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An exploratory study investigating the quality of life in parents of children with disabilities

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AN EXPLORATORY STUDY INVESTIGATING
THE QUALITY OF LIFE IN
PARENTS OF CHILDREN WITH DISABILITIES

by

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An Independent Study
Submitted to the Occupational Therapy Department
of the
University of North Dakota
In Partial fulfillment of the requirements for the degree of
Master’s of Occupational Therapy

Grand Forks, North Dakota
May 11, 2013
This Independent Study Report, submitted by Jeffrey Crain and Rebecca Lang in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

Breanna C. Lamborn
Faculty Advisor

Feb. 19, 2013
Date
Permission

Title An Exploratory Study Investigating the Quality of Life in Parents of Children with Disabilities

Department Occupational Therapy

Degree Master’s of Occupational Therapy

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ABSTRACT

The purpose of the study is to investigate caregivers' of children with disabilities perceptions related to their quality of life through engagement in meaningful occupations. Researchers hope that data from this study will contribute to the growing body of literature on caregivers of children with disabilities. Quality of life is an outcome measure that occupational therapists utilize in their practice.

Throughout the course of the study data was collected through the use of a semi structured interview tool. Researchers developed this tool to allow participants to openly express their thoughts, emotions, and experiences related to having a child with a disability. Results of the study indicated that there is a broad impact of having a child with a disability. Participants rated their quality of life high, and expressed the added love and enjoyment that their children bring into their lives.

Data from the current study is targeted at developing a more comprehensive view of the quality of life of caregivers of children with disabilities. This data may assist occupational therapists in developing a greater understanding of the quality of life needs related to this population. Ultimately, researchers intend for this data to be utilized by therapists who work with this population to better provide holistic, family- centered care.
CHAPTER I

INTRODUCTION

Rationale

The purpose of the study is to investigate the perceptions of caregivers of children with disabilities in relation to the quality of life these caregivers perceive that they experience through engagement in meaningful occupations. According to Law et al. (1996), occupations are "those clusters of activities and tasks in which the person engages in order to meet his/her intrinsic needs for self-maintenance, expression, and fulfillment" (p. 16). According to Crowe, VanLeit, and Berghmans (2000), there is a scarcity of literature related to paternal caregiving. According to Crowe and Florez (2006), there is a lack of literature relating to the time use of mothers as their children with disabilities age.

Since occupational therapists treat children with disabilities, they are in a viable position to act as an agent of change in the family's lives and affect quality of life issues important to the family. Through developing a greater depth of understanding related to the perceptions of parents of children with disabilities, therapists can provide more applicable intervention strategies which target the actual needs of caregivers.

Theoretical Framework

The study is grounded upon an occupational therapy model of practice called Person -Environment -Occupation- Performance (PEOP). The PEOP model of
occupational performance is pertinent to this study because it "is a client-centered model organized to improve the everyday performance of necessary and valued occupations of individuals, organizations, and populations and their meaningful participation in the world around them" (Christiansen & Baum, 2005, p. 244). The current study includes an exploration of quality of life for caregivers of children with disabilities in relation to meaningful occupations. The PEOP model provides guidance in the development of research questions and the underlying topics being researched. The PEOP Model was included throughout the research project and was fundamental in the development of interview questions. Concepts of the PEOP model involving person, occupation, performance, and environment (including the spiritual, cognitive, and psychological aspects) were utilized in the current study. Other aspects of the PEOP model include social support, social and economic systems, culture and values, built environment and technology, as well as the natural environment: these aspects were also considered in the formation of the study.

Natural environments were selected for the interview location, which were conducted in the participants’ homes and at the times of their convenience. Interview questions were tailored to include aspects relating to the participants' quality of life in relation to the PEOP model. Specifically, interview questions were categorized into sections including an introductory section, quality of life questions, occupation questions, and environment questions; questions were structured to enable an increased understanding of the participant's occupational performance and participation.

Statement of the Problem

Currently, there is a lack of literature investigating caregiver's perceptions of their individual quality of life and the impact that caregiving for a child with a disability has on
the caregiver's engagement in meaningful occupations. The scarcity of literature leads to a lack of understanding of the needs of this population.

Assumption

Being a primary caregiver of a child with a disability will have an impact on the roles and responsibilities that vary from those of parents of typically developing children. Quality of life is enhanced through the engagement in activities that the individual finds meaningful and enjoyable. Therefore, limited opportunity to engage in these activities can have a negative effect on a caregiver's quality of life.

Scope of Delimitation

Principle variables of the study include quality of life and well-being as they are defined in the American Occupational Therapy Association's Practice Framework (2008). This study is examining quality of life through engagement in personally meaningful activities. The locale of the study is Casper, Wyoming and the interviewers were assisted with finding participants through the ARC of Natrona County, a non-profit organization serving individuals with disabilities and their families. The interviews and analysis took place from September 2012 through November 2012.

Importance of the study

A family-centered approach is preferred in the practice of occupational therapy (Law et al., 2003; Crowe et al., 2000). Developing a deeper understanding of caregiver's perceptions related to quality of life and well-being will assist practitioners in providing family-centered care.
CHAPTER II
LITERATURE REVIEW

Introduction

Becoming a parent comes with excitement and responsibility, however according to Crowe and Florez (2006) the parental role requires additional demands that impact daily time use. Crowe and Florez (2006) point out that being a parent often involves a struggle to maintain balance between family, work, and recreational time demands. Parents have a variety of responsibilities related to caring for their child and performing the parenting role. As the typically developing child grows older, the responsibility of the parent towards the child decreases. Crowe and Florez (2006) further state that parents of children with disabilities have additional caregiving responsibilities unique to their child's disability. The caregiver role may persist and require additional responsibilities, as the child grows older. Ultimately, this increased responsibility may result in the parent spending less time engaging in meaningful occupations.

Caregiving of a child with a disability. Caregiving is a multifaceted experience that involves a variety of different responsibilities such as: providing financial stability, supervision for safety, assistance for self-care activities, and making sure individuals' basic needs are met (Eiser, 1993). Eiser (1993) finds that being a caregiver for a child
with a disability includes escalating demands. For example, mothers of children with disabilities spend a large portion of their waking hours in childcare activities (Crowe & Florez, 2006). Individuals in the caregiver role have a variety of responsibilities that affect their ability to actively participate in meaningful occupations.

**Time use.** Mothers of children with disabilities report having fewer "typical" days and poorer quality of their days than mothers of children without disabilities (Crowe & Florez, 2006). Data from Sawyer et al. (2010) indicates that mothers of children with autism have additional time demands and spend, on average, six hours a day performing caregiving duties; mothers also reported increased mental health problems. The amount of time-spent caregiving depends on a variety of factors, such as the age of the child, the child's functional status, and the amount of time that the child spends with other caregivers (Crowe & Florez, 2006; Crowe, VanLeit, & Berghmans, 2000). Thus, caregivers may not feel that they have enough time for their own meaningful and necessary occupations, personal time, or time for rest. According to Donovan et al. (2005), mothers may experience these feelings due to perceptions related to "scarcity of time" and because time spent lacks quality and is fragmented between a variety of different activities. The variable of time has varied effects on the individual and their role participation and may lead to stress and impact on well-being, social participation, and relationships. However, VanLeit and Crowe (2002) note that interventions addressing the time concerns of mothers of children with disabilities may lead to improved perceptions of life satisfaction.

**Well-being.** Individuals in the primary caregiver role have unique challenges that include but are not limited to emotional stress, feelings of isolation, and desire to improve their child's quality of life (Donovan, VanLeit, Crowe, & Keefe, 2005). Being a caregiver
of a child with a disability places a great responsibility on the caregiver. A study by Khanna et al. (2010) indicates that primary caregivers for children with autism experience exceptional stress and anxiety. Mothers in the primary caregiver role may be especially susceptible to decreased psychosocial wellbeing due to the physical and emotional demands of caring for a child with a disability (Higgins, Bailey, & Pearce, 2005). They may experience difficulty balancing responsibilities and creating a satisfactory division of workload between other caregivers and professionals (Grosse, Flores, Ouyang, Robbins, & Tilford, 2009). Most caregiving mothers report difficulties balancing responsibilities such as caregiver, homemaker, spouse, etc. (Crowe, VanLeit, Berghmans, & Mann, 1997; Bourke-Taylor, Linsey-Howie, & Law, 2010).

Social participation. A study by McGuire, Crowe, Law, and VanLeit (2004) indicates that mothers in the caregiver role experience feelings such as a desire for increased social contact and wanting to have more quality time with significant others and friends. The volume of daily caregiving activities, emotional exhaustion, social stigma due to a child's sometimes inappropriate behaviors, and labor intensive transporting needs may present barriers for social participation for caregivers (Donovan et al., 2005).

Caregiving mothers report that the relationship with their partner can also be affected by their caregiving demands. According to Mitchell and Hauser-Cam (2010) increased parental stress may contribute to poorer relationships between fathers and mothers and their adolescents with disabilities. Research by Grosse et al. (2009) supports the findings of such relationship dissonances, indicating that mothers have reported that their relationship with their significant other was affected by caregiving requirements, but further indicates that emotional support, assistance from spouses, and education from
healthcare professionals have been shown to assist caregivers in coping with the stresses of caregiving (Grosse et al., 2009).

**Rest and leisure.** With the increased demands and responsibilities, many primary caregivers find it difficult to participate in valued activities such as sleep, leisure, and social activities (Grosse et al., 2009). Caregiving mothers of children with disabilities report less time spent in recreational activities in comparison to mothers of typically developing children. An additional concern expressed by caregivers in the Crowe et al. (1997) study include difficulty maintaining regular uninterrupted sleep patterns, leaving caregivers feeling perpetually fatigued. Mothers who are the primary caregiver spend a varying number of hours each week in the caregiving role. According to VanLeit and Crowe (2002) addressing the time concerns of mothers of children with disabilities may lead to improved perceptions of life satisfaction.

**Roles and economic factors.** In a study by Kersh, Hedvat, Hauser-Cam, and Warfield (2006) individuals in the primary caregiver role reported feelings of increased role demands and economic constraints. The authors indicated that mothers of children with autism who have low socioeconomic status are more likely to have depressive symptomology than mothers of children without autism. Research by Crowe et al. (1997) indicates that mothers of children with disabilities engage in more roles than mothers of typically developing children. The constraints that pertain to increased role demands in caretakers of children with disabilities have been identified as: increased caretaking responsibilities, decreased time spent in quality social participation, relationship stressors with children or spouse, decreased time spent in recreational and leisure activities, economic concerns related to decreased time spent working or cost of medical needs of
having a child with a disability. Resulting changes to roles required by the identified
restraints are highlighted by Crowe et al. (1997) who stated that mothers often give up the
role of student or worker in order to care for their child with a disability. The resulting
disruptions to established roles, such as “worker” or “student”, often result in increased
economic constraints.

In sum, multiple constraints create a wide range of effects on roles, relationships,
economics, caregiving, rest and leisure, and time utilization for the caregivers. “Mothers
were challenged by specific aspects of the child’s care, reduced participation in
occupations of their own choice, effects on the family, difficulty with services and
physical and social barriers” (Bourke-Taylor et al., 2010, p. 134). These aspects may be
unique to each individualized parenting experience, which may in turn impact their
quality of life in unique ways. Yet, what these studies do not fully explicate is the lived
experience of having a child with a disability, and its impact on quality of life including
both negative and positive aspects. According to Hasselkus (2002), engaging in activities
that are personally meaningful and fun are believed to directly increase an individual’s
happiness and well-being. "The opportunity, or lack thereof, to engage in and experience
meaningful occupation can significantly impact a person's subjective QOL" (Pizzi &
Renwick, 2010, p. 124). In the following section of the literature review, the concept of
quality of life is explored further.

Quality of Life

The term quality of life (QOL) is a broad concept and there have been many
attempts to define what it is. The American Occupational Therapy Association’s (AOTA)
Practice Framework lists QOL as a possible intervention outcome along with
occupational performance, adaptation, health and wellness, participation, prevention, role competence, self-advocacy, and occupational justice. AOTA defines QOL as:

[A]n individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment. (WHO, 1998, p. 1596)

Because QOL is such an overarching concept, there have been many methods developed to examine QOL. One way of measuring QOL is through an individual’s health, known as “health-related quality of life” (HRQOL). HRQOL often is divided into a mental component and a physical component. Current literature on the topic of HRQOL and caregivers of children with autism spectrum disorder (ASD) has shown that these parents report having a lower overall HRQOL than the general population (Khanna et al., 2011). A study conducted by Rizk, Pizur-Barnekow, and Darragh (2011) further adds that
the physical aspect of the HRQOL in caregivers of children with ASD did not significantly differ from the general population. However, the mental component of the HRQOL scores for these caregivers was significantly lower than the scores of the general population. More profoundly, these findings are not exclusive to caregivers solely in the United States.

Other studies with similar purposes of evaluating the QOL of caregivers of children with disabilities have been conducted internationally with similar results. A commonly used QOL questionnaire utilized throughout the world is the World Health Organization Quality of Life (WHOQOL) measure. This questionnaire is a 100-item measure with a simplified version containing only 26 items, known as the WHOQOL-BREF. The questionnaire is available in over 20 languages and is easily applied cross-culturally utilizing culture-neutral terminology, and only requires a short time period to complete (WHO, 1998). In a study originating in Taiwan, Gau et al. (2010) examined HRQOL in mothers of children with a chronic illness using the WHOQOL-BREF questionnaire to gather data. Gau et al. (2010) concluded that these mothers have a negative perception of physical health with somatic pain, discomfort, dependence on medication, and negative feelings. Interestingly, another study from Taiwan focused on the QOL of mothers of children with developmental disabilities (DD). This study utilized the WHOQOL-BREF and found that mothers of children with DD had increased negative affect, adjustment problems, and more frequent mental health issues than mothers of well children (Hsieh et al., 2009). Thus, having a child with a disability has been shown to negatively affect the HRQOL of the caregivers; this type of impact has the same effect on the entire family.
Other QOL studies have utilized a family-centered approach (Summers et al., 2005) when considering the impact of a child with a disability, and thus, the use of a family quality of life (FQOL) scale can be beneficial to professionals who work with children with special needs. Summers et al. (2005) proposed the concept of FQOL and introduced the Beach Center FQOL Scale for families with a child who has a disability. This scale measures the perceptions of importance and satisfaction of such concepts as: family interaction, parenting, emotional well-being, physical well-being, and disability-related support. In a study using the Beach Center FQOL scale, Wang et al. (2006) examined variance in responses between mothers’ and fathers’ scores. The study concluded there is little difference between the perceptions of FQOL in fathers and mothers. The results of this study showed that the scores of importance in these concepts were consistently higher than the scores of satisfaction in these concepts, suggesting that mothers and fathers of children with disabilities perceive they have lower FQOL than they should. In summary, primary caregivers of children with disabilities have less time and energy to engage in the activities that are meaningful to them. In a recent study, parents who experience a decrease in engaging in activities have a decrease in overall QOL (Kuhlthau, Kahn, Hill, Gnanasekaran & Ettner, 2010).

Gaps in the Current QOL Literature

Despite the previous QOL studies, literature pertaining to the experience of mothers and fathers of children with disabilities is still lacking. Research is still lacking pertaining to the perceived well-being of mothers and fathers of children with disabilities (Kersh et al., 2006; Saloviita, Italinna, & Leinonen, 2003). According to Tilford et al. (2005), past research has failed to gather data that correctly portrays caregiver impacts across the lifespan of the child. In addition, Rupp and Ressler (2009) note that previous
studies have focused on the relationship between the child's disability and parental activities or evaluated the relationship between the child's disabilities and parental employment, but did not utilize any information on the intervening variable: parental caregiving. According to Rupp and Ressler (2009), the failure to look at parental caregiving in past studies has had undesirable consequences, such as an inability to address the important effects of caregiving on parents themselves. Therefore, by providing literature on the perceptions related to quality of life of parents of children with disabilities, a deeper understanding may be developed for further utilization by various professionals.

**Lack of literature on fathers.** A study by Crowe et al. (2000) found that parents of children with disabilities are very busy. Fathers spend varying amounts of time with their children with disabilities and may change their work schedule to accommodate for the needs of their child with a disability (Crowe et al., 2000). Currently, there is little literature on the perceptions and quality of life of fathers of children with disabilities. The current study explores the perceptions of primary caregivers of children with disabilities. Perceptions of fathers in the primary caregiver role were included in the inclusion criterion within the study. This data may provide exploratory knowledge into the perceptions of fathers fulfilling the primary caregiver role.

**Occupational Therapy Implications**

One of the primary populations that occupational therapists work with is children with developmental disabilities. When working with children, a family-centered approach is believed to be best practice, where the needs of and involvement of all family members should be encouraged (Law et al., 2003; Crowe et al., 2000). "Family-based practice operates on the main principle that parents know their children best and that the
best way to promote the functioning of a child with disability is to foster their family and immediate environment” (Egilson, 2011, pg. 277). An effective therapeutic use-of-self requires a good rapport with the caregivers of the child and will enable the occupational therapist to provide a better family-centered service.
CHAPTER III
METHODOLOGY

Introduction

A child spends more time with his/her parents than any other caregiver, and by supporting the parents, the child will also benefit. According to O'Sullivan (2007), occupational therapists are one of the best professionals to provide that support to parents of a child with a disability because they have the skills to observe and recognize signs of depression, anxiety, or stress within a caregiver. The closeness that develops as occupational therapists work with the families of children with a disability positions occupational therapists in the unique position to provide psychosocial supports or provide referrals to other mental health professionals that the caregiver could benefit from (Bourke-Taylor et al., 2010; Rizk et al., 2011). Occupational therapists also advocate for their clients, and in this case families, to receive the supports and services they need to be healthy, productive beings. The profession of occupational therapy utilizes models and frames of reference to guide practice.

Selected Occupational Therapy Model

There are several models that guide occupational therapy practice including the Person-Environment-Occupation-Performance (PEOP) Model. This model views occupational performance as "the dynamic experience of a person engaged in purposeful
activities and tasks within an environment” (Law et al., 1996, p. 16). The interaction between the person, environment and occupation form the occupational performance (Baum, Christiansen & Bass-Haugen, 2005). Occupational performance may be decreased for the population of caregivers of children with disabilities for several reasons relative to the person, such as emotional distress or health issues related to their caregiving role. Environmental factors that may impact this population’s occupational performance are limited time, finances, and lack of social supports. The time that these parents spend in the caregiver role has a negative impact on the time spent engaged or the ability to engage in personally meaningful occupations. These interactions are dynamic and change over the span of a person’s lifetime. A deep understanding of the perceptions of parents of children with disabilities will promote greater quality of life and well-being for these individuals. This includes a more holistic approach to providing resources, assistance, and treatment to parents of children with disabilities. The current study being conducted will provide a greater understanding related to the perceptions of caretakers of children with disabilities. The study will contribute to a growing body of literature and will place greater emphasis on the perceptions related to quality of life of parents of children with disabilities.

Current Study

What sets this study apart from similar studies that have been conducted is the manner in which this study measures QOL. In this study, the researchers will be exploring the perceived QOL of parents of children with disabilities in relation to their engagement in meaningful occupations. In addition to how the QOL will be measured, this study does not use a survey or tool to gather data. The data will be gathered through semi-structured interviews with the aim of discovering enriching details that are
associated with the experiences of parents of children with special needs and their QOL. The purpose of this study is to explore QOL of parents with a child with a disability, add to the body of evidence, and to enhance occupational therapy service delivery.

**Research Design**

The current study is an exploratory study, which utilizes qualitative techniques. The purpose of the study is to evaluate the perceptions of caregivers of children with disabilities related to their quality of life and engagement in valued activities. According to Polgar and Thomas (2000), phenomenology "emphasizes the direct study of personal experience and the understanding of the nature of human consciousness" (p. 92). A phenomenological approach was utilized in order to develop an understanding of the caregivers’ perspectives related to their caregiving experience. A phenomenological approach was selected over other approaches due to the fit with the purpose of the intended study. For example, a phenomenological approach was selected over an ethnographic approach due to risks associated with an ethnographic approach including becoming invisible, and risk of harm to participants; in conducting ethnographic research, the very presence of a researcher in the field may also taint the data collected (Berg, 2009).

Data collection methods included the use of a semi-structured interview developed by the researchers, which were based on the Person-Environment-Occupation-Performance (PEOP) model. This model was selected because of the comprehensive view of the person in regard to how the individual, occupation, environment amalgamate in the form of occupational performance. The study was reviewed and approved by the Institutional Review Board at The University of North Dakota.
Sources of Data

The study was completed in Casper, Wyoming through the months of September and October, 2012. The population for the study included primary caregivers of children with developmental disabilities between the ages of five and thirteen years old. Primary caregivers were selected due to their expansive experience providing for the caregiving requirements of their children. The ages of the children were selected based on the time caregivers have spent in the caregiver role. Caregivers who are parents of children ages five to thirteen have presumably been in the caregiver role for a prolonged enough time to have exhaustive perspective on the experiences of being a parent of a child with a disability.

Locale of Study

Participants for the study were given the opportunity to choose the location of the interview for their convenience. The meeting locations suggested by the researchers included the ARC of Natrona County or the homes of the participants. All of the participants chose to complete the interviews in their homes, due to work and childcare scheduling.

Population

The sample population for the study was found through the ARC of Natrona County, which is a non-profit organization in Casper, Wyoming that serves families of children who have a disability identified through the state Medicaid waiver. The ARC provides services to families including respite services, case management, after school/summer inclusion programs, community service inclusion services, and homemaking assistance. A purposive sampling method was utilized to gain participants for this study.
due to time constraints and limited access to the population. The Executive Director of the ARC of Natrona County, Codylou Taubert, assisted as a gatekeeper for gaining participants for the study. The researchers informed Mrs. Taubert of inclusion criteria and she facilitated finding and selecting subjects for the study.

The study included four participants, 3 mothers and 1 father. Inclusion criteria for the study consisted of participants who had a child with a disability between the ages of 5 and 13 years old and had been in the caregiving role for at least five years. Participants were excluded if their child did not meet the age requirements or have a disability. In addition, participants were excluded if they were not the primary caregiver for the child or had not been in the caregiving role for five years or more. All participants signed an informed consent form prior to participation in this study.

**Data Collection**

The researchers devised interview questions that were aimed at uncovering rich details about the caregivers' roles, perceived quality of life, and engagement in meaningful activities. Discovery of rich details are important to qualitative studies due to the development of stronger understanding behind the meaning and the reasoning behind the participants' thoughts and feelings. In addition, perceptions are complex and cannot accurately be measured through one-dimensional approaches such as objective data; in order to fully understand it is imperative to incorporate aspects of the participants' lived experience (Berg, 2009). Each participant completed two interviews with the purpose of reviewing the first interview with the participant to ensure that the information they have presented is accurate and to keep interview length within an hour time limit so that participants would not feel overwhelmed with the amount questions being asked of them. Interviews were recorded and later transcribed verbatim to ensure accuracy. The
researchers and the scholarly project advisor reviewed all interviews as a form of member checking and to increase the study's reliability. Auditing promoted accuracy of data as well as reliability and validity within the study.

**Data Analysis**

After the interviews were completed, the researchers transcribed the interviews verbatim. Participants reviewed the transcriptions to ensure that the information shared was accurately communicated and received during the interview process. This process is known as member checking and is used to enhance the validity of the study. The transcriptions were then reviewed by the researchers and coded. Main themes were revealed and the codes were categorized into corresponding themes; this leaves what is known as an audit trail, which means that anyone who reviews this process can see how the researchers came to identify the themes. The faculty advisor, who has experience in qualitative research methods, conducted auditing throughout the duration of the study.
CHAPTER IV

RESULTS

During the study, three major themes emerged which encompassed the experiences of participants within the study. These themes included the experiences of caring for a child with special needs, occupational performance, and personal factors of the participants. The experiences of participants included aspects related to parenting and providing care to their children with disabilities. Occupational performance encompassed the participant's abilities to participate in activities and the factors that impacted activities. Personal factors included intrinsic aspects impacting performance such as: neurobehavioral factors, physiological factors, cognitive factors, psychological and emotional factors, and spiritual factors. Pseudonyms are used to protect the identity of the participants and their children.

Experiences of Participants

The experiences of caring for a child with a disability are multifaceted and encompass many responsibilities, roles, and factors impacting the parent. Parenting entails personal responsibility that is unlike any other role in life. When one participant, Melanie, was asked about caring for her children she replied, "Definitely their needs above your own". This quote articulates the responsibility and values caregivers in this sample perceive in their experiences as parents.
Another responsibility that participants identified was being an advocate for their child. Melanie discussed her perceptions related to advocacy in the following quote: "It has made me a little more motivated to do things that maybe before I would not have done, 'cause I think before Ben I was almost, not shy, but quieter. Now when you have to speak up for someone else it helps." Roxy discussed her experience with advocating for her son within the school district:

Stan has school at home and believe it or not school is probably the most challenging thing we have ever experienced with Stan, because of the fact that Stan is so involved physically, and medically has so many issues. In other peoples' minds, or the school district minds, or things like that, those issues are a top priority compared to schooling or his academics or things like that. But that is the exact opposite of our views for Stan, so you can see that is kind of a head-butting situation where we fought very hard for Stan to be in school.... School is a nightmare that has been the biggest fight we have had to fight for Stan.

Parents also placed a high importance on the responsibility of making sure their children are provided the best circumstances possible. Each parent voiced hopes for their child as they develop, and advocacy is frequently a part of this process. When participants were asked about the hopes they hold for their child, each had a unique response. Connie expressed, "My biggest hope is just to make sure he is happy. I just always want him to feel happy and know that he is loved. And I really hope that at a future time he will be able to communicate with us." Another
parent, Jason, stated, "God will make him what he wants him to be and I'm a big believer in God. God will make him what he wants him to be. I believe that he will have a purpose in life."

Each parent had a different interpretation of the question and replied with their hopes and beliefs related to their child's future. Some parents focused on hopes for the short-term, such as goals to learn to use a communication device. Other parents expressed hopes that over-arched their child's life span. One commonality among the participants was the desire for their child to be happy and loved throughout their lifespan. Participants placed high value on their child's success in varied aspects of their lives. Each participant identified a strong connection between their child's health and their own wellness.

In regard to health, Jason stated, "I think it still has to do with them. If they're feeling good, I'm feeling good. If I feel that there is something wrong with them then I'm not feeling good." Roxy expressed her perceptions related to caring for a child with a disability in the following quote:

I guess if you had to put it in a word: hard. But I have to tell you about that word. When Stan was first born, when he was a premature baby, I read in some place about special needs kids. One lady said it's hard but that's all it is, is hard. It's hard but if you don't give any power to that word, it's just hard, that's all it is. Saying that having a child with special needs, number one, the bigger picture, is just having a child just like how we all do we have our kids, we love our kids and they're precious to us and Stan is different than typical kids but he is just Stan
and everyone is different.... I guess there are significant challenges with having a child with special needs. I think you have to .... the focus sometimes... they have needs that are so great that scream louder than your needs, but I do know that typical kids, little kids can scream louder than other kids too and their needs might need to be met first.

Many of the participants discussed their child's ability to communicate. Jason discussed his child's anger with regard to being understood, "I actually got a call from his school, from his teacher, and he busted a guy's lip [because] the guy didn't understand what he was trying to tell the guy." This is one example of the difficulty communication can pose to children with disabilities. Connie expressed her hope for her non-verbal son, "I really hope that at some future time he will be able to communicate with us with a communication device that he is using at school because he is improving on that." Other needs identified by participants included medical needs and the need for equipment.

Many pieces of equipment are often necessary when caring for children with special needs and attending to medical needs. The equipment is needed to help the child stay healthy, as well as be able to function in activities that are meaningful. Melanie goes into detail describing some of the equipment her son Ben requires:

Well he is on an oxygen concentrator. He is also, because of the trach[eotomy] he has a compressor and it has a nebulizer that provides condensation that is attached to his trach collar so that his throat wouldn't dry out where his trach is. He also has an oximeter that measures his oxygen saturation and also his heart rate and he has
portable oxygen when we leave the house; he also has a portable oximeter to do random checks. He has a suction machine to clear his secretions out of his trach if he is unable to cough them out himself. He has an air purifier. He has a generator in case the power was to go out and we have to run all of those machines, or in case we want to go camping, which I wouldn't want to do. He also has a tricycle that is adaptive for him to ride, he has a stroller, he has a feeder seat, he has a feeding pump to feed him, and various sensory toys [and] a communication device, an iPad. So he has a lot of stuff.

Connie also talked about the amount of equipment they utilize with her son:

We have the shower chair, his wheelchair, [and] we have our conversion van. He has his own special bed with rails on all four sides and one side lowers for us to get him in and out. We have a feeding chair for him to sit and be with the family, but he loves to be on the floor and roll too. He has his own little area in our living room with his own little TV and we just acquired switches that allow him to turn his own TV on. He also has a cushioned mat over there so there is not so much pressure on his muscles and joints.

Another facet, discovered from the interviews, is that being a parent of a child with a disability means having to adapt to medical needs that are complex and require parents to gain a great deal of additional knowledge. One parent, Roxy, describes her experience having a child who requires additional medical considerations:
I actually wanted to be a nurse, but my mom said I wouldn’t be able to do the math, which is totally true. But I am a full-time nurse with my son. I mean I don’t get the big bucks, but I have done everything. I have given him shots. I have checked his oxygen. I have resuscitated him. I have done all of those things that a highly qualified nurse has to do. I can do more than a CNA [Certified Nursing Assistant]; I can do the equivalent of an RN [Registered Nurse]. And I am just a mom.

These medical needs of their children require the parents to plan and structure routines throughout their daily lives. Melanie discusses the importance of having a schedule and staying with a routine:

We have a lot of fun, but we are very busy. You have to schedule around them, you know. A lot of doctors’ appointments, a lot of checking. You know you always have to think before you go, if people are going to be sick, or if you know his medical needs, there is a lot. There’s a lot to know when you have a child with special needs but there is a lot of resources. A lot of people that help you. It’s definitely a learning experience.

Increased medical needs also impact the parent’s financial circumstances. Three of the participants have access to the Medicaid waiver, which pays for respite services, home keeping, medical bills, and equipment needs for their child. Roxy tells a story about when her son qualified for Medicaid, highlighting the almost serendipitous and tenuous process parents undergo to qualify for assistance:
Stan is full on Medicaid. He by the grace of God weighed 1 gram less than the weight requirement to get on Medicaid when he was born. One gram! A piece of sand. So ever since that day...he has been on Medicaid. Stan has been taken care of, and Stan is a very expensive kid. He would have capped out if there was a dollar marker, like on insurance that we had, which is pretty typical, that happens. He would have maxed out before he would have gotten out of the hospital when he was born. So I don't even know how many of millions they have spent on Stan. He is taken care of and I am very, very grateful for that.

Connie talks about how her son is on Medicaid and her amazement at some of the prices for things he needs every month:

Just his formula is almost a thousand dollars a month and his diapers are about two hundred a month. And then we just get so many things, his bags, the tubing, the vent tubes, the G-tubes; and the G-tube alone is like four hundred dollars. So yeah, his supplies are very costly each month and without help, I just don't know how we could do it.

Participants frequently discussed the positive emotions and sense of fulfillment that their children bring to their lives. Each parent had a different perception of life enjoyment and the experience of having a child with a disability. Overall, the data that was collected through the participant interview process simultaneously held the difficulties and the primary focus on the love, joy, hope, and fun that parents experienced through having a child with a disability. In the
following quote Melanie answers a question pertaining to activities she finds most meaningful in her day. "I think waking Ben up, I like doing that. He is a pretty happy little guy and even when he is not and doesn't want to get up he covers up and gets in the blanket and I think it's cute." This quote reflects Melanie's daily routine of awakening in the early morning hours in order to give her son his tube feeding prior to dressing him, preparing his medical supplies for the day, and getting him ready for school. In the next quote Roxy describes her experiences of parenting a son with cerebral palsy. "He's fun, he makes my life joyful and I really enjoy being with him."

A primary focus of Roxy's description of her son is the fun and laughter that he brings into her life as well as the time she enjoys with him. Another mother Connie describes feeding her son, "I still insist on holding him while I am feeding him, just because I love that closeness and time to stare at his little face and talk to him."

Another participant, Jason, who is a single father who is the primary caregiver of his son Jeremy, discussed his life enjoyment related to having a child with special needs, "I enjoy life even more with him because I enjoy a challenge." It is evident that participants view a deep and meaningful connection with their children. It is important to recognize that despite the challenges that participants experience on a daily basis there is a silver lining including the meaningful time that these parents experience with their children through the things they do every day. In the following quote Roxy describes her thoughts about the future with her son,

And hopefully Stan will live a really long life. He will be 50 when I will be 80 and I will be Yoda and he will be way bigger than I am [ha ha],
wrinkly little Yoda, that is exactly what I will be with my osteoporosis and wrinkles.

From an outsider perspective, or on an objective rating form, the experiences might be construed as one-dimensional with regard to caregiving for a child with a disability such as providing for the medical needs of their children, spending many hours each day providing caregiving, and decreased time spent in leisure activities. However, this representation lacks accuracy of the parent’s full scope of actual experiences caring for a child with a disability.

In summarizing the present theme, there are many aspects related to having a child with special needs that have an impact on the parent. These aspects include, but are not limited to, the responsibilities related to the child, advocacy, and hopes for their child; their child’s health, communication barriers, medical needs, level of the disability, equipment needed by the child, and financial considerations.

**Occupational Performance**

Another theme emerging from the interviews with the parents was their occupational performance and what factors affect their engagement in activities. The participants discussed some of the factors that made engagement in meaningful activities difficult and some of the factors that support engagement in these activities. One of the activities affected is the ability to attain restful sleep. Jason describes some of the issues he has with being able to get a good night sleep:

A scale of 1 to 10, maybe a 3. I think myself, I worry about these two. When I am sleeping I’m thinking about them and I don’t have a chance
to [sleep]. I can’t just watch them. My ex-wife thought I was crazy because I would stand at their doorways and make sure they were breathing. JJ, he has a habit of crawling in bed with daddy and since he has had that broken arm he has crawled into bed with daddy every night.

Roxy describes her difficulties with sleeping and what services aid her in achieving a full night sleep:

Luckily, Stan has a nurse at night. He has a nurse Sunday through Thursday nights. So I get to sleep on those nights. We have two nurses. We have had the one nurse for years and the other nurse we have had for about six months, so I am sleeping good when we have nursing. So on those [other] two days I don’t get enough sleep and especially when Stan is on the ventilator I have to stay up and run that ventilator. So I don’t sleep.

Thus, having enough sleep is important to parents in order to be alert and aware enough to care for a child with special needs and medical needs. However, one needs to have sleep to be aware at work as well. Work is another area of occupation the participants identified as being affected by having a child with special needs. Melanie states:

Ben’s needs, definitely. His needs come first. So if he was to need to go to Denver for whatever reason; unfortunately spend some time at the hospital there, I would have to go. And so I got to either find a job that
would let me do that, accommodate that. But it is also hard to keep a job that accommodates to that.

Jason also shared how his son’s needs impact his employment activities.

[B]eing a single dad with JJ it is very hard for me to be at work all the time. Like two weeks ago I had 58 hours instead of 80 because 2 days he was sick and another day broke his wrist and I had to take him to the doctor.

Jason also mentioned how it is hard for him to be at work all of the time with his caregiving demands. All of the participants in the study alluded to the time demands that are correlated with caring for a child with a disability. Melanie was asked about what factors impact her ability to participate in leisure activities:

Time. Sometimes I just don’t have the time and maybe I don’t have anybody to watch Ben on the weekend. ‘Cause a lot of times that is when things are going on. If I want to go do an activity, it’s on a weekend and I don’t have anybody to go watch him.

According to these parents, leisure activities are hard to participate in when so much of one’s time is spent caring for a child. When a parent has a child with special needs, it is hard to even leave the house to participate in leisure activities.

Roxy shared her experiences with pursuing leisure activities:

I don’t think I do any leisure activities. Well, what came to mind was to play volleyball or go to a book club. I don’t do those things but I do on a weekly basis get out of the house. I like to go shopping or go to a
movie, although not by myself. So every week is pretty consistent, I get 4 hours or sometimes longer to go out and so that would be a leisure activity for me and my circumstance. I would say, really consistently, across the board, I would 3 out of 4 weekends a month I get to do that. But it is usually just on the weekend, every once and a while I have to tell myself that going to Wal-Mart to buy groceries is a leisure activity. I haven’t convinced myself yet.

If it is very difficult for parents of children with a disability to leave the house for personal leisure activities; being able to leave the house to participate in meaningful activities with the child with special needs can be even harder. Connie sheds some light on just how hard it is to take her son out in the community for an activity:

[W]ith other children you can take them out to eat and if they need to use the bathroom, they just go use the bathroom. But with James, you have to find a place to change his diaper and that is not easy to do. Just everything takes longer with James, you know. You have to load him in his chair and buckle him; load him in the van and buckle him, and then go through all that process when you are done. And trying to find a place to change him and trying to feed him when you are out is difficult because you don’t have any place to hang the gravity fed bag. So then you have to do it through the vent tube, but then you’re holding the vent tube the whole time through the hour feeding and you just find that it is easier to do it at home and stay home.
With the struggle to complete activities such as sleeping, work, leisure, or going out in the community, it is easy to see how caregiving for a child with special needs can have an impact on a person’s occupational performance. It is important to have solid support systems, because these struggles can very possibly have a strong negative impact on many factors for the parent.

**Personal Factors**

According to Christiansen, Baum, and Bass-Haugen (2005), personal factors can be organized according to the PEOP model categories including: neurobehavioral, cognitive, physiological, cognitive, psychological, emotional, and spiritual factors and are also referred to as “intrinsic” factors. Many aspects of parenting a child with a disability affect intrinsic factors. When Melanie was asked which activities were the most meaningful to her, she replied:

*I think waking Ben up. I like doing that. He is a pretty happy little guy, and even when he is not and doesn't want to get up, he covers up and gets in the blanket and I think it's cute. That's kind of where I get to see his expression of how his day is going to start out. If he is smiling and happy then I know he is in a good mood. Or if he wants to go back to sleep he will cover up his face. And also when I come home from work and get to visit with him. Like "Ben how was your day?" and he smiles, it's definitely coming home.*

Melanie and the other parents within the study placed high value on their relationships with their children. Jason stated "My kids are my whole world" when
asked about his family relationships. Relationships played a large role in providing support for the participants and also causing stress. Roxy shared her story about her struggles with maintaining a successful marriage:

I think it could put some pressure on the marriage, the mom and dad.
It definitely did with us, that was, especially when we were first married. Like I said we were married twice, we got divorced, and I think we were married for a year before Stan was born, I guess I could say we didn’t have enough time to establish our relationship as a husband and wife and to be able to handle a crisis situation.

Roxy also articulated the effect that stress can place on relationships with significant others: "If there are dumb little things, like if Dan and I are fighting about something, stupid, you know how everyone does; those are just dumb little stresses." This statement indicates the status of a relationship affected an individual’s stress level on mental, emotional, and physical levels.

In addition, the child’s health status affects the participants in a variety of ways. When asked what contributed to her sense of wellness, Connie stated, "If everything is going well. I think for me it would be eating healthier and getting some exercise getting some sleep. Ben being in good health, Donald doing good in school that definitely helps."

When Connie was asked how having children with special needs affected her energy level she replied; "I am up late feeding him and up early feeding him and I can’t get a full night sleep. And then...his tone is getting stronger and just getting
him dressed sometimes, afterwards I am just worn out." The demands of care giving for a child with a disability places additional impact on the individual's emotional, mental, and physical health. Jason referred to mental health in the following quote: "I'm 36 years old and we still have personal problems." When asked what caused stress in her life Melanie replied, "My biggest panic: a phone call from school. It stresses me out. I panic right away. I'm not there I feel horrible when that happens." Many of the participants identified feeling stressed when something happened that affected their child's health negatively. These events were identified as being some of the most stressful in the parents' day-to-day lives.

Participants each found their own individual ways to adapt to and cope with stress within their lives. When Connie was asked how she adapts to stress she replied "It helps when I get respite for James; that does help relieve some stress. Hugging my children relieves stress." Some of the participants identified spiritual aspects in their lives, which helped them to feel satisfied within their lives, Roxy expressed this through saying:

To know God is in control and he can see the big picture and it is good. And now I can see that it is good. So I would say that it is a big part of being healthy internally. And obviously I have been depressed before and sad before, and that it's hard to be healthy when things are sad and hard. And I think that just having the joy that comes from Jesus. So that is an important part of being healthy and I think that's why I have the joy of being with Stan. I think that is important.
Quality of life also had a different meaning to each individual and could be hard to define. Jason discussed quality of life as follows:

Quality of life can mean so many things; you know you have quality of love, quality of stature in life, your quality of how you live work wise, and those types of things. I guess quality of life to me, the quality of life that I understand most is friend's family, and if I look at that kid of quality of life on a scale of 1-10 I have a 12. My kids love me and I have a great relationship with my friends, my church and all that. That is the most important thing to me, that not to say I don't have worries.

Each participant rated their quality of life as good or excellent. Having a child with special needs places a special significance to the word *care giving*. Parents provide for their child's needs while maintaining a milieu of other roles and responsibilities. The participants perceptions related to their internal factors were impacted by the disability of the child. Disability has a negative connotation and stigma at the societal level. However, the participants found ways to adapt to the impact of the disability of the child. Ultimately, participants described their lives in terms of the both the impact of their child's disability and the broad enrichment that their children bring into their lives.
CHAPTER V

DISCUSSION

Some of the key concepts within the study included the experiences of caring for children with disabilities and the broad variety of aspects related to this role. Another important theme included the participant's views of their occupational performance related to having a child with a disability. This theme included an insider's view of the world of the participant's lives and their specific perceptions of their activity performance. Personal factors provided another integral aspect to the data and developing an understanding of the participants and each of the factors impacting them and their perceptions related to the varying factors within their lives.

Participants shared their views, which heavily influenced the responsibility they perceived related to caring for their child with a disability. Additional considerations came up regarding caring for a child with a disability and having to structure their lives with great care. Parents within the study shared information regarding their child's medical needs, which made it evident that these individuals had amassed a great amount of knowledge. In addition to the knowledge that the participants had obtained, their
children's needs required a vast amount of money, which created a need for additional supports.

Each parent in the study had a unique way of conducting their lives in accordance to their own values and preferences. The parents were asked questions regarding their performance in areas of occupation such as sleep, work, leisure, and social participation. They expressed their perceptions related to performing activities within their lives and having a child with a disability. Some of the barriers posed within the participants' lives included perceptions of limited time, ability to leave the house for activities, and energy level. Parents also identified the supports within their lives, including respite services provided by organizations such as the ARC of Natrona County, family, and friends.

Each parent's interview reflected an overarching perspective related to having children and the enrichment the children provided within their lives. Parents identified various aspects of providing care giving for their child with a disability. Many areas in their lives were impacted such as their energy level, relationships, and mental and physical health. Spiritual concepts were evident in each interview and appeared as a source of strength for the participants.

Despite the studies cited in the literature review, parents within the study identified a good quality of life, and in spite of difficulties associated to their child's disability, still found joy in the parenting role. Parents identified a deep and overwhelming fulfillment that their children bring into their lives. They expressed the fun and enjoyment in their daily lives while spending time with their children. This feeling of connectedness and the positive impact that children bring into their lives is imbedded in how these individuals perceive their quality of life.
Chapter VI

CONCLUSION

As occupational therapists working with a child with a disability it is important to be aware of the caregivers' struggles and demands. Occupational therapists believe in the family-centered approach when treating children, because occupational therapists understand that by helping the parent/caregiver we are ultimately helping the child. A decrease in engagement in meaningful activities and an increase of stress and demands have a negative impact on a person's quality of life. Caregivers of children with a disability experience all of these factors, thus making them at risk for a low quality of life.

There are many ways of examining quality of life, including surveys that are focused on a person's health in relation to quality of life. This study explored the concept of quality of life in relation to engagement in meaningful activities and the barriers of caring for a child with a disability may have their opportunities for that engagement. The unique feature of this study was exploration of the caregivers' perceptions of their quality of life in contrast to the factors that can impact quality of life; a determination was made if their quality of life was high or low without examining their feelings and views. This
study found that despite the caregivers’ reports of increased demands and limited opportunity for leisure, they all viewed their quality of life at a high level.

Recommendations/ Limitations

Due to the limited availability of participants through the ARC of Natrona County, only four participants were interviewed. Each of the participants was found through the same non-profit organization and all participants live in Casper, Wyoming. In addition, all of the participants were receiving services through the ARC, including respite, housekeeping, nurse home care, and other services. The particular services that each family received differed from participant to participant. Three of the four participants were receiving services through the Medicaid waiver. One of the participants was a single father whose experiences, although valuable, varied from the experiences of the mothers within the study. This participant's feedback was important to the researchers and could potentially provide limited knowledge to support further inquiry regarding the experiences of fathers of children with disabilities.

Further Research

A larger sample size could have strengthened the findings of the study and is a recommendation for further studies. Another recommendation for further studies includes the utilization of mixed methodology. Data from a mixed methodology study may provide further exploration and data regarding the experiences of caregivers of children with disabilities. Mixed methodology may also provide objective data that would be of value for providing therapy and other resources to this population. Variance in participant location and demographics would have provided a broader potential for generalization of findings.
APPENDIX
May 21, 2012

To Whom It May Concern

The Arc of Natrona County is a local non-profit that serves individuals with disABILITIES, primarily through The Wyoming State Medicaid Waiver. The Arc’s current case load consists of approximately 105 families that vary in age, socioeconomic status, education, and diagnosis. Due to The Arc’s close working relationship with those that we serve, The Arc has been asked to participate in Mr. Jeffrey Crain and Ms Rebecca Lang’s Independent Study, addressing the quality of life of parents who have children with disABILITIES. The Arc of Natrona County will assist in the data collection process through facilitating parent participation in Mr. Crain and Ms Lang’s project. Additionally, The Arc of Natrona County will provide an interview room, if the subjects so choose.

The Arc of Natrona County is looking forward to assisting Mr. Crain and Ms Lang in their pursuit of graduate degrees in a field that directly impact those that we have the pleasure of serving. If there are additional questions, concerns, or comments, please do not hesitate to contact me.

Respectfully,

[Signature]

CodyLou Taubert
Executive Director
The Arc of Natrona County
INFORMED CONSENT DOCUMENT TEMPLATE: NON-MEDICAL PROJECTS

THE UNIVERSITY of NORTH DAKOTA
INSTRUCTIONS FOR WRITING AN INFORMED CONSENT DOCUMENT
NON-MEDICAL CONSENT TEMPLATE

INSTRUCTIONS:

• This consent document template is recommended for non-medical studies.

• The text in bold throughout this document offers suggestions and guidance. It should be deleted and replaced.

CONSENT DOCUMENT INSTRUCTIONS:

• Consent documents should be written in the second person (e.g., “You are invited to participate”). Use of the first person (e.g., “I understand that...”) can be interpreted as suggestive and can constitute coercive influence over a subject.

• The consent form should be written at about an eighth grade reading level. Clearly define complicated terms and put technical jargon in lay terms.

• The consent form must be signed and dated by the subject or the subject’s legally authorized representative. The signed consent form each subject must be retained by the investigator and a copy of the consent form must be provided to the subject.

CONSENT DOCUMENT FORMAT:

• To facilitate the IRB review process, the sample format below is recommended for consent forms.

• Prepare the entire document in 12 point type, with no blank pages or large blank spaces/paragraphs, except for a 2 inch by 2 ½ inch blank space on the bottom of each page of the consent form for the IRB approval stamp.

• Multiple page consent documents should contain page numbers and a place for the subject to initial each page.

ASSISTANCE

• If you have questions about or need assistance with writing an informed consent please call the Research Development and Compliance office at 701 777-4279.
INFORMED CONSENT

TITLE: An Exploratory Study Investigating the Quality of Life in Parents of Children with Disabilities

PROJECT DIRECTORS: Jeffrey Crain & Rebecca Lang

PHONE #: (307) 268-2534

DEPARTMENT: Occupational Therapy

STATEMENT OF RESEARCH

A person who is to participate in the research must give his or her informed consent to such participation. This consent must be based on an understanding of the nature and risks of the research. This document provides information that is important for this understanding. Research projects include only subjects who choose to take part. Please take your time in making your decision as to whether to participate. If you have questions at any time, please ask.

WHAT IS THE PURPOSE OF THIS STUDY?

You are invited to be in a research study about the quality of life related to being a parent of a child with special needs because you are associated with the ARC of Natrona County.

The purpose of this research study is to gain exploratory knowledge about the quality of life and well-being of parents of children with special needs. It is hypothesized that being a parent of a child with special needs has an impact on the individual's quality of life and well-being. It is also hypothesized that parents of children with special needs spend additional time in the care giving role and decreased time spent engaging in leisure activities. Currently, there is only a small amount of literature evaluating the quality of life of parents of children with special needs. The aim of this study is to contribute further knowledge about the experiences of parents of children with special needs.

HOW MANY PEOPLE WILL PARTICIPATE?

Approximately 6-8 people will take part in this study in Casper, WY. Interviews will be completed in a location that has been chosen by the participant. The location choices will be at the ARC of Natrona County, the participant's home or any other public location

HOW LONG WILL I BE IN THIS STUDY?

Your participation in the study will last from August 2012 to November 2012. You will need to participate in two interviews during this time. Each interview will take about an hour to complete.
WHAT WILL HAPPEN DURING THIS STUDY?

The Executive Director of the ARC of Natrona County will approach you to participate in the study. You will then be contacted by one of the primary researchers to set up a time and location to meet and have an interview. The time and location will be of your convenience. The interview will last one hour long at the most. You have the option of skipping any question that you are uncomfortable answering. You have the right to end your participation in the study at any time during the study.

After your first interview, a second interview will be scheduled for a time and location that is convenient for you. After the interviews have been completed from all the participants, the researchers will review the interviews and look for common themes that emerge. The researchers will write up the findings of the study and quotes from the interviews will be used to back the findings. Participant identities will be protected through the use of pseudonyms. No information will be released associated with the participant's name.

WHAT ARE THE RISKS OF THE STUDY?

There may be some risk from being in this study. Through involvement in the study you may encounter emotional distress due to the subject matter. Participating in the study will include discussing perceptions related to being a parent of a child with special needs. These discussions may cause the participant to be uncomfortable. If discomfort occurs the participant is free to discontinue or pause the interview at any time. The risks of this study are minimal and caution will be taken in conducting the research, and collecting data.

The ARC of Natrona County will provide support services if they are needed for participants of the study. If the participants are distressed or in need of additional supports they will be referred back to case manager at the ARC of Natrona County.

WHAT ARE THE BENEFITS OF THIS STUDY?

You may not benefit personally from being in this study. However, we hope that, in the future, other people might benefit from this study because the information gathered through the research, which will contribute to treatment being more encompassing of parents' needs and feelings.

WILL IT COST ME ANYTHING TO BE IN THIS STUDY?

You will not have any costs for being in this research study.

WILL I BE PAID FOR PARTICIPATING?

You will not be paid for being in this research study.
CONFIDENTIALITY

The records of this study will be kept private to the extent permitted by law. In any report about this study that might be published, you will not be identified. Your study record may be reviewed by Government agencies, and the University of North Dakota Institutional Review Board.

Any information that is obtained in this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of the use of pseudonyms. The data will be kept in a locked filing cabinet in the faculty advisors office for a period of 3 years.

If we write a report or article about this study, we will describe the study results in a summarized manner so that you cannot be identified.

The interviews will be recorded digitally and kept on the researchers PC. Participants have the right to review/edit the recordings if they so desire. The information gained through the interviews will be used for educational purposes. The data will be kept for a period of 3 years before they will be erased. Only the researchers will have access to the data.

IS THIS STUDY VOLUNTARY?

Your participation is voluntary. You may choose not to participate or you may discontinue your participation at any time without penalty or loss of benefits to which you are otherwise entitled. Information gained during your participation in the study will be utilized in the research. Your decision whether or not to participate will not affect your current or future relations with the ARC of Natrona County.

CONTACTS AND QUESTIONS?

The researchers conducting this study are Jeffrey Crain and Rebecca Lang may ask any questions you have now. If you later have questions, concerns, or complaints about the research please contact Jeffrey Crain or Rebecca Lang at (307) 277-4496 or (307) 689-7971 at your convenience. The advisor for this project is Dr. Carla Wilhite, you may contact her at (307) 268-2534.

If you have questions regarding your rights as a research subject, or if you have any concerns or complaints about the research, you may contact the University of North Dakota Institutional Review Board at (701) 777-4279. Please call this number if you cannot reach research staff, or you wish to talk with someone else.
Your signature indicates that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You will receive a copy of this form.

Subjects Name: ____________________________________________

_________________________________________  ________________
Signature of Subject                         Date
Hello, my name is:
I'd like to talk to you today about your quality of life as a parent of a child with a disability. I may take some notes and will be using a digital recorder. Is that okay? Before we begin, do you have any questions for me?
Okay, let's get started.

Introduction

• Tell me about yourself?
• Tell me about your children?
• Tell me about what it is like having a child with special needs?
• What kind of hopes do you have for your child with special needs? What worries?
• Tell me about your family relationships?
  o Do you have any concerns?
  o What is going well? Not so well?
• Can you share some information about your social supports?
  o Who are your primary social supports?
  o What kind of support do they provide?
• Do you network with other parents of children with special needs?
  o Do you find this helpful?

QOL Specific Questions

• How would you rate your quality of life?
  o Has your rating changed significantly in the last few years? Months?
  o How does having a child with special needs affect your daily life routines?
  o How does having a child with special needs affect your life enjoyment?
  o To what extent?
• Tell me about your perceptions related to your health and wellness?
  o How would you describe your current health and wellness?
  o What contributes to feeling healthy? Not healthy?
  o What contributes to feeling well? Not well?
• How would you describe your energy level?
  o How does having a child with special needs affect your energy level?
  o In positive ways? In challenging ways? Good ways?
• How is your family's financial situation?
  o Are you concerned about money? Home? Bills? Medicine? Having enough food?

Occupation Questions

• Tell me about a normal day? What activities do you do? What things take the most time?
  o Which activities are the most meaningful for you?
  o Which activities cause stress in your life?
    • How do you adapt to these stressors?
• How many times each week do you participate in personal leisure activities?
• What things impact your ability to participate in leisure activities?
• Do you feel that you have enough time to complete activities for home maintenance?
• Do you feel that you have sufficient time to complete financial management activities?
• Do you feel that you have enough time to complete home chores including meal preparation and cleanup?
• Do you feel that you have adequate time for caring for your children?
  o What impacts your ability to complete these tasks?
  o Which take the most time out of your day?
• How would you rate the amount and quality of sleep you receive on average?
  o What factors impact your ability to engage in restful sleep?
• Are you currently employed?
  o What factors impact your ability to pursue and maintain employment?
  o What factors impact your ability to complete work activities?
• Tell me about your leisure interests?
  o How often do you engage in leisure activities?
  o Do you feel that you have adequate time to pursue and engage in leisure activities?
  o What factors impact your ability to pursue leisure interests?
• How do you view your ability to engage in activities with friends, family, and within the community?
  o Describe factors that support your ability to engage in social activities?
  o What factors prevent you from engaging in social activities?
• How often do you engage in social activities?
  o What opportunities do you have for social activities?
• How do you think your pattern of time use is similar to other parents? Different?

Environment Questions
• Do you own your own home? Rent? Is it a single-family home or apartment? Mobile home?
• What kind of condition is your home in? Is it pleasing? Any concerns?
• What has been done to increase accessibility? What still needs to be done?
• Overall, does your home support a quality family life?
• Do you have all the equipment you need to care for your child? What equipment do you need? How do you see it making a difference within the home?
• Does your home have environmental controls? Cooling? Heating? Do these make a difference to you? How much?
REFERENCES


