VOICING THE STRENGTHS OF PARENT CAREGIVERS OF MEDICALLY FRAGILE CHILDREN FROM THE PACIFIC ISLANDS AND THE PHILIPPINES

A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE UNIVERSITY OF HAWAII IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY

IN

NURSING

August 2003

by

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This work is affectionately dedicated to

my husband Dick

my daughters Lisa and Marci

and my mother and father

who are angels

who supported me through many experiences

with their love, confidence and encouragement

and brought me to this point in my life
ACKNOWLEDGMENTS

This dissertation emerged from a song of many voices, a holistic blend of every experience to which I have ever been exposed. There were many wonderful people along this path who so generously shared their hearts, talents and minds with me.

I wish to begin by first thanking the many parents of medically fragile children who I have worked with throughout the years. You inspired and motivated me to ask, “Where do you find the strength to provide ongoing care for your child’s intensive needs. To the six parents who participated in this study, I am grateful for your value of this study and your participation. I hold the highest respect for your example of ongoing dedicated love and support for your child.

I wish to convey my deepest gratitude to my Chair, Rosanne Harrigan, for her unfailing support and encouragement. Her mentorship, enthusiasm for knowledge and constructive critique throughout this process provided me with motivation and confidence to pursue this goal. You have stretched my understanding and application of knowledge to a new level. Dr. Harrigan is an outstanding researcher, writer and visionary in health care whom I will forever admire.

My gratitude flows abundantly to all members of my Committee for their thoughtful words of wisdom and continuous support. To Dr. M.J. Amundson, Dr. Dianne Ishida, Dr. Nancy Smith, Dr. Norma Jean Stodden and Dr. Carol Waslien, I wish to express my sincere gratitude. You asked questions and provided suggestions to enhance the expression of the uniqueness of this study and strengthen the results.
I would like to thank all of my colleagues and friends who encouraged me, had faith in my abilities and provided a shoulder to lean on whenever I needed. I will begin with my dear friends, Barbara and Donna, who so graciously informed me that ‘the Universe’ is offering me this opportunity to pursue knowledge. To Clark Ratliffe, my friend and peer who shares the beautiful experience of working with these wonderful families, thank you for your perspective and support throughout this research study. My colleagues at Hawaii Pacific University, Dr. ReNel Davis, Dr. Carol Winters-Moorhead and Barbara Tomlinson, whose willingness to listen and unwavering support provided energy and perspective. I am deeply grateful to Walter Kahumoku III, my qualitative instructor and guide, for giving your time and thoughtful suggestions. To Iris Nolan and Dee Soyo for your sense of humor and positive encouragement that brought a sense of balance to my life.

But most of all, I will forever be grateful to my wonderful family who provided continuous support, respect, perspective and balance and whatever I asked for and did not ask for---they brought a smile to my face and a song to my heart along the way. To my husband Dick, who wholeheartedly encouraged me to pursue this dream. His patience, love, understanding and computer skills helped to make this possible. To my daughter Lisa - my cheerleader, whose presence, love, vibrant energy, humor, realistic perspective and brilliance provided support and motivation in innumerable ways. A special thanks to my mother Lorene, who encouraged me to take care of myself throughout this process and who prays for me often.
ABSTRACT

The growing number of medically fragile children being discharged home to the care of the parent/s and the impact this has on them, demands that health care providers responsibly address the well-being of this population of parent caregivers. Although studies have revealed that this shift to home care greatly impacts the caregiver’s quality of life, research is deficient regarding assessment of the strengths of these parents in providing long-term care for their child, and is deplete of parents from Pacific Island and Filipino populations. The literature reveals that parent caregivers have voiced concern about their own future health. The fundamental purpose of this study was to explore the “strengths”, both internal and external, that are utilized by parents of children who are medically fragile from the Pacific Island and Filipino cultures in caring for their child. The sample consisted of 6 parents who are the primary care providers for their child. Data generation methods included audio-taped interviews and participant observation. Transcripts and field notes were analyzed qualitatively to yield domains, themes and theme clusters. The domains were beliefs, values and attitudes. Twelve themes emerged: 1) handling emotional feelings, 2) problem solving skills, 3) spirituality, 4) taking care of self, 5) family support, 6) finding meaning to the child’s condition, 7) social/community support, 8) positive attitude, 9) resourcefulness, 10) sense of hardiness, 11) focusing on the present, and 12) spending time in nature. The themes were categorized into four theme clusters: positive energy, connectedness, openness to what is and meeting a challenge. The goal of this study was to increase the understanding of parent caregivers of children who are medically fragile, to identify and build on their “strengths” and to
empower these parents to utilize their strengths to better take care of themselves and maintain their well-being.
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Chapter 1
INTRODUCTION

The number of children who are medically fragile being cared for in the U.S. homes continues to rise. Although the actual number of children who are technology dependent and living at home is unknown, these children do fall under the much broader classification of the approximately 6.5% of children in the United States who have a disability (Newacheck & Halfon, 1998). The trend toward home care is increasing based on the cost of hospital care and reduced reimbursement as well as advancement in medical technology which have improved survival rates (Baumgardner & Burtea, 1998; O’Brien, 2001; Patterson, Jernell, Leonard & Titus, 1994). Thus, parents advocate care for the child at home to provide a better quality of life for their child compared to the hospital setting (O’Brien, 2001). To do so, portable equipment has been developed to accommodate the home environment and to facilitate transport of the child.

Little is known about the experience of Pacific Island parents who care for their medically fragile child in the home. Included in this study will be parent caregivers of Filipino ethnicity who are living in Hawaii. The purpose of this study is to explore the strengths, both internal and external, utilized by Pacific Island and Filipino parents who are primary caregivers at home for their child who are medically fragile.

The Office of Technology Assessment [OTA] (1987) defines a child who is medically fragile as, “one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability” (p. 3). Many require significant technological support and intervention including ventilation, oxygen, tube feeding, tracheostomy care, intravenous therapy with
complex medication protocols (Ratliffe, Harrigan, Haley, Tse & Olson, 2002). The
impairments or disabilities of most of these children are frequently of long term duration,
only lasting throughout life.

This shift to home care for the child who is medically fragile has an impact on the
family’s quality of life (Ray & Ritchie, 1993). When a child who is medically fragile
enters into the everyday lifestyle of a family, the impact is felt by the whole family
(Teague et al., 1993) and life as the family once viewed it has changed. The roots of the
family system, their patterns of functioning and their worldview as described by
McCubbin and McCubbin (1996) have been shaken. The parent is in an ongoing position
of vigilance and responsibility, a sense of “never feeling off” (Ratliffe et al., 2002,
p.183). Although a certain number of nursing hours for respite care can be provided, it is
ultimately the parent caregiver who is responsible for assessing and intervening on behalf
of the child in the home (Scharer & Dixon, 1989).

Study Significance

Little is known about the experience of Pacific Island and Filipino parents who live in
the Pacific Islands who care for their child who is medically fragile in the home.
Although Pacific Islanders come from Polynesia, Micronesia, and Melanesia, for
purposes of this study the Filipino population who are at least third generation living in
Hawaii will be included in this population of Pacific Islanders for this study.
Pacific Islanders inhabit thousands of islands with differences in languages, lifestyles,
historical backgrounds, and cultural norms. “Pacific Islanders do share core cultural
values of family, community, spirituality, and a holistic view of life and health”
They also very much value children and their value of children is not dependent on the competency of the child. In these core values, interdependence is a philosophy that is embraced. Working and living in harmony are strongly valued by the Pacific Island cultures (MCH).

The literature has revealed that parents of children who are medically fragile are concerned about their own future health as well as their child’s (Bluebond-Langer, 1996; Miles, Holditch-Davis, Burchinal & Nelson, 1999; O’Brien, 2001; Patterson et al., 1994; Teague et al., 1993). In a study by Ray and Ritchie (1993) parents perceived that they “were expending a level of effort for coping that was depleting their personal health and energy” (p. 222). It is interesting to note that approximately one-third of the parents in this study referred to their own health as a personal factor that influenced their appraisal of coping ability. A form of home care that exerts extraordinary demands on the parent caregiver is children on home ventilator management (Aday & Wagner, 1988; O’Brien, 2001; Scharer & Dixon, 1989; Teague et al., 1993; Wilson, Morse & Penrod, 1998). Incorporated in a philosophy of nursing is the perspective of building on the strengths of clients (Adam, 1980). In an assessment of these parents of chronically ill children, McCubbin and Figley (1983) note that it is important to assess each parent’s strengths and positive coping outcomes. Melnyk, Moldenhauer, Feinstein, and Small (2001) note that “future studies to enhance coping outcomes in parents of chronically ill children are urgently needed” (p. 555).

**Purpose**

The purpose of this study was to explore the strengths, both internal and external, utilized by Pacific Island parents of children who are medically fragile who provide care
for their child in the home. The goal was to identify and build upon the strengths of the individual to mobilize energy and enhance a sense of well-being. For purposes of this study, strength was defined as: an energy which one may replenish via internal and/or external resources that brings forth a sense of connectedness to the present situation. Knowledge is certainly needed concerning what Pacific Island parents use as resources (strengths) in caring for their child who is medically fragile and to provide evidence for approaches to nursing management for these families.

Research Questions

The research questions that were examined in this study are:

1. What do parents from the Pacific Islands describe as strengths, both internal and external, that allow them to provide care for their child who is medically fragile in the home?

2. Specifically where do these Pacific Island parents who are the primary caregiver for their child who is medically fragile find strength?

The literature was reviewed to explore the studies that have been done in the home setting as they are related to: strengths of caregivers, parent caregivers of medically fragile children, Pacific Island parent caregivers of medically fragile children, parent caregivers of chronically ill children, and Pacific Island caregivers of chronically ill children.
Chapter 2

REVIEW OF THE LITERATURE

The following review of the literature begins by clarifying the terms medically fragile children and chronically ill children as referred to in this study. Discussion of the philosophical perspective concerning the nature of this study is then addressed. This chapter then explores the research based literature related to parents as caregivers of children who are medically fragile and children who are chronically ill. Research based studies have been reviewed to identify the strengths of these caregivers. Articles related to concept analysis of themes of strength that emerged from the literature have also been explored. The number of studies about the Pacific Island population are also addressed. Finally, the national perspective reflecting the gaps in health care are discussed.

Medically Fragile versus Chronically Ill Children

Multiple terms are used in the literature in referring to children who are medically fragile and children with a long-term chronic illness. Terms such as: ventilator dependent (Scharer & Dixon, 1989; Wilson et al., 1998), technology dependent (O’Brien, 2001; Teague et al., 1993), technology-assisted (Stephenson, 1999;), medically complex (Diehl, Moffitt & Wade, 1991), medically fragile (Leonard, Brust & Nelson, 1993; Youngblut, Brennan & Swegart, 1994;), chronically ill (Ray, 2002; Ray & Ritchie, 1993), and children with special health care needs (Hartman, Radin & McConnell, 1992) have been found in the literature to refer to children who are medically fragile. Although these terms include a wide range of severity of health needs, they are often used interchangeably. This makes for confusion in identifying a specific population of
children. In keeping with the respectful and acceptable manner of addressing the “person first”, throughout this study, the “child who is medically fragile” will be referred to in this manner or simply as the “child”.

Although the OTA (1987) identifies five classifications for children with chronic complex medical needs, for purposes of this study, the population will only include “one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability” (OTA, 1987, p. 3). These children represent those with the most pervasive and intensive needs to be addressed by the parent caregivers. All others are considered chronically ill children.

Conceptual Orientation

The conceptual orientation of this study was based on the Non-dualistic Paradigm: Beyond Connectedness by Ratliffe and Haley (2002). This Paradigm was initially presented as an inclusive ontologic and epistemologic basis to address individuals with a wide array of disabilities. The Non-dualistic Paradigm acknowledges that each individual is unique and interprets and expresses thoughts through an understanding of information and life experience which becomes the perspective through which the world is viewed. The two major concepts in this Paradigm, connectedness and energy, provide the conceptual orientation for this study.

Connectedness is defined in this Paradigm as, “a unification of the body, mind, and spirit in which a sense of the physical boundaries of one’s body/mind extend to include other persons and the natural environment in an unconditional oneness. The antecedents of connectedness are identified as: 1) life experience, 2) interpersonal connection, 3)
presence and 4) openness and receptivity. Outcomes of connectedness are harmony and an increased meaningfulness of life (Ratliffe & Haley, 2002, p.131).

The second major concept of this Paradigm is energy. Energy is seen as the person-environment being energy fields involved in an ongoing interaction where boundaries extend beyond the physical mass (Ratliffe & Haley, 2002, p. 132). This is akin to Martha Rogers’ Theory, which she called the “Science of Unitary Human Beings.” To Rodgers, “A unitary human being is a unified human being integral with the environment. Man is in continuous mutual process with his environment in his totality and the whole cannot be understood when it is reduced to particulars” (Rodgers, 1970, p.44). Rodgers goes on to describe man as being, “an irreducible, indivisible energy field in constant interaction with the environment, which is a pandimensional energy field. Each environmental field is specific to its given human field. Environmental fields are infinite, and change is continuously innovative and unpredictable. Environmental and human fields are in continuous and mutual process” (1992, p.32).

In the Non-dualistic Paradigm persons are a totality that are constantly interchanging matter and energy with their environment. Here body, mind, spirit and environment are also one and the same thing. In viewing existence as “one seamless whole” people are, therefore, born neither good nor bad, but rather as a particular expression of all the causes that result in this moment. One many tend in one direction or another, but the underlying principle is one of infinite possibility at each moment. Existence is made up of energy fields that can be thought of as spheres that extend in all directions to infinity. These “spheres of influence” are dynamic, without fixation and in constant and pervasive flux. Since these spheres are infinite, the distinction between self and other is illusory. Ratliffe
and Haley (2002) refer to this as "interbeing", noting that our nature is interdependent and intimately intertwined with everything around us.

It is proposed that the philosophy of this Paradigm can be applied to human beings in infinite situations to “promote well-being”. In this study, it will be applied to parent caregivers to promote their well-being or harmony. “Interventions, whether medical, educational or otherwise are usually an attempt to introduce some measure of equilibrium in an out of balance energy interplay” (Ratliffe & Haley, 2002, p.135). In the Non-dualistic Paradigm, interventions are not viewed as ‘caring for’ others, but more of a ‘dance’ with them. In the interest of providing a more thorough understanding of the dynamic experience of the parent caregivers of children who are medically fragile, the literature is reviewed to identify their strengths.

Strengths of Parent Caregivers

The review of the literature of parent caregivers of children who are medically fragile and children who are chronically ill revealed several resources (strengths) that parents had that were found embedded in these studies done for a variety of purposes. Defining attributes are those characteristics most frequently associated with the phenomenon of study (Walker & Avant, 1995). In the review of the literature on “strength”, the attributes that emerged were: coping, spirituality, taking care of self, finding meaning, social support, family support, optimism, vitality, resourcefulness, and meeting a challenge. A thematic table was developed in an effort to categorize and provide a synthesized definition of these themes of strength (Table 1).
<table>
<thead>
<tr>
<th>Author/year</th>
<th>Variable</th>
<th>Synthesis/Definition</th>
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<tbody>
<tr>
<td>Cohen &amp; Lazarus (1983); Diehl et al. (1991); Hartman et al. (1992); Lazarus &amp; Folkman (1984); O'Brien (2001); Ray (2002); Ray &amp; Ritchie (1993); Wilson (1998)</td>
<td>Coping/Problem Solving</td>
<td>Coping regulates emotional responses &amp; is used to solve problems. It is used to regulate both internal and external demands.</td>
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<tr>
<td>Haase et al. (1992); Hover-Kramer et al. (1996); Nightingale (1860); Westbrook (1998); Wilson et al. (1998); Youngblut, Brennan &amp; Swegart (1994)</td>
<td>Spirituality</td>
<td>&quot;A source of strength and guidance for doing one's work in the world&quot; (Nightingale, 1860 p.205). A resource that enhanced the provision of home care of the child; an integrating and creative energy based on beliefs &amp; feelings of interconnectedness with a power greater than self-outcomes are: purpose and meaning in life/guidance of human values/transcend &amp; reach out /rise above personal concerns &amp; the realm of the material (Haase et al., 1992).</td>
</tr>
<tr>
<td>Gibson (1995); Hover-Kramer et al. (1996); O'Brien (2001); Ray (2002); Ray &amp; Ritchie (1993); Setz &amp; Brown (1997); Williams &amp; Williams (1990)</td>
<td>Self-Care/Finding Meaning</td>
<td>One's sense of connectedness with an inner-source of strength. Ability to integrate present with past experience, motivations &amp; goals &amp; find meaning in the present experience. Experiencing life in a meaningful way even within a difficult situation. Attention given to one's own body, mind or spirit in the present moment. Re-examining own values and developing talents and a sense of personal power-awareness of one's own strengths and abilities.</td>
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Themes of Strength related to Caregivers (continued)

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<th>References</th>
<th>Social Support</th>
<th>Family Support</th>
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<tr>
<td>Diehl et al. (1991); Gibson (1986); Hartman et al. (1992); Kohlen et al. (2000); Leonard et al. (1993); Melnyk &amp; Alpert</td>
<td>Social support has been identified as a factor that contributes to an individual’s state of wellness (physical &amp; mental, as well as social functioning). It reduces psychological stress related to intense stressors. The concept of empowerment may be viewed as an outcome of this variable; it is an intervention by another and the caregiver that is designed to optimize the family’s power/strength and enhance the member’s ability to effectively care for the child and sustain their family life.</td>
<td>Family relations were found to be a source of strength regardless of type of hospital discharge. In exploring the concept of resiliency, the family strengths/support is identified as an attribute. Communication was also brought out as a variable in 2 studies that enhanced family support by providing a strong sense of relationship.</td>
</tr>
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<td>Gillis (1998); O’Brien (2001); Patterson et al. (1994); Ray (2002); Scharer &amp; Dixon (1989); Stephenson (1999); Wilson et al. (1998); Youngblut et al. (1994)</td>
<td></td>
<td></td>
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<tr>
<td>O’Brien (2001); McCubbin &amp; McCubbin (1996); Ray &amp; Ritchie (1993); Scharer &amp; Dixon (1989); Stephenson (1999); Youngblut et al. (1994)</td>
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<td></td>
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<tr>
<td>Themes of Strength related to Caregivers (continued)</td>
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<tr>
<td>Hover-Kramer et al, (1996); O’Brien (2001); Ray (2002); Ray &amp; Ritchie (1993); Scharer &amp; Dixon (1989); Wilson et al. (1998); Youngblut et al. (1994)</td>
<td>Optimism/ Vitality</td>
<td>Believing that things will work out; maintaining a positive attitude; finding positive aspects in the situation emerged in these studies of caregivers. The concept of vitality encompasses maintaining a personal energy &amp; enthusiasm—“it is a sense of aliveness, optimism and well-being that arises from within; a positive energy that comes from within” Hover-Kramer, Mabbett &amp; Shames (1996).</td>
</tr>
<tr>
<td>O’Brien (2001); Ray (2002); Scharer &amp; Dixon (1989); Stephenson (1999); Wilson et al (1998)</td>
<td>Resourceful</td>
<td>A broad category that was identified to support the caregiver; recognizing the need for assistance/support and seeking it out.</td>
</tr>
<tr>
<td>McCubbin &amp; McCubbin (1996); O’Brien (2001); Ray (2002); Ray &amp; Ritchie (1993); Teague et al (1993); Wilson et al (1998)</td>
<td>Meeting a Challenge/ Fortitude</td>
<td>An individual is hardy to the degree that one evaluates a stressor as a challenge, is committed to living with the changes &amp; perceives that one has control over those changes (McCubbin &amp; McCubbin, 1986). Fortitude encompasses one’s inner strength and durability—a readiness, strength &amp; stamina to face the challenge.</td>
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The literature review reflected qualitative, quantitative and triangulated studies with the number of participants ranging from 1 to 172. The purpose of most of the studies was directed toward examining the experience of the family or caregiver. Central to this experience was care giving burden, psychological distress, quality of life, relationship of stressors and coping mechanisms, and the impact the child had on the family.

In the majority of the studies, a mix of chronically ill and medically fragile children was combined in the participant population. A wide range of severity of chronic illnesses and medical fragileness of health conditions were included. These ranged from premature infants with low birth weight on apnea monitors and children needing crutches to assist with mobility to children on ventilators 24 hours a day. There were only three studies that truly reflected the child who was medically fragile with a level of intense care needs and dependence on technology identified as a distinct population from the chronically ill population. Two focused on the family’s quality of life and one examined the mother’s overall experience. Most of these studies reflected a convenience sample of caregivers varying from parents, grandmothers, aunts, uncles, legal guardians. Only one study with participants solely of “mothers” identified the caregiver as the “primary” caregiver of the child, all other studies assumed the mother to be the primary caregiver. One study included fathers. There was only one study that addressed long term care of the child in the home, and this was identified to be greater than 1 ½ years duration.

Of all the studies found in this review of the literature, only three identified the ethnicity of the population in the studies and these strongly represented the Caucasian ethnicity. O’Brien (2001) identified the study population as Euro-American and one African American and stated the study was done in the Mid-West; Setz and Brown
identified their study population to be 24 Caucasian and 2 African Americans (1997); Teague et al. identified the population in their study to be composed of 67% Caucasian and 33% mixed with no breakdown of the mixed population (1993). The remainder of the studies did not address ethnicity, however, six of the studies noted that they were done in the Mid-West (Leonard et al., 1993; Patterson et al., 1998; Scharer & Dixon, 1989; Stephenson, 1999; Youngblut et al., 1994). No studies reflecting Pacific Islander populations were identified.

As the themes emerged from these studies, concept analysis articles were used by this researcher to further clarify concepts related to an understanding of strength. Based on all of these studies, there is an absence of research specifically designed to address the strengths of mothers and fathers as long term caregivers of children who are medically fragile. Furthermore, there is no research reflecting this population of caregivers in the Pacific Islands.

A representative sampling of the overall findings in the research studies and concept analysis for each theme of strength is discussed below.

Coping

A few studies identified the broad concept of coping as a strength (Cohen & Lazarus, 1983; Lazarus & Folkman, 1984; Stephenson, 1999). In these studies the researcher simply identified that caregivers found strength through the use of coping strategies. In their classical work related to coping, Lazarus and Folkman (1984) identified two types of coping: 1) emotional coping—where one seeks to regulate emotional responses to stress and 2) functional coping—where one seeks to solve a problem. They defined coping as, "constantly changing cognitive and behavioral efforts to manage specific external and
internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p 141).

Studies that specifically identified problem solving as a means of managing stress included O’Brien (2001), Ray (2002), Ray and Ritchie (1993), and Wilson et al. (1998). O’Brien (2001) discussed the parents’ in-depth knowledge about various devices and treatments for the child. Other studies (Ray, 2002; Ray & Ritchie, 1993; Wilson et al. 1998) described the parents’ need to assess and differentiate emergency from non-emergency type symptoms and know when and how to respond. Diehl et al. (1991) discussed interacting with other parents to help define their needs and work on problem solving as a means of acquiring skills.

Furthermore, O’Brien (2001), Ray (2002) and Youngblut (1994) all addressed the parent caregivers handling their emotional feelings and their need to communicate these feelings. O’Brien found that extended family and sometimes friends provided emotional support. However, Hartman et al. (1992) in their discussion of parent-to-parent support noted that because family members and previously close friends are often uncomfortable around the child or they are grieving for the child and the parents, the new parents of a child with a chronic illness or disability are often burdened with coming to terms with their own grief. It is noted that it is often the parents of these children who are the ones who are comforting their own parents and/or extended family members. Diehl et al. (1991) agreed with Hartman et al. in their findings that parents of children with special health care needs experienced conflicting emotions, and their need to talk with someone who would understand their experience. They usually spoke with another parent whose child had a similar health problem to their own child’s.
Spirituality

Wilson, Morse, and Penrod’s study (1998) addressed children who are medically fragile and found that religious beliefs, as well as personal/social support were attributes that enhanced the mother’s effort to provide home care. These mothers perceived responsibility for their children’s care as being a “shared” responsibility with others. This represents strengths found in spirituality, as well as social and family support. Westbrooks (1998) and Youngblut et al. (1994) agreed that spirituality is a resource that enhances the ability of the caregiver to provide ongoing home care of the chronically ill child. Haase, Britt, Coward, Leidy and Penn (1992) and Florence Nightengale (1860) also concurred with the perception of spirituality as a theme of strength. Nightengale described it as, “A source of strength and guidance for doing one’s work in the world” (p.205). Hover-Kramer, Mabbett and Shames (1996) found spiritual support to be a key element in maintaining “vitality”. Hover-Kramer et al. (1996) and Haase et al., (1992) both agreed that one integrates or is dependent upon an energy source greater than one’s own in defining spirituality.

Taking Care of Self

Ray and Ritchie (1993) found parents in their study who had a perception of constant unending care giving and their inability to have a break from the care giving role experienced a sense of being overwhelmed and exhausted. It is proposed that self-care or taking care of self is an essential component of those who provide caring for others. “In addition to being strengthened by the basics of adequate rest, relaxation, exercise and nutritional balance, vitality is strengthened by having an ally who understands your vision and supports you in your aims” (Hover-Kramer et al., 1996, p. 43). One of the
themes that emerged as a consequence of care giving, in a study by Setz and Brown (1997), was “coming to know one’s own strength” (p. 19). They noted that “in the presence of suffering, many of these caregivers reported that their strengths emerged” (p. 19). “Learning to care for self” was a sub-theme that also emerged and is defined as “giving oneself permission to focus on one’s own needs” (p. 19). This is in agreement with Hover-Kramer, et al. (1996) noting that self-care is an important aspect for caregivers in order to provide ongoing care without being overwhelmed. Despite its importance, Ray (2002) found that all parents had fatigue, few exercised, and most claimed they did not care for their own physical health as they should.

Critical reflection can be considered as another form of self care. Gibson (1995) found critical reflection to be a necessary process for caregivers to be able to take charge of their situation. This activity enhanced the development of a sense of personal power. Gibson noted that through this process, “mothers became aware of their strengths, abilities, and resources” (p. 206).

Finding Meaning

Williams and Williams’ (1990) found that parents of infants on cardiac and apnea monitors tried to normalize, reframe, or give meaning to their situation. Similarly, a study by O’Brien (2001) examined the family experience of living with a child who is medically fragile. She found that reframing the situation contributed to the family’s adjustment and adaptation. This included reexamining beliefs and values, changing some priorities in life, having a sense of humor, optimism and hope for future. Other strengths identified were: reconciling past and present (not blaming or feeling victimized), and finding purpose in events that have occurred. Ray (2002) interestingly identified an outcome of her study to be
“constructing sustaining interpretations”. She found that parents who constructed a more positive interpretation of the child’s situation were more successful in receiving help.

Social support

Melnyk and Allpert-Gillis (1998) identified social support as being a significant factor in buffering parents’ ability to adapt to caring for a chronically ill child after hospital discharge. In a study of chronically ill children, Youngblut et al. (1994) noted the specific strengths of social support to be: advice from professionals and mobilizing the family to acquire and accept help. Similar findings of strength were reported by Gibson (1986) in her study of parents with a chronically ill child, stating that “parents reported social support and concentrating on positive aspects of the situation to be the most helpful coping strategies” (p.16). Support groups were described as an invaluable service by participants in a study by Diehl et al. (1991). This study reflected caregivers of both children who are medically fragile and chronically ill children. Hartman et al. (1992) also agree that social support, specifically in the form of an informal peer support network of parents to be beneficial in the line of buffering stress and promoting health. Since parents with similar situations are supporting each other, parent-to-parent support works because they are particularly qualified to help each other. O’Brien (2001) agrees, sharing that parents dealt with feelings of isolation and decreased support from previous friends by receiving support from other parents who had children with special needs. Stephenson (1999) found that each family identified a family member, friend or person/s in the community to be a source of support.

Ray (2002) and Patterson et al. (1994) both discussed the professional and social support received from respite nurses. Patterson et al. found that professionally trained nurses were
viewed as sources of support to parents in comparison to those who were para-professionals. A few studies found that mothers believed they shared responsibility for the child's care and well-being with other caregivers (Kohlen, Beier and Danzer, 2000; Leonard et al., 1993; Wilson et al., 1994).

Family support

Youngblut et al. (1994) identified the following as strengths of parents in the area of family support: trust, shared values and beliefs, ability to express feelings with few conflicts, sharing difficulties with relatives, family pride and loyalty, and the belief that things will turn out well. In a study by Stephenson (1999), family support as well as religion and personal self-fulfillment emerged as strengths. In studies involving parent caregivers of children who are medically fragile, O'Brien (2001), Ray and Ritchie, (1993) and Scharer and Dixon (1989) also agree that family support was an important factor in coping. Interesting Wilson et al., (1998) note that although it is expected that in the home setting the whole family shares conjointly in the care of a child who is medically fragile, in reality it is the mother who assumes the primary caregiver role in addition to her other roles.

Vitality

Hover-Kramer et al. (1996) provided a concept analysis of vitality which stemmed from a concern for caregiver stress. They noted that "vitality" is maintained when one perceives a higher purpose to one's activities. It is also strengthened by focusing on the present moment. Incorporated in this concept is a sense of optimism. A theme that emerged in several studies (O'Brien, 2001; Ray 2002; Ray and Ritchie, 1993; Scharer and Dixon, 1989; Youngblut et al., 1994) was that of maintaining an optimistic outlook. It encompassed the parent having a
positive attitude toward the child, toward his/her life and having a sense of optimism in the present situation. Ray and Ritchie found that this need to have a positive outlook was noted in half of the 29 parents in their study.

The concept of vitality also included the parent’s ability to focus on the present time. Wilson et al. (1998) discussed a mother’s reframing time to focus on the present. Ray and Ritchie (1993) identified the parent’s ability to address time-limited portions or event-limited portions of problems. In both Ray and Ritchie’s study and Scharer and Dixon’s (1989) study the parents stated the need to take and live one day at a time. Ray and Ritchie, Scharer and Dixon and Wilson et al. all agree that focusing on the here and now is a means of managing multiple tasks and roles.

Resourcefulness

Stephenson (1999) compared coping and well-being of families with healthy infants to families whose infants had varying levels of severity of medical fragility. She found no significant difference between the two groups in mobilizing their resources to deal with the needs of their new infants. In a study by Scharer and Dixon (1989), parents of children who were medically fragile spoke of finding resources to educate themselves as a means of obtaining answers. Wilson et al. (1998) found that parents were committed to learning and seeking information as a means of addressing identified needs. O’Brien (2001) identified exchange of information among other parents to be a key resource for parents. Ray (2002) spoke of parents “working the system” to try to address the needs of their child. She noted that parents spent an extraordinary amount of time by trial and error or word of mouth searching for information, people and services.
Meeting a Challenge/Fortitude

Teague et al., (1993) found that parent caregivers of children identified that although the job of caring for a child who is technology dependent is rigorous, parents felt that providing care for the child was the best aspect and “learning to manage their child’s illness made them feel better about themselves” (p. 230). O’Brien (2001), Ray (2002) and Ray and Ritchie (1993) discussed how parents were dedicated to doing their best and doing everything possible for their child.

To summarize, a number of attributes of strength emerged from the literature. These attributes were used as a framework to develop the interview guide to promote discussion on the topic of “strength” following the open-ended questions. These studies reflected those of caregivers of both children who are medically fragile and chronically ill children. Other literature included were concept articles that further explained concepts that emerged from the themes of strength that were identified in the studies. No studies representing the Pacific Island population have been identified in the literature.

National Objectives

The Healthy People 2010 goals and objectives reflect the gaps in health care identified by the U.S. Department of Health and Human Services (USDHHS) that need to be addressed. Both of the overarching goals of Healthy People 2010 (USDHHS, 2000) apply to this problem. One of the goals is “to eliminate health disparities among different segments of the population”. It has been identified that no research studies are reported in the literature regarding parent caregivers of children who are medically fragile in Hawaii. Hawaii reflects a rich representation of diverse ethnicities. The parents in this study represent a broad variety
of cultures that include Hawaiian, Marshallese, Samoan, and Filipino. The majority of families are from Hawaiian and Pacific Island heritage whose cultures predominantly foster values of collectivism (MSH, 2001).

The experience of caring for a child who is medically fragile in the home is multifaceted. Healthy People 2010, Objective 16-22, reads that the purpose of this legislation is, “to increase the proportion of children with special health care needs who have access to a medical home”. It also notes that “Family-centered care recognizes that the family is the principal caregiver and the center of strength and support for these children” (USDHHS, 2000). Families are considered key to an effective rehabilitation effort (Flannery, 1991), especially when one or both of the parents assumes the role of primary care giver for the medically fragile child, as well as other roles and responsibilities in the family system.

The second overarching goal addressed is “to increase quality and years of healthy life” (USDHHS, 2000). This goal addresses issues related to helping individuals of all ages increase life expectancy and to improve their quality of life. Caregivers of children who are medically fragile voice concern about both issues.

Although the whole family is affected, this study addresses the primary caregiver/s of the child who is medically fragile. The literature reflects multiple studies documenting the pervasive stressors that parents caring for medically fragile children encounter. These include: need for constant vigilance, lack of privacy, strain on financial resources, management of high tech equipment, navigating the health care system, communicating with a variety of health care providers and support systems, making decisions about their child’s health care, disrupted relationships, and social isolation (Baumgardner & Burtea,
1998; Boland & Sims, 1996; O’Brien, 2001; Ratliffe et al., 2002; Stephenson, 1999; Teague et al. 1993; Youngblut et al., 1994). However, there is a lack of research identifying the strengths found by the primary care givers providing long-term care to medically fragile children. There is no research on the population of parent caregivers from Pacific Islands. Building on these strengths may improve the quality of life for the parent caregiver.
Chapter 3

METHODOLOGY

This chapter presents the procedures that were employed to examine where parent caregivers of children who are medically fragile from Pacific Island populations found strength to address the pervasive needs of their child. Discussion of the research design, background and role of researcher, setting and sample, protection of human subjects, data collection procedure, insurance of credibility and quality, and method of data analysis are presented.

Research Design

This research reflects a naturalistic paradigm in an effort to explore the strengths of Pacific Island parent caregivers of children who are medically fragile. Lincoln and Guba (1985) identify the salient aspects of the naturalistic paradigm to be:

1) nature of reality: realities are multiple, constructed and holistic, 2) relationship of knower to the known: knower and known are interactive, inseparable, 3) possibility of generalization: only time- and context-bound working hypothesis statements are possible (this is not to be confused with generalizing to a larger population), 4) possibility of causal linkages: all entities are in a state of mutual simultaneous shaping, so that it is impossible to distinguish causes from effects, 5) role of values: inquiry is value-bound (p. 37)

The research design is also ethnographic in that such studies try to uncover the beliefs, values, and attitudes that lie beneath the behavior of a specific group of people (Merriam, 2001). In this study, the society or culture was that of parent caregivers of children who are medically fragile. This population of caregivers live in the Pacific
Islands and are of Hawaiian, American Samoan, Filipino and the Marshallese ethnicities who are living in Hawaii. The researcher sought to uncover the beliefs and values of individual caregivers and investigated the idea of 'strength' in terms of its source and how each participant uses it to replenish his/her energy. In viewing these understandings against the backdrop of the participants’ overall worldview or 'culture', the researcher strove to see each strength from the perspectives of the participants (Merriam, 2001). This study provided a voice to this population and the information gained could hopefully expand nurses’ understanding of this phenomena and be used in developing interventions to be tested and utilized so that the client’s strengths can be enhanced or at least recognized.

Background of Researcher

This section discusses the researcher of this study in an effort to acknowledge the threat of bias. Since the investigator is the primary instrument for gathering and analyzing data in qualitative research studies, the instrument is limited by being human. “Human instruments are as fallible as any other research instrument” (Merriam, 2001, p.20). The researcher must not only be sensitive to her own personality characteristics and skills necessary for this type of research, but must also be aware of any personal biases and how they may influence the investigation. The following description of this researcher attempts to bring forth this information.

I am a 50 year old, English speaking, Caucasian female, who has worked as a registered nurse in both the hospital setting and in the community with children and families for more than 30 years. Twenty five years ago I had a child who was diagnosed
with cancer, was medically fragile and died within one year of diagnosis. I feel that I can understand many of the situations that parents of children who are medically fragile experience. I have worked as a school nurse practitioner for a large, multi-ethnic, low socio-economic school district in Southern California for a period of 7 years. In this setting I functioned as a pediatric nurse practitioner and case manager for infants 0-3 years of age who were severely disabled and medically fragile. I followed these children in their homes as well as in the school setting.

For the past 7 years I held the position of graduate assistant in a research study. One of my roles was to act as a community health nurse, case manager for children who were medically fragile in the State of Hawai`i. I followed these children from discharge planning in the hospital, through discharge, and provided weekly home visits or phone follow up for a period of 12 months. These families had a supportive relationship with me.

I am also on faculty in the School of Nursing at Hawaii Pacific University. As an Assistant Professor of Nursing, I teach pediatrics and community health nursing in both the graduate and the undergraduate programs. I am a certified pediatric nurse practitioner and a family nurse practitioner. I have a post-masters Interdisciplinary Certificate in Disability Studies.

My world view is that of a non-dualistic paradigm versus that of a dualistic paradigm. I do not see myself as separate from other. Whatever happens to the other also influences me and visa-versa. We are all equally of one energy or spirit. In caring for numerous families throughout the years, I have observed first hand that some parent caregivers of children who are medically fragile have appeared to incorporate the
accompanying enormous changes in lifestyle more smoothly than others. Although I appreciate this to be a complex phenomenon, I have often wondered what strengths these families draw upon.

Role of Researcher

The primary role of the researcher is that of being “the instrument” for collecting and analyzing data. Prior to each interview, I reflected on my previous experience, both personal and with prior visits to these participants as having a potentially biasing effect. I consciously tried to set aside any preconceived ideas or expectations about strengths to the best of my ability so as not to influence the participant’s view.

This researcher was previously in the role of participant/observer with these Pacific Island families in a former research study. In that study the researcher worked with the parents and the child who was medically fragile prior to hospital discharge and followed them into the home environment. Each family was followed for a period of twelve months on a weekly basis. Relationships were developed between the researcher and the families during this period. The researcher was in the role of observer/participant. The participants were knowledgeable of the researcher’s roles of observation and participation. However, participation was the more dominant role rather than observer (Merriam). Wing (1989) defines participant-observation as, “the collection of data from a community, whereby the researcher becomes a member of the community” (p. 126). The researcher played an active membership role as a case manager in this previous research study. Trust had been established with this population of parent caregivers prior to beginning this present research study.
Data Collection

The location of the study was in the State of Hawai’i on the islands of O’ahu and Hawai’i. The participating families resided in both suburban and rural areas. The homes of the participants became the setting for the interviews. The parents created an optimal place for the child to be included in family activity in spite of all the necessary and noisy equipment. The child’s room represented a “miniature intensive care unit” with ventilators, compressors, oxygen tanks, suction, feeding and intravenous equipment and accompanying alarms. Medications, boxes of supplies and documentation records were strategically placed out of view. All of these children resided in the front and central living area of the home or shared a bedroom with a sibling.

Participants

Purposive sampling was used in obtaining participants for this study. Purposive sampling is used when the researcher wishes to discover, understand, and gain insight into a specific phenomena, therefore, selects a sample from which the most information can be gained to achieve this objective (Chein, 1981). Selection of respondents on the basis of what they could contribute to the understanding of the phenomenon of “strength” of parent caregivers of children who are medically fragile was the objective. The criteria for sample selection was that: 1) the parent be a caregiver of a medically fragile child who is of Pacific Island ethnicity and living in the State of Hawai’i, 2) the parent must speak English---this is the language the researcher speaks, 3) the parent was in an intact relationship with their spouse/partner---this was kept consistent to equally give each participant the opportunity to identify the spouse as a source of strength, 4) the parent was to be the primary caregiver for their child who was medically fragile in the home.
setting, providing at least 50% of the child's care—it was felt that this parent may feel
more stress and need to identify and tap into sources of strength related to the role of
parent caregiver more frequently than one who provides less care for the child—it also
gave mothers and fathers an equal opportunity to state who provides most of the care for
the child—and an opportunity to hear both female and male voices, and 5) the child was
considered medically fragile for this study if he/she met the previously stated criteria—
these children represented those children who are medically fragile who have the most
pervasive and intensive needs to be addressed by the caregiver—their health is in the
least stable state of this population of children. Children were to be less than 18 years of
age. The sample of parents was selected from those who participated in the previous
study and were previously cared for in the children's hospital that serves children in the
Pacific Basin. The sample size was that of six parents who represented six different
families. Of the twelve families in the previous study, seven met the criteria, however
only six agreed to participate. Trust had already been established—this researcher
supported these parents on a weekly basis during the stressful period of transitioning their
child to the home setting for a period of one year. Continued contact with them occurred
over the following 1 ½ years.

Six parents identified themselves as being the primary caregiver who provided at
least half of the care for their child who is medically fragile in the home were
interviewed. There has been an ongoing supportive relationship between the researcher
and these parents for the past 2 ½ - 3 years. This relationship was created through a
previous research study in which these parents participated. It occurred during the
stressful period of transitioning their child from hospital to home. The ethnicity of
participants were: Hawaiian (2), Filipino (2), Samoan (1) and Marshallese (1). Three of the participants were male and three female. The age of the parent caregivers ranged from 22–37 years old. In addition to the child who is medically fragile, all participants had from one to five other children ranging in age from 7 months to 19 years old. At the time of the interview, three of the six families were expecting another child. It was also interesting to note that three of these six parents lived in homes adjacent to their parents.

Protection of Human Subjects

Prior to data collection, the participant consent form (Appendix A) was submitted to the University of Hawaii Institutional Review Board (IRB) for approval (Appendix B). After receiving approval, the researcher phoned each perspective participant to obtain permission to participate in the study. Written consent for the interview was obtained by the researcher prior to data collection.

The study was described to all participants. The researcher described the voluntary nature of the study, and the participant’s right to withdraw at any time without any consequence to the parent or the child. Questions parent caregivers had about the study were addressed. Each participant received a copy of the signed consent form which contained the researcher’s phone number should there be further questions at the time of signing the consent.

To assure confidentiality, the researcher offered the participants the option of using a pseudo-name or their true name for identification purposes during the taped interview. The participants chose any pseudo-name they liked. No names were used for any of the participants in this study report. Unidentifying terms, such as mother, father or parent were used in referring to participants. The researcher kept a separate list of participant’s
true names and the pseudo-name chosen to use in the study in a locked file. This was available if needed for clarification purposes. Only thesis committee members and one outside expert in the field had access to reviewing the transcribed interviews.

Data Collection Procedure

The researcher was the interviewer in this study. “Interviewing is necessary when we cannot observe behavior, feelings, or how people interpret the world around them” (Merriam, 1998, p. 72). The interview is described as being a powerful tool for data collection (Tashakkori & Teddlie, 1998). It offers one-to-one interaction between the researcher and the participant and it provides an opportunity to ask for clarification or to provide it if a question is not clear (Tashakkori & Teddlie). A large amount of information can result from open-ended interviews. Such information might lead to an understanding of phenomena in ways totally different from what the researcher may expect. This was an appropriate method in the home setting environment, to carry on a focused and purposeful conversation to get into the thoughts and perceptions of the caregivers. The “primary” parent caregiver was interviewed. However, if both parents claimed to equally share this role, then they decided which one was to be interviewed.

An initial phone call was made to assess willingness of potential subjects to participate in the study. Following the agreement to participate, the researcher set up a date and time for the interview. The researcher arrived as scheduled with the interview guide. The semi-structured interview guide consisted of questions related to demographic data, 4-5 open-ended questions and probes that focused on the purpose of the research (Appendix C).
The interviews were tape recorded to insure a thorough collection of data and to preserve everything for analysis. Participants were informed of the taping of the interview and a small tape recorder was placed between the researcher and the parent. The interview began when the participant was ready. Five of the parents had arranged for someone to provide care for their child during the interview, and one addressed the needs of the child throughout the interview period. The interview questions were given to the participant one at a time. The researcher did use supplemental comments or follow-up questions such as, “How did you feel when….?” and “Can you tell me more about…?” to encourage further elaboration of ideas. These questions are also known as probes, and they are dependent on how the participant answers the lead question (Merriam, 2001).

Participant interviews lasted from 65 to 135 minutes. When a new theme emerged during data analysis, the participants were offered the option of a home or phone interview to provide data pertaining to the new theme. Phone calls were also made to clarify data.

Field notes were taken throughout the interview and during the period following the tape recorder being turned off. This was done to describe the environment, the body language and the behaviors that cannot be captured on the audio tape. It was also used to note other comments the parent stated following turning the tape recorder off, such as, during the period of walking together to the front door or the car.

Upon completion of the initial interview the researcher thanked each participant. A gift certificate of $25 was presented to each participant as acknowledgment for their time and effort. Participants were informed that they would be hearing from the researcher in the near future to verify the write up of the findings.
Analysis of Data

Data analysis was done simultaneously with the data collection using the constant comparative method. Following the first interview, the tape was transcribed, the narrative was read and reread, coded for thematic statements and entered into the Text-Smart qualitative analysis computer program. This program analyzed the text for frequency of words and synonyms to the words then categorizes the data. Participant follow-up phone calls occurred as needed to clarify and/or add to data when new themes were identified as the study progressed. The second participant's interview was then taped, transcribed, read and reread, coded and submitted to the Text-Smart Program. This information was compared with the first set of data. After the third interview was completed, transcribed, read and reread, coded and analyzed by the Text-Smart Program, this data was then compared with the two previous sets of data. The three remaining data sets were taped, transcribed, read and reread, coded, inputted and analyzed in the same manner as described above. When the data had been inserted, the themes were categorized. The researcher knew that enough data had been collected when saturation of categories and emergence of regularities was perceived as described by Lincoln and Guba (1985). This occurred when there was no new information being shared by the parents as to sources where they found strength and repeated regularities of responses were noted.

Ensuring Quality and Credibility

Trustworthiness is identified as the fundamental criterion for study integrity in qualitative research. This study design included the criterion identified by Lincoln and
Guba (1985), to establish trustworthiness of findings. These criterion are: credibility, transferability, dependability and conformability.

* **Credibility.** The "truth" of the findings, as viewed through the eyes of those being observed or interviewed and within the context in which the research is carried out.

* **Transferability.** The applicability of the findings to different settings. In order for findings to be transferable, the contexts must be similar. Therefore, it is the role of the researcher to identify key aspects of the context from which the findings emerge and the extent to which they may be applicable to other contexts.

* **Dependability.** The extent to which the research would produce similar or consistent findings if carried out by others as described, including taking into account any factors that may have affected the research results.

* **Confirmability.** The evidence that corroborates the findings. The subjects and research context provides such evidence (Lincoln & Guba, 1985).

These broad sets of criteria for qualitative research parallel the criteria for quantitative research respect fully: internal validity, external validity (or generalizability), reliability and objectivity. In addition, credibility and transferability can be thought of as paralleling validity in quantitative research; whereas, reliability in qualitative research can be thought of as dependability and consistency of results obtained from qualitative data.

Credibility is to qualitative research as internal validity is to quantitative research (Devers, 1999). Credibility was enhanced through: 1) prolonged engagement with the participants in their home setting, interviewing the parents for as long as needed to answer the questions and providing time at the end of the interview to see if there was
anything more they would like to add and offering the opportunity to contact the
researcher by phone should other information arise, 2) development of ongoing, trusting
relationships with the participants over a minimum of a 2 ½ year period for them to feel
comfortable to reveal personal feelings, 3) assurance of confidentiality, and 4) member
checking process during which the content and meaning of participants statements were
reflected back to them to assure correct interpretation of the meaning. Member checks
were also completed following transcription of data to honor the participants’ voices for
their perception of accuracy. The data the researcher identified to use in this study was
reviewed with each participant for verification of their statements and meanings.
Participants were informed that following the transcription of the interviews, the
researcher would send them a copy of this information to review/confirm thematic
statements that would be used as data in this study. This was accomplished and
participants were provided a period of three weeks to review and return the data
information with any comments or changes they requested. If a participant wished to
change a statement or delete a statement, this was honored by the researcher and the data
adjusted to reflect this change. Only one participant chose to make a change in the initial
interview response. The researcher identified the themes from the data using the voices
of the participants to support the themes. Observation was also utilized throughout the
interviews. This included observation of the salient factors related to the parent’s
participation and understanding of the questions (ie. eye movements, furrowed brow,
shoulder shrugging), as well as observations in the home environment related to the
participant’s responses (ie. artifact portraying spiritual connectedness).
Transferability is to qualitative research as external validity is to quantitative (Devers, 1999). Although a key aspect of the context of this study was the parent in the home setting who addressed the pervasive, intensive care giving needs required by the child who is medically fragile, generalizability is not the intent of this study, nor is it the intent of ethnographic research. “Thick description” of the participants responses/voices are provided and one can determine its applicability to their own situation (Lincoln & Guba, 1985; Merriam, 2001).

Dependability is to qualitative research as reliability is to quantitative (Devers, 1999). All interviews were conducted in the same manner, using the Interview Guide as a framework. This was accounted for by the researcher’s previous experience on three multi-year research studies: two block state grants in a school district in Southern California and one privately funded grant in Hawai‘i. The researcher held a variety of positions related to these grants, such as assistant grant writer and grant facilitator for a state grant to research assistant for a privately funded grant. Multiple roles and responsibilities were experienced. The participation in previous grants provided multiple mentored opportunities for hands on experience in assessing dependability. Specifically, knowledge and experience was obtained related to: appreciation of the aspects of grant writing, review of literature and statistics related to the subject of the grants, obtaining IRB approval, recruiting participants for studies, respecting confidentiality, maintaining meticulous data collection and documentation, analyzing both quantitative and qualitative data, allocating and accounting for the budget and submitting periodic reports related to progress of the studies. This experience also allowed this researcher to actively participate in these studies in roles such as: educator, case manager, health care provider,
advocate and support group facilitator. Lincoln and Guba discuss creating an audit trail and peer review under both dependability and confirmability. Both are discussed under confirmability.

Confirmability is to qualitative research as objectivity is to quantitative (Devers, 1999). An audit trail was kept to be able to explain how the researcher arrived at the results. It began with the keywords and searches used to obtain the literature, and continued with noting how categories were derived, and how decisions were made. Peer debriefing of the data was also conducted with one member of the dissertation committee who was familiar with qualitative data analysis and has worked with parent caregivers of children who are medically fragile. This was done in “a paralleling analytic session for the purpose of exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer’s mind” (Lincoln & Guba, 1985, p. 308). The researcher sent copies of the participants transcripts to the Chair. Both analyzed the transcripts separately then later met to discuss the analysis. This was done to check that the peer identified similar themes with those identified by the researcher and by the Text-Smart Program.

Summary

This study described the meaning and the sources of strength of Pacific Island parent caregivers of children who are medically fragile living at home. The exploratory questions that guided the study and helped to keep a focus on the purpose of the study are found on the interview guide (Appendix C). Chapter One identified the need for this study, the purpose, and the significance of research. Chapter Two provided a review of the literature, illuminating what is known and what is not known about the strengths of
parent caregivers of medically fragile children. Chapter Three described the methodology and research design, the role, background and beliefs of the researcher, the setting and participants, data gathering and analysis methods, as well as methods to ensure quality and credibility of this study.
Chapter 4

Results

Chapter Four presents the results, including a description of the context of the population interviewed and findings of the analysis of the interview data. This ethnographic inquiry, into the meaning and sources of "strength" of Pacific Island and Filipino parents, provided an opportunity to understand the attitudes, beliefs and values voiced by this population of primary caregivers. The primary aim of this research was to explore the strengths, both internal and external, utilized by these parent caregivers.

Context

At the point of the initial hospital discharge to home, the ages of the medically-fragile children ranged from 8 months to 4 years of age. At the time of the interview, they were 3, 3, 3 ½, 6, 6 and 7 years old. All of these children had been home for at least 2 ½ years since their initial hospital discharge. All have had at least two re-hospitalizations with two of them returning home from the most recent hospitalization only two weeks prior to this interview. This affirms the medical fragility of this population. When the parents were asked to describe the current medical problems of their child, a summary of the responses were: 5 required oxygen; 4 were ventilator dependent and 1 on artificial nose; 4 had tracheostomies and required suctioning several times throughout the day/night; 6 had feeding tubes for nutrition and medications; 1 had an IV for medications; 4 required wheelchairs for mobility due to neuro-muscular impairment; 1 had brittle/fragile bones; 2 were blind; 2 were deaf; and 1 had a V/P shunt. All children had two or more of the above health concerns.
Parents rated the severity of their medically-fragile child’s health condition as follows: 2 moderately severe, 2 more than moderately severe and 2 as extremely severe fragility. When asked if the parent felt their child’s time to “get well” would take a long-time or a short-time, five responded as “a long time” and one responded that “it may be a short-time, depending on his ability to eat”. Parents were asked to identify what they “feared most” at this point about their child. Five of the parents stated that they “fear their child will get ill and may die”. One parent said, “He is stable right now, so my greatest fear now is that I or the system is not able to provide the best care for his condition---so he cannot reach his best ability”. These children live in the home setting, which most often resembles a miniature intensive care unit. By the time the child’s health status requires hospitalization, the child is usually admitted to an intensive care unit or a step-down intensive care unit. Most of these children will require multiple hospitalizations throughout their life, thus, the critical concerns voiced by the parents were: “for the child becoming ill, requiring hospitalization and possibly dying”.

The literature reveals that multiple stressors are encountered by parents who are caregivers of children who are medically fragile. These stressors can be categorized into four core themes: financial/monetary burden, care burden, role conflicts and lack of independence (Ratliffe, et al., 2002). These areas were briefly discussed during the interview to gain an understanding of the parents perspective of the impact of caring for their child who is medically fragile for the past 2 ½ years or more. Parents were asked, “Is (theme) a problem for you (related to you child) now?” If the response was “yes”, then they were asked, “How much of a problem is it?” Parents were allowed to describe how much of a problem they felt the theme was for them, however, many parents asked,
"What do you mean how much?" It was at this point the researcher would state, "Tell me, do you feel it to be: a small problem--meaning very little, not much at all; or a medium size problem--meaning I am bothered by it, but I have learned to adjust; or a very large problem--meaning huge, very big and bothersome".

Financial problems were identified by three parents to be present at this time and three denied financial problems. One reported, "no financial problems, thanks to Medicaid" and another stated, "There is no problem financially thanks to my deceased husband’s insurance coverage". Two of these parents described financial problems as having a medium impact and one stated it was a huge problem for him to contend with.

Care burden was assessed under the term “feeling extra responsibility as a parent of a child who is medically fragile”. Five of the parents identified that they do have feelings of extra responsibility as a parent of a child who is medically fragile and that this was a problem for them. Three felt this extra responsibility to be a medium problem and two revealed that this continues to be a very large problem for them since their child has come home. The one mother who stated this was "no longer a problem”, added that “it was a problem when he first came home from the hospital, but no longer is a problem.” This mother lives next door to her parents and the child’s has been steadily progressing without any hospitalizations in the past 6 months. He also has attended preschool with special education services for one month, which has allowed this mother more independence.

Under the theme of role conflict, parents were asked if they felt “caring for their child interferes with other things they have to do—a problem for them”. They identified that caring for their child interferes with other responsibilities and activities. One stated
that this was a very small problem and four said the interference had a medium impact on her lifestyle and other responsibilities. One stated, “it was a problem when he first came home, ‘cause he was worse then and had a lot more care needs. But now it’s no problem.”

The final stressor, lack of independence, was phrased as “feeling isolated, a change of friends and/or not able to get out much” when trying to assess the parents’ perspective on this stressor. Four of the parents said that since their child came home, they have continued to “feel isolated”, they have “changed friends” and they “still do not get out of the house much”. They related this to the care needs of their child. Three parents stated this to be a medium problem and that they are adjusting to it. One parent felt that this stressor continued to have a very large impact on his life. Two parents felt no impact from this potential stressor.

Participants were asked if they perceived any other stresses in life. Other life stressors that emerged in the interview identified to be “problems related to extended family members”. The three parents who revealed this felt it to be a medium ongoing problem in their life. Although there were no family members present during these three in home interviews, no participant wished to further describe or discuss the problem.

Meaning of Strength

The interview proceeded by asking parents to define “strength” in their own words. All participants included the term “energy” in their own description of the meaning of strength. Additional descriptions included: “strength is my family; my child’s continuing progress makes me feel the energy to push further; it is an inner energy within me filling me with love and spirituality; strength means power, open communication, faith, praying
and serving God; strength has to do with my ability to cope, my perspective of a situation and level of acceptance of it; it is a constant understanding or ability to accept; I surrender and let go of my worries; it is the ability to stretch myself; I believe there are different planes than this one—this is just one portion of our being; I derive strength from my child and his contentment with his life—we have a spiritual bond”. All were looking toward a “greater source” beyond the human realm. Some of these descriptions were inseparable from where the source of strength emerged. Parents were asked if these sources were perceived as “positive” sources of strength and they all responded affirmatively.

Congruent with ethnographic studies, the beliefs, values and attitudes that lie beneath the behavior of this specific group of people were explored. Data of this investigation was organized into domains and categories. Analysis generated concepts and themes that demonstrated where parent caregivers of children who are medically fragile found strength. In addition to themes that emerged during the literature search, which involved mostly Caucasian populations, a new thematic category emerged during the analysis of this investigation which was “interacting with nature”. The beliefs, values and attitudes became the central core or the categories. Each category was analyzed to identify themes.

Beliefs, Values and Attitudes

This section is organized in accordance with categories of beliefs, values and attitudes. Examples about beliefs, values and attitudes reported by the parent caregivers
are described in the following sections, and those that emerged that were unique to this population will be highlighted.

Beliefs: Prior to using specific questions to gather data, parents were asked to respond to the following question; “Tell me about what you believe parents of a child who is medically fragile need in order to care for a child like your own?”

The theme of “spirituality” was clearly voiced among all participants. Examples included, “a spiritual connection, spiritual bond, God, a higher source that can lift you up, friends from church, communicating with a higher spiritual being, prayer, meditating and believing in divine healing.” This theme continued to be voiced multiple times throughout the interviews.

The second most frequent theme identified by parent caregivers as something they need to care for their child was that of “family”. One parent stated that “I feed off the energy of my family. Family is my strength, especially my wife.” When speaking of family, the participants referred to their spouse, their children, and the grandparents of the child who is medically fragile if they lived adjacent to them.

“Social support” was the next most frequently described theme related to perceived needs. This theme included the greater community support that provided assistance to the caregiver. Respite care nurses, friends, neighbors, and church friends were included in this theme and identified by the majority of participants as being a factor that is needed by these parents.

Another belief that emerged included having the strength and energy to meet a challenging situation and a commitment to continue to meet the ongoing needs of their child. This theme portrays the parent’s love and dedication to the child. An example of
this theme provided by a father was, “It gives you drive to provide care for your medically fragile child and keep him healthy and alive. You do not give up on your child. Caring for our son is a big responsibility, it is a commitment, it is caring, it is love.”

Acceptance of the child as he/she is at the present time emerged as another theme. These attributes may reflect having a positive attitude and focusing on the here and now respectively. The voice of one parent stated, “I find strength from accepting my child as he is at this time with the situation.” Another parent shared, “If I look into the future I become anxious and feel overwhelmed.”

Following these open ended questions allowing the voices of these parents to bring forth their strengths, they were asked to identify whether or not they believed each of the following attributes of strength/theme was something they needed as means of providing strength to them. The results revealed that all of the participants believed that they need each of the following attributes: 1) having the ability to handle emotional feelings, 2) having problem solving skills, 3) turning to a source of spirituality, 4) finding meaning with child’s condition, 5) taking care of yourself, 6) having family support, 7) having social/community support, 8) having a positive attitude, 9) being resourceful, and 10) meeting a challenge and having a sense of dedication.

The parents were also asked to discuss how or in what ways they believed each of the above themes gave them strength. The majority of the responses reflected how they used these themes.

Handling Emotional Feelings: Spiritual strategies were once again identified as the most frequent means these parents used to handle their emotional feelings. Examples
included: going to church, talking with God, meditating, and praying. One parent stated, “I surrender and let go of my worries.” Other strategies used that provided strength to manage emotional feelings that emerged in order of frequency were: 1) participating in activities, 2) letting out feelings, 3) maintaining a positive attitude, 4) interacting with family, 5) interacting with nature, 6) having a social network, and 7) focusing on the present. One participant stated:

I think it is good to cry and to talk to others to let your feelings out. I have good support from my spouse and talk with her. I believe in God, pray and talk with him, meditate on good things and try to think positively.

Problem Solving Skills: In reply to the inquiry of: “How does your ability to problem solve help to give you strength” the most frequent response that emerged was that problem solving provided confidence. Confidence in: “feeling in control of the situation, troubleshooting, responding properly to unexpected problems that arise” were all responses voiced by these parents. In addition to confidence, other responses that emerged to demonstrate how problem solving skills provided strength were: “having knowledge, having a sense of reassurance and feeling power to explore the bureaucratic system.”

Spirituality: The next theme explored was that of spirituality. The parents revealed that connecting with a sacred source was the central theme that was shared by all. Words such as bonding, connecting, positive energy, go to church, talk with God, read the bible, praying, singing, meditating, and spiritual were used to describe the connection of the participant with a sacred source. Spirituality was also found to be a means to better appreciate and value family. One participant stated, “Spirituality helped me to cherish
my family. It helped me to learn more family values, and not to take things for granted.” Letting go of problems by surrendering and sharing, healing through faith, having a sense of peace and reassurance were other themes that were mentioned in the discussion of how spirituality provides strength.

Finding Meaning: Parents were asked to describe how attributing meaning to their child’s health condition provided strength. All stated that they asked themselves “why” this happened to their child. For example, “why this happened, why this child, why did I place him there, why me, why us” were statements voiced by all parents. One participant clearly stated that, “It was an accident.” Three of the six mentioned working through guilt feelings. All the male participants clearly stated that after searching for meaning they could find no meaning in their child’s condition. One father stated, “I have asked why this happened to her and got no answer, but I think it’s a good thing to work through.” Another father voiced, “The search goes on and on for a long time. I have not found meaning to his health condition, however, I do believe my son is going to get stronger. I turned it over to God.” The other father shared, “It’s the way the cards were dealt. It just happened. I feel no meaning to that”. However, it was noted that being able to attribute meaning to the child’s illness gave strength to the mothers in this study. One mother stated, “I have a very religious background which allows me to have a bigger and broader perspective of this life. If you search without anger or can accept it for just this time and place, you can cope better and find new meaning to the place the child is in now.” Another mother shared, “I always wondered why—why us. And later I found out when other children came home from the hospital I was asked to talk to the family about how to take care of their child. I said ‘Of course’ and it gives me strength that I
know I'm helping some other family to take care of their medically fragile child.” All these voices described how finding meaning or searching for meaning has helped these parents to gain strength.

Taking care of self: The question of “how or in what way does taking care of yourself provide strength” resulted in two parents stating: “It renews/replenishes my energy.” All of the participants shared methods they utilized to replenish their energy. One parent stated, “If you cannot take care of yourself, you cannot take care of your child. I go to the movies, play the piano, take walks in the nature parks and watch the waves.” A father stated, “I play with my children, go to the gym and exercise and work on my cars as a hobby.” One mother shared, “I sleep, spend time with my husband out of the house, take small vacations together, go for walks, take long baths and read.”

Themes that emerged in the frequency they were reported included: personal enjoyment, interacting with family, spending time in nature, resting/sleeping and eating right. Personal enjoyment included activities such as exercising, working on hobbies, playing the piano, shopping, keeping well groomed, taking long baths and reading. Family interaction included playing with the children, spending time with spouse. Spending time in nature included gardening, walking in the yard and parks, and watching the waves.

Family Support: Under the area of the support of family as a means of providing strength, all participants reported that the family members helped to some degree with providing care for the child who is medically fragile, helped the parent caregiver with the other children in the family and allowed the parent caregiver to tend to other responsibilities. Some described the family as reassuring and helping them to let go of the child who is medically fragile to some degree by trusting another to care for the child.
They also stated that family support provided an opportunity for them to regain energy and take time to take care of themselves. One participant stated, “Living with my family so close helps financially.” Another shared that, “My parents cook for us often and take care of me and my children when we are ill. With my family’s help there is less responsibility for me.”

Social Support: “How the support of others in the community helped provide strength” received a response from the majority of these parents sharing that they received strength from: “the respite nurses provided care for the child.” Others went on to discuss other ways the nurses provide strength to the parent. One parent stated, “They provide reassurance that he is being well cared for.” A mother shared, “They provide company for me. I can talk with them about my feelings.” Yet another parent voiced, “Respite nurses allow me to have time for myself-time to rest-to attend to other children-to get out of the house.” One father spoke about, “The nurses help get support services and what we need for our child. They allow me to go to work and to keep appointments.” Still another mother shared, “I can do my other household duties. They allow me time to tend to other responsibilities.” Two of the parents mentioned therapists, and the public school system as sources of community support. One shared: “Friends and church members we can talk with, but the real strength for me comes from the nurses and therapists and school who pitch-in and help to provide the care and gives me time for myself and other thing that need to be done.” Another parent shared: “It is a quiet knowledge to know that our neighbors and church friends can help get the other kids out of the house, provide transportation and attend our other kids functions when we cannot.”
Positive Attitude: The most frequent response that emerged from the discussion of how keeping a positive attitude provides strength was that it kept the parents’ spirit up. A comment made by one parent was, “It keeps me happy, helps me find the good in all things and circumstances, and to dwell of the positive.” Another parent shared, “It helps me stay ‘up’. It gives me energy to go on.” One parent described, “It’s a positive feeling within me.”

Positive attitude was also a strength in the form of reassurance of finding a solution, coping with everything and knowing that the situation could be worse. One father shared, “It helps you cope with everything going on.” Another parent stated, “It is reassuring to know that there is always a solution. I tell people that it could be worse.” The theme of energy also emerged with comments of one mother, “having a positive attitude keeps me going, there is an energy that I get from a positive attitude, and it gives me energy to go on”.

A theme that emerged under the discussion of positive attitude was focusing on the present. Two of the participants shared that focusing on the present, such as “just think about today and it’s OK” and “to dwell on the positive at this time”, assisted them in finding strength.

Resourcefulness: All caregivers stated resourcefulness allowed them to find information essential to the care of their child. This knowledge gave them strength. Knowledge came through “communicating with others to find answers”, “broadening one’s perspective” and “enhancing one’s understanding”. Resourcefulness also allowed parents to meet the needs of their child who is medically fragile. Meeting their child’s
needs also gave the parents strength. Parents also shared that being resourceful gave them “confidence to do things on my own and to make decisions.”

Meeting a Challenge through Dedication and Love: In the final area of meeting a challenging situation and being dedicated and loving to their child provided strength to these parents. Dedication and love allowed them to provide the care for their child and meet the child’s needs at home. One father stated, “I love challenges and my daughter is a real, daily challenge for me. I push her to progress. I want her to be the best she can be.” A mother stated, “It makes me feel like I am a good mother and that I can give my best possible care and love that I equally give to all my children.” Another parent shared, “It gives you drive to provide care for your fragile child and to keep him healthy and alive. You do not give up on your child. Caring for our son is a big responsibility. It is a commitment. It is caring. It is love.” Family togetherness and the sense of being a “good mother” were voiced by two parents.

Beliefs about Other Parents of Children Who Are Medically Fragile

Following the discussion about beliefs of self, these parents were then asked their beliefs about all other parents of medically fragile children related to the themes discussed. This was asked to better understand this culture of parents and their perspective of “feeling similar with” or “feeling unique from” other parents who care for their child who is medically fragile. They were presented with the following question on each theme, “Do you believe all other parents with a medically fragile child feel the same way as you do about (theme)?” A simple “yes” or “no” response was requested. If the participant was uncertain, the answer was categorized as a “no” response. The findings
showed that by far the majority of the responses indicated that these participants felt that
other parents with a child who is medically fragile felt the same as they did about each of
the themes. It was interesting to note that all of the participants believed that other
parents with children who are medically fragile believed the same as they did about
taking care of self and being resourceful.

Values: “A value is a standard that prescribes the relative worth, utility, or
importance of a particular belief, custom, or behavior” (Huff & Kline, 1999). In
exploring the values of this population of parents about each theme that was previously
discussed, the question was posed as to “How important is it to (theme)?” The results
showed that all participants felt that each of these themes were important.

Parents began to state that some were extremely important. An effort was made to
capture this by requesting that the parents use the terms important or extremely important
to differentiate the degree they valued each theme. The results revealed that about half of
the themes were valued to be important and half were valued to be extremely important.
The themes identified as being extremely important by the majority of parents were:
spirituality, family support and having a positive attitude. At the end of the interview the
parents were again asked to reflect on the themes and identify the two most valuable to
them. The themes of spirituality and family emerged again as the two that were most
frequently reported.

Attitude: Attitude is another core category that was discussed to enhance the
understanding of this population of caregivers. The question that was posed to assess
attitude was, “Do you think that (theme) is good or bad?” All of these areas were
affirmed. Each of these parents expressed that every one of the themes was “good”; there was not one response of “bad”.

An additional theme that emerged as the participants discussed where they found strength was: interacting with nature. As this theme was beginning to emerge it was incorporated into the interview. The previous two participants were contacted and also asked if they felt this theme was “needed” by parents of children who were medically fragile, “important” to them and if they felt it was “good or bad”. The results related to this theme showed that most parents believed they needed to spend time in nature. One parent stated, “I take walks and look up at the sky; I also garden in the yard.” Another shared, “I go for walks in nature parks and watch the waves.” One parent felt that, “It is not something that I need, I think I would spend more time with my family if I had more free time”.

Another theme that emerged was that of focusing on the present. Four parents stated they believed that focusing on the present circumstances was something that parents of children who are medically fragile need to do. “If I look too far ahead, I get anxious. I just keep my mind on the present. I think about today and everything is OK.” In assessing their value of both of these themes, the majority of parents felt that spending time in nature was extremely important and two parents felt this was important. As far as the value of focusing on the present time and circumstances, half of the parents said it was important and half said it was extremely important. All parents felt that interacting with nature and focusing on the here and now and the present circumstances were “good”.
Summary

The qualitative data derived from six personal interviews were examined. The meaning of strength for these parents had the central theme of “positive energy”. These participants believed that parents of children who are medically fragile needed to: handle emotional feelings, have problem solving skills, connect with spirituality, find or search for meaning, take care of self, have family support, have community support, have a positive attitude, be resourceful, meet a challenge and be dedicated to it, interact with nature and focus on the present. All of the participants’ attitudes toward each of the themes was “good” and these themes were all valued by these parents as being important or extremely important. The themes of spirituality and family emerged as being the two most important strengths valued by these parents.

In conclusion, the findings described in this section can be portrayed in a model, the Integrative Harmony Model, which depicts phenomenon of the parent caregiver experience. Beliefs, values and attitudes, a component of culture, are the lens through which the world is viewed. As the parent caregiver incorporates the strengths (and stressors) into their perspective, the sense of harmony is shifted toward or away from balance. The Integrative Harmony Model, which is dynamic, will be further described in the following chapter. In an effort to portray the dynamic phenomenon of this Model, the results of the data will be applied to the meta-theoretical principles of Sense-Making Methodology which was originally developed in 1972 by Brenda Dervin (Dervin, 1992) which also supports the results of this study.
Chapter 5

DISCUSSION, CONCLUSIONS AND IMPLICATIONS

This chapter first addresses the research questions of this study through a discussion of the findings in relation to the existing literature. In synthesizing the findings, one overarching theme cluster and three sub-theme clusters emerged. Using the philosophical and conceptual orientation of the Non-dualistic Paradigm and connectedness of the caregiver to sources of strength as means of replenishing energy and maintaining balance, the Integrative Harmony Model will be portrayed. The chapter concludes with a discussion of the limitations of this study, implications for nursing and recommendations for future research.

The literature review included studies related to parents as caregivers of children who are medically fragile, ranging from those who required no technological support or were on apnea monitors to those who were ventilator dependent. Some studies also included children who had a long term chronic illness. The focus of this study, however, is on parents of children who are technology dependent with ongoing, intensive care giving demands needed to continuously maintain vital organ function. Few studies were found that solely incorporated this population of children in their research. Therefore, studies about parents as caregivers of chronically ill children with special needs were also included in the review of the literature. Articles that further explained concepts that emerged from the themes of strength were also reviewed. The results revealed that positive energy, positive attitude, spirituality, family support, social/community support, taking care of self, interacting with nature, focusing on the present, handling emotional feelings, finding meaning, meeting a challenge/dedication, problem solving and
resourcefulness were all themes that emerged from the population of parents in this investigation.

Integrative Harmony Model

The Integrative Harmony Model integrates all these themes into one framework. The first theme cluster is the overarching theme of "Positive Energy" which includes the themes of focusing on the present time and having a positive attitude. The second cluster of themes is that of "Connectedness" with the themes of spirituality, family, social/community, self-care and nature. "Openness to What Is" is the third cluster of themes which encompasses the themes of handling emotional feelings and finding meaning. The fourth and final theme cluster in the Integrated Harmony Model is that of "Meeting a Challenge". This includes the themes of problem solving skills, resourcefulness, and dedication and love. This Model, portrayed in Table 2 follows.
### Table 2: Integrative Harmony Model

**Integrative Harmony Model**

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<thead>
<tr>
<th><strong>CULTURE</strong></th>
<th><strong>STRENGTHS</strong></th>
<th><strong>STRESSORS</strong></th>
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<tbody>
<tr>
<td><em>Positive Energy</em></td>
<td>Positive Attitude</td>
<td>Pre-existing Stressors</td>
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<td><em>Positive Attitude</em></td>
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<tr>
<td>Focusing on the Present</td>
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<td><em>Connectedness</em></td>
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<td>Spirituality</td>
<td>Financial</td>
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<td>Family Support</td>
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<td>Taking Care of Self</td>
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<td>Interacting with Nature</td>
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<td><em>Openness to What Is</em></td>
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<td>Handling Emotional Feelings</td>
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<td>Finding Meaning</td>
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<td><em>Meeting a Challenge</em></td>
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<td>Problem Solving</td>
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<td>Resourcefulness</td>
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<td>Dedication</td>
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**CAREGIVER**

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<tr>
<th><strong>Stressors</strong></th>
<th><strong>Strengths</strong></th>
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<td>Pre-existing Stressors</td>
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The Integrative Harmony Model reflects a dynamic system. Caregiver harmony is the central core or goal. This harmonic state is influenced by the culture, that is the beliefs, values and attitudes, of the individual which colors the lens through which the strengths and stressors are perceived. Four themes of stress which are frequently cited in the literature (Ratliffe et al., 2002) to be perceived by parent caregivers are listed under the “Stressors” column. The “Strengths” that are cited in the literature coincide with the
findings of this study, and the additional theme, interacting with nature which emerged in this study, are categorized under four theme clusters. The overarching theme is that of “positive energy”; perceiving that one has an abundance of positive energy is the goal – “Harmony”. This positive energy is obtained through one’s own sources of “Strengths”. As a parent caregiver perceives a situation, it is taken-in as “just another situation in life—perhaps even an opportunity for growth” or a “Stressor”. If the “Harmony” is not vibrant, full and balanced, the “Stressors” will break through the gaps or weakness of “Harmony” causing an imbalance and a shift toward the “Stressors”. A discussion of the “Strengths” follows.

Positive Energy

The beliefs, values and attitudes that underlie the themes can be expressed in the overarching theme of positive energy. Based on the data of this study, positive energy is identified as: a positive energy which one may replenish via internal and/or external resources that brings forth a sense of strength and connectedness to the present situation. In Martha Rogers “Model of Unitary Human Beings” (1970), people exist as unified body/mind/spirit entities whose energy fields interact with energy fields of the environment. This is in agreement with the Non-dualistic Paradigm (Ratliffe and Haley, 2002) where person and environment are seen as “one”, and are constantly interchanging as matter and energy. These energy fields are infinite and change continuously and creatively.

Of the themes noted in the literature, the one that most closely reflects this sense of renewed positive energy is that of vitality. Hover-Kramer and colleagues (1996) determined that vitality is enhanced when one perceives a higher purpose to one’s
activities. It is important to note that the parents in this investigation cherish their child who is medically fragile. One mother’s statement reflected her perceiving a higher purpose to her caregiver activities. She shared:

I realize that I have little control over most matters. I surrender to the spirit. My son and I have a spiritual bond. There are different “planes of being” than this one. This physical humanity is just a phase, one portion of our being. My son chose to stay in this life. I am grateful for the opportunity to take care of him. I feel confident that he trusted me enough to take care of him.

These parents have waited months or even years for their child to be discharged from the hospital to home so that they can “become a whole family again,” as one parent stated. Another parent stated, “He has given back to me—uh—a better appreciation for life. I have grown and have been stretched in many ways because of him.”

Focusing on the Present

The theme focusing on the present is also discussed by Hover-Kramer and colleagues (1996) as a means of strengthening vitality or one’s energy. Ray and Ritchie (1993), Scharer and Dixon (1989) and Wilson et al (1998) also identified taking portions of time or taking one day at a time as one of the management strategies utilized by parent caregivers. This is consistent with the findings of this investigation. Parents discussions reflected statements of focusing on the present. One parent voiced, “When I look too far ahead I get anxious and overwhelmed.” Another father stated, “I just keep my mind on the present. I think about today and everything is OK.” It appears that in their connecting with present circumstances, one can open to and appreciate the gifts that the present experience offers.
Positive Attitude

The theme of having a positive attitude or maintaining an optimistic outlook was consistent with the literature. As noted in the literature by Ray and Ritchie (1993) and Scharer and Dixon (1989), this quality was found to enhance the coping of families. Maintaining a positive attitude was also evident in this investigation. One parent responded, “Having a positive attitude keeps me going; there is an energy that I get from a positive attitude, and it gives me energy to go on.” Having a positive attitude can be incorporated under the overarching theme of “positive energy” as it reflects a perspective or lens through which one views a situation, such as a cup that is half full or half empty.

Connectedness

The second theme cluster, connectedness, emerged because parents expressed a connection with sources that replenished their strength. It is interesting to note that when they were asked to discuss “how or in what ways (theme) gave them strength”, the responses reflected the application and usefulness of their connection with each of the themes. For purposes of this investigation the definition of connectedness, which was reflected through the data, is: A valued awareness, a unification within one’s self (body/mind/spirit), with other persons, the natural environment, and a sacred source of spirituality to which one feels joined through an individual’s perceived experience. This closely reflects the definition of Ratliffe & Haley (2002), who define connectedness in their Paradigm as “a unification of the body, mind and spirit in which a sense of the physical boundaries of one’s own body/mind extend to include other persons and the natural environment in an unconditional oneness” (p.141). In this investigation, the
unconditional oneness was often reflected between the parent caregiver and the child and parent caregiver and the family, but not as often in the realm of parent caregiver with social/community support.

Spirituality and family emerged as the most critical sources of strength for these parent caregivers. One parent’s statement reflects this, “I find strength from God and from my family mostly.” Another echoed, “Parents need family support and spirituality – someone who you could pray to, that will lift you up.” Regardless of religious affiliation, these parents believe they will endure stressful situations because they are connected with a higher spiritual source and family support to see them through.

Spirituality

The theme of spirituality was affirmed by the literature. Haase et al. (1992), Westbrooks (1998), Wilson et al. (1998), and Youngblut et al. (1994) report that spirituality enhances the caregiver’s efforts to provide ongoing home care. Spirituality emerged in multiple areas of discussion with each parent in this investigation. The theme spontaneously emerged in responses to the initial request for the parents to define or describe “what strength means”. One response was, “An energy within me filling me with love and spirituality.” Spirituality was the only unanimously voiced response by all participants in this study when they were asked to describe what they believed parents needed to care for a child like their own. Although “God” was the most frequently referenced source of spirituality, one parent’s referred to spirituality as, “a spiritual connection”. A father spoke specifically of “Jesus”. Another parent stated, “a higher source that can lift you up.” These sources of spirituality were emphasized during this period of discussion and echoed throughout the interview.
Religious artifacts were also observed in four of the six child’s rooms. These visual reminders of a sacred source can prompt one to connect with a spiritual source of strength. Connecting with spirituality may open one to receiving the grace/blessings/gifts which could enhance one’s strength and courage to go on.

Family Support

The parents in this investigation placed great emphasis and value on the nuclear and extended family. This is supported in both the nursing literature in multiple studies (O’Brien, 2001; Ray & Ritchie, 1993; Scharer & Dixon, 1989; Stephenson, 1999; Youngblut et al., 1994), as well as the literature on providing culturally competent health care for the Pacific Islander population (MSH, 2001). O’Brien (2001) notes that maintaining connections with extended family served as a source of both emotional and instrumental support. This can be related to handling emotional feelings and problem solving skills. According to the literature on the Pacific Island culture (MSH) the well-being of the collective family is valued more than that of the individual. The father of a child who had multiple technologic needs in this investigation provided this perspective:

My family is my strength. I feed off their energy. It brings joy and a positive feeling just being around family. I have strength because we are there for one another.

Another parent described her value of family support as:

They are able to take care of my other children while I take care of my medically fragile son. And, umm, they give me strength by cooking for me, letting me rest, and umm, basically taking care of me whenever I’m ill or my other children are ill. It is less responsibility for me.
Another mother stated, "I think the other kids in the family are learning skills that they'll use at some point. They learn a lot of compassion. He's part of our whole family, not just my child." There appears to be a strong commitment to take care of one's own business within the family.

Social/Community Support

The Pacific Islander population considers the community as a part of the collective unit. They value a sense of interdependence. "The more interdependence in their life, the greater a person's worth" (MSH, 2001, p. 1). One mother shared that having friends from church available to help out when needed is a "quiet knowledge - a source that I could tap into if things get too hard." Another's comment was, "When others help, it helps me to let go of him a little bit." Findings of this investigation showed that social/community support is valued as important or extremely important to these parents. The literature supports these findings and describes a variety of social supports that assist parent's adaptation to caring for their child in multiple studies (Diehl et al., 1991; Gibson, 1986; Hartman et al. 1992; Kohlen et al., 2000; Leonard et al., 1993; Melnyk and Allper-Gillis, 1998; O'Brien, 2001; Patterson et al., 1994; Ray, 2002; Scharer & Dixon, 1989; Stephenson, 1999; Wilson et al., 1988; Youngblut et al., 1994).

Relationships were developed with the respite nurses who cared for the child. It should be noted that all respite nurses were registered nurses. Parents shared that most respite nurses were a source of strength. Parents did note that the personality of the nurse needs to reflect a caring and understanding nature to fit into the family dynamics. This perspective was also reflected in the study of Kohen et al. (2000). All parents shared favorable comments related to respite nurses. One parent stated, "Respite nurses are a
big source of strength for me. I’m content that he’s well cared for. I look forward to having somebody to talk with— to ask questions about my child.” Another mother shared, “They give me time to take care of other responsibilities and time to take care of myself.”

It was repeatedly stated by these parents how much they valued the competent care and opportunity for time to take care of themselves because of respite nurses. This finding coincides with the literature (Leonard et al., 1993; Patterson et al., 1994; Ray, 2002; Scharer & Dixon, 1989) that reported that professionally trained respite nurses allowed parents an opportunity for personal replenishment, provided critical relief, and that some respite nurses fulfilled family and best friend roles. One father shared his perspective as:

Friends and church members we can talk with, but the real strength for us comes from the nurses and therapists and school who pitch-in and help to provide the care and give me time for myself.

A few parents voiced that help from friends, neighbors or nurses allowed them to address other commitments such as: work, appointments and needs of other children. Two mothers shared an additional perspective of their respite nurse as, “a good friend, having someone to bounce ideas off of about your child, in addition to caring for my son she is someone I look forward to seeing and talking with during the day.” This coincides with what Ray (2002) reported: that parents spoke of the personal support they received from the respite nurses. Kohlen (2000), Leonard et al., (1993) and Wilson et al., (1994) found that the parent caregivers believed that they had a shared responsibility for providing care and resources for their child with others. Hover-Kramer et al. (1996) noted that “vitality is strengthened by having an ally who understands your vision and
supports you in your aims" (p. 43). This may be reflective of the interdependence or the connectedness with the family and/or the greater community.

Although the literature (Diehl et al., 1991; Hartman et al., 1992) reported peer support groups were found to be a valuable stress buffer as well as a source that promoted health, no one in this investigation ever participated in a peer support group even though this resource was provided to them. One mother in this investigation identified herself as a "mentor" for parents at the time of a child’s discharge from the hospital and as a point of future contact if they would like. Another mother shared that she turned to other parents who had a child who was medically fragile for support. These were the only two extensions of parent-to-parent contact that were mentioned during this interview.

Caring for Self

Hover-Kramer, et al. (1996) noted that taking care of self was an important measure for caregivers to replenish their own needs. These authors also noted that this allowed one to provide ongoing care without being overwhelmed. Setz and Brown (1997) also discussed the importance of giving oneself “permission” to take care of oneself. The data in this investigation revealed that these parents saw the importance of taking care of themselves. One mother stated, “If you cannot take care of yourself, you cannot take care of your child.” Statements from these parents frequently related to the methods they used during this personal time they had to replenish or renew their energy. During this self-care time, parents often stated that they met their basic needs such as: resting, sleeping or proper eating. It was interesting to note that half of these parents shared that they valued spending time with spouse or other children as a way to take care of themselves. Here again the interconnectedness with the family emerges. This finding was not congruent
with the literature. Other activities that were identified as means of caring for the self included: exercising, shopping, going to movies, taking long baths, going for walks, gardening and reading.

Although these parents identified ways in which they cared for themselves, they felt that they did not routinely take care of themselves. This agrees with Ray's (2002) findings that most parents claimed they did not care for their own physical health as they should. In this investigation one parent stated, “I do take care of myself when I have the time.” A father shared, “You forget sometimes because you have so much going on”. Yet another agreed by stating, “It’s a good thing to do, but I think I should take care of myself more often”.

Interacting with Nature

Although this has not shown up in the literature, half of the parents in this study identified replenishing their strength through interacting with nature. One parent shared, “I go to the beach and watch the waves, this gives me renewed energy.” Another stated, “I lose myself in nature and I go for long walks in the park.” One father shared, “When things get tough, I step outside, look up at the big sky, walk around the yard and garden. This strengthens me.” One may associate these responses with the transcendence of human boundaries and the pursuing of oneness with the natural environment (Ratliffe and Haley, 2002). It can be perceived that connecting with another energy system is a means of replenishing one’s own energy and strength.
Openness to What Is

"Openness to what is" is a receptivity. It is a sense of leaving behind the usual boundaries of the world view one possesses and being open to a new perspective. In this state of openness, barriers that were once erected through one's world view disappear and the usual boundaries of the five senses become porous allowing a new perspective or world view to emerge (Ratcliffe and Haley, 2002). Two themes that emerged through the interviews that represent the parents' effort to move from their past world view toward a new perspective were handling emotional feelings and finding meaning. Handling emotional feelings can be seen as a means of letting go of their past expectations; and finding meaning represented their search for a new level of understanding or a new perspective.

The themes of handling emotional feelings and finding meaning met with varied responses in this investigation. The parents' reconciling the past and present, coming to terms with or acceptance of the child's condition, and communication were cited in the literature (O'Brien, 2001; Ray, 2002) as means to help parents adapt to the multiple and frequent changes they encounter as caregivers. In the Integrative Harmony Model, working through disturbing emotional feelings and searching to find meaning can be seen as means of breaking through a past world view or expectations parents had for their child, and allowing themselves to open to a new perspective or world view. Expectations from the past can block one from opening up to and accepting positive energy permitting one to evolve toward a new world view and harmony.
Handling Emotional Feelings

In the studies of O’Brien (2002), Ray (2002) and Youngblut and colleagues (1994), the need for parents to communicate their feelings was discussed. O’Brien (2001) noted that extended family and at times, friends were sources for parents to share their emotional feelings. Those findings were consistent with this population of parents. One parent stated, “when I handle my emotional feelings, I surrender and let go of my worries.” This investigation found that parent caregivers shared emotional feelings mostly with his/her spouse and sometimes extended family. God and church members were also frequently mentioned. The literature did not mention interacting with a spiritual source as a means of handling emotional feelings. However, in this investigation this was frequently brought forth throughout discussion of this theme. Specific discussion about how parents handled their emotional feelings was not discussed in the literature. All parents in this investigation believed that they needed to handle their emotional feelings and valued it as being an important or extremely important way to replenishing their strength. Although the responses varied, they most often expressed talking with spouse, family, God and church friends, nurses and case manager. One parent responded, “I talk to God, our case manager, the nurses, and my wife. This helps me to work through and let go of my feelings”.

Another father stated,

I think it is good to cry and to talk to others to let your feelings out. I have good support from my spouse and talk with her a lot. I believe in God, pray and talk with him. I also meditate on good things and try to think positively.
In handling emotional feelings, the sense of letting one’s feelings out and letting go of or releasing any uncomfortable feelings that can build up and act as a barrier is a means to open to sources of positive energy which replenish strength.

Finding Meaning

The theme, finding meaning, is supported in the literature by O’Brien (2001) Ray (2002) and William and Williams (1990). They found that participants struggled to find a reason for and give meaning to their child’s situation and to accept the circumstances of their lives that could not be changed. The literature was congruent with the findings of this investigation. All parents in this investigation asked “Why?”, and searched to find a meaning for their child’s health condition. It was interesting to note that all the primary caregiver mothers responded with an answer to make sense of their situation and attempted to incorporate the changes into their overall belief systems and perspectives on life. The fathers, however, could not find meaning but felt that searching was an important process one must go through. One mother describes her search for meaning as:

I used to ask, ‘why us?’ I found that in assisting and teaching other parents of medically fragile children when they come home from the hospital, I feel like I’m sort of an expert who can be their coach or mentor. It gives me strength to help other families. We build a relationship and it makes me feel good.

This parent’s response captures what Hartman et al. (1992) found in their study on parent-to-parent support. This mother, who experienced the reality of caring for a child who is medically fragile, is qualified to and finds value and meaning in supporting another parent with similar needs. This mother found meaning through her mentoring of other
parents in similar situations. This also agrees with Hartman et al.'s (1992) findings of informal parent support. Another mother described finding meaning as:

Although this was an accident, I wondered why did I place him there where the other children could accidentally push something onto him. I had to address other issues, such as, the other two children not feeling guilty for causing the accident, then we could focus more lovingly on our son/brother and not worry about how it happened or why, and understand that we are in this "new place" and it's good and let's move forward. If I search without anger about my child's condition, I can better accept it for just this time and place. This helps me to carry on and move forward.

One father's response was:

I used to think why her, why not some other child? I just have to deal with it. I cannot describe why this happened to my child. I don't think there is a reason for it. I think it just happened that way. It was the way the cards were dealt. I still do not feel meaning to that.

Another father voiced:

I asked why this happened to her, and I get no answer. I feel a little guilty, maybe something to do with me. This does not give me strength, but I think it is a good thing to work through.

Clearly some parents have come to some definition of what this child who is medically fragile meant in their life and some did not. All accepted it, none the less.
Meeting a Challenge

Although the parents of children who are medically fragile are sensitive to the needs of their child prior to discharge from the hospital, the impact of the vital and intensive needs and responsibility of caring for the child is not fully appreciated until the child arrives at home. "Meeting a challenge" can be portrayed in the Integrative Harmony Model as a key element in attaining/maintaining a sense of harmony. The ability of the parent to problem solve unexpected occurrences, to be resourceful in obtaining answers to identified needs and to be dedicated to caring for their child are important themes. These themes can enhance a parent's ability to meet unexpected challenges in providing ongoing care and strengthen the sense of harmony.

Problem Solving

Parents in this investigation described the ability to problem solve as being an important aspect of strength. They were responsible for the assessment and symptom management of their child and their child's equipment. The literature agrees that parents need problem solving skills to manage their child's health. One study notes the parents' in-depth knowledge about various devices and treatments (O'Brien, 2001). The studies of Ray (2002), Ray and Ritchie (1993) and Wilson and colleagues (1998) revealed that parents described strategies of discriminating symptoms as either immediate or non-immediate. This skill resulted in the family's response to the child's emergencies being rapid and efficient.

In response to how problem solving provided a sense of strength, one parent responded: "I know how to handle and control the situation and this gives me confidence." Another stated, "It is reassuring to be able to troubleshoot a problem with
his signs and symptoms or his equipment. I am confident I can maintain his health and comfort.” Overall, having problem solving skills provided a sense of confidence, reassurance and control in the parents’ ability to provide quality care for their child in a safe manner without placing the child at risk by not being in the hospital setting.

Resourcefulness

Resourcefulness has been represented in the literature to be a strategy needed by parents of children who are medically fragile and chronically ill as a means of coping (O’Brien, 2001; Ray, 2002; Scharer & Dixon, 1989; Stephenson, 1999; Wilson et al., 1998). A search for information to provide answers to problems or potential problems, or the gaining of knowledge to make better informed decisions was congruent with the findings of this investigation. One mother’s response reflected how resourcefulness helped replenish her strength:

It gives me strength to believe there are many nice, caring, loving and helpful people in the community. I wrote letters to two large companies requesting their help in tinting the windows in his room and providing an air purifier and they came through for us. Having a good public health nurse, respite nurses and others who know the resources help direct me to resources so I can be more resourceful.

Another parent shared:

Being a resourceful person helps me meet my needs and my child’s needs by identifying other support services for us. I go to the library and look in books to get answers. I ask other people questions that I need answered such as the public health nurse or other parents who have children who are medically fragile. It is a way of getting more knowledge about addressing my child’s needs.
A way in which resourcefulness provided strength that continued to emerge throughout the discussion on this theme was that of knowledge. Apparently, knowledge is power. Resourcefulness also gave these parents a sense of control.

Dedication and Love

Throughout multiple studies in the literature, the parents absolute commitment and dedication to caring for their child is well documented (O’Brien, 2001; Ray, 2002; Ray & Ritchie, 1993; Teague et al., 1993; Wilson et al., 1998). In this investigation, parents repeatedly echoed their dedication to do everything they possibly could for their child. One father stated, “I love challenges, and my daughter is a real, daily challenge for me. I push her to progress. I want her to be the best she can be.”

Another father shared:

It gives you drive to provide care for your fragile child and to keep him healthy and alive. You do not give up on your child. Caring for our son is a big responsibility, it is a commitment, it is caring, it is love.

A mother described how meeting a challenge through dedication and love provided her strength:

It gives me more confidence to meet challenges. Families who take care of their medically fragile child will do anything to keep them home and out of a hospital or long-term care institution. I love him and I am committed to us being a family all together in the same home.

Their love for their child and their willingness to do whatever it takes for their child to meet the highest potential and to be the best he/she can be were clearly voiced. The value of family togetherness was also unmistakably stated by these parents.
This investigation also revealed that overwhelmingly, these parents believed that all other parents caring for their child who is medically fragile do believe as they do about each of the above themes. Their attitude revealed that they felt that each of the themes was a “good” or a “very good” quality to possess as a parent caregiver. Some stated that they wished they had “more” of these qualities, such as: taking more care of myself, more of a positive attitude, finding meaning to my child being in this medically fragile condition.

The attributes of strength that were found embedded in the literature were used as a framework to develop the interview guide for this investigation. The findings of this investigation agreed with these themes and identified one additional theme that emerged. The Integrative Harmony Model portrayed the dynamic experience of the parent caregiver incorporating these themes of “Strength”, as well as the “Stressors”. It revealed that these strengths and stressors are viewed through the “Culture” (world view/perspective) of the parent caregiver, which must be understood in assisting the parent to attain the goal of “Harmony”.

There were a few cultural aspects that appear to be unique to the Pacific Island and Filipino parent caregivers that were not revealed in the literature review on parent caregivers. The first being “interacting with nature”, which was identified and valued as a means of replenishing energy. Great emphasis was also placed on nuclear and extended family. The well-being of the collective unit is valued more than that of the individual in the Pacific Islander culture (MSH, 2001). Most of these parent caregivers lived in close proximity to their extended family who provided multiple aspects of support to them such as: child care for other children, transportation, cooking meals, emotional support and
taking care of the parent caregiver when she/he is ill. Although three of the six participants of this study were fathers, four of the six parent caregivers and their spouses felt that they “equally shared the role” of primary care provider for their child who is medically fragile. Their interdependence on family and the community, especially with their respite care nurses, was clearly voiced by these caregivers.

Limitations of this Study

There are several limitations of this study. This study is based on a small population of 6 parent caregivers. This was due to the criteria used to create this purposive sample population (e.g.: parents of Pacific Island ethnicity; are primary caregivers for their child who is medically fragile and technology dependent, have children who have been cared for at home for a period of time and speak English). Although the participants in this study did represent a variety of Pacific Island ethnicities, multiple ethnicities of the Pacific Islands were not represented. Also, all parents in this study were married, or living with their significant other. In addition, the children in this population represented ages 3-7 years old who have been home for at least 2½ years. Investigations focusing on other age groups at different time periods following discharge are needed for this population.

Implications for Nursing

This investigation gave voice to Pacific Islander parent caregivers of children who are medically fragile living in Hawai`i. The Integrative Harmony Model demonstrates the dynamic impact a child who is medically fragile can have on the caregiver.
Investigations are needed to determine if the nurse’s incorporating of the parent’s cultural world view is a way to better understand the perspective of the parent’s strengths and stressors. Understanding parents interpretation of their context may be critical to understanding the well-being of these caregivers who juggle ongoing, vital responsibilities for their child. In addition to assisting parents to address the stressors, it is within the philosophy of nursing to “build on the strengths” of the client (Adams, 1980). Investigations are needed to assist parents in: 1) identifying their strengths, 2) reflecting on their strengths, and 3) applying and expanding their strengths. An increased understanding from nurses and awareness of the parents’ strengths may facilitate the parents’ stage of acceptance of the child’s illness, allow them to function more effectively in their role, promote the development of an expanded world view and enhance their well-being. Nurses should view this as an ongoing, dynamic assessment and intervention process to be incorporated into each parent caregiver visit. Interventions then can be designed and tested to see if they strengthen and promote the well-being of parent caregivers moving the caregiver toward a state of balanced harmony and well-being.

Recommendations for Future Research

Synthesis of Study

The following recommendations are being made and they are affirmed by both Ratliffe and Haley’s work (2002) utilizing the Non-dualistic Paradigm and Mentro and Steward’s work (2002) utilizing Sense-Making Methodology. This section discusses the application of the Non-dualistic Paradigm with the Integrative Harmony Model and the
application of Sense-Methodology with the Integrative Harmony Model.

Recommendations for future research are then made.

The Integrative Harmony Model was utilized throughout Chapter 5 and descriptions of the philosophy of the Non-dualistic Paradigm was discussed in the introduction of each of the cluster themes: “Positive Energy”, “Connectedness”, “Openness to What Is” and “Meeting a Challenge”. Further discussion of the application of the Non-dualistic Paradigm follows.

The two major concepts in the Non-dualistic Paradigm are energy and connectedness. “Positive energy” was found to be the overarching theme in this investigation and “Connectedness” one of the theme clusters. Energy is seen as the person-environment being energy fields involved in an ongoing interaction where boundaries extend beyond the physical mass (Ratliffe & Haley, 2002, p. 132). Connectedness being defined as “a unification of the body, mind, and spirit in which a sense of the physical boundaries of one’s body/mind extend to include other persons and the natural environment in an unconditional oneness (Ratliffe & Haley, 2002, p.131).

Antecedents of connectedness: life experience, interpersonal connection and presence were voiced throughout the parents’ discussion. The last antecedent, “Openness to What Is” (receptivity) was another theme cluster. Outcomes of connectedness: harmony and an increased meaningfulness of life were also voiced. Further validation of this Paradigm is needed.

In the Paradigm persons are a totality that are constantly interchanging matter and energy with their environment. Body, mind, spirit and environment are one and the same thing. In viewing existence as “one seamless whole” people are, therefore, born neither
good nor bad, but rather as a particular expression of all the causes that result in this moment. One many shift toward Harmony (with abundance of “Strength”) or away from Harmony, but the underlying principle is one of infinite possibility at each moment. These “spheres of influence” are dynamic, without fixation and in constant and pervasive flux. Since these spheres are infinite, the distinction between self and other is illusory. Ratliffe and Haley refer to this as “interbeing”, noting that our nature is interdependent and intimately intertwined with everything around us.

The Non-dualistic Paradigm, the Integrative Harmony Model and the relationship to Sense-Making Methodology and its application to the caregiver follows. Strengths could be viewed as how or what means parents use to adapt to home care. This could be likened to gap-bridging as described by Mentro and Steward (2002) in their discussion of Sense-Making Methodology developed by Dervin and associates in 1972. The Integrative Harmony Model supports this framework. The following discussion will demonstrate how the components of the Integrative Harmony Model (Culture, Harmony, Strengths and Stressors) relate to the components of Sense-Making Methodology (Situation, Gaps, Bridges and Outcomes). (See Figures 1 and 2)
Figure 1: Combined Integrated Harmony Model with Sense-Making Methodology

Figure 2: Combined Integrated Harmony Model with Sense-Making Methodology
The caregiver can be seen as an unified whole being (body/mind/spirit) represented as a rainbow and the water in the stream. This person is influenced by culture, and has a central core of Harmony. A sense of balanced Harmony is portrayed as a complete rainbow. A “Situation” (floating down the stream) is perceived by this caregiver. The “Situation” can be perceived as simply another experience in life to fully appreciate and/or perhaps growth from it---depicted as a full radiant rainbow. This rainbow is likened to the “Bridge” in Sense-Making Methodology, and Strength in the Integrative Harmony Model, which is over a narrow-gently flowing stream; OR it can be perceived as a Stressor----depicted as only a piece of the rainbow- if any. This partial rainbow is likened to the “Gaps” in Sense-Making Methodology, over a full-chaotic-rushing stream. The goal or the “Outcome” as stated in Sense-Making Methodology is Harmony, as described in the Integrative Harmony Model. The “outcome” or shift of harmony depends on the caregiver’s perception of the situation, and strengths the caregiver has to tap into to be open enough to allow the situation to flow through and appreciate it. If the situation is viewed as a stressor and there are not enough strengths to “Bridge” a perceived stressful “Situation” there will be a gap in the rainbow—preventing the rainbow, the caregiver, from growing to its potential radiant fullness as described in the Non-dualistic Paradigm. In agreement with the recommendations of Mentro and Steward (2002), this qualitative investigation used the verbing approach, such as: caregiving, as opposed to the “nouning” approach, such as: care or care burden, to assess human behavior. This is reflected in the themes that emerged in this investigation.
Follow-up recommendations would include: 1) identify the stressors and strengths of Pacific Island and other cultures of parents who are the primary caregivers for their child who is medically fragile, 2) develop measures for these stressors and strengths, 3) compare across cultures, 4) explore how successful families manage stressors and strengths, and 5) see if families who balance stress and strength are more resilient.

Future research could integrate the strength and stressor dyad as a simple assessment tool for nurses to use in their plan of care. Investigation of what facilitates the parent caregivers opening up to or connecting with these identified strengths may lead to better understanding and utilization of them. Research of other Pacific Island cultures not represented in this study may help to better understand the whole Pacific Island population. Also, long-term follow-up of a population of parent caregivers from a time just prior to hospital discharge through the first year and again at 2-3, 5 and 10 years post discharge may help obtain a holistic perspective of the parent caregiver of children who are medically fragile and technology dependent.
Appendix A

Consent Form

Agreement To Participate In
Voices of Strengths of Parent Caregivers of Medically-fragile Children
from the Pacific Islands and the Philippines living in Hawaii

Principal Investigator
Janice Haley APRN, CPNP, PhDc Nursing student; University of Hawaii, Manoa
47-661-7 Hui Kelu St.
Kaneohe, HI  96744
(808) 239-7432

Institution
School of Nursing & Dental Hygiene
2528 McCarthy Mall, Webster Hall
Honolulu, HI  96822

This research project will help us learn what resources parents who are caregivers of a medically-fragile child use in taking care of themselves. Since you provide ongoing care for your child’s complex needs 7 days a week, and sometimes 24 hours a day, the literature reveals a need to understand how parents cope and adapt. The research project will include 6 parents who take care of their medically-fragile child in the home. The study will consist of you participating in a 1-1½ hour audio-taped interview responding to questions in which you describe what “helps you” to continue on with providing for the care needs of your child.

Joining the research project is voluntary. It requires that you participate in an interview at your home or where you choose with the Principle Investigator and a follow up phone call or home visit so you may check that the information that you gave during the interview is correct. Upon completion of this study, all data (including the tapes) will be stored in a locked cabinet for 7 years and then destroyed.

All information will be kept confidential to the extent allowed by law. If you choose to use another name than your own for the interview, you may do so.

At this time we know of no risks or harm caused by participating in this study. Sometimes being in a study causes anxiety.

There is no cost to be in this research project.

In appreciation for your time and effort for participation, a $25 certificate will be given to each participant.

If you have any questions or concerns, Janice Haley can be reached at (808) 239-7432.
I certify that I have read and that I understand the foregoing, that I have been given satisfactory answers to my inquiries concerning the project procedures and other matters and that I have been advised that I am free to withdraw my consent and to discontinue participation in the project or activity at any time without prejudice.

I herewith consent to the participation in this project with the understanding that such consent does not waive any of my legal rights, nor does it release the principle investigator or the institution or any employee or agent there of from liability for negligence.

Signature of Parent

____________________________________
Address

____________________________________
City, State, Zip

____________________________________
Phone Number

____________________________________
Date

If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact: Committee on Human Studies, University of Hawaii, 2540 Maile Way, Honolulu, HI 96822. (808) 956-5007

c. Signed copy to study participant
Appendix B

Internal Review Board Permission

Protection of Human Subjects  
Assurance Identification/IRB Certification/Declaration of Exemption  
(Common Rule)

Policy: Research activities involving human subjects may not be conducted or supported by the Department and Agencies adopting the Common Rule (56FR28003, June 16, 1991) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

1. Request Type  
2. Type of Methodology  
3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No.  
4. Title of Application or Activity  
5. Name of Principal Investigator, Program Director, Fellow, or Other

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This Assurance, on file with Department of Health and Human Services, covers this activity:

Assurance Identification No. 1158-5007, the expiration date, October 31, 2002, IRB Registration No. 01

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Certification of IRB Review (Respond to one of the following if you have an Assurance on file)

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8. Comments

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.

10. Name and Address of Institution

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<td>2444 Dole Street, Bachman Hall</td>
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<td>Honolulu, HI 96822</td>
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12. Fax No. (with area code)  
13. Email:

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<td>(808) 956-5007</td>
<td>(808) 539-3554</td>
<td><a href="mailto:dendle@hawaii.edu">dendle@hawaii.edu</a></td>
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14. Name of Official  
15. Title

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<td>William H. Dendle</td>
<td>Compliance Officer</td>
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16. Signature  
17. Date

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Appendix C
Interview Guide

In this study I am trying to understand more about parents from the Pacific Islands who are the main caregivers for their medically fragile child (MFC). Your child and all of her/his equipment have many needs that you take care of many hours of the day – every day of the week. The purpose of this study is to find out where parents of children who are medically fragile find strength to carry on...to find out what “helps you” to continue on with providing for the many complex needs of your child?

1. What culture/ethnicity are you?
2. Do you have any other children? How many?
3. What kind of problems does ________ have?
4. How severe is his/her condition? Extremely/not very/a little/not at all/unsure
5. Will it take a long time or short time for your child to get well?
6. What do you fear most about your child’s condition?

1. First I would like you to tell me “what does strength mean” (define strength).

2. Tell me about what you believe parents need to care for a child like__________?
   Beliefs (interviewer to adjust language/terms as needed)
   A. As a parent of a MFC do you BELIEVE you need to be able to handle your emotional feelings? How do you handle feelings (ie: anger/sadness/frustration/disappointment)? What helps you to handle and get through these feelings?) How does this give you strength? Is this good or bad?
   B. Do you believe all other parents with MFC feel the same way you do?
   C. As a parent of a MFC do you believe you need to have problem solving skills? (to solve problems that unexpectedly happen) In what ways does this give you strength? Is this good or bad?
   D. Do you believe other parents with MFC feel the same way as you?
   E. Do you believe you have turned to a source of spirituality for strength? How has this helped/give you strength? Is this good or bad?
   F. Do you believe all other parents with MFC feel the same as you?
G. Do you believe that “finding meaning” to ____condition gives you strength? Have you thought of why this has happened to (your child)? If so does “knowing this” give you strength? How? Is this good or bad?

H. Do you believe other parents with MFC feel the same way as you?

I. Do you believe that it is important to take time to take care of yourself throughout day/week as you continue to provide care for your child? What kind of things do you do to care for yourself? Is this good or bad?

J. Do you believe other parents with MFC feel the same way as you?

K. Do you believe you need support of family members to care for a child like ________? In what ways does this give you strength? Is this good or bad?

L. Do you believe all other parents with MFC feel this same way?

M. Do you believe you need the support of others in the community / social support? How does this give you strength? Is this good or bad?

N. Do you believe all other parents with MFC feel this same as you?

O. Do you believe having a positive attitude/being optimistic gives you strength? How does this give you strength? Is this good or bad?

P. Do you believe all other parents with MFC feel this same way?

Q. Do you believe that being a resourceful person (finding answers or people to help meet your needs) helps you find strength? Tell me about different ways you have found help to meet your needs (books, people, on-line). How does this help you replenish your strength? Is this good or bad?

R. Do you believe all other parents with MFC feel this same as you?

S. Do you believe you need to have a sense of hardiness (having a feeling of being commitment and meeting a challenge and sticking with it) are important to finding strength to go on in caring for your child? In what ways does this help (give you strength)? Is this good or bad?

T. Do you believe all other parents with MFC feel this same way?
3. How important was each of the above topics to you (extremely important/ important/ not so important)

Values

A. being able to handle your emotional feelings
B. being able to solve unexpected problems
C. connecting with spirituality
D. finding meaning to your child's condition
E. doing things to take care of yourself/self-care
F. support of family
G. support of friends/professionals/others in community (social support)
H. keeping a positive attitude/optimistic
I. being resourceful/you find help to meet yours or child's needs
J. commitment/meeting a challenging situation (hardiness)

4. Are there other things that are important to you that gives you a feeling of strength to carry on with providing care for (child) that were not yet mentioned?

5. Sometimes parents who have a child who is medically fragile feel the following (5) stresses. I am going to ask you if these are problems for you related to your child—and you can just answer "yes or no". If you answer "yes" then I would like to know how much of a problem this has been—"a very large problem" (a very big/huge bother); "a medium sized problem" (we are bothered by it but we have learned to adjust); "a very small problem" (very little—not much at all of a bother).

a. financial/monetary
b. feeling extra responsibility as a parent giving care for ______
c. caring for ______ interferes with other stuff you have to do
d. isolation/change of friends/not able to get out as much
e. Are the other life stresses not mentioned that are bothering you? What are they?
References


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Devers, K.J. (1999). How will we know “good” qualitative research when we see it? Beginning the dialogue in health services research. In K.J. Devers, S. Sofaer, & T.G. Randall (Eds.), *Health services research: Qualitative methods in health services Research, A special supplement to HSR, 34*(5), 1153-1174.


