for ___(child’s name)?”
    c. “How about your social network or friends, how has ___(child’s name) needs impacted your social life or relationship with friends?”
    d. “In your opinion, what do you think would have been the most helpful for you during the first year that ___(child’s name) lived at the facility?”
    e. “Is there anything you’d like other people to know about what it’s like to be in your position?”

Appendix I
Sociodemographic Questionnaire

Participant name/Alias:
Partner's name/Alias:
Gender:
Age:
Ethnicity:
Location/Where participant resides:
Role in child's life (if not primary, please describe):
Location of child's SNF:
Employment:

- Full-time
- Part-time
- Unemployed

Marital Status

- Single
- Married
- Widowed
- Divorced

Education level

- College graduate
- Some college
- Highschool
- Some highschool

Family situation

- Location of home (What city do you currently live in?)
- Number of other children and relationship to participant

Appendix J
Field Notes

Field Note #: **Participant/Alias:** **Partner/Alias:** **Child's name/Alias:** **Date:** **Time:** **Participant setting:** **Total time spent interviewing:**	
Reflection of notes:	**Field Notes**

Appendix K
Research Study Information Brochure

University of California, Los Angeles

RESEARCH INFORMATION SHEET

Experiences of Parents Whose Disabled Child Resides in a SNF and the Person Who Provides Support During That Experience

INTRODUCTION

Victoria Abatay, RN, MSN-Ed, PhD(c) from the School of Nursing at the University of California, Los Angeles are conducting a research study. This study is being funded by Victoria Abatay. You were selected as a possible participant in this study because *you are a parent or identified as a support person of the parents whose disabled child has been living at a subacute nursing facility for at least one year.* Your participation in this research study is voluntary.

WHAT SHOULD I KNOW ABOUT A RESEARCH STUDY?

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide to participate.
- The interview will be audio recorded.

WHY IS THIS RESEARCH BEING DONE?

The purpose of this research study is to explore and describe the unique experiences of parents whose disabled children have been residing at a subacute nursing facility for at least one year. I am conducting this research study to learn more about how you and your support person have experienced transitions during this time, how this situation has impacted your overall well-being, and how your support person has been helpful for you during this experience.

HOW LONG WILL THE RESEARCH LAST AND WHAT WILL I NEED TO DO?

Participation will take a total of about 1-1.5 hours. I do not anticipate any follow-up interviews.

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Give a verbal consent to voluntarily participate in the study.

- Participate in an interview together with your support person. This interview will be done through video call at a place and time that is convenient for you (ex: Face Time, What'sApp, etc…). The interview will not be video recorded, only the audio will be recorded.
- If you prefer to interview in-person (along with your support person), you can choose a time and place that is most convenient for you.
- If you decide to participate, you may choose to decline the interview being audio recorded. Instead, the researcher will take notes of key findings and observations.
- Answer a 5-7 minute questionnaire about demographics after your interview (ex: age, gender, marital status, education level…).

ARE THERE ANY RISKS IF I PARTICIPATE?

- There are no anticipated physical risks to this study.
- Participating in this interview might bring back some uncomfortable feelings, sadness, or some anxiety from telling your story. If you find some questions difficult to answer, just let me know and we will skip that question.

ARE THERE ANY BENEFITS IF I PARTICIPATE?

You will not benefit directly from participation in this study.

The results of the research may help the nurses and healthcare teams become more aware of your needs and your support person's needs to provide you with improved care. The results of the research might also give helpful information for future parents that are bringing their children to the subacute nursing facility.

What other choices do I have if I choose not to participate?

Participation is strictly voluntary. Your alternative to participating in this research study is to not participate. There is no penalty for choosing to not participate in this study. If you choose to participate, you have the option to withdraw from the study at any time without penalty. Your choice to participate or not participate in the study will not affect the parent's or child's relationship with the subacute nursing facility.

HOW WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible, but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. Study data will be physically and electronically secured. As with any use of electronic means to store data, there is a risk of breach of data security.

In case you disclose information that reveals that you or the child is being harmed or neglected, as a Registered Nurse, I have a legal mandate to report this information to proper authorities to protect your safety. I will also provide you with contact information to receive counseling or support.

Use of personal information that can identify you:
Your name and your support person's name will be attached your interview. All personal identifiers will be kept confidential by the researcher and the research team. Any data collected in this research study will remain confidential, the only people with access to the data will include myself and my selected research team who have all completed research training on how to protect your confidentiality and protect your rights as a participant. Each person that participates in the research will receive a code name or alias during the write up of the findings to protect your identities.

How information about you will be stored:
All information that is collected during the research study will be stored on a password-protected device and on a HIPAA-Compliant file storage system called UCLA Box. While the researcher is traveling to and from interviews, anything that contains information from the participants will remain directly with the researcher until she returns to her private office. The researcher and the trained-research team are the only people that has access to the data that is collected in this study. Any information that is on paper will be kept in a locked cabinet in the private office.

People and agencies that will have access to your information:

The research team, authorized UCLA personnel, and the study sponsor, may have access to study data and records to monitor the study. Research records provided to authorized, non-UCLA personnel will not contain identifiable information about you. Publications and/or presentations that results from this study will not identify you by name.

Employees of the University may have access to identifiable information as part of routine processing of your information, such as lab work or processing payment. However, University employees are bound by strict rules of confidentiality.

How long information from the study will be kept:
All research data will be maintained by the researcher until the study is completed and the results written into the dissertation.

USE OF DATA FOR FUTURE RESEARCH

Your data, including de-identified data may be kept for use in future research.

WILL I BE PAID FOR MY PARTICIPATION?

You and your support person will each receive a $25 Visa gift card (electronic, or physical) at the completion of your interviews.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The research team:
If you have any questions, comments or concerns about the research, you can talk to the one of the researchers. Please contact:
Victoria Abatay, RN: VAbatay2@ucla.edu or (657) 549-1454
Eunice Lee, RN, PhD: EElee@sonnet.ucla.edu

UCLA Office of the Human Research Protection Program (OHRPP):

If you have questions about your rights as a research subject, or you have concerns or suggestions and you want to talk to someone other than the researchers, you may contact the UCLA OHRPP by phone: (310) 206-2040; by email: participants@research.ucla.edu or by mail: Box 951406, Los Angeles, CA 90095-1406.

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

- You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time.
- Whatever decision you make, there will be no penalty to you, and no loss of benefits to which you were otherwise entitled.
- You may refuse to answer any questions that you do not want to answer and still remain in the study.

You will be given a copy of this information to keep for your records.

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