



---

Theses and Dissertations

---

2012-03-16

## A Qualitative Exploration of Family Strength and Unity in Family Crucibles

Taralyn Clark  
Brigham Young University - Provo

Follow this and additional works at: <https://scholarsarchive.byu.edu/etd>



Part of the [Recreation Business Commons](#)

---

### BYU ScholarsArchive Citation

Clark, Taralyn, "A Qualitative Exploration of Family Strength and Unity in Family Crucibles" (2012). *Theses and Dissertations*. 3152.

<https://scholarsarchive.byu.edu/etd/3152>

This Thesis is brought to you for free and open access by BYU ScholarsArchive. It has been accepted for inclusion in Theses and Dissertations by an authorized administrator of BYU ScholarsArchive. For more information, please contact [scholarsarchive@byu.edu](mailto:scholarsarchive@byu.edu), [ellen\\_amatangelo@byu.edu](mailto:ellen_amatangelo@byu.edu).

A Qualitative Exploration of Family Strength and Unity in Family Crucibles

Taralyn Clark

A thesis submitted to the faculty of  
Brigham Young University  
in partial fulfillment of the requirements for the degree of

Master of Science

Stacy T Taniguchi, Chair  
Patti Ann Freeman  
Julie Dawn Melville Hite  
Susanne Olsen Roper

Department of Recreation Management and Youth Leadership

Brigham Young University

April 2012

Copyright © 2012 Taralyn Clark

All Rights Reserved

## ABSTRACT

### A Qualitative Exploration of Family Strength and Unity in Family Crucibles

Taralyn Clark

Department of Recreation Management and Youth Leadership, BYU  
Master of Science

The purpose of this study was to qualitatively examine family relationships in families where one adult member was diagnosed with chronic illness resulting in chronic pain to determine why the crucible, or trial, of chronic illness triggered some families to strengthen while others weakened. The introduction of chronic illness instigates a process of change in family life, yet there is a paucity of research examining families in this situation, specifically when the chronic illness results in chronic pain. Utilizing grounded theory methodology and qualitative data analysis methods, dyadic interviews and periods of observation were conducted with six families across the United States. Questions were focused on family relationships and the impact of adult-onset chronic illness on relationships and family life. Open, axial, and selective coding were conducted during the process of data analysis, illuminating the important role family unity played in helping families remain strong. Findings detail the relationship between family strength and family unity. Adult-onset chronic illness provided a catalyst for families to establish and/or maintain family unity. Five families established or maintained family unity and reported positive changes in family strength, while one family failed to maintain or establish family unity and reported negative changes in family strength leading to separation and eventually divorce. This study has important implications for families facing adult-onset chronic illness and for practitioners serving this population.

Keywords: chronic illness, chronic pain, grounded theory, family strength, family unity

## ACKNOWLEDGEMENTS

Glory be to God for the completion of this research and any good that has or will come from it! I feel an incredible amount of gratitude for God's personalized plan for me, and for all who have offered their love and support along the way. To my thesis committee—Dr.'s Stacy Taniguchi, Patti Freeman, Julie Hite, and Susie Roper—I owe a debt of gratitude. Their lessons about determination, faith, and leadership will stay with me throughout my life. Other professors and fellow graduate students have left a similar mark.

I'd like to dedicate this research to my grandma, Carol Clark. Her undying love and belief in my ability to move mountains led me to believe in my own ability to find answers to my questions, and her memory pushes me to do my best and make a difference in this world. I miss you and wish you could read the final project; this is for you, Grams! My parents, Stuart and Teresa Clark, have always been my strength. Their vision of my ability to succeed and be an influence for good takes my breath away and gives me wings to fly. The six families who invited me into their homes and hearts deserve mention—without them this research truly would not have been possible! Thanks also go to Mark Longhurst, who doubles as the most amazing boss in the world. I never could have finished without his immediate and unquestioning support!

I cannot name everyone who deserves mention, but special thanks go to Kim Molyneux, Rob Henderson, Rachel McGovern, Paula Curtis, Camilla Hodge, Courtney Gosling, Shaun Nua, the Bryan Tidlund family, the Steve Clark family, Taunalee Clark, Glenn and Geraldine Boyer, Linda Hanks, Michael Phelan, William DeGolyer, Scott Hall, Julie Rawle, Jen Mortensen, Janelle Hanks, Julie Asay, and Christi Hicken. Whether your name is spelled out or not, words cannot express my gratitude for each and every person who has reached out to offer me love and support. Thank you and God bless!

## Table of Contents

List of Tables .....	v
A Qualitative Exploration of Family Strength and Unity in Family Crucibles .....	2
Introduction.....	2
Literature Review.....	2
Methods.....	8
References.....	27
Tables .....	32
Prospectus .....	35
Families Enduring Chronic Illness: Forces Compelling Change in the Family .....	36
Introduction.....	36
Literature Review.....	42
Methods.....	52
References.....	62
Appendix A1 .....	68
Appendix A2.....	69
Appendix A3.....	71
Appendix B.....	72
Appendix C.....	74

## List of Tables

Participant Demographics.....	32
Similarities in the Impact of Chronic Illness on Families.....	33
Family Strength and Family Unity by Case.....	34

A Qualitative Exploration of Family Strength and Unity in Family Crucibles

Taralyn Clark

Stacy Taniguchi, Ph.D.

Patti Freeman, Ph.D.

Julie Hite, Ph.D.

Susanne Olsen Roper, Ph.D.

### A Qualitative Exploration of Family Strength and Unity in Family Crucibles

Adult-onset chronic illness instigates a process of change in family life, resulting in either weakened or strengthened family relationships. This dichotomy in the way families respond to chronic illness or disability is supported by empirical research (Bocarro & Sable, 2003; Carroll et al., 2000; Donoghue & Siegel, 2000; McDaniel, Hepworth, & Doherty, 1997; Rolland, 1994).

The purpose of this study was to qualitatively examine family relationships in families where one adult member was diagnosed with chronic illness resulting in chronic pain to determine why the crucible, or trial, of chronic illness triggered some families to strengthen while others weakened. Although similar populations have been studied (Bocarro & Sable, 2003; Radina, 2009; Radina & Armer, 2001; Robinson, Carroll, & Watson, 2005; Scholl, McAvoy, Rynders, & Smith, 2003), there is a paucity of research focusing specifically on family relationships in families where one parent is diagnosed with chronic illness resulting in chronic pain.

#### **Chronic Illness and Disability**

Approximately one of every two adults was diagnosed with at least one chronic illness in the United States in 2005. Of those diagnosed, one of every four was limited in their daily activities (Center for Disease Control [CDC], 2010a). When an adult experiences a spinal cord injury, cancer, or breast cancer-related lymphedema, quality of life is influenced (Bocarro & Sable, 2003; ; Radina, 2009; Radina & Armer, 2001; Robinson et al., 2005; Scholl et al., 2003 ). Family caregivers are also seriously impacted by the illness (Dupuis & Smale, 2000; Puymbroeck, Payne, & Hsieh, 2007; Rogers, 1999; Samborn, 2000). In such situations, both individuals and families make changes to meet new needs and adapt accordingly. Notwithstanding this research, few studies examine families that include a parent diagnosed with chronic illness including chronic pain.



**Chronic pain.** Fibromyalgia, chronic fatigue syndrome, and multiple sclerosis fall under the family of chronic pain, are characterized by chronic pain, fatigue, and difficulty sleeping, and greatly impact quality of life (Center for Disease Control, 2010b, 2010c; Lorig et al., 2006; Mayo Clinic, 2010; Pekmezovic et al., 2009). Fibromyalgia, characterized by widespread muscular pains and fatigue, results in difficulty sleeping, morning stiffness, migraines, and problems with memory. The causes of this illness are unknown, and diagnosis is difficult. Though symptoms of fibromyalgia can be treated and controlled, the illness is not curable. Fibromyalgia treatment requires many visits to health practitioners and expensive medications, often causing financial strain for affected individuals (CDC, 2010c). In 2005, five million adults in America were affected by fibromyalgia, with most patients being women.

Chronic fatigue syndrome affects up to four million Americans and results in profound fatigue, weakness, muscle and joint pain, headaches, impaired memory, and insomnia. At least 25% of individuals diagnosed with chronic fatigue syndrome are unemployed or on disability due to the illness. This illness is difficult to diagnose as it is often confused for other illnesses with similar symptoms. Though chronic fatigue syndrome cannot be cured, it can be controlled through medications (CDC, 2010b).

Multiple sclerosis is a difficult to diagnose progressive disease affecting the central nervous system. Symptoms include weakness, chronic pain, vision problems, tremors, depression, and fatigue. The cause of this disease is unknown and although treatments exist to address symptoms, the disease is chronic and incurable, often resulting in disability and even death. Multiple sclerosis is typically diagnosed in adulthood, and is more common in women than men (CDC, 2011; Mayo Clinic, 2010).

Support groups exist throughout the United States to increase understanding and facilitate self-management of diseases such as fibromyalgia, chronic fatigue syndrome, and multiple sclerosis (Lorig et al., 2006). These groups are marketed to individuals diagnosed with chronic illness. Families are also greatly impacted by such diseases, though few studies examine perceptions of the whole family in seeking to understand the impact chronic illness, including chronic pain, has on the families of affected individuals.

### **Family Crucibles and Strong Families**

In chemistry, a crucible is a furnace-like vessel in which chemical reactions requiring intense heat are conducted, resulting in the refinement and transfiguration of original materials, creating something entirely different (Carroll et al., 2000). “A metaphorical meaning of crucible is a severe...trial that refines or purifies” (Carroll et al., 2000, p. 278). This definition lends to studying the family crucible, a trial influencing change in the family. Such a trial could result in positive and negative outcomes, such as strengthened or injured relationships. Carroll et al. (2000) posit adversity “may actually promote growth and adaptation” (p. 279). Thus, chronic illness may serve as a crucible experience influencing family change.

**The impact of chronic illness on families.** Improvements in modern health care enable people to survive more health crises and spend less time in hospitals, resulting in the majority of healing taking place in homes and causing family caregivers to make daily life changes in order to effectively care for the ill or disabled family member (Bocarro & Sable, 2003; Samborn, 2000). For example, Bocarro and Sable (2003) found dichotomous results in spousal relationships, these relationships either strengthened or dissolved after one partner experienced a debilitating spinal cord injury including chronic pain. Radina (2009) also found contrasting results in women suffering from breast cancer-related lymphedema; they either continued family

leisure pursuits by making needed modifications or stopped participating altogether, depending on the perceived amount of familial and societal support. Puymbroeck et al. (2007) found family caregivers experienced increased stress and decreased coping skills while caring for an ill family member. Although many of these results are negative, researchers argue stress-causing situations such as adult-onset chronic illness including chronic pain can produce positive as well as negative outcomes, such as increased family strength and positive family functioning (Donoghue & Siegel, 2000; Folkman & Moskowitz, 2000). Due to minimal research and potential import for families, a better understanding of the choices family members make to manage the change brought on by a chronic debilitating disease is important. Ostensibly, the family crucible of adult-onset chronic illness may result in positive and/or negative changes in family strength, though the factors contributing to each outcome remain nebulous.

Family support helped to ease burdens placed on the individual suffering from illness (Cohen, 2004; Donoghue & Siegel, 2000; Estess, 2004; Leone, 2010; Robinson et al., 2005). Robinson et al. (2005) referred to cancer as a catalyst for change that was both exhausting and empowering for the individual as he/she was given family support. These studies illustrate the important supportive role families can play in the care of an individual diagnosed with chronic illness. Additionally, research shows situations such as adult-onset disability including chronic pain are “life altering for both the person and his/her family” (Bocarro & Sable, 2003, p. 59), substantiating the existence of a family crucible and highlighting the need for a better understanding of family crucibles. Family systems theory (White & Klein, 2008) aids in understanding the importance of studying families in crucible situations.

**Family systems theory and family strength.** In family systems theory, families are defined as a system in which each individual family member influences the entire family unit.

Additionally, family systems are made up of sub-systems consisting of dyadic relationships, also influencing the entire family unit. An understanding of each part of the system can only be achieved through studying the entire family. All systems seek to establish and maintain balance, but have the ability to adapt to changes and grow stronger (Butler, 2010; White & Klein, 2008). Understanding is deepened by explaining why family systems operate in the ways they function through examination of family relationships and interaction (White & Klein, 2008).

Using systems theory, Olson and DeFrain (1997) described the Circumplex Model, wherein family relationship strength is defined in terms of cohesion, flexibility, and communication. By balancing these three aspects of a system, family systems continue to function in positive ways. However, when a family system is out of balance (not cohesive, not flexible, not communicating), the system weakens and sometimes collapses. “Families need to become more flexible and cohesive to cope with life’s bumpy terrain” (Olson & DeFrain, 1997, p. 79). An example of such an obstacle is the introduction of chronic illness including chronic pain (Boyd, 2001). In a memoir regarding his own battle with chronic illness, Cohen (2004) substantiates the role of the family system: “Every member of the family was a vital player, and the whole...was greater than the sum of its parts...my family’s burden is equal to mine” (p. 129, 215). Therapeutic practitioners recognize the impact of chronic illness on families and have developed treatment plans for entire families, rather than simply for individuals (Atwood & Gallo, 2010; McDaniel, Hepworth, & Doherty, 1992; Rolland, 1994). Moreover, family therapists often use systems theory to assist families in dealing with chronic illness and other family crucibles (Bohn, Wright, & Moules, 2003; Keitner, Archambault, Ryan, & Miller, 2003).

Because “the diagnosis of chronic illness is a significant life crisis for families” (McDaniel et al., 1992, p. 184), the view of families as systems guided this research as families

were viewed as systems impacted by individual family members and sub-systems, and as chronic illness was understood to impact the entire family. As chronic illness can cause considerable disruption in family life (CDC 2010a, 2010b, 2010c, 2011), a diagnosis of chronic illness including chronic pain often serves as a family crucible, influencing both positive and negative changes in family relationships. Although researchers tend to focus on the negative aspects of these changes, Stinnett and DeFrain (1985) explained the need to study the characteristics of strong families, defined as families who face the storms of life just as other families do, growing closer together and being enabled to face continued trials rather than allowing those storms to destroy them. “To function as a healthy family is more than being without problems” (Stinnett & DeFrain, 1985, p. 7). In their national and international research with thousands of self-reported strong families, Stinnett and DeFrain (1985) identified six characteristics of these families: (a) appreciation for each other, (b) commitment, (c) effective communication, (d) coping well, (e) spiritual wellness, and (f) time together. Interestingly, these characteristics of strong families align with Olson and DeFrain’s (1997) research on family strength, helping families to be cohesive, flexible, and communicate effectively.

The roles these characteristics of family strength (Olson & DeFrain, 1997; Stinnett & DeFrain, 1985) play in families facing chronic illness are substantiated by research and personal memoirs. It is important for families to express appreciation for each other, especially when chronic illness alters an individual’s ability to contribute to family life in normative ways (Cohen, 2004; Donoghue & Siegel, 2000; Estess, 2004; Leone, 2010). Some posit commitment to family is the most important characteristic to maintain when facing trials: “With all of the rocks over which we have tripped, stumbled, and fallen, the commitment is strong. It had to be” (Cohen, 2004, p. 92). Families are only able to overcome trials faced as they communicate

effectively with each other. When individuals diagnosed with chronic illness are unable to communicate their needs, weakened family relationships become a reality (Donoghue & Siegel, 2000; Greal, 1994; Leone, 2010). Families able to cope well with crisis remain strong in the face of trial, using stress as a growth opportunity (Cohen, 2004; Donoghue & Siegel, 2000; Estess, 2004; Stinnett & DeFrain, 1985). Additionally, families with a strong sense of spiritual wellness, whether formal religion or some other shared belief and purpose, are enabled to remain strong when dealing with the vicissitudes of life (Estess, 2004; Stinnett & DeFrain, 1985). Families are also strengthened as they make needed changes and continue to spend time together as a family (Cohen, 2004; Estess, 2004; Stinnett & DeFrain, 1985). Researchers continue to call for research on strong families, specifically in the context of chronic illness (Atwood & Gallo, 2010; Rolland, 1994; Stinnett & DeFrain, 1985), illustrating the need for this research.

### **Methods**

The question of why family relationships either strengthen or weaken when one parent is diagnosed with chronic illness is most effectively addressed with up-close observation and constant comparison to determine the underlying factors affecting these families. Therefore, this study was qualitative, based on Glaser and Strauss' (1965, 1967) grounded theory methodology and utilized qualitative data analysis methods (Strauss & Corbin, 1998).

### **Sample**

Six families participated in the study, consisting of 26 individual participants with at least one parent and one child interviewed in each family. Participating families resided in Utah, Idaho, Ohio, and Nevada. A parent in each family was diagnosed with at least one of the following chronic illnesses: (a) fibromyalgia, (b) chronic fatigue syndrome, and/or (c) multiple sclerosis, in part to reduce researcher bias as the researcher had no personal experience with

individuals diagnosed with these illnesses. In all cases, these illnesses required daily management, limited normal activity and routine, and included chronic pain. At least one adolescent child of the ill parent who was between the ages of 12 – 18 years and living at home during the time of diagnosis participated in the study, ensuring the child was old enough to remember and acknowledge the impact of adult-onset chronic illness and resulting changes in family life. All family members willing to participate were interviewed, and parents consented to allow children under the age of 18 to be interviewed. Child participants ranged in age from 9 – 31, and in one case the child interviewed was an adult. Additionally, one grandparent who resided in the same town and spent time daily with her ill daughter participated in this study (see Table 1). Type of illness and age of children at time of diagnosis were inclusion criteria for this study. [insert Table 1 about here]

### **Data Collection**

Families were contacted via snowball sampling or through online invitations posted by chronic illness support groups. Interested families contacted the researcher, who selected families according to the inclusion criteria. Three families were selected via snowball sampling, and three families were selected via support groups. To protect confidentiality, code names were assigned to each family and individual family member.

Based on support group information and the researcher's experience with families where one adult member was diagnosed with chronic illness, an initial list of six interview questions was created for this study, referring to chronic illness and its impact on family life and relationships. Over the course of the study, three additional questions were developed from data collected and literature read (specifically Stinnett and DeFrain's (1985) work on strong families), resulting in nine final questions. A degree of flexibility in instrumentation allowed the

researcher to ask relevant follow-up questions during observations and dyadic interviews with study participants. Questions were designed for both adult and child participants. To establish trustworthy questions, 15 individuals from varying backgrounds reviewed the questions to ensure face validity. Additionally, a demographic survey was designed to collect family information.

A parent in each family completed the demographic survey, and all nine interview questions were asked in dyadic interviews with study participants, in addition to relevant follow-up questions. Relevant questions were also occasionally asked in conversations that arose during periods of observation. These questions helped to build rapport with families, and mainly referred to family patterns and routines, in addition to interests of individual family members.

### **Procedures and Analysis**

Only the primary investigator collected data, an important aspect of study design serving to establish rapport with study participants in the most unobtrusive way possible. The researcher visited each family to introduce herself and provide consent statements and an explanation of study procedures. Participants read and signed informed consent statements and were given an opportunity to ask questions and/or state concerns. One parent also completed the demographic survey. At this point, appointments were made to conduct interviews and observations. All adults were interviewed, in addition to all children willing to be interviewed. In all cases where the researcher traveled long distances to collect data, the initial visit was extended to include interviews and observations in order to condense data collection and reduce travel time. The researcher visited each family 1 to 4 times, with visits lasting from 1 to 4 hours depending on the size of the family and the length of time needed to establish rapport. In this manner, 4 to 16 hours were spent with each family. Participant statements referring to their being comfortable



with the researcher, excited to see the researcher, and/or initial nerves in participating in this study dissipated as the researcher spent time in their homes evidenced the establishment of rapport.

Dyadic interviews with individuals were not conducted in isolation as other family members were often within hearing distance. Per Glaser and Strauss' (1965) Grounded Theory (GT) methodology, data were collected in the homes of participants to reduce possible confounding influences, such as uncomfortable or unfamiliar environments. Data collection was ongoing for the duration of the study (Glaser & Strauss, 1965, 1967) enabling data collection and analysis to occur concomitantly, meaning data collection informed analysis, and analysis also informed further data collection. Questions were developed during the process of data collection and used in interviews and observations with remaining families. To procure a more complete data set, the researcher also revisited each of these families via phone calls and emails as further questions developed. In this manner, all six families were asked the same questions.

GT methodology (Glaser & Strauss, 1965, 1967) requires the researcher to convert field notes to a typewritten document immediately after the interview or interaction, unlike conventional methods of qualitative data collection (Strauss & Corbin, 1998), which use tape-recorded interviews and direct transcriptions. In this manner, immediate perceptions are retained and utilized in analysis of the data. As such, data were recorded via field notes, which were immediately converted to a typewritten document, analyzed via theme and pattern in NVivo 9, and used to develop additional questions asked of other families in this study. The researcher maintained contact with study participants in order to conduct member checks, procure additional information, and seek answers to questions that emerged during the analysis process, thereby establishing trustworthiness. The researcher engaged in the process of open, axial, and

selective coding (Strauss & Corbin, 1998) for approximately one year, engaging in the process of constant comparison until saturation in the data was achieved and a core variable (family unity) emerged that seemed to explain all other themes and patterns. Themes and patterns were determined to be meaningful when discussed by at least 4 of the 6 (over 60%) families.

The researcher sought to establish trustworthiness in this study in multiple ways (Erlandson, Harris, Skipper, & Allen, 1993; Gibbs, 2007; Lincoln & Guba, 1985; Miles & Huberman, 1994). As she engaged in a process of constant comparison through data collection and analysis, she worked closely with other members of the research team to validate patterns and results. Moreover, triangulation was built into data collection and analysis through collecting data from multiple sources and including all members of the research team in the process of analysis. Thick description of participating families and the use of participant quotes in writing help to determine transferability of findings. Additionally, the researcher established an audit trail consisting of notes, memos, queries, and a reflexive journal, enabling external auditors to review the analysis process and clearly see how results were achieved.

## **Findings and Discussion**

### **Impact of Chronic Illness on Families**

Families who participated in this study were affected by the chronic illness(es) of the ailing parent on a daily basis. Individuals across all families discussed well family members being impacted physically, mentally, socially, and financially due to the presence of an adult with chronic illness (see Table 2). Similarities in how adult-onset chronic illness impacted families in this study are further demonstrated by examining individual families. [insert Table 2 about here]

Sam Keller's diagnosis of fibromyalgia and chronic fatigue syndrome had clearly influenced his family of eleven. The family reported being on the "edge of the cliff" (wife, Shayna, age 41), always on the brink of unraveling because Sam's illness had added so much stress to their lives. Sam continued to work full-time after his diagnosis in order to support his family financially, but things were tight. His treatment was expensive, and he came home from work exhausted and unable to help with household chores and childcare responsibilities. Previously commenced remodeling projects were left unfinished, and his wife and children did their best to maintain some semblance of normalcy. The family used to define themselves by their outdoor recreation pursuits and love for being together, but this definition has now been restructured to include Sam's illness, "chronic disease has really defined our family" (Shayna). His wife, Shayna, was tired and missed his support, saying, "I didn't choose this. I don't even know who I'm married to anymore." His illness "taints everything." His children missed their dad. "There's moments when you need your dad there, and I've really felt that loss" (Amanda, 16). "It's hard...He used to wrestle with us, but now that he's sick he can't" (Ethan, 9). "It's just hard" (Nathan, 11). Sam experienced a substantial amount of guilt for his inability to complete tasks that used to be his alone, and just wanted to be his old self again: "The biggest thing—I know it's hard for my wife, but the person that's sick [has it] hard—I don't want extra rest. I want to be my old self" (Sam, 46).

The Goodsons told a similar story. Sarah (43) was diagnosed with chronic fatigue syndrome early in their married life, and the illness was "an every day awareness". She was constantly worried about how her choices would impact her daily life: "The process is just knowing when to stop...by the time I feel the fatigue it's too late" (Sarah). Her illness worsened when she moved close to her extended family because "mental stress will trigger an episode

faster than physical stress.” “I didn’t think it could get any worse, but it did...every muscle—my teeth would ache, my eyelids” (Sarah). When things got worse for her, they also got worse for her family. Her husband, Richard (40), stated, “It’s frustrating, I won’t deny that.” He served in the Navy and came home to a wife who was much sicker than the wife he’d left. “He admitted that he thought I was just lazy and liked to sleep...if he can’t see it then it doesn’t exist” (Sarah). Aaron, age 13, was also impacted by her fatigue episodes: “Since she gets so tired...it puts a little bit more on my Dad and I.” After exerting herself physically, it took days and sometimes weeks to recover, leaving Richard alone with household chores and childcare. The winter months were especially hard for her. Sarah expressed feeling some guilt about this, “When I’m having an episode where I’m more fatigued and Aaron wants to go out and build a snowman, to have to say [I can’t], that’s hard...to say to him” (Sarah). Like Sam, Sarah just wanted to be herself again: “I get depressed that my husband is having to do all the work, and so I get depressed about that. I want to be me again” (Sarah).

Jessica’s fibromyalgia impacted the Cloward family similarly to how illness impacted the Kellers and Goodsons, though they responded differently. Jessica was active in the fibromyalgia community and pulled her family into the action. When talking about her illness, she reported, it “[has] changed my life. It has changed my family’s life.” At the peak of her illness, she “was in the cage with the tiger. Nothing made sense to me—time, nutrition, responsibilities.” It “was a nightmare” (Jessica, 55). She literally lay on the couch for the first year of her illness, plummeting into severe depression, unable to contribute to family life in meaningful ways. Her husband, Justin (55), reported: “It scared the hell out of me.” Her daughter, Sharon, took on a lot of household responsibilities as her older siblings left for college and her father continued to work to support the family. “It’s consuming” (Sharon, 18). At the time Jessica was interviewed,

she had an easier time of managing her illness and pain levels, but it was a constant presence. Justin explained, “Until you’ve personally experienced the chronic pain you can’t understand it.” Justin reported Jessica once said, “If I can’t get rid of this pain I don’t want to be alive.” However, when interviewed she had learned to manage her pain and was giving her life to teach and support others dealing with similar situations, helping others to realize they could move forward. Her family supported her in this mission.

Jennifer’s diagnosis of fibromyalgia came during a period of marital strain, acting as the last straw. Leaving a note stating he no longer loved her, her now ex-husband walked away, leaving her a single mother of three girls, facing her new diagnosis alone. She began working full-time and learned to stand on her own, yet her illness worsened as the years progressed, and standing alone was no longer possible. “It was really hard when I had been totally independent to have to depend on Rebecca [who was in her teen years]” (Jennifer, 63). Her daughter, Rebecca, took on the role of caregiver, helping with chores, healthcare, and financial responsibilities. Rebecca, now 31, continued to live with and care for her mother, who was on disability and unable to work. Jennifer took pride in her involvement with the fibromyalgia community, and believed her illness had a purpose, “I am who I am today because of it.” Although Jennifer’s positive attitude helped her to cope, it did not dampen reality. “Very seldom do people know how much pain I’m in...I’ve never been able to...play with my grandchildren like other grandmothers...that is the hardest...change.” Rebecca reported it’s been a “long road.” Support from her daughters has been pivotal in Jennifer’s journey with illness.

Lorena’s illness was old news, though it continued to impact daily life for herself and her family. Chronic fatigue was only one of a litany of illnesses Lorena carried. “I’m always just tired and exhausted. I have no energy ever” (Lorena, 49). Lorena and Matthew have one

adopted son, Jared, who missed time spent with his mother. “If one person’s sick we all can’t do stuff together and one person feels left out” (Jared, 14). Matthew took on the role of “single dad,” cooking, cleaning, attending family functions, working to support the family financially, and caring for Jared. This was not “exactly how I thought I’d be spending my life” (Matthew, 64). He was tired, but kept things together. Matthew and Lorena had both stepped away from their social lives, as their energy was consumed by illness and caring for the family. Lorena reported, “It’s frustrating...no one knows what to do with me.” She was nervous about the future and missed doing things with her family and friends. They missed her too, “I would like to be able to do more with her. I think he [Jared] misses that” (Matthew). Like other ill individuals in this study, Lorena wished she could be her old self, “I don’t expect to be cured, but I’d love to have energy.”

Kari’s diagnosis of multiple sclerosis helped to tear the Swintons apart. Initially, Kari (43) “didn’t want to accept that it was a real physical problem.” Her husband, Adam (45), stated, “It’s aggravating that I don’t know what to do. I help her when I can help her. That kind of sucks, in general, seeing her in pain.” He had resorted to alcohol to deaden his pain and frustration with her illness and encouraged Kari to drink as well, creating relational tension with other family members. “Just fix her. I’m not asking for much—just fix her” (Adam). Alternatively, daughter Katie (18), reported: “It’s not really hard for me.” The two teenage children talked about how Kari’s illness had made things more difficult for them because they did not do as many things together as a family. Unlike other families in this study, however, their descriptions of struggles were individually based, rather than focused on the ill parent or the family as a whole. Each family member spent more time with friends and co-workers than with each other. Moreover, two of the five family members were the only people in this study who

did not discuss social and emotional impacts of chronic illness. Dolores (age unknown), Kari's mother, reported frustration at the lack of familial support. Kari reported divorce is now a reality, and family relationships are strained. Differences in the way this family responded to chronic illness as compared to other families in this study illuminated the need to understand what helps families grow stronger when facing adult-onset chronic illness.

### **Strong Families**

Family strength was evidenced and measured by six characteristics identified by Stinnett and DeFrain (1985), coinciding with Olson and DeFrain's (1997) three traits of strong families. Strong families reported growing closer together through times of trial, whereas weak families tended to break apart via divorce or separation. Chronic illness undoubtedly affected these families' daily lives, yet the majority (83.3%) of families in this study continued to exhibit all six of the characteristics of strong families.

Expressing appreciation for each other was one means by which families were strengthened. All participating families either expressed appreciation for other family members during the course of data collection or discussed the importance of doing so. Jessica Cloward's (55) children expressed appreciation for each other as they "recognize and acknowledge ability growth in each other," while Justin (55) appreciated Jessica and "would consider [her] to be a pretty stoic individual." Jessica reported appreciation is one thing that "holds [their] family together." Likewise, all interviewed members of the Franklin family reported being "very blessed" (Jennifer, 63) because "we're closer" and "more grateful for the time we have with my mom" (Rebecca, 31). Sam Keller (46) expressed appreciation for his family by giving "all the credit to Shayna. Through all our trials she has had to step up and do more than her share...her diligence and desire...has kept our family strong." While discussing Amanda's (16) sporting

ventures, she expressed appreciation for her family who doubles as her “own fan section.” Kari Swinton’s (43) “biggest joy of [her] life is being a mom.” Katie (18) agreed, her friends would “[tell me] my mom is the nicest person in the world...My mom cares for everybody that walks through this door.” Although chronic illness often altered family roles and created tension, strong families continued to value and express appreciation for each other.

Families were strengthened via their commitment to the family unit, as mentioned by 100% of families in this study. Jessica Cloward (55) “chose motherhood” and was committed to her family and that role, in spite of how her illness altered family roles. Both interviewed members of the Franklin family reported growing closer together through Jennifer’s illness, due to their commitment to each other. Likewise, when asked what kept their family together, Sarah Goodson (43) reported, “We’re just so dedicated. Richard and I are dedicated to the family—to the marriage.” Similarly, Shayna Keller (41) said, “We both struggle, but we’re both committed, so it works,” and Sam (46) reported, “there is a strong sense of belonging in our family.” Matthew Zale claimed, “We are committed to each other...that keeps us going...You don’t go running off just because things don’t turn out how you expect. It is what it is” (Matthew, 64). Lorena (49) acknowledged her family is “always there if I need them.” As these families remained committed to each other in spite of chronic illness, families were strengthened. Alternatively, the Swintons, who made the least amount of comments in regard to commitment, were not able to remain committed and are now facing divorce and separation: “I’m frustrated with the whole family ‘cause they don’t help out like they should” (Dolores, age unknown).

Spiritual wellness also strengthened families. Three of six families in this study had unified beliefs, while religious beliefs of the other three families varied by individual. In spite of this variance, two of these three families maintained spiritual wellness via other means, including



service to others and hope for the future. Eleven individuals in this study, representing four of the six families, commonly expressed belief in God, or help from a higher power. “In the end it was never about anyone but God and me. And that’s the same for everyone” (Jessica Cloward, 55). “I’m a strong person. And I know who helps me...the Lord” (Jennifer Franklin, 63). “The gospel [our religious belief] is the main thing that holds our family together. Without the gospel my mom might not even be married to my dad because it’s so hard living with someone who’s sick all the time and can’t help out” (Jacob, 13). Moreover, individuals who did not express this belief in God attributed their hope and wellbeing to other sources of power. “I think we’ll have better technology in the future and we’ll probably be able to find cures for stuff” (Aaron Goodson, 13). “I’m blessed...and I know it could be so much worse...The power of thought is amazing” (Kari Swinton, 43). “There had to be a reason to get sick...if I can help” (Lorena Zale, 49). Familial ability to establish spiritual wellness helped five of the six families to cope, find meaning in illness, and stay strong.

All individuals and families in this study were strengthened as they worked and played together, however, chronic illness drastically altered the ways families spent time together. “Our recreation has...been impacted in a serious way” (Shayna Keller, 41). Four of the six families reported being more active as a family before the diagnosis of chronic illness. Although illness prohibited active leisure pursuits, the majority of these families continued to spend time together via more passive means, “We still do things together, but there’s not as much movement” (Jacob, 13). “Now we get excited if we watch a Netflix [laugh], and Sam usually falls asleep” (Shayna). “Even with the sickness we still have fun times” (Sam, 46). Jessica Cloward (55) discussed the role spending time together played in helping her family cope, “spending time together is very

valuable. It gave my family opportunities to find our new normal.” As families were flexible and spent time together in new ways, family strength was bolstered.

All participating individuals and families were strengthened as they coped in different ways with the changes chronic illness brought into their lives. Jessica Cloward (55) learned to listen to her body, understanding what she needs to do to care for herself, “Now when a little tension occurs in my body...I rejoice because I know how to help myself.” Several families reported reaching a point of new normalcy, “My life feels so normal to me now and I forget it’s not” (Jessica). Still others acknowledge, “life will go on” (Sharon, 18), and work to adapt accordingly. “I don’t allow myself to be stagnant. That’s when self-pity comes in...I don’t want pity...Life is tough but it’s the life I have and I’m gonna live it to the fullest” (Jennifer Franklin, 63). “I’ll step up and do more of [the housework]. I don’t really have a problem doing that kind of stuff” (Richard Goodson, 40). “We’ve tried to carry on our celebrations in the same way that we always have” (Amanda Keller, 16). In addition to being flexible when facing challenges that arose, maintaining some semblance of hope helped families to cope with chronic illness, “I see it [the illness] as getting better. I guess I’ve always had that hope” (Sam, 46). Developing effective coping strategies such as being flexible in family roles and responsibilities, modifying traditions, and maintaining hope, helped individuals and families to remain strong.

Finally, all individuals and families demonstrated strong families communicated effectively with each other. When asked what kept his family strong, Richard Goodson (40) reported, “Probably communication more than anything...you can survive just about anything if you’re talking to each other.” Similarly, Sam Keller (46) stated, “Communication does seem to be a strong glue binding our family together.” Chronic illness can greatly impact a family’s patterns of communication as family roles change and individual family members seek to

understand and come to terms with the illness. Families communicated effectively with one another in spite of chronic illness and continued to exhibit and report family strength.

Though these characteristics individually served to bolster family strength, each characteristic was also influenced by others; communication was developed as families spent time together, spiritual wellness was established when families were committed to each other, et cetera. All 15 of these relationships between characteristics were discussed by at least one individual in each family, demonstrating each characteristic worked with the other five to create a web of family strength and support (Stinnett & DeFrain, 1985). Moreover, each of these relationships was directly tied to statements about the impact of chronic illness on families, evidencing the powerful role chronic illness played in strengthening or weakening families as the illness directly influenced the web of family strength. Jacob, age 13, stated it best: “Even though it impacts a lot when you have a parent that’s really sick like this it’s also a strengthening thing for you because you have to pick up their slack.” Families were only able to maintain family strength as they unified in the midst of their crucible.

### **Family Unity**

Unity is a measure of strength in agencies and political groups and is often the topic for motivational addresses to such parties (Glasby, 2008; Kearney, 2009; Zedillo, 1995). In this study, family unity was defined as a family acting as one, harmoniously working toward some goal or objective. Though family unity is a tool utilized by therapeutic practitioners serving married couples and families (Duncan, 1992), our results illustrated the power of family unity in times of trial. Chronic illness provided an opportunity for participating families to unite and move forward together through crucible experiences. All individuals and families emphasized a need for family unity, demonstrated by the presence of four characteristics in each family: (a)

unified perspective, (b) family stories, (c) common purpose and goals, and (d) a universally altruistic outlook. Of the six families in this study, only the Swintons did not demonstrate family unity via all four of these traits, and faced both strained relationships and the reality of divorce.

A unified perspective was the first aspect of family unity observed. Strong families were united in the way they thought, talked about, and planned for illness and its impact on family life, as mentioned by all families in this study. “My family knows the terrors of this illness” (Jessica Cloward, 55). In private dyadic interviews, each member of the Keller family told me about how Sam would wrestle with the young boys when he got home from work. His illness prevented him from continuing this tradition. The family viewed this loss as affecting each individual family member and worked together to develop a realistic continuation of the tradition, projecting a unified perspective. He now plays ball or reads with them upon arriving home. Moreover, strong families worked to establish a unified perspective of a new normal. “I just see us as normal” (Jennifer Franklin, 63). “I think we’re pretty typical. Maybe it’s the normal we’ve made” (Rebecca, 31). Conversely, Katie Swinton (18) expressed disunity in the way her family perceived things, “It’s hard because we all do different things and we’re all individual people in this family.” The ability to establish a unified family perspective when suffering from chronic illness was related to a family’s ability to maintain family unity.

Family stories were a means of creating and maintaining family unity, and were shared by all families in this study. Rebecca Franklin (31) talked about how stories had not really changed over the years, “The stories we heard before we all pass on [to nieces and nephews].” This transference of family lore helped teach younger family members family culture and expectations, creating unity in working through trials. When asked to share common family stories, all individuals in five of six families were able to do so. In dyadic interviews with the

Swintons, however, several individuals were unable to share a common family story, explaining they did not have any or could not think of any. “We don’t usually have one story that we tell” (Katie, 18). The inability to share a family story set the Swintons apart from other families.

A common purpose and goals served to unify families. All families discussed the existence and/or importance of a common family purpose and goals. “We didn’t have a common purpose like that before” (Jessica, 55). The Clowards sought to advocate for the fibromyalgia community, serving to unify them in spite of Jessica’s illness. Though Jessica was the most involved, her family supported her efforts and attended events benefitting the fibromyalgia community. Common goals also fostered unity, “Whatever my family does, we’re good at it...my family doesn’t accept average” (Amanda, 16). Other members of the Keller family made similar statements, reflecting a common goal to succeed. As the Kellers individually sought to do their best, they uniformly encouraged each other to do the same. Five of six families planned and took part in family celebrations and traditions, another form of common goal. In contrast, Katie Swinton (18) stated, “We don’t really have family traditions.” However, in most families chronic illness served as a unifying factor in helping families to establish a common purpose.

Finally, all individuals and families demonstrated a universally altruistic outlook, meaning they reached out in service to others in their communities dealing with similar trials. “I hope that we can be of help to you and eventually other families like us” (Matthew Zale, 64). “I’m glad that Rebecca and I can have a chance to help you” (Jennifer Franklin, 63). The Franklins and Clowards were the most unified families in this study and also the most altruistic. This outlook was evidenced by engagement in the fibromyalgia community, religious community, and by reaching out to ill individuals in the neighborhood. Seven individuals, representing four of six families, reported serving others as a family to forget their own

problems, bringing them closer together. Again, chronic illness fostered this trait, “She is more compassionate than...before” (Rebecca Franklin, 31). Kari Swinton exhibited an altruistic outlook, “she’s a giver” (Dolores, age unknown), serving to unify her family in some ways, though it also served as a dissenting factor in the family as only Kari exhibited the trait and others wished she would put that energy into caring for herself.

Much like the characteristics of strong families, the four characteristics of family unity fail to tell the entire story. Family unity was related to each of the characteristics of family strength: family unity helped families cope well with crises, time spent together fostered family unity, et cetera. In this way, family unity served as a seventh characteristic of strong families, working to bolster the web of family strength. Moreover, a failure to foster family unity led to weakened family relationships and divorce. Interestingly, the relationship between family unity and time spent together was by far the strongest, as it was the only relationship demonstrated by 100% of individuals and families.

### **Family Strength and Family Unity**

In order to substantiate the relationship between family strength and family unity for each family in this study, strength was examined in terms of the six characteristics outlined by Stinnett and DeFrain (1985), and unity was examined in terms of the four emergent characteristics demonstrating family unity in this study. Table 3 presents a summation of the positive to negative ratio, with ratios representing the number of positive expressions of strength and/or unity to the number of negative expressions of strength and/or unity for all individuals in each family. Families were then rank ordered by ratio (see Table 3). For example, the family with the most positive comments in ratio to the number of negative comments was rated number one. Interestingly, strength and unity ratings were identical for four of the six families, and nearly

identical for the other two families. These findings suggest family unity is an important element in strong families, serving as a seventh characteristic in addition to Stinnett and DeFrain's (1985) six characteristics, working together to create a web of family strength within the context of adult-onset chronic illness including chronic pain. This additional characteristic of family unity needs to be further understood. [insert Table 3 about here]

Data from this study clearly showed the important relationship between family strength and family unity when a parent was diagnosed with adult-onset chronic illness including chronic pain. It was no surprise each individual member of participating families was impacted by adult-onset chronic illness, as this is discussed in the literature (Bocarro & Sable, 2003; Carroll et al., 2000; Donoghue & Siegel, 2000; McDaniel et al., 1997; Rolland, 1994). "Illness brings out the best in families or highlights the worst. It forces profound growth or it splits marriages and families. What it does not do is leave a family untouched" (Donoghue & Siegel, 2000, p. xii; see also Bocarro & Sable, 2003; McDaniel et al., 1997; Rolland, 1994). This dichotomy in the way families respond to chronic illness was supported by this study. Due to this dichotomy and impact, and the lack of literature discussing the importance of establishing and maintaining family unity in crucible situations, future research needs to examine family responses to chronic illness and disability, specifically the role of family unity.

### **Directions for Future Research**

Studies examining families as systems when a parent suffers from adult-onset chronic illness including chronic pain are minimal. Based on the results of this study, several avenues exist for further research. Studies should be conducted with larger sample sizes in order to validate results of this study. In addition, given the inclusion criteria for this study did not delineate between mothers and fathers with chronic illness, future research should examine how

families may respond to chronic illness differently depending on the family role of the newly diagnosed individual. Future researchers should work to establish a universally defined construct of family unity, particularly detailing how families can work together to establish and maintain unity. The emergent characteristics of family unity in this study could be the basis of such research. Moreover, inasmuch as the family strength characteristic of spending time together as a family was more closely tied with family unity than any of the other strength characteristics, a deeper understanding of this relationship may assist therapeutic practitioners in working more effectively with this population. Additionally, the relationship between family strength and family unity could be further understood by developing quantitative measurement tools to be utilized in this and other contexts, as the relationship likely exists regardless of the nature of family crucibles.

The purpose of this study was to qualitatively examine family relationships in families where one adult member was diagnosed with chronic illness resulting in chronic pain. Findings detail the relationship between family strength and family unity. Adult-onset chronic illness provided a catalyst for families to establish and/or maintain family unity. Five families established or maintained family unity and reported positive changes in family strength, while one family failed to maintain or establish family unity and reported negative changes in family strength leading to separation and eventually divorce. This study has important implications for families facing adult-onset chronic illness and for practitioners serving this population. Based on study results, a focus on establishing and maintaining a unified perspective, the telling of family stories, common purpose and goals, and a universally altruistic outlook may serve to increase family unity and thereby strengthen individuals and families within the crucible of adult-onset chronic illness including chronic pain.



### References

- Atwood, J. D., & Gallo, C. (Eds.) (2010). *Family therapy and chronic illness*. New Brunswick, NJ: Transaction.
- Bocarro, J., & Sable, J. (2003). Finding the right P.A.T.H.: Exploring familial relationships and the role of a community TR program in the initial years after a spinal cord injury. *Therapeutic Recreation Journal*, 37(1), 58-72.
- Bohn, U., Wright, L. M., & Moules, N. J. (2003). A family systems nursing interview following a myocardial infarction: The power of commendations. *Journal of Family Nursing*, 9(2), 151-165.
- Boyd, T. V. (2001). Relationship systems: Exploring the role of the emotional system in understanding dual chronic pain couples. *Dissertation Abstracts International, Section A: Humanities and Social Sciences*, 61(7), 2935.
- Butler, M. H. (2010). Systems theory. In H. Johnson (Ed.), *Family recreation* (pp. 28-33). Provo, UT: Brigham Young University.
- Carroll, J. S., Robinson, W. D., Marshall, E. S., Callister, L. C., Olsen, S. F., Dyches, T. T., & Mandelco, B. (2000). The family crucibles of illness, disability, death, and other losses. In D. C. Dollahite (Ed.), *Strengthening our families: An in-depth look at the proclamation on the family* (pp. 278-292). Salt Lake City, UT: Bookcraft.
- Center for Disease Control and Prevention (2010a). *Chronic diseases and health promotion*. Retrieved from <http://www.cdc.gov/chronicdisease/overview/index.htm>
- Center for Disease Control and Prevention (2010b). *Chronic fatigue syndrome*. Retrieved from <http://www.cdc.gov/cfs/>

- Center for Disease Control and Prevention (2010c). *Fibromyalgia*. Retrieved from <http://www.cdc.gov/arthritis/basics/fibromyalgia.htm>
- Center for Disease Control and Prevention (2011). *FAQs about hepatitis b vaccine (hep b) and multiple sclerosis*. Retrieved from [http://www.cdc.gov/vaccinesafety/Vaccines/multiple\\_sclerosis\\_and\\_hep\\_b.html](http://www.cdc.gov/vaccinesafety/Vaccines/multiple_sclerosis_and_hep_b.html)
- Cohen, R. M. (2004). *Blindsided: A reluctant memoir*. New York, NY: HarperCollins.
- Donoghue, P. J., & Siegel, M. E. (2000). *Sick and tired of feeling sick and tired: Living with invisible chronic illness*. New York, NY: W. W. Norton.
- Duncan, S. F. (1992). A program for building remarried family strengths. *Families in Society*, 73(3), 158.
- Dupuis, S. L., & Smale, B. J. A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research*, 32(3), 303-340.
- Erlanson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA: Sage.
- Estess, J. (2004). *Tales from the bed: A memoir*. New York, NY: Washington Square Press.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist*, 55(6), 647-654.
- Gibbs, G. (2007). *Analyzing qualitative data*. Thousand Oaks, CA: Sage.
- Glasby, J. (2008). Strength through unity. *Community Care*, 1722, 32-33.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of dying*. Hawthorne, NY: Aldine.
- Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Piscataway, NJ: Aldine Transaction.
- Grealy, L. (1994). *Autobiography of a face*. New York, NY: Houghton Mifflin.

- Kearney, G. (2009). Strength in unity. *Australian Nursing Journal*, 16(9), 48.
- Keitner, G. I., Archambault, R., Ryan, C. E., & Miller, I. W. (2003). Family therapy and chronic depression. *Journal of Clinical Psychology*, 59(8), 873-884.
- Leone, M. (2010). *Knowing Jesse: A mother's story of grief, grace, and everyday bliss*. New York, NY: Simon & Schuster.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- Lorig, K., Holman, H., Sobel, D., Laurent, D. Gonzalez, V., & Minor, M. (2006). *Living a healthy life with chronic conditions* (3<sup>rd</sup> ed.). Boulder, CO: Bull.
- Mayo Clinic (2010). *Multiple sclerosis: Symptoms*. Retrieved from <http://www.mayoclinic.com/health/multiple-sclerosis/DS00188/DSECTION=symptoms>
- McDaniel, S. H., Hepworth, J., & Doherty, W. J. (1992). *Medical family therapy: A biopsychosocial approach to families with health problems*. New York, NY: BasicBooks.
- McDaniel, S. H., Hepworth, J., & Doherty, W. J. (1997). *The shared experience of illness: Stories of patients, families, and their therapists*. New York, NY: BasicBooks
- Miles, M. B., & Huberman, A. M. (1994). *An expanded sourcebook: Qualitative data analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.
- Olson, D. H., & DeFrain, J. D. (1997). *Marriage and the family: Diversity and strengths*. Mountain View, CA: Mayfield.
- Pekmezovic, T., Svetel, M., Ivanovic, N., Dragasevic, N., Petrovic, I., Tepavcevic, D. K., & Kostic, V. S. (2009). Quality of life in patients with focal dystonia. *Clinical Neurology and Neurosurgery*, 111, 161-164.

- Puymbroeck, M. V., Payne, L. L., & Hsieh, P. (2007). A phase I feasibility study of yoga on the physical health and coping of informal caregivers. *Evidence-based Complementary and Alternative Medicine*, 4(4), 519-529.
- Radina, M. E. (2009). Breast cancer-related lymphedema: Implications for family leisure participation. *Family Relations*, 58, 445-459.
- Radina, M. E., & Armer, J. M. (2001). Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *Journal of Family Nursing*, 7, 281-299.
- Robinson, W. D., Carroll, J. S., & Watson, W. L. (2005). Shared experience building around the family crucible of cancer. *Families, Systems, & Health*, 23(2), 131-147.
- Rogers, N. B. (1999). Family obligation, caregiving, and loss of leisure: The experiences of three caregivers. *Activities, Adaptation, & Aging*, 24(2), 35-49.
- Rolland, J. S. (1994). *Families, illness, and disability*. New York, NY: BasicBooks.
- Samborn, H. V. (2000). Making caring easier: Attorney-caregivers call on support from firms as well as family. *ABA Journal*, 84-85.
- Scholl, K. G., McAvoy, L. H., Rynders, J. E., & Smith, J. G. (2003). The influence of an inclusive outdoor recreation experience on families that have a child with a disability. *Therapeutic Recreation Journal*, 37(1), 38-57.
- Stinnett, N., & DeFrain, J. (1985). *Secrets of strong families*. Boston, MA: Little, Brown, and Company.
- Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage.

- Vidailhet, M., Vercueil, L., Houeto, J., Krystkowiak, P., Lagrange, C., Yelnik, J.,... The French SPIDY Study Group. (2007). Bilateral, pallidal, deep-brain stimulation in primary generalized dystonia: A prospective 3 year follow-up study. *The Lancet Neurology*, 6, 223-229.
- White, J. M., & Klein, D. M. (2008). *Family theories* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Zedillo, E. (1995). Mexico's strength in unity. *Presidents & Prime Ministers*, 4(1), 8.

## Tables

Table 1

*Participant Demographics*

	Family Size	Family Role	Diagnosis	Years Since Onset of Symptoms	Age Range
<b>Cloward Family</b>	7	Dad	---	30 years	51-55
		Mom	Fibromyalgia		51-55
		Daughter	---		16-20
<b>Franklin Family</b>	4	Mom	Fibromyalgia	20 years	61-65
		Daughter	---		31-35
<b>Goodson Family</b>	5	Dad	---	12 years	36-40
		Mom	Chronic Fatigue Syndrome		41-45
		Son	---		11-15
<b>Keller Family</b>	11	Dad	Fibromyalgia and Chronic Fatigue Syndrome	5 years	46-50
		Mom	---		41-45
		Daughter	---		16-20
		Son	---		11-15
		Son	---		11-15
		Son	---		6-10
<b>Swinton Family</b>	4	Grandma	---	1 ½ years	Unknown
		Dad	---		41-45
		Mom	Multiple Sclerosis		41-45
		Daughter	---		16-20
		Son	---		16-20
<b>Zale Family</b>	3	Dad	---	6 years	61-65
		Mom	Chronic Fatigue Syndrome		46-50
		Son	---		11-15

*Note.* Family size is reported family size, not actual number of participating individuals. Not all grown children participated in this study. Demographics are only included for individuals interviewed. Individuals with chronic illness typically had more than one chronic diagnosis and multiple complications from diagnoses and treatment. The diagnosis listed here was the qualifying diagnosis for participation in this study.

Table 2

*Similarities in the Impact of Chronic Illness on Families*

<b>Type of Impact</b>	<b>Percentage of Families</b>	<b>Percentage of Individuals</b>
Physical Self of Ill Individual	100%	100%
Physical Selves of Healthy Individuals	100%	> 80%
Emotional (i.e. feelings)	100%	> 80%
Social	100%	> 80%
Mental (i.e. depression)	100%	> 60%
Financial	100%	> 40%

Table 3

*Family Strength and Family Unity by Case*

	<b>Strength Ratio</b>	<b>Strength Rank</b>	<b>Unity Ratio</b>	<b>Unity Rank</b>
<b>Franklin Family</b>	11.5 : 1	1	1 : 0	1
<b>Cloward Family</b>	9.7 : 1	2	38 : 1	2
<b>Keller Family</b>	7.1 : 1	3	15 : 1	3
<b>Zale Family</b>	5.9 : 1	4	5 : 1	5
<b>Goodson Family</b>	5.5 : 1	5	13 : 1	4
<b>Swinton Family</b>	1.4 : 1	6	1 : 1.4	6



Appendix A

Prospectus

### Families Enduring Chronic Illness: Forces Compelling Change in the Family

When asked about family life, tears immediately come to my friend's eyes as she explains how family life changed after her diagnosis of fibromyalgia. Both her husband and 16-year-old daughter left her to deal with the illness on her own because they "couldn't handle it." She now lives alone, only receiving occasional visits from her mother. Her pain and depression prevent her from leaving home and making friends who might support her. Conversely, when my father was diagnosed with a litany of chronic illnesses, including diabetes and various respiratory illnesses causing chronic pain and depression, our family grew closer together. Through three long years of illness and treatment, with no end in sight, my family continues to exhibit increased understanding and strengthened familial relationships. This dichotomy in the way families respond to adult-onset chronic illness or disability is supported by empirical research (Bocarro & Sable, 2003; Carroll et al., 2000).

In both my friend's and father's situations, the introduction of a chronic illness causing chronic pain and depression served as a crucible that influenced change in the family, whether negative or positive. "A metaphorical meaning of crucible is a severe...trial that refines or purifies" (Carroll et al., 2000, p. 278). A family crucible, then, could be defined as a trial, such as the onset of a chronic illness, which refines the family by influencing change in the family. Research has shown crucibles to be "life altering for both the person and his/her family" (Bocarro & Sable, 2003, p. 59). I have seen this firsthand as my father has struggled with chronic illness. When asked how his illness has changed my mother's life, she replied, "you ask how it's changed my life; it's changed my paradigm completely. It's completely rocked my paradigm" (T. B. Clark, personal communication, January 14, 2010). Likewise, my sister, who was still in high school when the illness began, talked about how family life changed completely

after the onset of the illness. When asked what these changes were, both my mother and sister cited negative changes, such as required sacrifices and loss of family identity, as well as positive changes, such as increased communication and deeper love and respect in the family.

Additionally, discussion of negative and positive changes was couched in leisure terms for both my mother and sister. While loss of leisure seemed to cause negative changes, positive changes were also attributed to leisure activities and choices. Clearly, the impact of chronic illness on my family's relationships and leisure choices verifies the definition of a crucible, as my father's situation is influential in the change within our family.

In order for a family to function in ways that benefit society, an understanding of how families function in stressful situations is essential. Systems Theory suggests that individuals impact the family, and families impact our societal system as individual families seek to establish and maintain balance in their lives (White & Klein, 2008). Another sociological theory, Symbolic Interaction (Glaser & Strauss, 1965; White & Klein) suggests that we cannot understand the behavior of family systems without first understanding meanings created within the family, and that families create meaning as they seek balance in adapting to new life situations. Both Systems Theory and Symbolic Interaction will facilitate theory development in regard to changes in family relationships and leisure choices in crucible experiences.

Leisure in this study will be defined as free-time, or time individuals and families have free from other obligations (Russell, 2005). Hornig (2005) posits family leisure "plays a vital role" (p. 47) in healthy family functioning. Therefore, the time families spend together is important in individual and family development (Dickstein, 2002) as it serves to strengthen family relationships (Greeff & Leroux, 1999; Hornig). Research also shows the introduction of chronic illness directly impacts both individual and family leisure (Bocarro & Sable, 2003;

Cohen, 2004; Estess, 2004; Pekmezovic et al., 2009; Radina, 2009; Samborn, 2000).

Consequently, it is plausible that the ways families respond to changes in leisure patterns may influence family strength and functioning when a parent suffers from chronic illness.

### **Statement of the Problem**

The problem of this study is to examine family relationships in families where one adult member suffers from chronic illness to determine why the crucible of chronic illness causes some families to strengthen while others weaken. Additionally, this study specifically seeks to determine what role leisure plays in mediating the nature of family change. More specifically, the study will attempt to answer the following research questions:

1. How have family relationships changed since onset of chronic illness?
2. How has time spent together (leisure time) as a family changed since onset of chronic illness?
3. Have changes in leisure patterns impacted family relationships?

### **Purpose of the Study**

This study aims to increase understanding of why family relationships either strengthen or weaken in families struggling with the crucible of adult-onset chronic illness and to describe and explain the role leisure choices may play in strengthening family relationships in such circumstances.

### **Significance of the Study**

Due to improvements in modern health care, people are living through more health crises and are not spending as much time in hospitals (Samborn, 2000). This results in the majority of physical and emotional healing taking place in the home (Samborn), thereby creating new home situations where families must adapt to problems faced. In their study of families where a parent

suffered from a debilitating spinal cord injury resulting in chronic pain, Bocarro and Sable (2003) found dichotomous results in spousal relationships, either strengthening or dissolving post-injury marriages. Since families serve as the greatest source of support to individuals with chronic illness (Cohen, 2004; Mactavish & Schleien, 1998; Robinson, Carroll, & Watson, 2005), a better understanding of the choices family members make to deal with the change brought on by a chronic debilitating disease is important. There is a paucity of research, however, focusing specifically on family relationships in families where one adult member suffers from chronic illness.

Many leisure and family scholars recommend future studies examining the family as a whole, rather than as individual parts (Baxter, Braithwaite, & Nicholson, 1999; Dupuis & Smale, 2000; Hawks, 1991; Holman & Epperson, 1984; Mactavish, Schleien, & Tabourne, 1997; Orthner, 1998; Puymbroeck, Payne, & Hsieh, 2007; Radina, 2009; Robinson et al., 2005), and several specifically recommend including the perceptions of children (Bocarro & Sable, 2003; Freysinger, 1997; Mactavish & Schleien, 1998; Shaw, 1997). As a result of these recommendations, this study will conduct research on families with one adult member who suffers from chronic illness, gathering data from parents and children alike. Additionally, the whole family will be examined through researcher observations. Results of this study may benefit scholars, across multiple social science disciplines, searching for a greater understanding of families and individuals with chronic illness. Study results may also benefit practitioners across disciplines.

**Delimitations**

The scope of the study will be delimited to:

1. Families residing in Utah County, Salt Lake County, or southeastern Idaho, in which one member may be participating in a chronic illness support group.
2. Families where one member suffers from chronic illness resulting in chronic pain.
3. Families that include at least one dependent adolescent living at home between the ages of 12 years – 18 years.
4. Operationalized definitions regarding chronic illness and family crucible, which may influence sample selection.
5. Five months (August – December 2010) for data collection.

**Limitations**

The study will be limited to the following:

1. A purposive sample will be the source of data collected. Therefore, generalization beyond this sample cannot be made.
2. Primary study participants may be voluntarily participating in a support group without all family members. Therefore, some variables that may influence how families function cannot be controlled for.
3. It is possible that in some cases not all family members will be available for interviews and scheduled periods of observation. This may limit complete understanding of family relationships.
4. The researcher's personal experiences may serve as a limitation to this study, though conscious efforts have been made to reduce researcher bias.

### **Assumptions**

The assumptions of this study will be that adult-onset of a chronic illness including chronic pain causes considerable disruption in normal family life, and the factors contributing to either increased family strength or instability are observable. It is also assumed that onset of a chronic illness directly influences all family members, and that personal and family leisure may influence the nature of change in family relationships.

### **Definition of Terms**

The following terms are defined to clarify their use in the study:

1. *Chronic Illness.* Any illness lasting at least six months that cannot be prevented or cured, though it can be controlled. For this study, a chronic illness includes chronic pain, some level of uncertainty about the future, and requires daily management.
2. *Crucible.* This refers to “a severe trial...that refines or purifies” (Carroll et al., 2000, p. 278).
3. *Family.* For the purposes of this study, family is defined as two parents or guardians living at home with at least one dependent adolescent (aged 12 years – 18 years).
4. *Family Crucible.* This refers to a trial, such as the onset of a chronic illness, influencing change in the family.
5. *Leisure.* In this study, leisure will be defined as free-time, or time individuals have free from other obligations.
6. *Family Leisure.* This refers to free-time families choose to spend together.

## Chapter 2

### Literature Review

The problem of this study is to examine family relationships in families where one adult member suffers from chronic illness to determine why the crucible of chronic illness causes some families to strengthen while others weaken. Additionally, this study seeks to determine what role leisure plays in mediating the nature of family change. This literature review will be organized by the following topics: (a) importance of studying families, (b) chronic illness and disability, (c) family crucibles and leisure, and (d) summary.

#### Studying Families

Both Mactavish and Schleien (1998) and Robinson et al. (2005) found family support helped to ease burdens placed on the family member suffering from illness or disability. Robinson et al. specifically referred to cancer as a catalyst for change that was both exhausting and empowering for the individual as he/she was given family support. Pekmezovic et al. (2009) also suggest adults suffering from focal dystonias can greatly benefit from adequate family support that reduces the likelihood of a reduction in their quality of life. These studies illustrate the important supportive role that families can play in the recovery of an individual suffering with chronic illness.

Additionally, research has shown situations including adult-onset of chronic disability including chronic pain to be “life altering for both the person and his/her family” (Bocarro & Sable, 2003, p. 59). This substantiates the existence of a family, rather than an individual, crucible, and highlights the need for a better understanding of family crucibles. Several sociological theories aid understanding of the importance of studying families in crucible situations: (a) Systems Theory, and (b) Symbolic Interaction.



**Systems theory.** In Systems Theory, families are defined as a system in which each individual family member impacts the entire family unit. Additionally, family systems are made up of sub-systems consisting of dyadic relationships, which also impact the entire family unit. An understanding of each family member, or part of the system, can only be achieved through studying the entire family, or system. All systems seek to establish and maintain balance, but have the ability to adapt to changes. Additionally, a family system affects its environment, and the environment affects the family system. Theory is developed as researchers seek to explain why the family system functions in the ways it is shown to function through examination of family relationships and interaction (White & Klein, 2008).

The view of families as systems will guide this research as families are viewed as systems impacted by individual family members and sub-systems, and as environmental factors are understood to impact the entire family. More specifically, the environmental factor of the introduction of chronic illness impacts the family as a whole, as well as impacting individual members of the family. An understanding of why family systems and sub-systems function as they do in relation to this environmental factor of chronic illness will facilitate theory development.

**Symbolic interaction.** Researchers often assume that questions asked are interpreted the same way by different actors, when in reality interpretations may vary greatly across respondents. Symbolic interaction posits social actors interpret situations and social interactions differently depending on the meaning each actor attaches to the situation or social interaction (White & Klein, 2008). A researcher must understand meanings that actors attach to phenomenon in order to fully understand social behavior. Humans create shared meaning in order to make sense of their world, and as families create shared meanings, they are enabled to

survive and adapt to their environment. As such, meanings often vary depending on the context under study (White & Klein). White and Klein suggest, “families are crucial sites of meaning creation and verification” (p. 98). Studying family systems and sub-systems will facilitate correct interpretation of meanings attached to the situation of adult-onset chronic illness including chronic pain.

### **Chronic Illness and Disability**

Seven of every 10 deaths in the United States in 2005 were caused by chronic illness, and approximately one of every two adults suffered from at least one chronic illness. Of those adults suffering from chronic illness, one of every four was limited in their daily activities (Center for Disease Control, 2010a). Illnesses that fall under the family of chronic pain (such as fibromyalgia, dystonia, and chronic fatigue syndrome) share many symptoms including pain or physical discomfort, fatigue, depression, stress, shortness of breath, anger, and difficulty sleeping. Adult-onset of chronic illness often creates physical limitations greatly impacting quality of life (Center for Disease Control 2010b, 2010c; Pekmezovic et al., 2009; Vidailhet et al., 2007).

Research exists on various illnesses and disabilities impacting quality of life. Researchers have examined situations where families have a child with a developmental disability (Mactavish & Schleien, 1998; Mactavish et al., 1997; Scholl, McAvoy, Rynders, & Smith, 2003), a child with a learning disability (Amerikaner & Omizo, 1984), an adult member with a spinal cord injury (Bocarro & Sable, 2003), an adult member with cancer (Robinson et al., 2005), and an adult member with breast cancer-related lymphedema (Radina, 2009; Radina & Armer, 2001). Researchers have also examined the impact of such situations on family caregivers, finding that caregivers are greatly impacted by the illness (Dupuis & Smale, 2000;

Puymbroeck et al., 2007; Rogers, 1999; Samborn, 2000). Such situations greatly impact both individuals and families as changes are made to meet new needs and adapt accordingly.

Notwithstanding this research, families that include an adult member suffering from chronic illness including chronic pain have not been previously studied within the context of leisure.

**Chronic pain.** Fibromyalgia, dystonia, and chronic fatigue syndrome are some illnesses that fall under the family of chronic pain. These illnesses are characterized by chronic pain, fatigue, and difficulty sleeping, and greatly impact quality of life (Center for Disease Control, 2010b, 2010c; Pekmezovic et al., 2009).

Fibromyalgia is characterized by widespread muscular pains and fatigue. Additionally, individuals suffering from fibromyalgia experience difficulty sleeping, morning stiffness, migraines, and problems with memory. The causes of this illness are unknown, and diagnosis is difficult. Though symptoms of fibromyalgia can be treated and controlled, the illness is not curable. In 2005, five million adults in America were affected by fibromyalgia, with most patients being women. Fibromyalgia treatment requires many visits to health practitioners and expensive medications, often causing financial strain for affected individuals (Center for Disease Control, 2010c).

Dystonia is an illness typified by sustained muscle contractions usually producing twisting, repetitive movements, or abnormal postures. (Lim, Altenmuller, & Bradshaw, 2001; Pekmezovic et al., 2009). Adult-onset dystonias are the most prevalent form of the illness (Defazio, Berardelli, & Halett, 2007; Pekmezovic et al., 2009; Xiao et al., 2010). Research shows “dystonia is a complex syndrome” (Tinazzi, Fiorio, Fiaschi, Rothwell, & Bhatia, 2009, p. 1432) that is not fully understood (Ali Najee-ullah, 2009) and often goes undiagnosed for years after symptoms begin (Kowal, Davies, & Kiely, 1998; Van Zandijcke, 1995). No cure exists for

dystonia, though it is managed through oral medication, botox injections, surgery, and rehabilitative therapies (Lim et al.). Pekmezovic et al. found high levels of anxiety, depression, reduced mobility, embarrassment, reduced social interaction, pain, and low self-esteem result from dystonia, thereby greatly reducing the individual's quality of life.

Chronic fatigue syndrome affects up to four million Americans and results in profound fatigue, weakness, muscle and joint pain, headaches, impaired memory, and insomnia. At least 25% of individuals suffering from chronic fatigue syndrome are unemployed or on disability due to the illness. This illness is difficult to diagnose as it is often confused for other illnesses with similar symptoms. Though chronic fatigue syndrome cannot be cured, it can be controlled through medications (Center for Disease Control, 2010b).

Support groups exist throughout the nation to increase understanding and facilitate self-management of diseases such as fibromyalgia, dystonia, and chronic fatigue syndrome (Lorig et al., 2006). These groups are marketed to individuals suffering with chronic illness. Though individuals are greatly impacted by such diseases, no previous research includes perceptions of the whole family in seeking to understand the possible impact chronic illness including chronic pain has on the families of affected individuals.

**Impact on families.** Improvements in modern health care enable people to survive more health crises and spend less time in hospitals (Samborn, 2000). As such, the majority of physical and emotional healing takes place in homes, causing family caregivers to make daily life changes in order to effectively care for the ill or disabled family member (Bocarro & Sable, 2003; Samborn). Individuals recovering from illness in homes has various impacts on individual family members. Bocarro and Sable found dichotomous results in spousal relationships, finding these relationships either strengthened or dissolved after one partner suffered from a debilitating

spinal cord injury including chronic pain. Radina (2009) also found contrasting results in women suffering from breast cancer-related lymphedema; they either continued family leisure pursuits by making needed modifications or stopped participating altogether, depending on the perceived amount of familial and societal support. Puymbroeck et al. (2007) found family caregivers experienced increased stress and decreased coping skills while caring for an ill family member. Likewise, Pekmezovic et al. (2009) found adults suffering from focal dystonias intentionally limited their activities in order to avoid public attention. Although many of these results are negative, Folkman and Moskowitz (2000) argue stress-causing situations such as adult-onset of chronic illness including chronic pain include positive as well as negative outcomes, such as increased family strength and positive family functioning. Ostensibly, the family crucible of adult-onset chronic illness may result in positive and/or negative changes, though the factors contributing to each outcome remain nebulous.

### **Family Crucibles**

In chemistry, a crucible is a furnace-like vessel in which chemical reactions requiring intense heat are conducted. This results in the refinement and transfiguration of the original materials, creating something entirely different (Carroll et al., 2000). “A metaphorical meaning of crucible is a severe...trial that refines or purifies” (Carroll et al., p. 278). This definition lends to studying the family crucible, a trial influencing change in the family. Such a trial can result in both positive and negative outcomes, such as strengthened or injured relationships. Carroll et al. posit that adversity is not “automatically harmful,” but “may actually promote growth and adaptation” (p. 279). The onset of a chronic illness may serve as a crucible experience that may influence family change. Past research suggests family leisure choices may be influential in determining the nature of this change (Hornig, 2005).

**Leisure or free-time.** Leisure is defined in many different ways and through many different theoretical lenses. According to Hawks (1991), “leisure has been defined primarily in two different ways: as a portion of one’s time not specifically set aside for other obligatory duties [free-time] or as a quality of experience unconfined to particular times” (p. 388). Additionally, Russell (2005) claims “today leisure is commonly considered time available after obligations—time to use as one pleases,” or free-time. Simply put, leisure in this study will be defined as free-time, or the time that families and individuals have free from other obligations.

Voicing the opinion of many leisure scholars, Hornig (2005) infers “it’s a no-brainer that family recreation plays a vital role in the development of family health, function, and strength” (p. 47). Other studies support the hypothesis of family leisure improving quality of life (Mactavish & Schleien, 1998) and contributing to a family’s ability to cope (Bocarro & Sable, 2003; Dupuis & Smale, 2000). The benefits of traditional views of leisure, including greater life satisfaction, better family cohesion and stability, improved family strength, and enhanced family functioning, have been extolled by family and leisure scholars alike (Agate, Zabriskie, Agate, & Poff, 2009; Christensen, Zabriskie, Eggett, & Freeman, 2006; Dodd, Zabriskie, Widmer, & Eggett, 2009; Hornberger, Zabriskie, & Freeman, 2010; Hornig; Orthner, 1975; Orthner, 1998; Orthner & Mancini, 1990; Palmer, Freeman, & Zabriskie, 2007; Smith, 1997; Smith, Freeman, & Zabriskie, 2009; Wells, Widmer, & McCoy, 2004; Zabriskie, 2001).

Chronic illness has been reported to directly impact individual and family leisure (Bocarro & Sable, 2003; Pekmezovic et al., 2009; Radina, 2009; Samborn, 2000). When faced with a life-altering illness, family members (especially caregivers) often sacrifice leisure time in order to care for their chronically ill or disabled family member (Bocarro & Sable, 2003; Dupuis & Smale, 2000; Mactavish et al., 1997; Radina, 2009; Rogers, 1999; Samborn, 2000). In the

caregiving context, where it seems the ability to freely make leisure choices is more constrained, researchers found that caregivers often abstained from leisure by choice, thereby maintaining a perception of control over the situation (Dupuis & Smale, 2000; Rogers, 1999). For example, Cohen (2004) discusses the leisure activities both he and his wife had to give up in his battle against multiple sclerosis and colon cancer. Rather than enjoying trail runs as a couple, new leisure choices had to be made that would keep the family closer to home. Although his wife could have continued to enjoy trail runs, she chose to spend time with her family and reported no regret for her decision. Estess (2004) and her sisters also discuss choosing to give up previously enjoyed leisure activities in order to spend more time together as one of the sisters suffered from Lou Gehrig's disease (ALS).

Working and playing together as well as spending time together are included in Greeff and Leroux's (1999) list of 11 characteristics of strong families. Moreover, Hornig (2005) cites time spent together as one of the five factors contributing to family strength. Dickstein (2002) asserts family interaction, which requires time spent together, is important for individual and family development.

"Quality time events were perceived as universally positive in their effects on feeling like a family" (Baxter et al., 1999, p. 307), with quality time events including day-to-day activities such as eating meals together and having family councils. As long as time spent together was meaningful for family members, it was found to have a positive effect, yet it is unclear what factors caused time spent together to be meaningful. Bocarro and Sable (2003) found parent-child relationships often improved after adult-onset of chronic illness or disability including chronic pain, as parents had more time to spend one-on-one with their children. Children reported that actual time spent with the parent was more important than specific activities

engaged in (Bocarro & Sable, 2003). Meaningful time spent with family was also found to contribute to physical and mental healing in cancer patients (Robinson et al., 2005).

Additionally, in their study on the experiences of families who have participated in service expeditions, Palmer et al. (2007) found increased strength as families engaged in service together. However, “the term ‘family strengths’ did not capture the range of benefits or depth of responses expressed” (p. 446) by the families in their study. Researchers posit that rather than family strength, these families experienced family deepening, which was defined as a process that had a lasting impact long after the experience was over. In order to have a family deepening experience, Palmer et al. (2007) explain the experience must be purposive, unique, shared and interactive, challenging, and require sacrifice. A family crucible elicits these characteristics, though it is not generally seen as purposive. Consequently, in light of this and past leisure studies, it is plausible that leisure choices may be one of the factors influencing the nature of change in the family when one family member suffers from chronic illness including chronic pain.

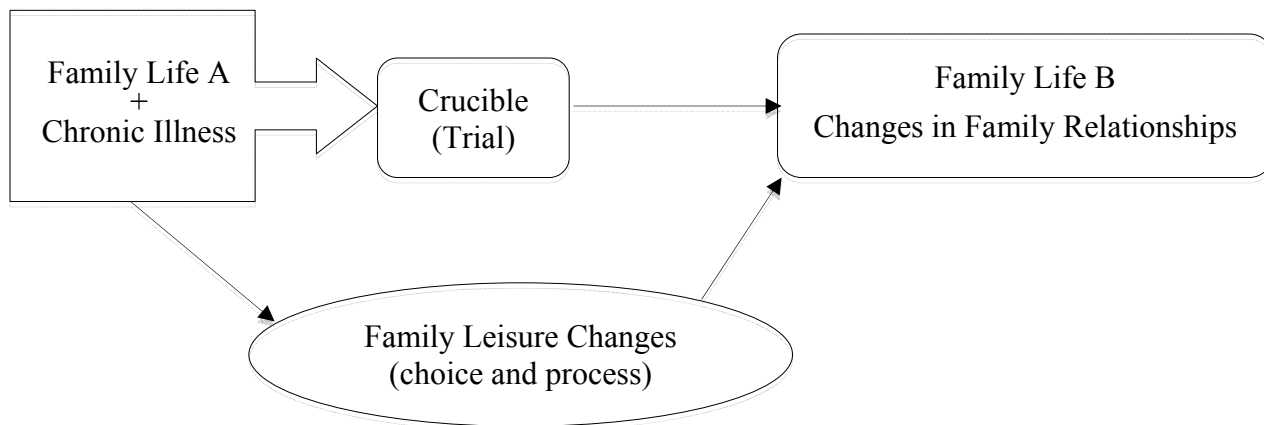
### **Summary**

Many leisure and family scholars recommend future studies looking at the family as a whole, rather than as individual parts (Baxter et al., 1999; Dupuis & Smale, 2000; Hawks, 1991; Holman & Epperson, 1984; Mactavish et al., 1997; Orthner, 1998; Puymbroeck et al., 2007; Radina, 2009; Robinson et al., 2005), and several specifically recommend including the perceptions of children (Bocarro & Sable, 2003; Freysinger, 1997; Mactavish & Schleien, 1998; Shaw, 1997). This is especially important when studying families where one adult member suffers from chronic illness as families serve as the greatest source of support for individuals suffering from chronic illness (Cohen, 2004; Mactavish & Schleien, 1998; Pekmezovic et al.,



2009; Robinson et al., 2005). Studying family systems and sub-systems will facilitate theory development in this study.

Chronic illness causes considerable disruption in family life (Center for Disease Control 2010a, 2010b, 2010c). As such, diagnosis of chronic illness including chronic pain often serves as a family crucible, influencing both positive and negative changes in family relationships. Leisure choices and practices may serve as a mediating factor in the nature of these changes (see Figure 1). The question of why family relationships either strengthen or weaken when one adult family member suffers from chronic illness will be most effectively addressed with up-close observation and constant comparison to determine the underlying factors affecting these families. The purpose of this study, therefore, is to qualitatively examine families, where one adult family member suffers from chronic illness resulting in chronic pain, to determine why the crucible of chronic illness causes some families to strengthen while others grow weaker, and to determine what role leisure plays in mediating the nature of family change.



*Figure 1.* Chronic illness creates a crucible situation in which family relationships change in both positive and negative ways. Leisure may mediate the nature of family change.

### **Chapter 3**

#### **Methods**

The problem of this study is to examine family relationships in families where one adult member suffers from chronic illness to determine why the crucible of chronic illness causes some families to strengthen while others weaken. Additionally, this study seeks to determine what role leisure plays in mediating the nature of family change. This chapter outlines the methods of the study, including: (a) selection of subjects, (b) instrumentation, (c) procedures and analysis, and (d) validity plan for establishing trustworthiness.

#### **Selection of Subjects**

Study participants will be selected through snowball sampling methods and will result in a purposive sample consisting of at least five families. This will result in a minimum sample size of 15 (at least three participants in each family), and will increase until the researcher has reached the point of saturation. Participating families will reside in Utah County, Salt Lake County, or southeastern Idaho and meet specific inclusion criteria, ensuring the researcher can study the phenomenon in question.

The first criterion is that selected families must include two parents living at home, one of whom has been diagnosed with chronic illness. The chronic illness should require daily management, limit normal activity and routine, and include chronic pain to ensure similarities in symptoms across participants. Examples of such illnesses are fibromyalgia, dystonia, and chronic fatigue syndrome.

A second criterion for this study's participants is that selected families must have at least one dependent adolescent between the ages of 12 years – 18 years. This will ensure that at least one of the children being interviewed will have a deeper understanding of the parent's illness and

what that illness entails. Families may have other dependent children who may participate in the study through interviews or scheduled observation, but only one child is sufficient.

Support groups exist to offer relief to individuals struggling with chronic illnesses. Two support groups in Utah and Salt Lake Counties have been contacted as resources for participant recruitment. Both of these groups have agreed to assist in participant selection. One group supporting individuals suffering from dystonia has been dissolved, though the former support group leader has agreed to send email invitations to qualifying families with whom she has maintained contact. Additionally, a group in Salt Lake City, Utah, holds monthly meetings to educate individuals suffering from fibromyalgia and chronic fatigue syndrome. The support group leader has agreed to allow the researcher to come to one or two of these meetings to invite individuals in the group to participate in this research with their families. An invitation will also be extended through the group's email service. As families are recruited for participation, they will be asked if they know other families who may qualify for participation. Any contacts obtained in this manner may also be included in the study. Additionally, study participants may be recruited through similar snowball sampling methods from other support groups and personal contacts of the researcher.

**Protection of subjects.** Data collection procedures will be IRB-approved, and subjects will complete an informed consent form (see Appendix A). Parents will complete an adult informed consent (see Appendix A1), and adolescents (aged 12 years – 18 years) will complete an adolescent informed consent including their own signature as well as the signatures of parents (see Appendix A2). In families with more than one child, all children may be interviewed. In these families, all adolescents (aged 12 years – 18 years) will complete the adolescent consent form including parent signatures, while all children under the age of 12 years will be informed of

the research process as they are read the child consent form that one of their parents will be required to sign (see Appendix A3). IRB requirements, in regard to the protection of subjects and confidentiality, will be adhered to. As such, names and identities of each participant will be kept anonymous to individuals outside of the research team consisting of the principal investigator and her thesis committee. Code names will be assigned to each individual during data analysis so their information and responses will be available only to the researcher and her thesis committee.

### **Instrumentation**

Based on support group information and the researcher's experience with families where one adult member suffers from chronic illness, a list of interview questions was created for this study (see Appendix B). There are six main questions, and each of these questions has multiple examples of follow-up questions in order to elicit more information as needed. Questions have been carefully designed in order to address the research problem, and have been crafted for both adult and child study participants. In order to establish trustworthy questions, 15 individuals from varying backgrounds have reviewed the questions to ensure face validity.

Following are examples of interview questions and sub-questions that have been developed for this study (see Appendix B). Questions crafted for child study participants are italicized.

1. Tell me about your family. (*This question and its follow-up questions will be the same for child participants.*)
  - 1a. How many people are in your family?
  - 1b. What do your parents do for a living?
  - 1c. What does your family do for fun?

2. Tell me about [family member's] illness.

*(For child: What can you tell me about your [family member] being sick?)*

2a. What is the diagnosis, and what led up to the diagnosis? How soon after symptoms began was a correct diagnosis made?

*(For child: How long has [family member] been sick? What's wrong with [family member]?)*

2b. What is required for maintenance/control of the illness?

*(For child: What does [family member] have to do to feel better?)*

3. How has life changed since onset of [family member's] illness?

*(For child: How have your days changed since [family member] got sick?)*

5. How has time spent together (leisure time) as a family changed since onset of [family member's] illness?

*(For child: How have free-time activities changed since [family member] got sick?)*

The researcher will ask these questions in dyadic interviews with individual members of the family. A degree of flexibility will enable the researcher to ask relevant follow-up questions and engage in additional unstructured interviews and discussions at optimal times in order to obtain further insight.

### **Procedures and Analysis**

Glaser and Strauss (1965) recommend prolonged engagement with study participants in order to gain trust and triangulate methods. Glaser and Strauss state, “fieldwork allows researchers to plunge into social settings where the important events (about which they will develop theory) are going on ‘naturally’” (p. 288). As such, data will be collected in the homes

of study participants in order to reduce the researcher's influence on the phenomenon being studied.

As per Glaser and Strauss' (1965) Grounded Theory (GT) methods, data collection will be ongoing for the duration of this study. This will enable data collection and analysis to occur concomitantly, meaning data collection will not only inform analysis, but analysis will also inform further data collection. The timeframe for this study will span from August 2010 through April 2011. The bulk of data will be collected during the initial five months of the study, from August 2010 through December 2010; and the majority of data analysis will occur in the final four months, from January 2011 through April 2011. After the initial period of data collection, the researcher will maintain contact with informants in order to conduct member checks, seek additional information, and seek answers to questions that may emerge during the analysis process.

Upon consent to participate in the study, an initial interview will be set up with each family. Prior to the initial interview, each participating family member will complete a consent to participate form (see Appendix A). Initial interviews with families will consist of questions to get to know the family, including the first two interview questions (see Appendix B), as well as a demographic questionnaire (see Appendix C) to be filled out by the parents. After this initial interview for the purpose of establishing rapport with families, the researcher will engage in further scheduled dyadic interviews with family members as well as scheduled periods of observation. Periods of observation will enable the researcher to observe family interaction during mealtime, morning and/or evening routines, and typical leisure activities. Observations will be scheduled after initial interviews with families, and will vary depending on family preference. Data collected through interviews and observation will be recorded through

researcher notes and memos. Multiple interview and observation sessions (including the initial interview) will be conducted with each family (both parents and all children willing and able to participate). During data analysis, member checks will be conducted with each family in order to verify that results reflect what is actually happening in the family.

More conventional methods of qualitative data collection (Strauss & Corbin, 1998) require tape-recorded interviews and direct transcriptions, whereas GT (Glaser & Strauss, 1965) requires the researcher to transcribe field notes immediately after the interview or interaction. In this manner, immediate perceptions are retained and utilized in analysis of the data. GT also differs in the data analysis process because analysis will be done concomitantly with data collection, meaning the researcher will begin analyzing transcribed field notes and memos from the beginning of data collection and data will be collected through member checks for the duration of data analysis.

Data analysis will be conducted utilizing an NVivo 8 software program. During analysis, the researcher will engage in the process of open, axial, and selective coding. In open coding, transcribed notes and memos will be organized by theme. The researcher will engage in this process multiple times in order to ensure saturation in the data. Once saturation has been achieved, the researcher will enter the process of axial coding, wherein themes will be tested against each other in order to identify patterns that are representative across cases. Through this process of constant comparison and pattern analysis, a core variable will emerge which seems to explain all other themes and patterns. At this point, the researcher will enter selective coding where focus will be placed on fully understanding the core variable. GT utilizes an emic approach, pushing toward theory development. As the researcher spends time with participating families, records her observations and impressions, takes good notes and memos, and engages in

a process of constant comparison, a core explanatory variable will emerge, whereupon theory will be developed (Glaser & Strauss, 1965).

As the researcher engages in this process of constant comparison through data collection and analysis, she will be working closely with Dr. Taniguchi, her thesis committee chair, as well as other committee members in order to validate patterns and results. Though researcher notes will not produce traditional interview transcriptions from audio-recorded interviews, they will be transcribed into an NVivo 8 software package to enable organization and analysis of the data through emerging patterns and themes.

### **Validity Plan for Establishing Trustworthiness**

Erlandson, Harris, Skipper, and Allen (1993) discuss the importance of establishing trustworthiness in naturalistic research, and state that “establishing trustworthiness enables a naturalistic study to make a reasonable claim to methodological soundness” (p. 131). Although Lincoln and Guba’s (1985) four criteria for establishing trustworthiness are not a part of Glaser and Strauss’ (1965) Grounded Theory methods, they are included here as they have become common and accepted in qualitative research. The four criteria are: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability. Following is a discussion on how this study seeks to establish trustworthiness in each of these four areas, thereby promoting trustworthiness throughout both data collection and analysis. Inherent weaknesses in this validity plan for establishing trustworthiness are also discussed.

**Credibility.** When a researcher can successfully create a “degree of confidence in the ‘truth’ that the findings of a particular inquiry” have resulted in, they have established credibility (Erlandson et al., 1993, p. 29). Triangulation is a well-established form of increasing credibility (Erlandson et al.; Gibbs, 2007; Miles & Huberman, 1994), and will be utilized in both data



collection and analysis. In data collection, triangulation will be achieved as various forms of data are collected, including data from dyadic interviews, scheduled observations, and member checks. In data analysis, triangulation will appear in the form of constant comparison through consultations with thesis committee members, peer debriefing with individuals who are not invested in this study, and member checks for validity of results. These methods of triangulation will enable the researcher to step outside of the study, thereby reducing researcher bias. Additionally, credibility will be enhanced by thick descriptions of study participants and observed interactions, which will serve to transport the reader into the setting with the researcher. An audit trail consisting of saved notes, memos, queries, and a reflexive journal will also strengthen credibility of this study as external auditors will be enabled to review the analysis process and clearly see how results were achieved.

**Transferability.** Erlandson et al. (1993) define transferability as the “extent to which [study] findings can be applied in other contexts” (p. 29). In discussing substantive theory developed from their study, Glaser and Strauss (1965) offer suggestions of how their theory could be applied in varying contexts, thereby allowing consumers of their research to determine the extent to which their findings were transferable. Application to other contexts is the responsibility of consumers of this research, though the researcher will seek to enhance transferability through purposive sampling, thick description, and a reflexive journal. Purposive sampling is “governed by emerging insights about what is relevant to the study” (Erlandson et al., p. 148). When combined with thick description, such sampling techniques enable readers to fully understand the context of the research, thereby enabling them to further apply it in varying contexts. A reflexive journal consisting of researcher thoughts and impressions throughout the

process of data collection and analysis contributes to both thick description and purposive sampling as an audit trail is created that denotes motives in study design and implementation.

**Dependability.** When a research study provides “evidence that if it were replicated with the same or similar respondents (subjects) in the same (or a similar) context, its findings would be repeated,” it is said to have dependability (Erlandson et al., 1993, p. 33). An audit trail for readers and reviewers to follow is an essential part of establishing dependability. The researcher will maintain an audit trail through transcribed notes and memos, a reflexive journal, and saved queries. This information will be saved in an NVivo 8 software program file, where the formulation of emerging patterns and themes will also be documented. This file will be reviewed with various auditors throughout the process of data collection and analysis, thereby enhancing dependability through triangulation of auditors.

**Confirmability.** Finally, Erlandson et al. (1993) explain confirmability as the “degree to which [a study’s] products are the focus of its inquiry and not of the biases of the researcher” (p. 34). Again, an audit trail containing saved notes, memos, queries, a reflexive journal, and well documented emerging patterns and themes, is essential here. The researcher will work closely with auditors consisting of her thesis committee in order to establish confirmability of this study. As auditors review the researcher’s data collection and analysis, researcher bias should be minimized. Additionally, the researcher will seek to reduce bias by conducting audit reviews with peers and study participants.

**Potential weaknesses.** Though this validity plan seeks to establish trustworthiness, there are inherent weaknesses in both data collection and analysis. Only the primary investigator will be collecting data, meaning that only the primary investigator will be transcribing field notes and memos. This is an important aspect of study design in establishing trust and rapport with study

participants in the most unobtrusive way possible, but may serve to weaken trustworthiness of study results. This will be minimized as the researcher transcribes notes, memos, and impressions immediately following each interview or observation period with each family in the study. Additionally, the researcher's personal experiences with individuals suffering with chronic illness may serve to weaken the study, though this will be minimized as the researcher conducts research with families suffering with different illnesses than she has had experience with. These weaknesses will also be minimized as the researcher reviews transcribed notes and memos with Dr. Taniguchi weekly, enabling her to address concerns in upcoming interviews with families.

### References

- Agate, J. R., Zabriskie, R. B., Agate, S. T., & Poff, R. (2009). Family leisure satisfaction and satisfaction with family life. *Journal of Leisure Research, 41*(2), 205-223.
- Ali Najee-ullah, M. (2009). *Examining the pathophysiology of focal dystonias using neuroimaging techniques* (Unpublished doctoral dissertation). Howard University, Washington D. C.
- Amerikaner, M. J., & Omizo, M. M. (1984). Family interaction and learning disabilities. *Journal of Learning Disabilities, 17*, 540-543.
- Baxter, L., Braithwaite, D., & Nicholson, J. (1999). Turning points in the development of blended family relationships. *Journal of Social and Personal Relationships, 16*, 291-314.
- Bocarro, J., & Sable, J. (2003). Finding the right P.A.T.H.: Exploring familial relationships and the role of a community TR program in the initial years after a spinal cord injury. *Therapeutic Recreation Journal, 37*(1), 58-72.
- Carroll, J. S., Robinson, W. D., Marshall, E. S., Callister, L. C., Olsen, S. F., Dyches, T. T., & Mandelco, B. (2000). The family crucibles of illness, disability, death, and other losses. In D. C. Dollahite (Ed.), *Strengthening our families: An in-depth look at the proclamation on the family* (pp. 278-292). Salt Lake City, UT: Bookcraft.
- Centers for Disease Control and Prevention (2010a). *Chronic diseases and health promotion*. Retrieved from <http://www.cdc.gov/chronicdisease/overview/index.htm>
- Centers for Disease Control and Prevention (2010b). *Chronic fatigue syndrome*. Retrieved from <http://www.cdc.gov/cfs/>
- Centers for Disease Control and Prevention (2010c). *Fibromyalgia*. Retrieved from <http://www.cdc.gov/arthritis/basics/fibromyalgia.htm>

- Christensen, O. D., Zabriskie, R. B., Eggett, D. L., & Freeman, P. A. (2006). Family acculturation, family leisure involvement, and family functioning among Mexican-Americans. *Journal of Leisure Research, 38*(4), 475-495.
- Cohen, R. M. (2004). *Blindsided: A reluctant memoir*. New York: HarperCollins Publishers.
- Defazio, G., Berardelli, A., & Halett, M. (2007). Do primary adult-onset focal dystonias share aetiological factors? *Brain, 130*, 1183-1193.
- Dickstein, S. (2002). Family routines and rituals—the importance of family functioning: Comment on the special section. *Journal of Family Psychology, 16*(4), 441-444.
- Dodd, D. C. H., Zabriskie, R. B., Widmer, M. A., & Eggett, D. (2009). Contributions of family leisure to family functioning among families that include children with developmental disabilities. *Journal of Leisure Research, 41*(2), 261-286.
- Dupuis, S. L., & Smale, B. J. A. (2000). Bittersweet journeys: Meanings of leisure in the institution-based caregiving context. *Journal of Leisure Research, 32*(3), 303-340.
- Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA: Sage Publications.
- Estess, J. (2004). *Tales from the bed: A memoir*. New York: Washington Square Press.
- Folkman, S., & Moskowitz, J. T. (2000). Positive affect and the other side of coping. *American Psychologist, 55*(6), 647-654.
- Freysinger, V. J. (1997). Redefining family, redefining leisure: Progress made and challenges ahead in research on leisure and families. *Journal of Leisure Research, 29*(1), 1-4.
- Gibbs, G. (2007). *Analyzing qualitative data*. Thousand Oaks, CA: Sage Publications.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of Dying*. Hawthorne, NY: Aldine Publishing.

- Greeff, A. P., & Leroux, M. C. (1999). Parents' and adolescents' perceptions of a strong family. *Psychological Reports, 84*(3), 1219-1224.
- Hawks, S. R. (1991). Recreation in the family. In S. J. Bahr (Ed.), *Family research: A sixty year review, 1930-1990*, (Vol. 1, pp. 387-433). New York: Lexington Books.
- Holman, T. B., & Epperson, A. (1984). Family and leisure: A review of the literature with research recommendations. *Journal of Leisure Research, 16*(4), 277-294.
- Hornberger, L. B., Zabriskie, R. B., & Freeman, P. A. (2010). Contributions of family leisure to family functioning among single-parent families. *Leisure Sciences, 32*(2), 143-161.
- Hornig, E. F. (2005). Bringing family back to the park. *Parks & Recreation, 40*(7), 46-50.
- Kowal, L., Davies, R., & Kiely, P. M. (1998). Facial muscle spasms: An Australian study. *Australian and New Zealand Journal of Ophthalmology, 26*(2), 123-128.
- Lim, V. K., Altenmuller, E., & Bradshaw, J. L. (2001). Focal dystonia: Current theories. *Human Movement Science, 20*, 875-914.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publications.
- Lorig, K., Holman, H., Sobel, D., Laurent, D., Gonzalez, V., & Minor, M. (2006). *Living a healthy life with chronic conditions* (3<sup>rd</sup> ed.). Boulder, CO: Bull Publishing.
- Mactavish, J. B., & Schleien, S. J. (1998). Playing together growing together: Parents' perspectives on the benefits of family recreation in families that include children with a developmental disability. *Therapeutic Recreation Journal, 32*(3), 207-230.
- Mactavish, J. B., Schleien, S. J., & Tabourne, C. (1997). Patterns of family recreation in families that include children with a developmental disability. *Journal of Leisure Research, 29*(1), 21-46.

- Miles, M. B., & Huberman, A. M. (1994). *An expanded sourcebook: Qualitative data analysis* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Orthner, D. K. (1975). Familia ludens: Reinforcing the leisure component in family life. *The Family Coordinator*, 24, 175-183.
- Orthner, D. K. (1998). Strengthening today's families: A challenge to parks and recreation. *Parks and Recreation*, 33, 87-98.
- Orthner, D. K., & Mancini, J. A. (1990). Leisure impacts on family interaction and cohesion. *Journal of Leisure Research*, 22, 125-137.
- Palmer, A. A., Freeman, P. A., & Zabriskie, R. B. (2007). Family deepening: A qualitative inquiry into the experience of families who participate in service expeditions. *Journal of Leisure Research*, 39(3), 438-458.
- Pekmezovic, T., Svetel, M., Ivanovic, N., Dragasevic, N., Petrovic, I., Tepavcevic, D. K., & Kostic, V. S. (2009). Quality of life in patients with focal dystonia. *Clinical Neurology and Neurosurgery*, 111, 161-164.
- Puymbroeck, M. V., Payne, L. L., & Hsieh, P. (2007). A phase I feasibility study of yoga on the physical health and coping of informal caregivers. *Evidence-based Complementary and Alternative Medicine*, 4(4), 519-529.
- Radina, M. E. (2009). Breast cancer-related lymphedema: Implications for family leisure participation. *Family Relations*, 58, 445-459.
- Radina, M. E., & Armer, J. M. (2001). Post-breast cancer lymphedema and the family: A qualitative investigation of families coping with chronic illness. *Journal of Family Nursing*, 7, 281-299.

- Robinson, W. D., Carroll, J. S., & Watson, W. L. (2005). Shared experience building around the family crucible of cancer. *Families, Systems, & Health, 23*(2), 131-147.
- Rogers, N. B. (1999). Family obligation, caregiving, and loss of leisure: The experiences of three caregivers. *Activities, Adaptation, & Aging, 24*(2), 35-49.
- Russell, R. V. (2005). *Pastimes: The context of contemporary leisure* (3<sup>rd</sup> ed.). Champaign, IL: Sagamore Publishing.
- Samborn, H. V. (2000). Making caring easier: Attorney-caregivers call on support from firms as well as family. *ABA Journal, 84*-85.
- Scholl, K. G., McAvoy, L. H., Rynders, J. E., & Smith, J. G. (2003). The influence of an inclusive outdoor recreation experience on families that have a child with a disability. *Therapeutic Recreation Journal, 37*(1), 38-57.
- Shaw, S. M. (1997). Controversies and contradictions in family leisure: An analysis of conflicting paradigms. *Journal of Leisure Research, 29*, 98-112.
- Smith, D. S. (1997). Strengthening family values in the twenty-first century—home-centered recreation. *Leisure Today, 68*(8), 19-21.
- Smith, K. M., Freeman, P. A., & Zabriskie, R. B. (2009). An examination of family communication within the core and balance model of family leisure functioning. *Family Relations, 58*(1), 79-90.
- Strauss, A. L., & Corbin, J. M. (1998). *Basics of Qualitative Research* (2<sup>nd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Tinazzi, M., Fiorio, M., Fiaschi, A., Rothwell, J. C., & Bhatia, K. P. (2009). Sensory functions in dystonia: Insights from behavioral studies. *Movement Disorders, 24*(10), 1427-1436.



- Van Zandijcke, M. (1995). Cervical dystonia (spasmodic torticollis): Some aspects of the natural history. *Acta Neurologica Belgica*, 95(4), 210-215.
- Vidailhet, M., Vercueil, L., Houeto, J., Krystkowiak, P., Lagrange, C., Yelnik, J.,... The French SPIDY Study Group. (2007). Bilateral, pallidal, deep-brain stimulation in primary generalized dystonia: A prospective 3 year follow-up study. *The Lancet Neurology*, 6, 223-229.
- Wells, M. S., Widmer, M. A., & McCoy, J. K. (2004). Grubs and grasshoppers: Challenge-based recreation and the collective efficacy of families with at-risk youth. *Family Relations*, 53(3), 326-333.
- White, J. M., & Klein, D. M. (2008). *Family theories* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage Publications.
- Xiao, J., Zhao, Y., Bastian, R. W., Perlmutter, J. S., Racette, B. A., Tabbal, S. D.,... LeDoux, M. S. (2010). Novel THAP1 sequence variants in primary dystonia. *Neurology*, 74, 229-238.
- Zabriskie, R. B. (2001). Family recreation: How can we make a difference? *Parks and Recreation*, 36(10), 30-42.

## Appendix A1

### Adult Consent Form

Taralyn Clark, a graduate student in the department of Youth and Family Recreation at Brigham Young University, is conducting a research study with the help of her thesis committee, Dr. Stacy Taniguchi, Dr. Patti Freeman, and Dr. Julie Hite, to determine what factors contribute to functioning families in families where one adult member suffers from chronic illness.

Participation in this study is completely voluntary. As a research participant, you will be asked structured interview questions consisting of open-ended questions in reference to the illness of the parent, family communication, and family life. These interviews will last approximately 40 minutes, and will take place in your home. You will be expected to be honest and forthright with your contributions. There is a possibility that you could experience discomfort from answering questions about illness, communication, and family life. These risks, however, are considered to be minimal. The researcher will record notes and impressions during interviews for analysis purposes only by the researcher and her thesis committee.

Your involvement in this study is completely voluntary. You may refuse to participate or withdraw from the research at any time without penalty. Your answers to research questions will be kept strictly confidential. All documented notes and observations will be labeled with code numbers and stored in secure facilities to strictly maintain confidentiality. You will be asked to sign an assumption of risk and release form prior to your participation in the research study.

If you have any questions or concerns regarding your participation in this study you may contact Taralyn Clark at (801) 422-3215, 281 Richards Building, Provo, UT 84602, or Dr. Stacy Taniguchi at (801) 422-3844. If you have any questions regarding your rights as a participant in a research project you may contact Dr. Lane Fischer, Chair of the Institutional Review Board, Brigham Young University, (801) 422-1461.

I have read, understood, and received a copy of the above consent, and willingly consent to participate in this study.

\_\_\_\_\_  
Participant Name (Please Print)

\_\_\_\_\_  
Participant Signature

\_\_\_\_\_  
Date

## Appendix A2

### Parent Consent Form for Adolescent (age 12-18)

Taralyn Clark, a graduate student in the department of Youth and Family Recreation at Brigham Young University, is conducting a research study with the help of her thesis committee, Dr. Stacy Taniguchi, Dr. Patti Freeman, and Dr. Julie Hite, to determine what factors contribute to functioning families in families where one adult member suffers from chronic illness.

Families who participate in this research will include adolescents between the ages of 12-18, who will be asked to participate in the study. Participation is completely voluntary. As a research participant, your child will be asked structured interview questions consisting of open-ended questions in reference to the illness of the parent, family communication, and family life. These interviews will last approximately 40 minutes, and a parent may be present. Your child will be expected to be honest and forthright with his or her contributions. There is a possibility that your child could experience discomfort from answering questions about illness, communication, and family life. These risks, however, are considered to be minimal. The researcher will record notes and impressions during interviews for analysis purposes only by the researcher and her thesis committee.

Your child's involvement in this study is completely voluntary. Your child may refuse to participate or withdraw from the research at any time without penalty. Your child's answers to research questions will be kept strictly confidential. All documented notes and observations will be labeled with code numbers and stored in secure facilities to strictly maintain confidentiality. You will be asked to sign an assumption of risk and release form prior to your child's participation in the research study.

If you have any questions or concerns regarding your child's participation in this study you may contact Taralyn Clark at (801) 422-3215, 281 Richards Building, Provo, UT 84602, or Dr. Stacy Taniguchi at (801) 422-3844. If you have any questions regarding your rights or your child's rights as a participant in a research project you may contact Dr. Lane Fischer, Chair of the Institutional Review Board, Brigham Young University, (801) 422-1461.

I have read, understood, and received a copy of the above consent, and willingly consent to participate and allow my child to participate in this study.

\_\_\_\_\_  
Child's Name (Please Print)

\_\_\_\_\_  
Parent or Guardian of Child (Signature)

\_\_\_\_\_  
Date

### Adolescent Consent Form (age 12-18)

Taralyn Clark, a graduate student in the department of Youth and Family Recreation at Brigham Young University, is conducting a research study with the help of her thesis committee, Dr. Stacy Taniguchi, Dr. Patti Freeman, and Dr. Julie Hite, to determine what factors contribute to functioning families in families where one adult member suffers from chronic illness.

Families who participate in this research will include adolescents between the ages of 12-18, who will be asked to participate in the study. Participation is completely voluntary. As a research participant, you will be asked structured interview questions consisting of open-ended questions in reference to the illness of your parent, family communication, and family life. These interviews will last approximately 40 minutes, and a parent may be present. You will be expected to be honest and forthright with your contributions. There is a possibility that you could experience discomfort from answering questions about illness, communication, and family life. These risks, however, are considered to be minimal. The researcher will record notes and impressions during interviews for analysis purposes only by the researcher and her thesis committee.

Doing this study is completely voluntary. You may refuse to participate or stop at any time without penalty. Your answers to research questions will be kept strictly confidential. All documented notes and observations will be labeled with code numbers and stored in secure facilities to strictly maintain confidentiality. You will be asked to sign an assumption of risk and release form prior to your participation in the research study.

If you have any questions or concerns regarding your participation in this study you may contact Taralyn Clark at (801) 422-3215, 281 Richards Building, Provo, UT 84602, or Dr. Stacy Taniguchi at (801) 422-3844. If you have any questions regarding your rights as a participant in a research project you may contact Dr. Lane Fischer, Chair of the Institutional Review Board, Brigham Young University, (801) 422-1461.

I have read, understood, and received a copy of the above consent, and willingly consent to participate in this study.

\_\_\_\_\_  
Participant Name (Minor, Please Print)

\_\_\_\_\_  
Participant Signature (Minor)

\_\_\_\_\_  
Date

### Appendix A3

#### Parent Consent Form for Child (under age 12)

Taralyn Clark, a graduate student in the department of Youth and Family Recreation at Brigham Young University, is conducting a research study with the help of her thesis committee, Dr. Stacy Taniguchi, Dr. Patti Freeman, and Dr. Julie Hite, to determine what factors contribute to functioning families in families where one adult member suffers from chronic illness.

Families who participate in this research will include children between the ages of 8-11, who will be asked to participate in the study. Participation is completely voluntary. As a research participant, your child will be asked structured interview questions consisting of open-ended questions in reference to the illness of the parent, family communication, and family life. These interviews will last approximately 40 minutes, and a parent may be present. Your child will be expected to be honest and forthright with his or her contributions. There is a possibility that your child could experience discomfort from answering questions about illness, communication, and family life. These risks, however, are considered to be minimal. The researcher will record notes and impressions during interviews for analysis purposes only by the researcher and her thesis committee.

Your child's involvement in this study is completely voluntary. Your child may refuse to participate or withdraw from the research at any time without penalty. Your child's answers to research questions will be kept strictly confidential. All documented notes and observations will be labeled with code numbers and stored in secure facilities to strictly maintain confidentiality. You will be asked to sign an assumption of risk and release form prior to your child's participation in the research study.

If you have any questions or concerns regarding your child's participation in this study you may contact Taralyn Clark at (801) 422-3215, 281 Richards Building, Provo, UT 84602, or Dr. Stacy Taniguchi at (801) 422-3844. If you have any questions regarding your rights or your child's rights as a participant in a research project you may contact Dr. Lane Fischer, Chair of the Institutional Review Board, Brigham Young University, (801) 422-1461.

I have read, understood, and received a copy of the above consent, and willingly consent to participate and allow my child to participate in this study.

\_\_\_\_\_  
Child's Name (Please Print)

\_\_\_\_\_  
Parent or Guardian of Child (Signature)

\_\_\_\_\_  
Date

## Appendix B

### Interview Questions

Following are a list of interview questions that may be asked during dyadic interviews with family members. There are six main questions, followed by possible follow-up questions to aid clarity and deeper understanding. The main questions will be asked of parents and older adolescents, while italicized questions may be asked of children. Fifteen people from varying backgrounds have reviewed questions in order to ensure face and content validity. The first two questions will be asked in an initial dyadic interview with each family member under study. Remaining questions may or may not be asked of families. A degree of flexibility will enable the researcher to ask relevant follow-up questions and engage in interviews at optimal times in order to obtain further insight.

1. Tell me about your family.  
*(For child: This question and follow-up questions will be the same for child participants.)*
  - 1a. How many people are in your family?
  - 1b. What do your parents do for a living?
  - 1c. What does your family do for fun?
  - 1d. Who in your family is your best friend?
  - 1e. Are you friends with everyone in your family?
2. Tell me about [family member's] illness.  
*(For child: What can you tell me about [family member] being sick?)*
  - 2a. What is the diagnosis, and what led up to the diagnosis? How soon after symptoms began was a correct diagnosis made?  
*(For child: How long has [family member] been sick? What's wrong with [family member]?)*
  - 2b. What is required for maintenance/control of the illness?  
*(For child: What does [family member] have to do to feel better?)*
  - 2c. What are reported potential outcomes (prognosis) of the illness? What do you expect in the future?  
*(For child: Will [family member] ever get all the way better?)*
3. How has life changed since onset of [family member's] illness?  
*(For child: How have your days with your family changed since [family member] got sick?)*
  - 3a. Is your daily routine the same as it was before?  
*(For child: Do you do the same things now that you did before [family member] got sick?)*
  - 3b. Is family routine the same as it was before?  
*(For child: Does your family do the same things now that they did before [family member] got sick?)*
  - 3c. Is your outlook on life the same as it was before?  
*(For child: Do you have the same attitude you did before [family member] got sick?)*
4. How have family relationships changed since onset of [family member's] illness?  
*(For child: How have your friendships with your family changed since [family member] got sick?)*

- 4a. Are you still closest with the same family members you were closest to before [family member] became ill?  
*(For child: Are you still best friends with the family members you were best friends with before [family member] got sick?)*
- 4b. Do family members communicate the same way they did before the illness?  
*(For child: Does your family still talk to each other the same way they did before [family member] got sick?)*
5. How has time spent together (leisure time) as a family changed since onset of [family member's] illness?  
*(For child: How have free-time activities changed since [family member] got sick?)*
- 5a. Do you still engage in the same leisure activities you did before [family member] became ill?  
*(For child: Does your family still do the same things with free-time that they did before [family member] got sick?)*
- 5b. If your family had an hour with nothing to do before [family member] became ill, how would they fill the time? How would they fill an extra hour now that [family member] is ill?  
*(For child: If your family had an extra hour with nothing to do before [family member] got sick, what would you do? What would your family do with an extra hour now?)*
6. Have changes in leisure patterns impacted family relationships?  
*(For child: Have changes in free-time activities made your family friendships different?)*
- 6a. Do you spend the majority of your leisure time with the same family members you did before [family member] became ill?  
*(For child: Do you still spend most of your free-time with the same family members you spent your free-time with before [family member] got sick?)*
- 6b. Does your family enjoy leisure time together?  
*(For child: Does your family spend free-time together? If you are together in free-time, do you have fun?)*
- 6c. Does your family enjoy the same leisure activities they did before [family member] became ill?  
*(For child: Does your family do the same things for fun now that they did before [family member] got sick?)*

**Appendix C**

**Demographic Survey**

1. What is your family’s annual income?

- |   |   |
|---|---|
| <input type="checkbox"/> Less than \$10,000 | <input type="checkbox"/> \$60,000-\$69,999      |
| <input type="checkbox"/> \$10,000-\$19,999  | <input type="checkbox"/> \$70,000-\$79,999      |
| <input type="checkbox"/> \$20,000-\$29,999  | <input type="checkbox"/> \$80,000-\$89,999      |
| <input type="checkbox"/> \$30,000-\$39,999  | <input type="checkbox"/> \$90,000-\$99,999      |
| <input type="checkbox"/> \$40,000-\$49,999  | <input type="checkbox"/> Greater than \$100,000 |
| <input type="checkbox"/> \$50,000-\$59,999  |   |

2. What is the father’s highest level of education completed?

- |   |  |
|---|--|
| <input type="checkbox"/> some high school               | <input type="checkbox"/> Associates degree |
| <input type="checkbox"/> completed high school/GED      | <input type="checkbox"/> Bachelors degree  |
| <input type="checkbox"/> some college/trade school      | <input type="checkbox"/> Masters degree    |
| <input type="checkbox"/> completed college/trade school | <input type="checkbox"/> Doctoral degree   |

3. What is the mother’s highest level of education completed?

- |   |  |
|---|--|
| <input type="checkbox"/> some high school               | <input type="checkbox"/> Associates degree |
| <input type="checkbox"/> completed high school/GED      | <input type="checkbox"/> Bachelors degree  |
| <input type="checkbox"/> some college/trade school      | <input type="checkbox"/> Masters degree    |
| <input type="checkbox"/> completed college/trade school | <input type="checkbox"/> Doctoral degree   |

4. What is the age of each member of the family?

- |                                  |                                  |                                  |
|----------------------------------|----------------------------------|----------------------------------|
| <input type="checkbox"/> Father  | <input type="checkbox"/> Child 2 | <input type="checkbox"/> Child 5 |
| <input type="checkbox"/> Mother  | <input type="checkbox"/> Child 3 | <input type="checkbox"/> Child 6 |
| <input type="checkbox"/> Child 1 | <input type="checkbox"/> Child 4 | <input type="checkbox"/> Child 7 |

5. What is the religion of each member of the family?

- |                                  |                                  |                                  |
|----------------------------------|----------------------------------|----------------------------------|
| <input type="checkbox"/> Father  | <input type="checkbox"/> Child 2 | <input type="checkbox"/> Child 5 |
| <input type="checkbox"/> Mother  | <input type="checkbox"/> Child 3 | <input type="checkbox"/> Child 6 |
| <input type="checkbox"/> Child 1 | <input type="checkbox"/> Child 4 | <input type="checkbox"/> Child 7 |

6. On a scale of 1-10, with 1 being ‘not religious’ and 10 being ‘extremely religious,’ how would you rate your family’s level of religiosity?

1      2      3      4      5      6      7      8      9      10

[-----]