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The Occupational Participation of a Family of Children with Disabilities

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The Occupational Participation of a Family of Children with Disabilities

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THE OCCUPATIONAL PARTICIPATION OF A FAMILY OF CHILDREN WITH DISABILITIES

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DEDICATION

This thesis is dedicated to my wonderful husband Keith Smith and my incredible parents Joe and Mary Steele for their continuous love and support.

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ABSTRACT

The purpose of this study was to obtain an understanding of how one family of children with disabilities views their occupational participation. A qualitative case study was used to provide a holistic view of occupational participation from individual family members. Data were gathered through interviews with all members of the family, observations of the family engaging in typical occupations, and artwork collected from the children. Data collected during interviews and observations were analyzed using the a priori coding method, with the Model of Human Occupation (MOHO) serving as the theoretical framework used to identify codes. Current findings indicate that an understanding of occupational participation of the family unit cannot be established from observation alone, but must consider the individual family members' perspectives as well. Discussion focuses on the influence of the MOHO framework, importance of family-centered care, and the implications for occupational therapists working with children and their families.

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CHAPTER 1

INTRODUCTION

This chapter provides an introduction to the study. First, a description of the background and need for the study is provided to support the relevance of the research. In addition, the theoretical framework used in this study, the problem statement, the purpose statement, and the research questions are also described. Finally, overviews of the qualitative case study design, researcher's assumptions and potential bias, as well as definitions of key terms are also included.

Background and Need

The key to occupational therapy is understanding occupation. In this profession, the term occupation is not limited to merely describing what one does as paid employment, but instead extends to include the many activities individuals participate in that provide meaning and value to their lives. Kielhofner (2008f) defined human occupation as, "the doing of work, play, or activities of daily living within a temporal, physical, and sociocultural context that characterizes much of human life" (p. 5). In addition to this view, the term occupation also refers to activities involving education, leisure, or sleep; activities done to support life in the home or community; and activities used to promote participation in a social system (American Occupational Therapy Association [AOTA], 2008). Thus, occupation encompasses virtually every aspect of an individual's life. In addition, occupational therapists believe that individuals' engagement in occupations should be supported as a means to promote health and wellness (AOTA, 2008). Closely related to this idea, is the concept of occupational participation, coined by Kielhofner (2008b) as, "engaging in work, play, or activities of daily living that are a part of one's sociocultural context and that are desired and/or necessary to one's well-being" (p. 101). Thus, occupational participation is a vital component of occupational therapy as it provides a basis for understanding how individuals engage in valued and necessary occupations.

Occupational therapists working with children with disabilities primarily focus on the occupational participation of the children they serve and may fail to consider the occupational participation of the family as well. DeGrace (2003) proposed that providing family-centered care was a challenge for the profession of occupational therapy and that in order to provide such care, occupational therapists should consider the meaningful occupations of the family as whole. In a subsequent research study, DeGrace (2004) found that parents of children with severe autism spectrum disorder tend to ascribe negative meaning to family occupations based on the challenges the family encounters for daily activities. Negative experiences related to occupational participation, may influence the ways in which families view their own participation both as a unit and as individuals.

Current occupational therapy research has focused largely on the roles and well-being of mothers of children with disabilities and the impact that this can have on participation in valued occupations. Mothers have been found to be the key providers of care for children with and without disabilities (Crowe, VanLeit, & Berghmans 2000), and although mothers may be satisfied with this role, it may limit their ability to engage in other occupations not related to childcare. In addition, mothers of children with disabilities tend to spend more time engaged in occupations related to childcare, to spend less time engaged in leisure pursuits, and have a poorer view of the quality of each day when compared to mothers of typically developing children (Crow & Florez 2006). However, such research provides limited descriptions of the ways in which mothers view their occupational participation. Donovan, VanLeit, Crowe, and Keefe (2005) found that mothers of children with disabilities reported a desire and need to spend more time alone/taking care of themselves, to share their workload, and to improve their children’s quality of life. Such findings suggest that the current occupational participation of these mothers may not be balanced and that this concept should be further explored.

Research regarding the occupational participation for fathers of children with disabilities is limited. Darling, Senatore, and Strachan (2011) reported that fathers of children with disabilities had more difficulty coping with parental stress and overall life stress when compared to fathers of typically developing children. Although parental stress levels maybe higher for mothers of children with disabilities than fathers (Oelofsen & Richardson, 2006), it is important to consider the points of view and occupational participation of both mothers and fathers when considering the impact on the family unit as whole. The views of mothers and fathers should also be considered in regards to the marital relationships that often serve as the basis for the family unit. Although conflicting research has been found regarding the impact of marital satisfaction for parents of children with disabilities, parents have reported significant relationship strain (Meyers, Mackintosh, & Goin-Kochel, 2009), and increases in stress could lead to withdrawal from partners (Neff & Karney, 2009). Such strain could lead to limits in spouses' opportunities to engage in valued co-occupations, activities which inherently require two or more participants (Zemke & Clark, 1996).

In addition, there are voids in current research relating to the view of family occupational participation as a whole. First, there is a limit in the research that specifically addresses occupational participation among family members. Because this concept is unique to profession of occupational therapy, this study will support the profession by better describing this concept. In addition, the study has been designed to address a second void in existing literature. Current research has not focused on gathering data from all members of a family. Because this study is designed to collect data from all members of the family, it will begin to fill this void. This study is needed to provide a better understanding of the ways in which one family with children with disabilities views their occupational participation both to further the understanding of occupational participation and also to address the needs of the family as a whole. Because families function as an interdependent unit, it is important to understand both the shared and individual perspectives of occupational participation. This deeper understanding will allow for a more comprehensive view which supports the premises set forth by DeGrace (2003) in her call to provide more family-centered intervention.

Frames of Reference

The theoretical basis for interpreting this study is the Model of Human Occupation (MOHO). This model is an occupation-based theory designed specifically to help guide occupational therapists in better serving and understanding their clients

(Kielhofner, 2008f). The model focuses on describing the aspects of occupation related to how occupational therapy services are provided. There are several components and subcomponents of MOHO related to the description of occupation. These include: volition, habituation, performance capacity, and the environment (Kielhofner, 2008a). These components are dynamic and interactive (Kielhofner, 2008c), and it is through this interaction that occupational participation (another term developed as a part of this model) occurs (Kielhofner, 2008b).

Volition. Volition is used to describe the motivation of an individual to participate in occupations. This area is defined as including one's "patterns of thoughts and feelings…" which influence how an individual "…anticipates, chooses, experiences, and interprets what one does" (Kielhofner, 2008g, p. 47). Volition also includes *personal causation, values*, and *interests*. These subthemes reflect the emphasis placed on awareness of one's own abilities and how these abilities are related to things that the individual considers important and the types of activities individuals enjoy.

Habituation. Habituation is used to describe how occupations are organized. This term is defined as "an internalized readiness to exhibit consistent patterns of behavior guided by habits and roles and fitted to the characteristics of routine temporal, physical, and social environments" (Kielhofner, 2008e, p. 52). This component of occupation is further described by looking in more detail at one's *habits* and *roles,* as well as the ways in which these characteristics are incorporated into *routines*. These aspects reflect the overall pattern of daily life and therefore are also descriptive of occupational participation.

Performance capacity. Performance capacity is used to describe the performance of occupations. This term refers to the "ability to do things provided by the status of underlying object physical and mental components and corresponding subjective experiences" (Kielhofner, Tham, Baz, & Huston, 2008, p. 68). Therefore, performance capacity not only looks at what an individual is physically or mentally capable of doing, but also how one views his or her own abilities. Thus, this component represents one's ability to participation in occupation.

Environment. In this model, environment is used to describe the influence of context on the three areas of occupations just described (volition, habituation, and performance capacity). In this model the environment includes “political and social, cultural, economic, and political features” of context (Kielhofner, 2008d, p. 88). This model further defines the impact that environment has on occupation by looking at several dimensions. The dimensions that are of particular relevance to this study include:

- *Opportunities and resources* which enable occupational participation
- *Demands and constraints* which limit occupational participation
- *Objects* that people use when engaged in occupation
- *Spaces* where occupation takes place
- *Social Groups* which are a part of the occupation, such as family, friends, or neighbors.

This model also includes a description of particular *occupational settings* which describe the way each of these dimensions creates meaning for a given occupation. It also includes a description of the influence of opportunities/resources and demands/constraints on occupation, referred to as *environmental impact.* For the purposes of this study, descriptions of environmental impact are reported alongside occupational settings.

In addition to use of MOHO, this study will also draw from family-centered care as a framework for providing occupational therapy services. MOHO will be used to emphasize dynamic aspects of occupation, whereas concepts from family-centered care will be used to emphasize the systematic influence of each individual family member’s perspective on the family as a unit. This framework was selected because of its use in healthcare practice as a means of shifting from focusing on the needs of the individual to focusing on the needs of the family. As a result, in family-centered care treatment goals are created only after considering the unique family context and individual family needs (Hanna & Rodger, 2002). This model also emphasizes the importance of empowering families through shared decision making (Rosenbaum, King, Law, King, & Evans, 1998), understanding each family’s unique needs as a whole and as individual members (Rosenbaum et al., 1998), consideration of factors outside of the families physical needs (Lawlor& Mattingly, 1998), and understanding that the family is a dynamic and continually changing unit (DeGrace, 2003). Thus, this model emphasizes the importance of gaining insight from all members of a family to better understand the family's strengths and needs in an effort to provide services that are not focused solely on the individual client, but encourage support and participation from all family members (Rosenbaum et al., 1998). Thus, use of both frameworks allows this study to present a more in-depth understanding of the occupational participation of a family.

Problem Statement

Current literature surrounding occupational participation of the family unit is limited in regards to families of children with disabilities. This lack of research is not consistent with the client-centered approach that is a tenant of occupational therapy (AOTA 2008) and does not support the family-centered approach that should be utilized by occupational therapists (DeGrace, 2003). In addition, the use of evidence-based practice is essential to the profession of occupational therapy (AOTA, 2008). A lack of evidence on occupational participation of the family unit does not adhere to the call of the profession to provide evidence-based services. To address this problem, this study serves as an initial source of research on the occupational participation of one family, while addressing the family-centered components relevant to client-centered care. By providing research on the occupational participation of one family, this study might also be used to provide a foundation for future work to support evidence-based practice in regards to intervention focused on the entire family unit.

Purpose Statement

The purpose of this qualitative case study was to obtain an understanding of how one family with children with disabilities views their occupational participation. A qualitative case study was used to provide an in-depth and holistic view of occupational participation from individual members of the family. In addition, this type of research uses multiple sources of data to ensure that the complex nature of the family unit is more fully represented.

Research Questions

This study will be used to answer the following research questions:

1. How does the family view their occupational participation?

2. How do parents in this family view their participation in co-occupations?
3. How do individual members of the family view their own occupational participation?

Use of a Qualitative Case Study Design

As mentioned, a qualitative case study design was selected for this study because the tenants of this approach are well aligned with the intent of the study. According to Creswell (2013), a qualitative case study approach is used to gain a more in-depth understanding of a single case or multiple cases by studying each case in the context of real life. As a part of the case study process, the researcher will observe a case overtime to develop a description of the case and identify case themes (Creswell, 2013). For this study, a single case was explored, one family with children with a disability. The use of a single case provides the researcher with an in-depth description of the family experience and individual points of view regarding occupational participation.

In addition, qualitative case studies use multiple sources of data to enable the researcher to develop this deeper understanding (Creswell, 2013). For this study, rich descriptions of the family experience were developed by using interviews, observations, and rapport building activities as sources of data. Because the family is a complex unit with many subsystems, this approach was also selected to allow the researcher to deeply explore a single case as a means of better capturing the complexity of the family unit. In addition, Noor (2008) suggests that the in-depth nature of the case study approach enables researchers to gain a more holistic understanding of the case. Because of the holistic nature of this design, it will allow the researcher to gain a better understanding of the family experience by exploring the individual occupations, family occupations, and co-occupations of this family.

Researcher’s Assumptions and Potential Bias

In qualitative research, it is especially important that the researcher be aware of potential sources of bias by understanding the ways in which his or her own beliefs, values, and experiences may influence the results of a study. This is reflected by Creswell (2013) through the concept of reflexivity, in which the researcher explicitly records the ways in which personal experiences, values, and bias may influence how the researcher relates to and interprets data. Several assumptions, which may influence the way in which she interprets the findings, were identified by the primary researcher of this study. These assumptions include:

- A belief that occupational participation will be impacted for a family of a child with a disability
- Time spent together in meaningful activities is valuable to the family unit
- Impaired occupational participation limits one's quality of life
- Engagement in valued occupations is a natural human life
- Engagement in co-occupations is a key component of a satisfying marriage
- The family is an interactive unit and therefore each family member's occupational participation will be influenced when a child in the family has a disability

In addition to initial identification of these basic assumptions, more personal assumptions and potential sources of bias were recorded by the researcher in a journal. This journal was used by the researcher as a means to further bracket her own sources of bias and will be discussed in more detail in chapter three.

Definition of Key Terms

Client Centered Care: An approach in which an occupational therapist seeks to understand what is important and meaningful to the client (AOTA, 2008)

Co-Occupation: Occupations which inherently require two or more participations (Zemke & Clark, 1996)

Family: A married, heterosexual couple and their dependent children, living in the same household.

Family-Centered Care: In occupational therapy, an approach that views the entire family as the recipient of intervention and is focused on empowering families by promoting growth, respecting the needs identified by the family, and enabling the family to participate in meaningful occupations (DeGrace, 2003).

Family Occupation: An occupation that is shared by family members or one in which multiple members of the family participate simultaneously

Model of Human Occupation (MOHO): An occupation-based, theoretical model designed specifically to help guide occupational therapists to better serve and understand their clients by describing the components which make up occupation, the influence of the environment on occupation, and the ways in which participation and occupational participation contribute to one's sense of identity and competence (Kielhofner, 2008f).

Occupations: Actives of work, play, or daily living; activities related to education, leisure, or sleep; and activities done to support life in the home/community or promote participation in a social system, which occur in a temporal, physical, or social context (AOTA 2008; Kielhofner, 2008f).

Occupational Participation: Engagement in occupations, related to social and cultural contexts, which are necessary and/or desirable to support an individual's well being (Kielhofner, 2008b).

Occupational Therapy: A profession which uses occupation as a therapeutic medium to promote health and wellness and participation in valued roles and activities (AOTA, 2008).

Reflexivity: The process of acknowledging and recording the ways in which personal experiences, values, and bias may influence how the researcher relates to and interprets data (Creswell, 2013).

Summary

In summary, this study was conducted to provide a better understanding of the occupational participation of family with children with disabilities and is unique in its consideration of the views each individual family member. In addition, this study not only looks at occupational participation of the family, but also parent participation in co-occupations as well as individual participation of each family member. By doing so, this study adds to current occupational therapy literature regarding families of children with disabilities and will provide more support for provision of family-centered care.

CHAPTER 2

LITERATURE REVIEW

The following chapter will provide an overview of the current literature related to families of children with disabilities. Areas of emphasis in this review include literature related to mothers and fathers of children with disabilities. This review also describes the impact on sibling, marital, and family relationships. Other areas described include time use, routines, stress, challenges, coping, and spirituality. Review of this literature is presented to provide a background and framework for the current study.

Mothers

Much of the research surrounding families of children with disabilities has focused on mothers. Mothers of children with disabilities are often the primary caregivers for their children (Brandon, 2007; Crowe, VanLeit, & Bergsman, 2000; Larson, 2000). This caregiving role is often experienced differently than the role associated with caring for typically developing children. Mothers of children with disability face greater challenges trying to follow and establish a daily routine, as well as finding time to engage in occupations that are beneficial to themselves as individuals, such as recreation or exercise (Donovan, VanLeit, Crowe, & Keefe, 2005; Brandon, 2007). In addition, these increased caregiving demands prevent mothers of children with disabilities from fulfilling additional roles as these women were found to have less roles than mothers of typically developing children (Crowe, VanLeit, Berghmans, & Mann, 1997).

Other factors might also influence mothers' ability to take on additional roles. One such factor is the amount of energy required to complete caregiving tasks, which leaves little energy available for other roles (Crowe, VanLeit, Berghmans, & Mann, 1997). In addition, the consistencies of caregiving demands often differ for these two groups of women. Differences in the demands between mothers of typically developing children and mothers of children with disabilities become more apparent as the children age, leading to a continually growing gap in the ability to fulfill other roles and participate in occupations not related to caregiving for mothers of children with disabilities (Crowe & Florez, 1996; Crowe, VanLeit, Berghmans, & Mann, 1997).

This caregiving role, as well as its associated responsibilities, may also contribute to the increased time constraints experienced by mothers of children with disabilities. These mothers have reported feeling not only constrained by time, but also feeling pressured to have an increased need for efficiency of time use (Crowe et al., 1997; Larson, 2000). This is further impacted when considering that mothers provide care for the entire family. Larson (2000) reported that mothers' roles become increasingly focused on providing a sense of balance and orchestration for the family in order to meet the complex caregiving needs, and that this experience is further complicated when one or more members of the family has a disability. Mothers responsible for this orchestration expressed the importance of being able to plan and organize activities, but also struggle to find the time or means to accomplish these important processes (Donovan et al., 2005; Larson, 2000). In addition, striving to find balance for the entire family might also contribute to time constraints. These mothers have reported having less time not only to meet their own needs, but to meet the needs of other family members as well because much of their time is focused on caring for the special needs of the child with a disability (Donovan et al., 2005; Larson, 2000). Mothers have also been found to express a desire to expand their own social life as well as to find sometime each week to devote to their own health and well-being (Donovan et al., 2005).

Increased demands on efficiency as a caregiver also influence the ways in which mothers perceive their ability to fulfill the caregiver role. Mothers who primarily fulfill the caregiver role have been found to associate their success in the performing the caregiver role with their child's progress, which may negatively impact emotional well-being due to the uneven progression of a child's development (Larson, 2000). Further strain on this role may also be contributed to struggle with emotional management and regulation of mothers. Mothers of children with disability reported a desire to improve their own abilities to regulate emotions and overcoming grief associated with the child's disability (Donovan et al., 2005). In addition, mothers have also reported a desire to improve their child's quality of life and promote health (Donovan et al., 2005), which might also contribute to feelings of inadequacy if they are unable to perform such takes to their own level of personal satisfaction. An additional emotional constraint on mothers can be tied to their responsibility to keep the family unit organized and synchronized. Feelings of stress, anxiety, and frustration may result when one member of the family is not fully synchronized with the rest of the family during participation in group activities (Larson, 2000).

Therefore, it is clear that mothers of children with disabilities face many additional challenges and demands in their daily lives. However, it is important to note that, although mothers have been reported to carry the majority of the caregiving workload for children with disabilities, mothers are not necessarily dissatisfied with fulfilling this role (Crowe et al., 2007). Though mothers, have been reported the desire to share this workload and to find trustworthy caregivers (Donovan et al., 2005), this does not mean that mothers desire to abandon this role altogether.

Fathers

Although the mother's role in parenting a child with disabilities has been studied extensively, less research exists regarding the father's role. In many instances, fathers of children with disabilities fulfill the provider role, while mothers often fulfill the daily caregiver role for their children (Bonsal, 2013; Carpenter & Towers, 2008; Darling, Senator, & Strachan, 2012). However, in some families, it is the father who fulfills this daily caregiving role (Carpenter & Towers, 2008). Whether they are fulfilling the worker role or the caregiver role, fathers of children with disabilities report involvement in some caregiving tasks on a daily basis (Carpenter & Towers, 2008). Fulfillment of the provider role may cause fathers to experience additional strain. Many fathers express a desire to be involved in appointments and service provision for their child, but healthcare appointments are often in conflict with work schedules (Carpenter & Towers, 2008).

Overcoming such strain can be difficult. Fathers who are fulfilling the provider role must often forfeit work opportunities and wages to find jobs that provide flexibility or benefits, and these factors contribute to increase work related stress (Carpenter & Towers, 2008; Darling et al., 2012). The struggle to overcome these challenges also impacts the parenting experience. Fathers of children with disabilities experience higher levels of stress outside of work than fathers of typically developing children and are likely to experience a greater demand in caregiving roles as well as greater strain on family resources (Carpenter & Towers, 2008; Darling et al., 2012). Other factors that may contribute to impaired well-being for father's of children with disabilities include the type of disability, paternal age, behaviors associated with the disability, and the depressive symptoms being experienced by their wives (Hartley, Seltzer, Head, & Abbeduto, 2012).

Again, this added strain does not indicate that fathering a child with disabilities will be a negative experience. For many fathers, having a child with disabilities is viewed as a positive experience (Bonsal, 2013; Carpenter & Towers, 2008; Darling et al., 2012). Despite the constraints of the provider role, these fathers often still focus on relationships with their children. Many of these fathers value emotional connections with their children and make an effort to be engaged in meaningful activities together (Bonsal, 2013; Carpenter & Towers, 2008). One way in which fathers are able to accomplish this is through co-created occupations, or activities that are adapted overtime to match both the father and child's interests (Bonsal, 2013). Such activities allow for fathers to communicate with their children and emphasis positive interactions that may easily be overshadowed by negative experience (Bonsal, 2013; Carpenter & Towers, 2008).

Marriage

The extent of the impact of raising a child with disabilities on martial quality is still unknown. This is a topic of controversy as previous research surrounding this topic has reported contradictory results (Risdal & Singer, 2004). However, current research suggests that raising a child with disabilities does not have a severely negative strain on marriage as assumed in previous research (Hartley, Barker, Baker, Seltzer, & Greenberg, 2012; Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Risdal & Singer, 2004; Wieland & Baker, 2012). Yet, this cannot be generalized to every family. Due to the unique needs of each family system, it is important to realize that each individual family will experience life with a child with disabilities in a different way (Risdal & Singer, 2004; Wieland & Baker, 2010).

Current findings, however, do not mean that increased strain does not exist. Although marital strain related to raising a child with disabilities may not be as severe as previously reported, additional strain is often present for parents of children with disabilities (Risdal & Singer, 2004; Wieland & Baker, 2010). Even for families who are well adjusted to raising a child with disabilities, fluctuations in stress over time may contribute to strain on the marital relationship (Hartley, Baker, Baker, Seltzer, & Greenberg, 2012; Risdal & Singer, 2004). There are various implications of this strain. For one, strain may indicate the need for external sources of support for these families (Kersh, et.al, 2006; Risdal & Singer, 2004). In addition, marital quality is not expected to improve after a child has left the nest due to the high level of involvement parents maintain in a child's life which may prevent them from devoting more time to one another (Hartley, Barker, Baker, Seltzer, & Greenberg, 2012).

As mentioned, the ways in which families adapt to life with a child with disabilities varies from one family to another. As a result, there is a wide range in the response to disability among married couples (Risdal & Singer, 2004; Wieland & Baker, 2010). Although for some couples, raising a child with disabilities has been cited as the source of strain (Risdal & Singer, 2004), for other couples raising a child with a disability may lead to a stronger, more satisfying marriage overtime after couples come together to face challenges (Hock, Timm, & Ramisch, 2012; Risdal & Singer; Wieland & Baker, 2010).

In addition, this experience may also vary from person to person as the influence of raising a child with disabilities is also likely to be experienced differently by mothers than by fathers. Quality of marriage perceived by mothers is more likely to be impacted by factors related to a child's disability, such as behaviors, which affect their view of self-efficacy as a parent and spouse, as well as perceptions related to spousal support (Kersh et al., 2006). Conversely, external sources have more of an impact on how fathers perceive marriage quality (Kersh et al., 2006). Yet, some common ground does exist. For both parents, fluctuation in behavioral problems related to a child's disability have been found to impact parental well-being and marital quality more than changes in concerns related to health, with stress related to behavioral concerns contributing to negative interaction among spouses (Hartley, Barker, Baker, Seltzer, & Greenberg, 2012; Kersh, et al., 2006).

Despite the conflicts in evidence, the importance of martial quality on the family system cannot be ignored. Poor marital quality has been associated with an increase in behavioral problems for typically developing children (Wieland & Baker, 2010). Therefore, the marital impact of having a child with a disability should not be ignored, as the marriage is likely to influence all members of the family.

Siblings

The lives of siblings of children with disabilities have also been an area of significant study. Research regarding the sibling relationships in families of children with disabilities is inconsistent, as both positive and negative experiences have been reported (Fisman, Wolf, Ellison, & Freeman, 2000; Giallo & Gavidia-Payne, 2006; Mandleco, Frost Olsen, Dyches, & Marshall, 2003; Myers &Vipond, 2005; Stoneman, 2005). For some children, having a sibling with a disability has lead to increases in self-control, assertion, and cooperative behaviors (Mandelco, et al., 2003; Stoneman, 2005). However, positive outcomes are not always reported. Children of siblings with disabilities have also been found to exhibit more difficulty with adjustments, higher incidence of emotional symptoms, and more difficulty with peer interaction (Giallo & Gavidia-Payne, 2006). Several factors may explain the discrepancy in these findings. These include the type of disability, overall family functioning, social economic status, cultural context, and parental stress levels, all of which have been associated with adjustment in typically developing siblings of children with disabilities (Fisman, et al., 2000; Giallo & Gavidia-Payne, 2006; Mandleco, et al., 2003; Myers &Vipond, 2005; Stoneman, 2005). In addition, the severity of a disability also impacts the stress levels experienced by siblings. Previous research reports that siblings of children with more severe disabilities are likely to have higher and more persistent than stress levels of siblings of children with less severe disabilities (Fisman, et. al, 2000; Stoneman, 2005).

The impact of disability on family life may also influence outcomes for siblings. Family life and functioning are considered key components that influence adjustment and stress for siblings of children with disabilities (Giallo & Gavidia-Payne, 2006; Mandleco et al., 2003; Myers &Vipond, 2005; Stoneman, 2005). Positive family life and functioning are influential on sibling experiences. Research has found that positive family functioning has been correlated with lower levels of stress, higher adjustment, and better behavioral outcomes in siblings of children with disabilities (Giallo & Gavidia-Payne, 2006; Mandleco et al., 2003). In addition, positive family interaction in shared activities has been found to improve sibling adjustment (Giallo & Gavidia-Payne, 2006) and parents may collaborate with children to encourage natural interaction (Myers &Vipond, 2005; Stoneman, 2005). Other factors also influence sibling adjustment. These include the amount of parental stress (Giallo & Gavidia-Payne, 2006; Fisman, et al., 2000) and the presence of effective routines, communication, and efficient problem-solving strategies (Giallo & Gavidia-Payne, 2006).

Literature has also reported the experience of sibling relationships both from the views of children with disabilities as well as from typically developing children. Children with disabilities may be likely to take a more subordinate role in the sibling relationship, even when they are not the youngest child (Myers &Vipond, 2005: Stoneman, 2005). However, this is not always the case (Serdity & Burgman, 2012). Regardless of the sibling's dominance, all siblings in families of children with disabilities appear to value their sibling relationships (Lardieri, Blacher, & Swanson, 2000; Moyson & Roeyers, 2010; Serdity & Burgman, 2012; Stoneman, 2005). This value is reflected in typical siblings as these children often value spending time in joint activities with a sibling with a disability (Moyson & Roeyers, 2010).

Shared activities are a dynamic part of the sibling relationship. Siblings with disabilities may begin to feel isolated or withdraw when they are unable to participate in activities with their typically developing siblings (Serdity & Burgman, 2012). In addition, shared activities also involve communication. Moyson and Roeyers (2010) reported that typically developing siblings are often able find ways to communicate with their siblings who have a disability. Therefore, this communication may be a support to participation in joint activities. However, siblings who are typically developing may also feel frustrated if their sibling does not appear to understand them which may hinder full participation in share occupations (Moyson & Roeyers, 2010).

Another aspect of the sibling relationship is acceptance of a sibling's disability. Typically developing siblings have reported that accepting their siblings' disabilities is a key component to building a relationship (Moyson & Roeyers, 2010). However, children at times might also find the behaviors of a child with a disability to be an occasional source of embarrassment (Lardieri, et al., 2000; Ludlow, Skelly, & Rohleder, 2011; Neely-Barnes, Hall, Roberts, & Graff, 2011). This acceptance might also include concerns regarding the health of children with disabilities. Typically developing children are often concerned about their siblings overall well-being and have expressed a desire to want to improve their siblings conditions (Moyson & Roeyers, 2010).

A number of other factors might also influence the relationship between typically developing children and siblings with disabilities. Typically developing children have reported a desire to spend time alone with their parents or engage in activities in which a sibling with a disability cannot participate (Moyson & Roeyers, 2010; Stoneman, 2005). Social groups might also influence sibling relationships. Some typically developing children have reported that social support groups are beneficial (Moyson & Roeyers, 2010; Stoneman, 2005), while others have more negative experiences with these groups (Giallo & Gavidia-Payne, 2006). Having another typically developing child in the family is often a more effective type of support as these children have more similar day-to-day experiences (Moyson & Roeyers, 2010). Parents' interaction might also influence sibling relationships, as both typically developing siblings and siblings with a disability have expressed expectations that all children in the family be treated equally (Moyson & Roeyers, 2010; Serdity & Burgman, 2012; Stoneman, 2005).

Family

In addition to having an impact on individual members of the family, raising a child with disabilities also influences the family as a whole. Family adjustment to raising a child with a disability is a process that may occur at different rates for individual family members (O'Brien, Bergeron, Duprey, Oliver, & Onge; 2009). For example, children with disabilities may have a more positive view of their condition than parents (O'Brien et al., 2009). However, extended family members, such as grandparents, may be slower to accept changes in the family dynamic related to the presence of a disability (Reichman, Corman, & Noonan, 2008). Yet, time can assist families in becoming better adjusted. Research suggests that many families of children with disabilities become more resilient overtime as they adapt to meet necessary demands created by a child's disability (Reichman et al., 2008; Thompson, Hiebert-Murphy, & Trute, 2012). Thus, even though families may experience many challenges while raising a child with a disability (DeGrace, 2004), one should not assume that family functioning will be negatively impacted (Thompson et al., 2012).

Raising a child with disabilities may be experienced differently for individual families. For some families, raising a child with a severe disability may feel like a never-ending challenge (DeGrace, 2004). For other families, achieving a sense of balance is difficult due to lack of support, time constraints, feelings of incompetency, and lack of individual identities (Stein, Foran, &Cermak, 2011). Thus, although one should not assume negative functioning, the challenges related to raising a child with disabilities should also not be ignored. When studying families of children with severe autism spectrum disorder, DeGrace (2004) reported that "Autism appears to have robbed the families of naturally experiencing satisfaction and happiness, making it hard to enjoy the day as a family" (pg. 546). She suggested that due to constraints on the types of activities in which they could engage, these families were unable to capture the feeling of being a family because even joyous celebrations, such as birthdays, revolved around the child's condition. Conversely, Segal (2004) found that other families of children with disabilities created opportunities to engage in occupations together by selecting and structuring their own shared occupations. She reported that parents in this study were able to structure occupations to meet a variety of family needs including enjoying time together, learning, and sharing traditions. Although the differences in these studies may be due, in part, to the severity and type of diagnosis as participants in the second study included children with physical disabilities and ADHD, it is important to consider each family as a unique unit with individual needs (Kim, Greenberg, Seltzer, & Krauss, 2003).

Time Use

Time use is a concept that may reflect occupational participation as the ways in which an individual spends his or her time reflects the occupations in which he or she engages. Time is seen as a valuable resource in families of children with disabilities, and is often also viewed as a constraint (Brotherson & Goldstein, 1992; Donovan et al., 2005; Crowe & Florez, 2006). When considering the family unit, the resource of time is especially important because this is a resource that must be orchestrated on both an individual and family basis. Because mothers are often primarily responsible for this orchestration of time use within the family, they are likely to experience excess stress when trying to meet the needs of each individual family member (Crowe et al., 2000; Donovan et al., 2005; Larson, 2000). One reason for time constraints on mothers is the increased amount of time spent on childcare in comparison to mothers of typically developing children, with mothers of children with disabilities also spending less time in recreational activities and reporting less satisfaction with time use (Crowe & Florez, 2006). Mothers of children with disabilities who spend more time in caregiving tasks also report not having time to think about their own needs (Crowe & Florez, 2006; VanLeit & Crowe, 2002). These constraints also contribute to the quality of time use perceived by mothers, as engagement in occupations of value may become fragmented (Donovan et al., 2005). Therefore time constraints may prevent mothers from participating in satisfying occupations.

Additional time constraints are often experienced by these families. One source of constraint for these families is a lack of family-centered care and flexible scheduling of healthcare needs for children with disabilities (Brotherson & Goldstein, 1992). Because families are already balancing the needs of multiple individuals, the inability to access services on a flexible schedule prevents them from being able to match provision of services with their individual and family needs (Brotherson & Goldstein, 1992). These constraints may magnify the already elevated caregiving demands. Trying to manage any additional responsibilities related to a caring for a child with a disability also contributes to time constraints when mothers are unable to balance responsibilities between work, home, and community life (Crowe et al., 2000; Donovan et al., 2005). These time constraints may also influence family occupational participation as they may also prevent families from accessing other beneficial services such as support groups (Brotherson & Goldstein, 1992).

Another area impacted by time constraints is that of employment. Time constraints hinder parents’ ability to engage in paid employment, a key area of occupation that is needed to provide financial support for the family unit (Brandon, 2011; Larson, 2000). Parents of children with disabilities are more likely to be involved in part-time employment, work non-standard work hours, or be unemployed when compared to parents of typically developing children (Brandon, 2011). Mothers of children with disabilities are more likely to be hindered in their ability to seek paid employment, and often lose their role as a worker (Brandon, 2011; Larson, 2000). This adds additional constraints to the family. Less time spent in paid employment leads to less financial support which might limit the types of occupations available to a family as they struggle to balance time use and financial demands (Donovan et al., 2005). In addition, parents must be more adept at orchestrating time spent with the family and time spent together, and time spent together may be further limited if mothers are working outside of the home during non-standard hours, while fathers provide childcare (Brandon, 2011; Crowe et al., 2000; Larson, 2000).

Routines

Routines are important components of daily life for all families. However, routines are often vital for families with disabilities due to the many purposes that these routines serve (Downs, 2008; Koome, Hocking, & Sutton, 2012). There are many benefits associated with effective routines for families of children with disabilities. This includes decreased feelings of stress and increased ability to cope with a child’s disability (Downs, 2008; Koome, et al., 2012). In addition to helping families cope with stress, routines might also be used a means to protect family from future stressors and provide a safe, comfortable environment (Koome et al., 2012). Additional benefits include providing the family with a sense of control despite the unpredictable nature of disabilities (Downs, 2008; Koome, Hocking, & Sutton, 2012) and providing time for interaction, shared happiness, shared meaning, and unity among all family members (Downs, 2008; Koome et al., 2012; Segal 2004). Therefore routines may also have a positive impact on family well-being. In addition, the value of routines may differ for these families. For many typical families, routines are often focus merely on achieving a necessary goal, however the rich meanings ascribed to routines for families of children with disabilities, may transform routines from mundane tasks to symbolic rituals (Koome et al., 2012; Segal, 2004).

Despite the benefits of routines, establishing an effective routine may be a difficult experience. For families of children with disabilities, strain may exist between the desire to establish a set routine, and the ability to adapt to unpredictable challenges associated with the child's disability which can lead to increased tension and stress (Koome et al., 2012). In addition, construction of routines for these families must take into consideration the needs each individual family member and how these needs can be meet without neglecting any special needs of a child with a disability (Kellegrew, 2000; Koome et al., 2012). This increases the complexity in establishing a family routine.

It is also important to consider the various types of routines that these families may desire to establish. Construction of routines is not limited to self-care alone, but other tasks such as those related to leisure and tasks completed away from home (Case-Smith, 2004; Downs, 2008). Because of this reliance on routine, families of children with disabilities may experience a decrease in family spontaneity (Cashin, 2004). Thus, parents and caregivers for children with disabilities must also establish ways to gauge the importance of their own needs versus the needs of the family, which is often a complex and stressful task (Koome et al., 2012).

Again, because of these complex needs and the increased need for collaboration, creation of routines is not a simple task, and this complex task is often assigned to mothers. When mothers serve as the primary caregiver, they are often required to create routines that balance the complex family needs (Larson, 2000). In order to do this, mothers must become more responsible for anticipating and responding to the unpredictable needs of the family unit that contribute to disruptions in routines (Larson, 2000; Kellegrew 2000). In addition, creation of such routines is further complicated due to individual family traits. These include family values, meanings, and cultural components which may influence which tasks are expected to be completed and the best way to accomplish each task (Kellegrew, 2000). Mothers must also respond to constraints such as time, environment, social support, and behaviors (Kellegrew, 2000; Koome et al., 2012). Thus, establishing routines is a complex and demanding tasks in these families.

Stress

Much research has also been dedicated to describing the stress experienced in families of children with disabilities, often focusing on the way this stress is experienced by parents. Studies have found that parenting a child with disabilities is associated with higher levels of parental stress (Islam, Shanaz, & Farjana, 2013; Oelofsen & Richardson, 2006; Seltzer et al., 2009; Siman-Tov & Kaniel, 2011). The experience of stress is a dynamic process as emotional responses to a child's condition change overtime (Siman-Tov & Kaniel, 2011; Webster, Majnemer, Platt, & Shevell, 2008). Stress is likely to be experienced differently by each family for a number of reasons. This includes variance due to the type of disability and severity of a disability (Hall & Graff, 2011; Lyons, Leon, Phelps, & Dunleavy, 2010; Webster et al., 2008), as parents of children with more functional impairments have higher levels of stress (Hall & Graff, 2011; Rogers & Hogan, 2003). Other factors associated to the severity of disability may also influence stress. Factors related to children's low functioning status include greater financial strain on the family, greater need for job changes among caregivers, decreased family sleep patterns, as well as more intense demands related to scheduling and accessing services (Rogers & Hogan, 2003). Services in and of themselves might also be a source for these families due to difficulty coordinating care, complications receiving insurance coverage for care, and difficulty on balancing these services with the needs of other family members (Rogers & Hogan, 2003).

In addition, the experience of stress also varies from person to person. The amount of stress parents experience is related to parent's personal perceptions (Siman-Tov & Kaniel, 2011). These personal responses may be impacted by a number of factors. For one, parents who perceive a greater sense of support and understanding from loved ones and social support systems feel less stress (Dempsey, Keen, Pennell, O'Reilly, &Neilands, 2009; Siman-Tov & Kaniel, 2011). In addition, stress is not experienced in the same way by mothers and fathers of children with disabilities (Keller & Honig, 2004; Oelofsen & Richardson, 2006; Thompson et al., 2012). Mothers are more likely to report higher levels of stress than fathers (Oelofsen & Richardson, 2006). Mothers are also more likely to feel stress associated to caregiver tasks and a child's level of dependence, whereas fathers are more likely to experience stress related to acceptance of the child's diagnosis (Keller & Honig, 2004). Although parents of children with disabilities are more likely to experience greater physical and mental stress than parents of typically developing children, mothers experience significantly more mental stress than fathers (Islam et al., 2013).

Response to this stress may again vary from family to family and parent to parent. For some, higher levels of stress may negatively impact parent's health as well as their feelings of self-efficacy (Oelofsen & Richardson, 2006). However, for others higher feelings of autonomy and the ability to make informed decisions have been associated with decreases in stress for these parents (Dempsey et al., 2009). It is suggested that parents of children with disabilities are more susceptible to stress, and that this can impacts their ability to cope with daily stressors (Oelofsen & Richardson, 2006). Thus, parents stress level and the impact of family functioning should not be ignored. Family-centered support that is targeted at assisting and empowering parents of children with disabilities has been found to help decrease such stress (Dempsey et al., 2009). Although stress has been found to decrease the adaptability of parents of children with disabilities, it also plays a role in helping parents learn how to better navigate struggles in their personal relationships and become more resilient (Siman-Tov &Kaniel, 2011; Thompson et al., 2012).

Challenges

There are a number of challenges that parents and families must face when raising a child with a disability. One major challenge for these families, particularly in relation to raising a child with an autism spectrum disorder, is coping with difficult behaviors (Hall & Graff, 2010; Ludlow et al., 2011). Many challenges have been reported in association with these behaviors. Some of these challenges, such as limits in family wide social interaction and feelings of exclusion, are attributed to the unpredictable nature of behaviors (Ludlow et al., 2011). In addition, management of such behaviors may contribute to families overcoming judgment from others (Ludlow et al., 2011), and this can cause parents to feel a sense of shame, feel ineffective in their parenting strategies, or feel hurt when others judge the child as naughty or abnormal (Hall & Graff, 2010; Ludlow et al., 2011; Neely-Barnes, Hall, Roberts, & Graff, 2011). In addition, the ways in which behaviors are viewed by others may also pose a challenge. For example, when a child's behaviors are attributed to bad behavior versus the presence of a disability it is more difficult for parents to receive support from extended family members (Neely-Barnes et al., 2011).

Other challenges also exist. One such challenge is a difficulty in accessing services (Hall & Graff, 2010; Van Hove et al, 2009). Families may struggle to access services for a variety of reasons. For one, families may have difficulty in affording many services available to them (Cashin, 2004; Hall & Graff, 2010; Van Hove et al., 2009). In addition, families might also have difficulty in finding the support needed to understand]the types of programs available due to difficulty communicating with professionals (Hall & Graff, 2010; Van Hove et al., 2009). Access to service is also limited due to the overwhelming amount of information that is provided to families (Van Hove et al., 2009). Furthermore, this is not a challenge that can be easily overcome. Even when parents receive support from health care providers, staff working in the schools, or mental health professionals, this support often does not meet their needs (Hall & Graff, 2010). Some families have even expressed the desire for healthcare services that support the entire family (Hall & Graff, 2010). These factors combine to limit the family's access to important services, such as respite care (Case-Smith, 2004; Hall & Graff, 2010; Ludlow et al., 2011).

Access in not the only challenge families face regarding service provision. Not only is it difficult to access services, but families might also feel overwhelmed when they are required to make decisions about services (Case-Smith, 2004; Hall & Graff, 2010; Van Hove et al., 2009). Decision making can be challenging for many parents. Parents are often unfamiliar with their child's diagnosis which can lead to anxiety when they feel unable to understand which treatments will be safe for their child (Hall & Graff, 2010). Parents having to make decisions may become dependent on professionals and this may contribute to anxiety due to confusion related to professional jargon, fragmented care, and difficulty communicating with various health care professionals (Van Hove et al., 2009). Thus, when parents are often asked to make difficult decisions regarding all types of service delivery, they may lack knowledge or feel uniformed (Case-Smith, 2004; Van Hove et al., 2009). Additional challenges may arise because of these decision making experiences. Parents often feel ineffective when they have to stand up to professionals regarding decisions about their child's medical care (Siman-Tov &Kaniel, 2011; Van Hove et al., 2009) and may end up feeling they must compromise with professionals when faced with opposition to decision making (Case-Smith, 2004; Van Hove et al., 2009).

Challenges also exist outside of the realm of service provision. A number of other challenges are present for these families in regards to daily life (Case-Smith, 2004: Cashin, 2004; Ludlow et al., 2011). For families of children with disabilities, each day must be highly structured and lack spontaneity (Case-Smith, 2004; Cashin, 2004). Furthermore importance of routines and structure may limit families' abilities to engage in activities outside of the home and any outing requires elaborate planning (Case-Smith, 2004). Daily challenges are also experienced related to personal care. When children have disabilities that make them dependent on caregivers, the day is structured around providing for these needs, which limits the amount of time the left to engage in socialization or recreation (Case-Smith, 2004; Cashin, 2004).

The struggle to meet these needs may lead to additional challenges for parents. One parent might have to give up on his or her career plans or dreams to stay at home and care for the child (Case-Smith, 2004; Siman-Tov & Kaniel, 2011). Parents are also forced to face many concerns for their child on a daily basis. This includes concerns related to their child's social interaction (Case-Smith, 2004), difficulty in communicating with and connecting to their child (Case-Smith, 2004; Ludlow et al., 2011), increasing the child's independence (Case-Smith, 2004; Ludlow et al., 2011), and planning for the future (Case-Smith, 2004; Hall & Graff, 2010; Ludlow et al., 2011). In addition, parents also are challenged to manage the daily impact on the families which may include impaired interactions with other family members due to stress as well as feelings that one is neglecting the other children in the family (Ludlow et al., 2011).

The impact of the challenges influences the entire family. It is because of these challenges that life often becomes centered on the disability (Case-Smith, 2004; Cashin, 2004; DeGrace, 2004). This can limit individual family member's ability to maintain a self-identity (Case-Smith, 2004). However, these experiences are dynamic. Although at times challenges may appear never ending, for some families these challenges may get easier with time (Ludlow, Skelly, &Rohleder, 2011). Furthermore, these challenges do not always overshadow the positive aspects of family life (Case-Smith, 2004; Cashin, 2004; Ludlow et al., 2011). Thus, challenges may have a positive influence on the family experience. Families of a child with disabilities often learn to celebrate life and feel more confident when they are able to become advocates for the child (Case-Smith, 2004). Families might also experience positive moments of reward when a child is able to meet a milestone (Ludlow et al., 2011). In addition, moments in which families are able to connect with the child, as well as parents ability to develop more patience have also been identified as positive outcomes (Cashin, 2004).

Coping

There are various ways in which families and individual family members cope when living with the presence of a disability. The type of disability and individual family needs influence the type of coping strategies utilized by these families (Kim et al., 2003). The type of coping families employ can impact the effect that raising a child with disabilities has on the family. Studies have found that families of children with disabilities using emotionally based coping strategies are likely to have more family problems (Lyons et al., 2010), experience less strength as a family unit (Judge, 1998), and have an increase in feelings of distress overtime (Kim et al., 2003). These types of strategies are focused mainly on managing emotional distress as opposed to focusing on problem resolution (Kim et al., 2003) and may include focusing on wishful thinking, controlling one's own emotions, distancing one's self from the situation, and also self-blame (Judge, 1998). For families of children with severe symptoms, the distancing strategy maybe more effective at decreasing stress due to the high demands on each parent (Lyons et al., 2010).

Another method, problem-based coping, has also been studied. Use of problem-based coping strategies is more effective for families of children with disabilities (Judge, 1998; Kim et al., 2003). These types of strategies are based on problem solving to attempt to change or manage a situation that is causing stress (Kim et al., 2003). Thus, problem-based coping may include actions such as actively seeking social support, having a positive outlook, and using internal as well as external resources (Judge, 1998), as well as seeking to learn more about a diagnosis and plan for a child's needs (Kim et al., 2003). However, this is not always the case. The effectiveness of problem based coping strategies is also dependent upon the type of disability (Kim et al., 2003). In addition, problem-based coping may not address every need. Although this method can improve well-being for caregivers and improve parent-child relationships, it may not reduce feelings of burden or depression (Kim et al., 2003).Therefore, another coping method may be considered. One such method is use of task-oriented coping strategies, in which one actively engages in attempts to alleviate stress, may also be used as means of coping for families of children with disabilities (Lyons et al., 2010).

When discussing coping, it is once aging important to remember that families are dynamic. The style of coping used by families of children with disabilities changes over time as families adapt overtime to meet new challenges (Kim et al., 2003). Additional types of coping have been used to meet these dynamic needs. Although the need to plan activities is often a challenge for these families, it is also a common way of coping that is often embraced by the family as routines become a way of reducing caregiver stress (Cashin, 2004; Hall & Graff, 2010; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010). Use of support systems is another common method of coping and may include spousal support, family support, and support groups (Hall & Graff, 2010; Kuhaneck et al., 2010; Ludlow et al, 2011). However, not all support groups are effective as children with the same diagnosis may have very different needs (Kuhaneck et al., 2010). Gaining knowledge about a diagnosis is also a means of coping as parents are then able to advocate for their child's needs (Case-Smith, 2004; Hall & Graff, 2010; Kuhaneck et al., 2010). In addition, many caregivers of children with disabilities often cope by setting aside personal time in which they do something for themselves (Hall &

Graff, 2010; Kuhaneck et al., 2010). Another means of coping often used by these families is finding ways to connect with the child and recognize the child as an individual (Kuhaneck et al., 2010; Van Hove et al., 2009). Finally, many families might also employ a positive outlook as means of coping by celebrating the small moments and looking for positive aspects of each day (Case-Smith, 2004; Cashin, 2004; Kuhaneck et al., 2010; Ludlow et al., 2011).

Spirituality

Another area of study related to families of children with disabilities is spirituality. Spirituality is often impacted when one child in a family has a disability (Parker, Mandleco, Olsen-Roper, Freeborn, &Dyches, 2011; Speraw, 2006). Because spirituality is a client factor that should be considered when providing occupational therapy services (AOTA, 2008) and a component in MOHO (Kielhofner, 2008g), this is an area of concern related to occupational participation. Research surrounding spirituality and beliefs of families of children with disabilities shows the ways in which can these beliefs may be either a hindrance or a support (Durà-Vilà, Dein, &Hodes, 2010; Speraw, 2006). Thus, it is again important to consider the unique family experience.

Raising a child with disabilities may impact spirituality in various ways. Having a child with disabilities may limit the ability families have to engage in both formal and informal religious activities, including public and private worship (Parker et al., 2011). However, although participation maybe affected, spirituality of parents may not be affected (Parker et al., 2011). Spirituality may, in-turn, impact the experience of raising a child with disabilities. Spirituality has been associated with higher levels of marital satisfaction (Parker et al., 2011). In addition, spirituality maybe a source of individual support for parents of children with disabilities to assist them in coping and accepting a child’s condition (Durà-Vilà et. al, 2010; Speraw, 2006).

However, spirituality does not always provide satisfaction and support. It is important to remember that some families may feel that they are not being supported by their spiritual organizations (Speraw, 2006). Although it is important for many families who have strong religious foundations to share religious beliefs with a child who has a disability, lack of support from their religious organizations may be lead to feelings of isolation and rejection, as well as negative impacts on parents own personal spirituality, (Speraw, 2006). Parents desire to find a system to support them in building a spiritual connection for their child with a disability may cause them to change churches, struggle with their own faith, or feel a sense of alienation (Speraw, 2006). Thus, the influence of spirituality or lack of influence of spirituality should be addressed individually for families of children with disabilities.

Summary

This review of literature has been presented to provide an overview for this study. In addition to providing an overview of current areas of research relevant to families of children with disabilities, this review also highlights the voids in existing research. Although current research addresses aspects of family life which may influence occupational participation, there is a lack of specific research related to studying occupational participation itself. In addition, there is a lack of research related to examining the experiences of a whole family of children with disabilities. Instead, most research has focused on individual family members or parents and siblings exclusively. Again, this speaks to need for this study to provide a more family-centered view of occupational participation. Thus, based on this literature, the design of the current study addresses the need to study occupational participation and family-centered perspectives in relation to the profession of occupational therapy.

CHAPTER 3

RESEARCH METHODOLOGY

The following chapter is meant to provide an overview of the research methodology used in this study. This includes a brief explanation of the study design as well as descriptions of the participations and data collection. In addition, this chapter also details the procedure, instrumentation, and data analysis process used throughout the course of this study. Finally, this chapter also describes the steps taken to ensure the trustworthiness of this research.

Design

As mentioned, the purpose of this study was to gain an understanding of how one family with children with disabilities views their occupational participation**.** To meet this objective, a qualitative case study design was selected. This design was selected to provide a more holistic view of the family. In addition, this design was also selected to allow the researcher to have a more in-depth understanding of the family's occupational participation as there are many facets of participation to be considered when looking at an entire family.

Participants

The "case" for this study was one family, with all members of the family residing in the same household. The family included two married parents, Paul and Margret, and their four biological children, Brad, Ann, Cindy, and David. The older of the two children, Brad and Ann, both have disabilities. Brad was diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD) and, as a part of this condition, struggles with regulation and management of his own behaviors. Ann was diagnosed with autism spectrum disorder (ASD) and a genetic disorder. She also experiences difficulty with feeding and eating. All children in the family were under the age of 10 during the data collection stage. The family was selected based upon convenience and a faculty member at EKU served as a gatekeeper for introductions.

Data Collection

Data collection for this study was completed from June 2013 through August 2013, with a follow-up phone interview that took place in October 2013. The types of data collected for this study included individual semi-structured interviews with family members, based on two MOHO assessments: the Occupation Performance History Interview- II (OPHI-II) and the Children's Occupational Self-Assessment (COSA). These assessments will be explained in more detail as a part of instrumentation.

A rapport building activity was used as a means of data collection during the first meeting with the family. Each child was asked to draw a picture of his/her favorite family occupation. This provided a chance to build rapport, but also data related to valued family occupations. Initial interviews took place upon the first visit with the family, at which time Paul and Margret participated in a joint interview. This interview included questions from the OPHI-II as well as original questions created for this particular study. Brad and Cindy participated in individual interviews using both questions from the COSA as well as original questions created by the researcher. Ann and David also participated in a joint interview which was conducted using the Smiley Face Data Sheet, also described as a part of instrumentation. A subsequent, semi-structured, individual interview with Margret was also conducted, as was an additional follow-up phone interview.

Data was also collected through observations of the family actively participating in a number of occupations. The first observation was of the family eating dinner in their home and the second observation was of the family, with the exception of Paul, participating in a ranch activity. The "Ranch," as referred to by the family, was a weekly one-hour program in which children are given the opportunity to participate in games and ranch related chores in an attempt to apply faith-based principles. The final observations all took place over the course of a single day and included observation of the family participating in grocery shopping, bike-riding, and swimming.

The various types of data collected were individually chosen to meet the needs of this study, as illustrated in Table 1. Each piece of data was collected to serve a specific purpose. In addition, the types of data used varied based upon the individual participant. Similarly, interview guides were constructed based upon the various theoretical

Table 1

Data Collection Overview

Types of Data	Purpose	Participants
Children's Drawings	Rapport Building Valued Family Occupations (Volition)	All Children
OPHI-II	Address all MOHO components	Paul & Margret (Parents)
COSA	Address all MOHO components	Brad & Cindy
Smiley Face Data Sheet	Overcome communication limitations Interests (volition) related to family occupations	Ann & David
Observations	Address all MOHO components	All Family Members

frameworks utilized throughout this study. The influence of these frameworks is noted in Table 3 (Appendix A) and Table 4 (Appendix B). Interview guides themselves are discussed in more in the proceeding instrumentation section of this chapter.

Procedure

Approval for this study from Eastern Kentucky University's Internal Review Board was granted on May, 23, 2013. Following this approval, a Faculty member in the occupational therapy department, who also served as the thesis advisor, contacted a family whom she felt would be interested in participating in the study via e-mail. Thus, she served as the gatekeeper for the study. This family was given the choice to contact the primary researcher for more information if they desired to participate. Upon receiving an e-mail from the mother of this family, Margret, expressing the desire to participate, the primary researcher then supplied the family with a cover letter describing the study in more detail. The family once again contacted the researcher in response to this letter, this time by phone, and a mutually agreed upon time was selected for the researcher to visit the family home and conduct initial interviews. E-mail correspondence was once again used to provide the family with copies of the appropriate consent, permission, and forms, to allow the family to review the forms before meeting with the researcher.

Upon arrival at the family’s home, the researcher reviewed the consent, permission, and assent forms with the family members. Family members were given time to ask questions about these forms before formal consent, permission, and assent were obtained. After this, the researcher spent time talking with the children and building rapport while waiting for Paul to arrive home for work. During this time, children were asked to complete the drawings of favored family occupations, given the prompt: “Draw a picture of your favorite thing to do as a family.” Before dinner, all children participated in semi-structured interviews that took place in a bedroom to prevent distractions and interruptions. All interviews were audio-recorded. Brad and Cindy completed interviews based upon the COSA individually, while Anna and David completed their interview together. Cindy, per her request, also completed a brief, individual interview, using the Smiley Face Data Sheet.

After these interviews, the researcher then observed the family as they participated in eating dinner at the family table. The researcher sat apart from the family during this time and recorded observations using an observation guide constructed specifically for this study. After dinner, a joint interview was conducted with Paul and Margret. Although Brad and Ann had already gone to bed, both Cindy and David were present during this interview which took place at the dining room table. At the end of this visit, the family and the researcher scheduled a second meeting at a mutually agreed upon time.

During this second meeting, the primary researcher observed all members of the family, except the father, participating in the ranch activity described above. This observation lasted for approximately one hour, with the researcher staying in the middle of the ranch to observe interactions of all family members. After this observation was completed, Margret and the researcher made plans to schedule the final observation.

During the final day of observations, the researcher had the opportunity to observe the family participating in grocery shopping at a local store. During this time, the researcher was more involved in the occupation than previous observations as she walked alongside the family throughout the store. This was followed by observation of the family participating in bike riding, during which time the children were riding their bikes, Paul was grilling a family meal, and both Margret and the researcher sat in lawn chairs. For the sake of convenience on behalf of Margret, an individual interview was also completed during this time. After eating, the family was then observed participating in the occupation of swimming at the neighborhood pool. Before leaving, the researcher discussed the best method to conduct a follow-up interview with Margret.

After beginning the analysis process, a phone interview was conducted with Margret in October of 2013. The decision was made to include these results as a part of the discussion based upon the temporal sensitivity of the previous data. In total, the data collected for this study consisted of four drawings, approximately 114 minutes of interview, and approximately 12 hours of observation.

Instrumentation

As mentioned, two occupational therapy assessment tools were used as guide during the interview process. Both of these guides are assessments created based upon the MOHO framework and were thus selected due to the theoretical basis of this study. The OPHI-II is a guided interview that is designed to gather a person's history in attempts of better understanding the impact of a disability (Kielhofner, 2004). For the purposes of this study the only section of the instrument utilized was the "Activity/Occupational Choices" portion to create a list of guided interview questions. (See Appendix C).This section was selected as it was the most relevant section for understanding the parents' view of occupational participation. The Child Occupational Self Assessment (COSA) was designed to gain a better understanding of how children with disabilities view their competence when performing occupations (Kielhofner, 2005b). This tool was therefore used as a model to design questions for the children in the family with disabilities as well as typically developing children, in effort to better understand how occupational participation influences their perception of performance (See Appendix D).

Finally, the Smiley Face Data Sheet, developed by Wittman & Bundy (2008) was also used as a part of the interview process. This scale consists of three smiley face icons to represent enjoyment, neutral feelings, and dislike. (See Appendix E). It was adapted and used in this study to gain a better understanding of interests, one aspect of volition, for the children who were unable to complete the COSA.

Data Analysis

Data was analyzed using the a priori coding method. In this method, codes to be used in the data analysis process are predetermined before analysis takes place and are often based on a theoretical framework (Creswell, 2013). The codes used for this study were based on the components of occupation described in MOHO: volition, habituation, performance capacity, and environment. To prepare data for the coding process, audio interviews, with the exception of the follow-up phone interview, were transcribed verbatim. Transcripts were then coded using the in vivo coding method and these codes where then sorted into themes identified above. Transcripts were reviewed multiple times to ensure that the researcher had a well-developed understanding of the data and the thematic connections. After this, information from observation notes were also reviewed and coded using this same method.

During the analysis process the researcher also sorted codes into emergent themes as appropriate. Toward the end stages of the analysis process, three emergent themes were identified. These were: Martial Struggles, Sibling Interactions, and Parental Encouragement. However, after discussing these themes with the Faculty advisor and reviewing the MOHO framework in more detail, the researcher determined that these themes were encompassed by the MOHO components. Therefore, these themes were collapsed into the a priori themes already established, as illustrated in Table 2.

Trustworthiness

Trustworthiness was also considered as a part of the procedures for this study and was addressed in a number of ways. One way in which this was addressed was through the use triangulation to strengthen the confirmability of this study. As a part of this process, the researcher reviewed multiple sources of data when framing and presenting the discussions of this study to substantiate these findings. In addition, peer debriefing was also used to increase the credibility of this study. The researcher met regularly with the Faculty advisor to discuss thoughts during all parts of the study. The frequency of these meetings increased during the analysis process to ensure that the researcher had the opportunity to discuss thoughts related to this portion of the research. The researcher also used bracketing to add to the credibility of this study by keeping a personal journal

Table 2

Overview of the Analysis Process

A priori Codes	Emergent Themes	Integration with MOHO
Volition *Personal Causation, Values, & Interests* Habituation *Habits, Roles, Routines* Performance Capacity Environment *Opportunities & Resources, Demands & Constraints, Objects, Spaces, and Social Groups*	Marital Struggles	Volition→ Values→ Conflicting Beliefs Between Spouses Habituation→ Roles→ Unfilled Roles Environment→ Social Groups→ Marriage
	Sibling Interactions	Environment→ Social Groups→ Sibling Interactions
	Parental Encouragement	Volition→ Values → Parenting Convictions

detailing her own basis both before and during the data collection and analysis process. This journal was reviewed throughout the data collection and analysis process to keep track of the ways in which these biases might influence the study. However, it is still reasonable to assume that biases are present and therefore this must be considered as a limitation to the study.

Another method that was used to strengthen the credibility of this study was member-checking. This is described by Cresewell (2013) as process in which the researcher seeks the participants' views regarding the findings and interpretations of a study. For this study, the mother participated in a member-checking process in which a narrative of the complete findings was sent to her via email. Approximately one month later, the mother had a phone discussion with the researcher to share her feedback about the accuracy and interpretation of the findings. The mother agreed with all findings in the narrative with the exception of wanting clarity regarding her description of work as being like a vacation. Based on this feedback, this portion of the results section was modified.

In addition to this journal, memos were also created to allow the researcher to frame her thoughts and better separate her opinions from the data. An audit trail was also used to strengthen the dependability of this study as the researcher kept track of all electronic correspondence, paper documents (including notes taken during data collection), and electronic drafts that were a used throughout this study. Finally, transferability is addressed through the description of the study participants to allow readers to better understand the context of the study as suggested by Shenton (2004).

Summary

This overview of the research methodology is presented to allow the reader to better understand the overall study design and research process. Many considerations were included during the design of the study to ensure that the research questions will be addressed in a trustworthy manner. This chapter will aid the reader in better understanding the study results which are presented in the following chapter, Chapter 4.

CHAPTER 4

RESULTS

In this chapter the results of the study are presented in relation to the themes established during analysis. As described in Chapter 3, analysis conducted using the a priori coding method resulted in the establishment of four themes: volition, habituation, performance capacity, and environment. Each theme is discussed below and has been further divided into subthemes to capture the richness of the data and depth of the MOHO model.

Volition

As mentioned, volition is a key element from MOHO that is used to examine an individual's motivation to participate in occupations. This domain examines feelings and thoughts through recognition of one's personal causation, values, and interests (Kielhofner, 2008g). Subthemes are used to present results related to this element.

Personal causation. According to Kielhofner (2008g), personal causation is one aspect of volition that includes "one's sense of competence and effectiveness" (p. 47). This can be further influenced by one's ability to choose as well as one's experience and interpretation of events. One way in which this was aspect was reflected by the family was through the lack of choice and control Margret has in regards to establishing her own values. "I feel like, because of Ann's special needs that, I was pushed into the things that are important to me now" (Margret). Margret had difficulty in recalling previous areas of life which she had considered to be important, but instead reflected upon new areas of importance which gained value secondary to Ann's specific needs. These values now include overcoming Ann's feeding issues, helping Ann through autism, and ensuring that Ann is able to attend her therapy sessions. Although Margret accepts both Ann and Brad's conditions, she would not have purposefully chosen to be raising children with disabilities. "It's not a path I would have chosen, but I wouldn't change it. It's just not something that I would've chose" (Margret). Paul also expressed a sense of lack of control in his life. He reflected that he was unable to choose the things that are important to him because working to provide for his family has become his primary focus.

However, both Paul and Margret were able to recognize the impact of Margret's efforts and her personal effectiveness. For Margret, this included recognition of her success in advocating for her children's needs. Margret felt that other individuals would not have shown the same fervor and dedication to her children. "I know that people would love her [Ann], but as far as all of what she really needs I don't know that anyone would follow through like me. I'm afraid they'd take the easy route out" (Margret). Paul also shared this point of view. "She put in many of hours and many, many of days trying to get all the resources for her [Ann] and for Brad too pretty much... I couldn't say I could have done it" (Paul).

Margret acknowledged several specific ways in which she has been able to affect change in the lives of her children. Margret is an active advocate for her children and she has credited this advocacy as the key to her success in being able to ensure that Ann was able to access the services she needed to address her severe feeding disorder.

> To overcome the obstacles, I just didn't accept no for an answer. You know, I dreamed high and I dreamed big and I didn't quit until I got what I wanted and I didn't let people discourage me. I had to take the role of the parent and not let other people influence me and I had to do what I thought was best for Ann rather than what everybody else thought. (Margret)

In addition to affecting the lives of her children, Margret is also aware of the impact she has been able to make on the lives of others. This has been accomplished through use of the Internet to create forums for other parents who are battling intensive feeding issues. "It makes me feel good to be able to share her story because I know that I can help other people and I was at a place where there was no hope" (Margret). In addition, these videos have also been used by a state university as an educational tool that has further contributed to the impact of Margret's efforts. "Knowing that [the school] used the video, that gives even more with having therapists here who are aware of intensive feeding programs and being able to give them a resource brings back to the kids in this state too" (Margret).

Values. Values are described in MOHO as "what one finds important and meaningful to do" (Kielhofner, 2008g, p. 47). One value that was noted during observation was the value placed on expressing affection. Physical affection was often displayed between parents and children, as well as from one child to another. Ann initiated hugs and kisses with both of her parents, but also with her youngest brother David. David verbalized his love for Ann and the rest of his family members by sporadically expressing "me love you" during family occupations. Cindy also explicitly expressed her love for her brother Brad. Although less physical affection was displayed by Brad toward his siblings, he expressed that he enjoys making funny faces at his younger siblings and indicated that making Ann smile was important to him. In addition, Margret also displayed her affection by asking for a hug or kiss after she corrected or disciplined one of her children. However, physical affection was not often displayed between Paul and Margret.

Members of the family also described various valued occupations. Ann and David's drawings of their favorite family activity reflected a value for bike riding, whereas Brad's drawing reflected a value for swimming. Cindy's drawing reflected her value of helping Margret do the laundry. Paul and Margret identified their most valued occupation as camping because this is a time in which the family can relax and come together. "That's why we enjoy the camping. Everybody kinda bonds together" (Paul).

> Everybody enjoys it and there's lots of activities….Nature's relaxing in itself so it's not too stimulating… everybody has something to do that they like. And you don't have to be rushed. We can take our time to feed Ann… we can just, we can set back and relax and we get to go on nature walks with the kids. (Margret).

Belief in God. Another aspect of values includes one's beliefs, referred to in MOHO as personal convictions which are used to define life (Kielhofner, 2008g, p. 40). For Margret, this included a belief in God. Margret believes that God has a reason for placing her in the specific role of parenting children with disabilities and that He has prepared her for this experience.

> I do believe that God has a reason for it. I believe you know, that everything I've been through in my life and every interest that I've had, I can look back and look

> at Ann now and I can see why I went through that. This is just to prepare me for her. (Margret)

This belief was also demonstrated through Margret's response to her children's disabilities. "God put me on this course for a reason, so uh I adapt to what has been given to me and I work with that" (Margret).

This belief was also reflected in the ranch program, observed during data collection, as this program reinforced Christian principles. During one ranch activity Brad and Cindy participated in a relay race in which one donkey was trained to complete the course quickly, while a second donkey was trained to complete the course slowly. The difference in speed was specifically used to illustrate the influence of addictive behaviors and bad habits. Discussion of such behaviors included explicit statements about the ways in which power of the Lord to can be used to help one overcome such habits.

The belief in God also included an underlying belief in the power of prayer. Margret noted prayer as resource when discussing how she copes with her disagreements with Paul. "[I] pray about it. That's all I can do" (Margret). She also requested that one of the camp employees continue to pray for her family. Notably, this belief in God and prayer was only expressed by Margret, and was not explicitly stated by any other members of the family.

Parenting convictions (beliefs). Once again, as described by MOHO, convictions are related to one's beliefs and used to define one's life (Kielhofner, 2008g). Both Paul and Margret reflected an underlying conviction that their children should be their first priority. For Margret, this included a belief that being a parent requires one to put his or her own needs aside to focus on the children's needs."When you have kids, just kids in general, you give up a whole lot. You don't get to do the things that you want to do necessarily. It's more about you've got to care about them" (Margret). Margret also expressed a belief that parenting a child with disabilities is a different experience than parenting typically developing children. "Nobody dreams about having children that have special needs. Nobody says I think I want a kid with special needs. So it makes life instantly different" (Margret). For example, as a result of her children's disabilities, Margret's role as a parent also includes addressing sensory processing needs.

> I do a lot of sensory stuff with the kids that I wouldn't have done normally because… if you didn't have special needs kids you wouldn't be doing all the sensory that you do, that I wouldn't have even known about if I didn't have special needs kids. (Margret)

Parental encouragement. These convictions about parenting also included a belief that the parents should be active in providing encouragement to their children. Margret explained this encouragement as something that was specifically purposed for Ann. It was provided to help Ann become a more active participant in family occupations.

> Depending on her ability we [Paul and Margret] continue to go, we continue to push her to do these things. And it's kinda like, we want her to see, we're gonna, you know, we got to keep doing it because she may see them doing it and want to do it. So that's, so we don't do something that she would be left out of, because we want to encourage her to do those things. (Margret)

This idea of encouragement was also reflected by Margret's statement about how her own life is now purposed around her children and is "about making Ann all she can be."

Another facet of this encouragement was Margret's effort to persuade the other children to develop a habit of helping Ann now. "I try to make them help each other. I kinda feel like I have to do that right now for when she gets older. So that they'll be used to helping, you know, when they need to" (Margret).

In addition to Margret's description of the ways in which the parents provided encouragement to the children, observations of such encouragement were also noted. This type of encouragement was provided to further engage the children in participation of family occupations. At the pool, both Paul and Margret encouraged the children. For Ann, this encouragement was provided through drawing her into to play by splashing, spinning, and dunking her in the water. Paul also employed good-natured teasing with Ann to draw her into play. For the other children, this encouragement was provided to get the children to jump into the deep end of the pool. Both Paul and Margret tried to persuade Brad and Cindy to do this through teasing and through reassurance. When trying to encourage Brad to jump into the pool, Margret reassured him that he could do it and she would be there to catch him. When trying to encourage Cindy to jump into the pool, Paul teased her about not being scared, while promising he would be there to catch her. For David, less encouragement was needed and he willingly jumped into Margret who caught him and then returned him to the shallow end of the pool.

Conflicting beliefs between spouses. Paul and Margret shared a number of conflicting beliefs. This was evident in the beliefs each expressed about work. While Margret saw work as time away, Paul saw it as an obligation. For Paul this was something he had to do to keep providing for his family. But to Margret, although she recognized that work was not an easy, it was still a break in the sense that it provided Paul with time away from home. Paul did not see work as down time, but an obligation that caused him to miss out on family activities.

> They'll be gone out to the ranch or doing this and I miss out on being there. You know, there have been a lot of activities outside of the home that I pretty much have to miss because I'm working. I wish I wasn't working and get to do those things too. (Paul)

The couple also experienced conflicts related to their beliefs about Brad's behaviors. Margret believed that Brad was unable to control his behaviors, whereas Paul did not share this view.

> It's hard for him [Paul] just to deal with some of the ADHD behaviors. You know, it's hard for him to see it because, it's for most people, like a mental issue, you can't really see that. It's not like a physical thing. And with ADHD he thinks it's more of a behavioral thing in general, that he [Brad] is just misbehaving. (Margret)

Beliefs related to Brad's behaviors directly influenced Paul and Margret's relationship. "That [Paul's view of Brad's behavior] does affect the relationship very much. You know how he interacts with the kids because he does have a difficulty with Brad, I have a problem with that. So it affects our relationship" (Margret).

In addition, more general beliefs about parenting also influence the relationship and the ability of the couple to work together as parents. "We were just different in beliefs and it affects how we parent. You know, not being on the same page, messes it all up. And it's kind a hard" (Margret). Despite these conflicts, Paul and Margret do make an effort to come to help the family be together. "We make the effort and we try to work and we try to come to somewhat of an agreement. Sometimes it doesn't work out. Sometimes we disagree" (Margret).

Interests. In MOHO, the term interests is used to refer to things which one finds "enjoyable or satisfying" or shows a preference toward (Kielhofner, 2008g, p. 42). Multiple members of this family identified common occupations of interest, including bike riding, swimming, fishing, and camping. Margret discussed the family interest in going to the park and spending time at the ranch. Cindy expressed her individual interest in playing games with her family, including board games as well as more active games such as "Duck, Duck, Goose" and tag. She also expressed an interest in going to school, spending time with her friends, and reading with her mother. Brad expressed an interest in playing ball and watching movies with his siblings. In addition, he also expressed an interest in being able to play by himself, which included playing video games. Margret explained that Ann has begun to develop an interest in occupations such as swimming and bike riding, which had not been present in previous years. Interests reported from the Smiley Face Data Scale are not included in the results, due to concerns related to children's understanding of this scale.

Members of this family identified a number of individual wants which reflected their preferences and therefore their interests. Both Paul and Margret expressed a desire to have more time to themselves as individuals, as well as more quiet time, which was not currently available. Margret expressed a desire to have this time to do something for herself, such as going out to a movie or shooting pool. In addition, both Paul and Margret also expressed a desire to be able to travel more often, with Paul also wanting to be able to travel further away from home during family vacations. Brad indicated that he wanted more time with Paul, and also mentioned that he too would like more time to himself. Cindy expressed a desire to spend more time with Margret and to play more games with Paul. She also wanted to spend more time with Brad and to be able to sleep in his room. Both children also expressed a desire to have more time to spend in the occupations of swimming (Brad and Cindy), fishing (Cindy), and golfing (Brad).

Additionally, Margret also expressed a desire she had for her children. She wanted her children more involved in a greater variety of activities.

> I would like to have Brad in something where he could, you know, expend that energy and I'd like to have Ann is something, you know swim lessons, or dance

> lessons, or singing…I'd like to do more movies with Cindy. There are just a lot of things I'd like to do, but things interfere. (Margret)

Habituation

Habituation is another foundational component of occupation that is used to describe the organization of occupations. According to Kielhofner (2008e), occupations are based upon stable patterns of behavior, with these patterns being influenced by one's habits and roles. These behaviors are then incorporated into routine performance of activities.

Created habits. In MOHO habits are indentified as "tendencies to automatically respond in certain consistent ways in familiar environments or situations" (Kielhofner, 2008e, p. 5). The habits that emerged for this family were developed in response to the presence of Brad and Ann's disabilities. In response to Brad and Ann's sensory processing deficits, the family has created the habit of avoiding crowded areas. In addition, the family does not participate in activities that would provide overstimulation for the children. Habits have also been created in response Ann's impaired feeding and eating abilities. One such habit is that of reviewing menu items before eating out a restaurant to ensure that there will be something on the menu that Ann is able to eat. In addition to careful selection of restaurants, Margret has also created a unique habit to provide an additional way for Ann to increase her caloric intake, "Sometimes I have to take butter in my purse. Those are things I wouldn't normally do, but I have to do that to boost her calories." Habits have also been created to assist the family in managing Brad's difficulties with self regulation that have arisen secondary to his having ADHD. One such habit is the establishment of rules for all situations. This includes creating rules for the necessary occupations, such as grocery shopping. "He likes to get things and you have to go over the rules. And once you go in, then you remind him of the rules" (Margret).

Roles. Roles are described in the MOHO framework as a part of a social or personally defined status that influences one's interactions (Kielhofner, 2008e). Brad and Cindy performed acts related to caregiving as a part of their sibling roles. Both Brad and Cindy helped their other siblings, David and Ann respectively, get dressed before the family headed out to the store. In addition, Cindy was also observed helping Ann clean her face after a snack and helping Ann get ready for bed. Cindy explained another way in which she helps Ann. “When her need help getting the play-dough, I’m tall enough to get it.”

Margret described her primary role as that of parent. As part of this parenting role, Margret’s daily focus is on meeting the needs of her children. “Each day as a parent it’s caregiving. You’ve got to me the basic needs” (Margret). She explained however, that meeting the daily needs is just one part of this role, and that she also fulfills numerous other roles associated with parenting.

> There’s all kinds of different roles I play as a parent. I play, I’m a teacher, I’m a little bit of everything. I’m a teacher, I’m a lawyer, I’m a doctor, I’m a pharmacist, I’m an insurance person, I’m a little bit of everything really. I just don’t have the title. (Margret)

Another role that was associated with parenting was Margret’s role as an advocate for her children. This role has included advocating for services both for Ann and for Brad. Margret has accepted this as a part of the parenting role. “I’ve done a lot of fighting, and so I’m kind of used to that. It has just become part of my life” (Margret). When describing her most recent need to advocate, to acquire funding to assist Brad in accessing services, Margret explained how she has become used to this role, “I’m just used to all of that with Ann and I’m kinda used to having to do a lot of extra steps.”

In addition, another aspect of the parenting role included meeting needs related to individual family members. “You wear different hats even within the same family” (Margret). This also includes situations in which she specifically fulfills the role of Brad’s Mom or Cindy’s Mom at school, while in other contexts she may be identified as Ann’s Mom. In addition, this role also requires that she work to meet the individual needs of her children, as well as assist the children in forming positive relationships with one another. This includes helping the siblings overcome jealousy associated with activities, such as therapy, that might be perceived as special treatment for Ann.

> I try to find things that they do, that they can do. I go, you know, you’ve got your special thing that you can do and she’s [Ann’s] got her special thing that she does… I do try to explain to them, because Sissy needs this to help her. It’s not like play, this is therapy, this is work. It looks fun, but really it is work. (Margret)

The parenting role has become a part of Margret’s identify. “You become a mother and you do lose your sense of self. Your life is no longer yours. You’ve got to think about how it affects everybody else. So your life choices change decisions change" (Margret). This role has also become the central focus of her life as Margret explained, "My life is all about kids now." This has included a slight feeling of role loss, as she is no longer able to work outside the home. "Sometimes I get upset that I can't work outside the home. Not very upset. But I miss work" (Margret). However, Margret ultimately finds her role as a mother to be satisfying and valuable. "I love my life the way it is and I still, I just love having kids" (Margret).

Brad and Cindy also saw Margret as fulfilling the parenting role and meeting the demands related to this role. Brad described her role as "She has stuff to handle. She has to handle the baby and stuff like that… She has to handle everything." Cindy also described that one way Margret fulfills this role is through helping Cindy complete her reading homework, one of Cindy's favorite activities to do with Margret.

Paul perceived himself as fulfilling the role of provider by working to support the family financially. Margret shared this perception, and both individuals view Paul as the main provider and Margret as the main caregiver. Due to the demands of the provider role, Paul is not able to participate in some family events. Although at times he is able to join Margret in attending therapy sessions for Ann, he would like to be more involved. "I miss out on a lot. I mean I miss out on a lot of stuff that they get to do cuz you know, I'm working" (Paul).

Brad also recognized Paul's fulfillment of the provider role. When describing the amount of work his father has to do, Brad reflected that Paul is "pretty much busy. A lot busy." Brad also acknowledged that Paul's role as a provider and worker prevented him from participating in family activities. When asked if his family goes to the pool together Brad replied, "Not really, but with Mommy" and explained "Daddy is at work."

The difference between the parenting and provider roles was also clearly delineated between Paul and Margret. When asked to define her role in the family, Margret replied, "I am the parent." She acknowledged that while she fulfills this role, Paul fulfills the role of provider. "I would say that I do most of the parenting and he does most of the working." These clearly defined roles were also described as a potential source for conflict and frustration.

> I get aggregated that he can't be here to help me when he has to work overtime…I get kinda aggravated. I'm like okay, I need help when you get home. It's like I need to take a break now and then he gets aggravated because he's got home and I've threw all the kids at him after he's been working all day. So yeah…we do blow up a little bit. (Margret)

Unfulfilled roles. The clearly defined roles mentioned above, contributed to Paul and Margret being unable to fulfill their roles as spouses. The division of roles prevents these two from coming together as a unit or a couple. "We're both here pretty much to take of the kids, but then we're two separate people, trying to make everything" (Paul). "He's just a provider. I'm just a parent. We co-exist" (Margret).

The couple also explained that one barrier that contributed this perception was the lack of time available in order for the two to participate in co-occupations. "Well, we don't get to do things as a couple. So therefore, it's more like we are two single people, living together, doing our own thing" (Margret). Margret also explained that a lack of time was available to be spent outside of the home as a couple. "There's not a whole lot that we get to do as individuals or as a couple. It's very rare that we ever get together as a couple." This lack of opportunity to spend time together was also present for the parents inside the home. Both parents explained that they experience a lack of time alone, as well as a lack of quiet time. This was illustrated using David's nightly routine as an example. "David sleeps in bed with us" (Margret). "He comes in there and goes to bed between us" (Paul).

Routines. Routines are described in MOHO as responses related to specific environmental influences, such as the physical, social, and temporal contexts (Kielhofner, 2008e). Although some routines were noted during observation of this family participating in specific occupations, Margret felt that she had not been able to establish an overall daily routine. "There's a lot of unpredictable. It's always unpredictable. Our routine here is chaotic" (Margret). Margret recognized that her family "should" have a more structured routine and desired to establish one. "We don't get up at, you know, 7 a.m. and go to bed right at 9 o'clock or have scheduled things throughout the day like we should, like I'd like it to be because it just doesn't work out" (Margret).

Margret identified a number of barriers that have interfered with the ability to establish a daily routine. One such barrier was the traveling demands that must be faced when managing Ann’s medical appointments, as her services are provided in another city. In addition, the family also spends an hour, one way, when traveling to and from the ranch that they attend each week during the summer. Another barrier identified was the daily changes in mood and behavior from Ann and Brad, as well as frequent conflicts between personalities for these two siblings. In addition, the family also experiences a lack of calmness each day. This lack of calm is experienced each morning because of Brad’s hyperactivity. “He’s [Brad’s] just, something else. You know, he’s screaming, running, and yelling. He cannot slow down*”* (Margret). According to Paul this lack of calm is still present at the end of the work day, as each day when he comes home the kids are typically, “hollering and screaming. He pulled my hair, he hit me. He poked me, he smacked me.” Paul also noted that there are unforeseen challenges with each activity that family participates that also inhibit the ability to establish a routine. “There’s always a new challenge. Every time you go out and do something” (Paul).

Another barrier to establishing a routine is the inconsistency in Ann’s behaviors during mealtime. According to Margret, “feeding is something that comes and goes. Sometimes she [Ann] does okay and sometimes she doesn’t.” This routine is further complicated by the various paces demonstrated by different family members. Ann takes much longer than the rest of her family to complete a meal. In addition, while Ann is still eating, the other children become engaged in other occupations and also distract both Ann and Margret from the task of feeding.

Although the efforts to establish a daily routine were ineffective, other routines had been established in association with various occupations. Paul has established a nightly routine in which the children take turns riding around the neighborhood in the golf-cart he uses for work, a routine that Brad listed when describing the activities in which he liked to participate. In addition, the family attempts to follow a routine in relation to travel. Although they would like to do more traveling, they “do try to go somewhere every year… [They] try to go camping or to an [indoor water park]” (Margret).

Brad also has an established routine that is used to assist him with managing his emotions and behaviors. When recounting an event earlier in the day that had caused him to be upset, Brad indicated that his response to the situation was to listen to a specific song on the computer to help himself calm down. “I got mad today…So I had to listen to my computer music on YouTube. Well I got to listen to it, ‘I Put My Hands Up in the Air Sometimes’ [song title]. That makes me cool down” (Brad).

Performance Capacity

A third aspect of human occupation is performance capacity. According to Kielhofner, Tham, Baz and Huston (2008), performance capacity is an individual’s ability to do, based not only on one’s objective physical and mental abilities, but also upon one’s subjective experience of his or her own capacity. Thus, performance capacity is based upon both what one can do as well as how one understands the action of doing. The concept of performance capacity in relation to this family is presented below with a focus on the areas of performance related to the overall concept of occupational participation.

Ann. Ann’s performance capacity is related to the presence of her disabilities. Ann has impaired ability to process sensory input, described by Margret as the tendency to become overstimulated. Ann also has limited abilities related to feeding and eating because of difficulty with chewing and swallowing, as well as a limited ability to recognize her need to eat. Ann does not currently possess the skills needed to dress herself without help or perform simple self-care tasks**.**

Another limitation for Ann is a low level of endurance that results in fatigue after participating in occupations. This was evident during observations in which Ann, after eating dinner, moved from the table to a bean bag chair in the family living area and fell asleep. In addition, Ann also demonstrated this fatigue during swimming as she got out of the pool before the rest of her family to lay in the one of the chairs.

Ann is able to participate in some forms of social interaction, as she does show affection to her family members. In addition, she does possess a basic understanding of social skills, as evident by her interactions at the store in which she would say excuse me when walking past other shoppers. However, she does not use these skills to consistently participate in group activities. This was demonstrated during observations of the family at the ranch in which Ann remained separate from group activities, as well as her tendency to stay by herself while in the pool, unless prompted to interact by others.

Her performance in this area is, however, improving. Margret indicated that "she [Ann] is starting to interact a lot more… like at the pool, she'll go up and she'll talk to people and play with people." Margret also noted how her improvement in the physical capacity to ride a bike has promoted her inclusion in sibling activities, "She's been getting out here and riding bikes with all of them [her siblings]. Last year, she would have been left out of that activity because she couldn't ride a bike."

Brad. Like Ann, Brad also showed some diminished areas of performance capacity related to his disability. This included limitations in his ability to process sensory stimulation, which could lead to overstimulation and limited self-regulation. Paul also reflected upon the ways in which this limited capacity is manifested with Brad by explaining how he responds to increased sensory input, "He won't sit still and be all upset and then he's gonna act out." In addition, Brad also does not possess the capacity to regulate his behaviors. "Sometimes he's not really [misbehaving], you know he can't really control it" (Margret). His inability to self-manage his own behaviors leads to actions such as hitting, smacking, yelling, becoming defiant, and not listening to directions. In addition, Margret explained that his limited capacity for self-regulation is also sensitive to competition as "a lot of jealousy between siblings… a lot of competition that really sets him off." This disability has also limited his capacity for understanding. Margret explained this as, "just basic things that kids should know Brad doesn't."

The areas of performance capacity that Brad chose to reflect upon were related to his ability to participate in sports. He felt that he possessed all the capacities needed for swimming but had more difficulty in golf because sometimes he often swings the club without hitting the ball.

David. David's limitations in performance capacity were related to his young age. David is not yet able to toilet independently, and wears pull-ups. However, he does possess the capacity needed to identify when he has dirtied his pull-up. In addition, David is not yet independent in feeding, as he requires assistance with opening some containers and cutting his food. He also, like Ann, required assistance for dressing, but has more success with undressing. David also has a tendency to remain energetic, which may relate to diminished self-regulation. Paul described this as, "David's got hyper in his diaper."

Margret. The areas of performance capacity emphasized by Margret were directly related to her ability to perform her role as parent. This included the ability to be flexible and adaptable to the changes and challenges she faces each day. "You just kind of go with the flow throughout the day and just try to make the best out of it" (Margret). In addition, Margret also explained other abilities she has developed during her role as a mother, which include being able to research and advocate for her children's needs by formally by fighting with Medicaid as well as the Senate and Congress. She also expressed an understanding of how her response to such challenges has increased her own capabilities. "I think it makes me a stronger person than I used to be" (Margret). She did recognize her current limitations, such as struggling to control Brad's behaviors. However, although she is aware of areas she would like to improve, Margret is also aware that she is performing to the best of her ability. "I'm just a parent doing the best she can with what she has to do it with" (Margret).

In addition, Margret did share awareness of her previous limitations in performance capacity related to experiencing depression. "For a while, I did go through bouts of depression of guilt. Feeling like I was to blame for the disabilities when I wasn't: (Margret). However, she is currently able to accept the disabilities and appreciate the life she has, as she expressed "I love my life the way it is." However, Margret did explain that this acceptance comes in cycles and is similar to the stages of grief one experiences after loss. She indicated that although at this stage in her life, she is able to accept Ann's disability, feelings of guilt and blame may eventually resurface. "Those cycles may come and go. But right now I feel like I've accepted it, but then later I might go through the guilt thing again. But not for now" (Margret).

Paul and Cindy. Fewer findings related to the performance capacity of Paul and Cindy were evident. Paul demonstrated the mental and physical abilities needed to engage in a number of occupations that included swimming, cooking, eating, cleaning, shopping, and working. Cindy appeared to possess the physical and mental capabilities that were typically expected at her given age and her skills enabled her to participate in many of the family occupations. Cindy was able to list many of the rules appropriate for the store before participating in grocery shopping and demonstrated the ability to understand the concept of sharing and giving to others as demonstrated by her actions during swimming.

Environment

Using the MOHO framework, environment consists of a number of contextual factors such as physical, social, cultural, and economic factors which together influence the three areas previously discussed: volition, habituation, and performance capacity (Kielhofner, 2008d). This model further divides these contexts into other dimensions such as opportunities and resources, demands and constraints, objects, spaces, and social groups.

Opportunities and resources. A number of resources utilized by this family were related to Brad and Ann's disabilities. Margret identified many resources used to assist with Brad's behavioral difficulties. These resources included counseling, applied behavior analysis therapy, and support through use of the Michelle Peabody Wavier system. This wavier has also been a resource for the family as it provides the opportunity for brief periods of respite support which can be used in emergency situations. In addition, medicine was also utilized as a resource to assist with Brad's self regulation. Margret described this as, "His [Brad's] medicine takes effect and he can slow down. And then he can do alright." Brad himself also identified another resource that he uses to manage his behaviors, specifically his anger. He explained that the computer music, discussed as a part of habituation, is used to help him manage his emotions.

For Ann, one resource related to her disability was enrollment in an intensive feeding clinic. Due to Ann's success with using this resource, Margret was able to craft an opportunity to share this success with others by documenting Ann's transformations via YouTube videos. "People watch my videos that I put up for Ann. So, I have an opportunity to help others, to help other kids with feeding issues" (Margret).

Other resources were identified through their relation to the season or time of year. A number of resources are accessed by this family as a support in the winter months. This included use of the neighborhood clubhouse as a gathering place to watch movies and the use of a local, indoor, family entertainment center. Another utilized during the winter months is membership pricing. Margret explained, “We look for some winter activities where we can get a membership. You know, it’s cheaper to get a membership than it is to pay your way in… things like that, that we can do in the winter time.”

Conversely, other resources and opportunities were utilized during summer months, such as swimming at the neighborhood pool, a resource reserved for residents only. In addition, the program at the ranch is a summer program. Similarly, the summer months and warmer weather provide the opportunity for the family to participate in outdoor activities such as bike riding, fishing, and camping.

Demands and constraints. Whereas resources and opportunities are used to promote participation, MOHO describes demands and constraints as limiting and discouraging specific behaviors and actions. One such constraint identified by this family was a lack of time. Margret expressed that “there is just not enough time in the day.” Margret felt that all of her time was devoted to her children. “I’ve got four kids. Four kids takes all my time” (Margret). In addition, Margret perceived time as a limitation which prevented Paul from being more involved in the caregiver role. “He [Paul] works so much that he doesn’t really have time when he gets home. He’s too tired. He doesn’t feel like watching kids so I can go do things” (Margret). Time was also viewed as a constraint by Brad and Cindy, both of whom felt that the amount of time each child spent with Margret was limited. According to Cindy, “Mostly I don’t get to spend time with my mom… cuz her got working to do.” According to Brad, “I don’t get much time. Daddy has to handle everything for me and mommy to spend time.”

Other constraints described by this family were associated with the nature of Brad and Ann’s disabilities. In regards to the general nature of Ann’s disabilities, therapy and the amount of appointments that Ann needed to attend were specified by Margret as a demand due to the amount of travel involved when meeting these needs. “We’ve got so many appointments for her [Ann]. I travel to [another city] with her to go to speech and occupational therapies. And then I've got ranch on Tuesdays that they'll go to, and so we travel a lot with that. So our day is very… it's on the fly" (Margret).

Other demands related to Ann's disability were associated with her feeding disorder. The family is "limited to certain restaurants" (Margret) based upon the menu selection and Ann's inability to chew and swallow certain types of food. In addition, preparing meals for Ann at home is also demanding. "She [Ann] has to be fed differently. And, I have to prepare her meals different. I have to calorie boost" (Margret). Other demands related to feeding include increased time constraints as well as Ann's moodiness in regards toward this task. "Ann's feedings routinely interferes. Her meal times can take up to an hour and, as you've seen tonight, she is not always cooperative. Her moods interfere" (Margret).

Constraints related to Brad's disabilities were also present. Brad's inability to manage his behaviors has constrained the relationship between Brad and Paul. Although Paul has become more understanding of these behaviors than he had been in the past, Margret "still feel[s] that their relationship is strained." Additionally, constraints that have been previously faced by the family in relation to Brad's behaviors include difficulty finding supportive environments, as Brad has been kicked out of both daycare and church in the past. When discussing these behaviors, Margret stated that Brad's behaviors are currently the biggest challenge the family is facing.

Other demands for this family were related to better meeting Brad and Ann's sensory needs. An associated constraint related to this demand is the family having to be selective in activities to prevent the children from being overstimulated.

> "We can't go to places that have a lot of people in it or a lot of noise because it's too overstimulating to them… it causes them to have meltdowns…that prevented us from going to air shows and things like that, that we wanted to do with the other kids. Fireworks and stuff like that... because it was just too much" (Margret).

Other constraints and demands were also evident based upon the general size of the family. In addition to being overstimulating, visiting crowded places is also difficult due to number of children in the family.

> “I do avoid crowded places… we’ve got too many kids. It’s hard to keep up with all of them. And then you’ve got some with sensory issues. So, things that they may really enjoy, it’s just too much of a hassle to try to do it” (Margret).

The size of the family has also increased the need for Margret to be selective in choosing occupations and activities.

> “Just having the four kids together at the same place…was really hectic… it makes it very difficult… it goes back to being selecting in what we do. So it kinda limits what we are able to do. There’s things I’d like to do with them that I just can’t do” (Margret).

Similarly, finding someone to care for the children in the parents’ absence is also difficult due to family size. “Not many people are gonna babysit for four kids. It’s too overwhelming for people” (Margret).

The family is also constrained by the lack of support system available to assist with childcare. This support was described as limited. “We have a little bit of a support system, that if I need it…[I] could have called that would have sat with the kids” (Margret). However, the desire not to overuse this system further limits the Margret’s perception of having support. “I don’t really have [support]. It’s just us. It comes down to us. That’s just the way it is” (Margret).

Another constraint for this family is finances. Margret described the family as being “financially limited.” This was cited by both Paul and Margret as one constraint that limits the family’s ability to travel more often or further away. The size of the family also contributes to this financial constraints faced as a part of traveling because “everything is double the price cause we’ve got six of us and you can only have up to four or five max. Six one knocks you out and you have to pay double” (Margret). As a result, the family takes local trips because of costs. When discussing a longer trip to the beach Margret explained, “we can’t afford to [go] very often.”

Another constraint specific to travel was related to the demands of packing for all six family members. “Looking back when we traveled you just get up and go…and now you’ve got to pack for all of you” (Paul). “Now you’ve got to pack up the whole house… It’s like you’re moving” (Margret). Another constraint related to traveling was being unfamiliar with environments and how these may or may not be an appropriate match for the children's needs. "We've got to watch to see stuff that she [Ann] can eat and then worry about is this place gonna be packed and then if it's jammed packed worry about…Brad won't sit still and be all upset and then he's gonna, act out cuz it just gets him all hypered up" (Paul). This is further limited by pressure to complete meals more quickly while traveling, which is difficult for Ann. "We often feel rushed when we travel because somebody else needs a table" (Margret).

The winter season was also found to be more demanding for this family. Margret described this time of the year as "miserable" because the children are unable to go outside. "We are at each other's throats. Everybody wants to fight everybody… Brad goes through the house beating everybody. Yeah. It's tough in the winter time" (Margret).

Brad and Cindy were also able to identify perceived constraints that they felt limited their ability to participate in occupations. For Brad, one constraint was being able to find an empty space at home to have time away from everyone else. From Cindy's perspective, she also felt constrained in her ability to fish with Paul on a more regularly basis. She explained the reason for this constraint as being "because I don't have a fishing pole."

Social groups. Social groups are defined by this model as "collections of people which come together for formal and informal purposes and influence what people do with them" (Kielhofner, 2008d, p. 92), including families, friends, and neighbors. When describing the family interactions, Margret explained how relationships vary among individual family members. "You've got a relationship with each one differently… It's just like with everybody you have a different relationship with. It's the same with, you know, each kid is different and so unique" (Margret). This type of interaction also extends to the relationships between siblings. For this family, siblings often interacted with one another in pairs.

> "They pair up. Brad and Cindy are kinda like the twins, but they're not. They're close and yet they fight. And David and Ann are that way. David and Ann will fight each other more, but when it comes to, if I get on David and Ann just ain't having it. That's her baby, you know. That's the way they are about each other.

> They're just like really protective of each other, but then they may fight each other. That's what siblings do" (Margret).

Brad explained that he chooses to participate in different activities with specific family members. He likes making faces at Ann and David, but stated that he did not have a favorite activity to do with Cindy. However, he did mention playing ball with Cindy and also how swimming was important to Cindy, David, and himself. He also expressed that he engages in other occupations with just Paul, such as golfing and helping his father at work.

Cindy also described ways in which she participates in the family social group. She explained that she liked to play with her siblings, especially Brad, and enjoyed playing games with the whole family. Cindy also discussed another social group that was of value to her in addition to the family, her friends at school. She explained that she enjoyed being able to spend time playing with her friends at play centers and also enjoyed time with her teachers. "I love my teachers and I love my school" (Cindy).

Marriage. A more specific social group, marriage, also emerged as a theme for this family. Margret experienced dissatisfaction with her marriage and expressed that this dissatisfaction has a negative impact on the perception of the family as a unit. "It feels like there's a tear. That there's a break in the bond of the family because of the issues." (Margret). She explained the ways in which these feelings of dissatisfaction influenced not only herself, but also impacted the children.

> It feels like, there's definitely effects. It affects the kids. It definitely affects, it affects them that we disagree. Because if we're not on the same page, you know you have to this, you know, to have a solid family unit. (Margret)

Because the issues with the marriage were impacting the kids and the sense of family, Margret shared this view, "This is where I am unhappy about my life, is because it's not, it's not whole. It's torn and broken." Although there has been improvement, this has not provided a complete resolution. "We're doing better than we were and I don't know… It puts a strain; it puts a strain on everybody at times. Some days are good, some days are not " (Margret).

Sibling interactions. A theme of sibling interaction also emerged as a part of the family social group. This theme is further divided under that headings presented below.

All four children. In many instances, all four of the children participated in the occupations together. During observations of play before going to the store, all children were downstairs playing in the living room. Although there was a mix of parallel and interactive play, all children were at times included in the activities. In addition, Cindy also described some activities in which all four children play together including tag and playing "Duck, Duck, Goose." Brad also described another occupation that all of the children participate in, watching their favorite movie. This in turn, lead to their own style of play in which they slap one another, which occurs between all four siblings. In other instances, such as the ranch, the children were not necessarily interacting with one another, but sat close by each other.

Margret did explain that tensions and rivalries did exist between the siblings. However, she also explained how such rivalries were a part of the typical sibling relationship. "They're just like really protective of each other, but then they may fight each other. That's what siblings do" (Margret). She went on to explain the ways in which the children are supportive of one another.

> The kids will encourage Ann to eat. They encourage each other, you know in swimming and activities. They'll say, "Oh you're doing so good." And they'll, they'll praise one another. And, they'll help each other. (Margret)

In addition, although Brad admitted a desire to have some more time alone, he also explained that he enjoyed summer and being able to spend more time with his siblings. "We just have a little bit of fun" (Brad).

Ann's preference to be alone. At times, Ann did not participate in activities with her siblings. There were a number of activities and play-based interactions that occurred between just Brad, Cindy, and David. For example, at the pool, these three siblings engaged in play together at times in the shallower end of the pool, while Ann remained in the deeper side. Before going grocery shopping, Brad was asked to help take out the garbage, which turned into an activity for all three children, while Ann and Margret stayed inside. Also during mealtime, these three children engaged in conversation with one another and, at times, their parents. Similarly, at the store, these three siblings engaged more in conversation with one another than with either parent or with Ann.

The siblings also discussed interactions with Ann. Brad explained how Ann sometimes does not participate in the same activities as the other three children. When asked if all of the children liked to swim Brad explained, “Not really for Ann, but Cindy, David, and me like to go swimming, but Ann kinda gets cold.” He went on to say that, “She [Ann] wasn’t really with us. She was just laying there with a cover. With a beach towel on her. She was laying in a chair.” When asked about her favorite thing to do with Ann, Cindy replied, “Her don’t want nothing to do with me.”

However, Ann’s lack of participation in these activities was not described as a concern by Margret due to Ann’s preference to be alone. “For the most part, no. She’s not really left. She’s not really left out. She’s just off to herself and doesn’t really care. She’s always been like that” (Margret). This was also apparent in observations. Although Ann did not participate in some activities, she did not appear to be upset by this situation as demonstrated when her siblings were busy helping with the garbage and spending time outside. While they were outside, Ann was inside dancing around the living room. She briefly paused to wave to them from the window, but then re-engaged in twirling around into her dance.

Children’s view of Ann’s disability. At times, Brad, Cindy, and David did exhibit jealousy toward Ann. “They get jealous because she gets to go to therapy and they’d don’t have their therapy. They want to go to therapy too. Why does Ann get to wear hearing aids? They want to wear hearing aids” (Margret). However, overall the children have accepted and adjusted to Ann’s disabilities. “They’ve just, they’re just adjusted to it and they know that Ann’s different and you know. And yeah, just kind of Ann’s Ann” (Margret). Although at times the children do interact differently with Ann based upon her needs, such as Brad “taking up for her” (Margret) or Cindy interacting in more of a caregiving role, Margret also pointed out ways in which Brad, Cindy, and David interact with Ann in the same manner that they would interact with each other. “They’ll smack her, just like they would the next one… it’s not like they have any sort of, or any pity for her really” (Margret).

Occupational Settings and Environmental Impact. Various dimensions of environment were also evident during observations of the family engaging in occupations. This reflects the concept of occupational settings, in which the various aspects of the environment (objects, places, and social groups) come together to create "a meaningful context for performance" (Kielhofner, 2008d, p. 97). In addition, environmental impact is used in MOHO to describe the influence of opportunities/resources and demands/constraints on occupation (Kielhofner, 2008d). In an effort to illustrate these influences, the various dimensions are presented by their relation to specific occupations. Although included as a part of environment, these occupations should also be considered for the impact related to habituation, more specifically routines.

Grocery Shopping. While participating in grocery shopping, resources and opportunities were available to the family as part of the store environment. This included the use of small shopping carts (objects) which Margret retrieved for Cindy, Ann, and David. In addition to the carts, Margret also used flyers located at the front of the store to serve as "grocery lists." Each of these three children was given a pen and a flyer to keep track of the sale items they purchased. In addition the grocery store employees served as a resource to assist the family in taking their purchased groceries to the cars. This assistance also included aid to help Paul load the groceries into the cars, while Margret made sure the children were safe while in the parking lot. The ability to unload both cars effectively was not only supported by the store employee, but also by the opportunity that Paul and Margret had to park each vehicle next to another.

Another opportunity was the store's promotional "Buy 10 items, get 5 items free" sale on select items. When coupled with the resource of coupons, gathered before and during shopping, Margret was able to capitalize on this opportunity and saved approximately $200 off of her original bill.

However, there were also a number of demands and constraints related to this occupation. One demand was the necessity of traveling to the store in two vehicles to ensure that there was enough space available for the groceries and children. This led to a greater constraint when Margret, Ann, Cindy, and David arrived at the store first because by the time Paul and Brad arrived, no more small shopping carts were available for Brad's use. Another demand was the general layout of the store, as toys were placed in almost every aisle. The children, with the exception of Ann, would beg their parents to buy these items, despite repeatedly being denied, and thus continually distracted Paul and Margret from their focus on keeping track of sale items. In addition, store aisles were narrow and crowded, leaving little space for other shoppers to move around the family. The fluorescent lighting used in this physical context was a constraint for Margret specifically, as this type of lighting induced a migraine headache.

During checkout, David contributed to the demands being placed upon Paul by his disregard of Paul's instruction to stay lined up behind Ann and Cindy with his cart. He would continuously move his cart out of the line and toward the exit of the store, often impeding other shoppers who were trying to exit. In general, children often ignored parents' requests, such as walking slowly, not asking for toys, and not touching items unless asked to retrieve them.

The influence of social groups in this context was also noted. Other shoppers would often stop and stare at the family or, in other cases, shoppers appeared to avoid the family as they would begin to start down an aisle before turning around and skipping the aisle all together. Ann participated in social interaction by repeatedly saying, "oh sorry" and "excuse me," when passing other shoppers. However, this was ignored by the shoppers she was addressing, although one man did smile and greet the family.

Swimming. There were a number of resources present during the occupation of swimming. This included the resource of having access to the private pool, available for neighborhood residents only. Additional resources available at the pool included the use of pool side chairs and tables, as well as restrooms and a concession stand. The chairs were used by Ann as she was able to lie on this chair and cover up with a towel when she became tired while the rest of the family remained in the pool. Margret provided additional resources for the children by bringing along pool toys and towels for the family to use. Other objects that served as resources were brought by other swimmers, such as additional toys and snacks. These were of special interest to Brad and David who both took turns playing with the toys of others and also asked to share food. On the other hand, the only significant demand noted was the expectation that children adhere to the pool rules, which were reinforced by Paul and Margret.

A variety of social groups were also noted during this observation. In addition to participating in play with one another, Brad, Cindy, and David all played with other children while in the pool. Other individuals at the pool were willing to share toys as well as food with the children. Cindy later reciprocated this act, sharing her toys with a young woman who allowed Brad and David to play with her son's toy. In addition, the family's next-door neighbors also arrived at the pool to swim. All members of the family interacted positively with the neighbors, a middle aged man and woman, through conversation and playing together in the pool.

Specific spaces related to this context were also noted during observations. The layout of this area included two in-ground pools that were located alongside of one another with a narrow seating area in between and additional seating around the edges of each pool. This spacing allowed for the family to remain in one pool, the shallower of the two, while the majority of the individuals at the pool were swimming in the deeper pool. The defined space within the pool was also evident as David spent the majority of his time swimming in the shallow end of the pool while Margret, Paul, and Ann stayed in the deeper end. The other two children went back and forth between both ends of the pool.

The ranch. The family, with the exception of Paul, also participated in attending what they referred to as "the ranch." This included a number of chores and activities that were presented for groups of children as weekly, one hour, summer sessions, which emphasized Christian beliefs.

There were a number of opportunities and resources available for the children while attending the ranch. Each child, with the exception of David, was paired with a teen-age worker to receive one-on-one assistance and interaction. In addition, the leader of the ranch specifically provided Ann with opportunities to choose the activities she desired and directed Ann's worker to let Ann do whatever she wanted. In addition, the camp provided the opportunity for the children to interact with other children and farm animals, all while learning religious lessons. For example, the theme for the observed session was the influence of bad habits and the importance of having self-control to overcome such habits.

However, demands and constraints were also present at the ranch. One demand was that children listen and attend to the rules, especially during group discussion time. At first, this was difficult for Brad. In addition, the ranch is an hour drive from the family home. Other demands and constraints were more notable for Margret as the children often ended up in three different areas of the ranch. She appeared to make an effort to watch all of the children participate in the camp activities, but this was difficult as she was not able to simultaneously watch each child.

The social group influence at the ranch was evident through the interactions between Margret and the camp leader. The leader of this camp knew many personal details about the family and offered support to the family by the means of prayer. Social groups among the children were less interactive during structured activities, in which Brad and Cindy chose to be partners with one another. However, Brad did engage in play with other boys when walking to the car and Cindy engaged in conversations with the workers. The mothers and younger children that were present during the camp activities remained at the playground, while older children participated in camp activities at another area of the ranch. Margret allowed David to move freely about the ranch, which prevented her from staying with the other mothers.

The influence of space was also evident in this context. As mentioned, the layout of the ranch included a playground that was located in a separate area from the animals and central area in which the older children spent most of their time. This layout created defined spaces in which the younger children and mothers stayed toward the playground, while older children participated in events. These defined spaces were ignored by Ann and David who roamed throughout the ranch with supervision. Another aspect of faith noted was the layout of the area used during the discussion portion of the camp. A circle of tables and benches were arranged at the center of the ranch and framed by trees and other plants. This layout was used to promote discussion among participants. During the discussion time observed, Ann chose to sit on the outside of the circle, near her other siblings, but did not sit in the inner area in which the discussion was taking place.

Family dinner. During dinner, the dining room chairs and tables were the same height as the chair that was used as a resource to assist Ann with feeding. While the chair was a resource for Ann, the height of the table was also a resource for the family as this allowed for Ann to be included in the activity. In addition, the family had the opportunity to eat dinner together in the same place and at the same time.

In addition to constraints mentioned related to feeding difficulties, such as Ann needing her own food and her periodic refusal to eat, other constraints were noted as well. This included demands for Paul and Margret who tried to meet all of the children's needs while also trying to eat their own meals. In addition, the children, with the expectation of Ann, did not remain seated at the table, but often moved freely about the room. Another demand related to this occupation was the various pace of eating for each individual family member. Ann needed more time to complete the meal than her siblings or parents, and Paul ended up taking Brad out on a golf-cart ride before Ann had finished eating. This lead to another constraint on Margret as she was the only one left who participated in clearing the table after the meal, although Brad did put his own dishes in the sink before leaving.

Social grouping amongst the family was also evident during this observation as Margret spent the majority of her time interacting with Ann, while Paul's attention was mostly focused on assisting David. There was limited conversation from Margret, even when addressed by Paul. In addition, although Brad, Cindy, and David remained in conservation with one another, Brad also appeared to be intent on engaging Paul in conversation.

In reference to space, the dining area was located in part of the family living area. Although there was a separate space for the table, there was nothing to define the separation of dining area from living area. Thus, children were easily able to wander from the table to the living area, where the couch and computer were located.

Bike Riding. The opportunity to engage in bike riding was supported by the large open parking lot outside of the family's residence, which had little traffic. Additional resources for the children included each child having his or her own bike as well as his or her own helmet. In addition, the children were also provided with the opportunity to participate in bike riding intermittently while engaging in other activities such as eating, drinking, singing, or talking to Margret or Paul. A glimpse of social groups was also evident during this occupation through the family's interaction with the neighbors who arrived home during the context of bike riding. Margret engaged in small conversations with each of these two neighbors, who arrived at different times, and invited them to join with the family in eating. However, this request was politely declined. In addition, Brad and David also engaged in conversation with each of these neighbors and were even able to ask questions showing a personal knowledge of the individuals. For example, Brad asked "How is the new grandbaby?" and "When are you moving?"

Summary

The results of this study were presented based on the various aspects of occupation described by MOHO. Thus, this chapter described the ways in which these components were represented during interviews and observations. The next chapter, Chapter 5, will discuss the ways in which these results reflect the family's view of occupational participation. This will be done through description of the impact on occupational participation, with an emphasis on representing the family's perspective as well as a connecting this perspective with family-centered care.

CHAPTER 5

DISCUSSION

As stated, the purpose of this study was to obtain and understanding of how one family of children with disabilities views their occupational participation. The discussion is organized using the occupational therapy theory, the Model of Human Occupation (MOHO), but is also impacted by the tenets of family-centered care. This second framework is necessary to have a complete understanding of family interactions and supplements the use of MOHO. The discussion portion of this study is presented below as it pertains to each of the research questions the study was designed to explore:

1. How does the family view their occupational participation?
2. How do parents in the family view their participation in co-occupations?
3. How do individual members of this family view their own occupational participation?

Family View

The results from this study suggest that this family has a multi-faceted view of occupational participation. This includes a focus on a number of factors which influence occupational participation itself, as well as the ways in which this participation is experienced. A diagram of these factors is also included in Appendix D to better explain the family view of occupational participation.

Participation in leisure occupations versus necessary occupations. One such facet is the individual value of the ability to participate in occupations as a family. In particular, all members of this family expressed a value and interest in active leisure occupations such as swimming, bike riding, and camping. Previous studies have pointed out benefits for families who are able to participate in leisure-based occupations both for families as a whole as well as individual family members (Downs, 2008; O'Mullan, Wayne, & Krishnagiri, 2005). These types of occupations may have additional benefits for families of children with disabilities such as experiencing moments of happiness as well as a sense of normalcy, which contributes to the overall well-being of the family

(Downs, 2008). The idea of happiness and family well-being was also reflected by this family's view of their leisure occupations. When discussing camping, Paul and Margret described this as an activity that helped the family bond and allowed everyone to come together and relax. Thus, occupational participation in these activities was a key to obtaining a sense of togetherness. In a follow-up phone interview, Margret discussed that participation in such occupations allowed her to experience a stronger connection as a family.

The findings related to participation in leisure occupations also demonstrate the importance of volition as well as the impact of volition on family occupational participation. Leisure based occupations were found to be both a value and interest for the family as a whole. Values and interests are representative of one's motivation, or volition (Kielhofner, 2008g), and therefore this family's view of leisure activities also reflects their overall family motivation to participate in such occupations. Similarly, the influence of volition may also play a role in the overall family well-being mentioned above. In a study describing the well-being of university students, Yazdani, Jibril, and Kielhofner (2008) reported that a perceived value for an occupation was related to more positive wellbeing. Therefore, it might be suggested that in addition to the overall experience of family unit, the family's preference for leisure occupations is also influenced by motivation to experience more positive well-being.

Although Margret was the only member to explicitly express feelings of unity, it can also be inferred from observation data that Margret was not the only family member to share this view. There was a notable difference between the family interactions during leisure-based occupations and more necessary occupations. For example, before grocery shopping, Margret stated that she was dreading this task. During the actual event, there was less family interaction between parents and children due to parents' focus on the goal of this occupation, selecting and buying the groceries. As a result, although this was an occupation that the entire family participated in, the goal of this activity prevented the family from perceiving the same bond that was felt during leisure occupations.

Thus, this finding demonstrates the combined influence of both MOHO and family- centered care. Family-centered care is represented through the sense of interdependency and bonding represented during leisure occupations. MOHO, however, explains how the change of goal impacted the motivation to participate in necessary occupations. In this example, the values and interests related to necessary occupations were not as strong as those reported for family leisure, leading to decreased motivation for necessary occupations. Kielhofner (2008g), describes interests as positively influencing the enjoyment gained from an occupation. Thus, this change in goal might also explain the decreased sense of enjoyment perceived during necessary occupations.

This same idea was also apparent during family dinner. Segal (2004) reported that even for families of children with disabilities, mealtimes can be a time of enjoyment in which members grow closer by sharing stories about the day. However, for this family, the mealtime was more focused on meeting family needs rather than interaction. Most conversation was exchanged between Brad, Cindy, and David, while Paul and Margret remained mostly silent. Margret was also focused on attending to Ann and meeting Ann's feeding and eating needs. This also illustrates how the goal of the occupation, Margret's focus on assisting Ann, hindered overall positive family engagement and interaction.

This same perception was not evident during participation in leisure-based occupations. During swimming, all family members were observed laughing and smiling. Despite a brief period of disagreement between Paul and Margret, as well as between Paul, Margret, and Brad, the overall mood was positive. In addition, the increase in interaction between all family members, as well as individual attention from parents to children, suggest that this experience was more family-centered than the necessary occupations mentioned above. Also, during bike riding, although each individual fulfilled different roles and at times participated in different activities, there was still a greater sense of unity and togetherness. All children interacted with one another and with their parents. In addition, parents were better able to respond to children without being focused on other goals. Thus, this speaks to the family need to have occupational participation in leisure activity as this strengthens their identity as a family. Such a concept is also supported by Branholm and Fugl-Meyer (1992) who reported that life satisfaction and overall happiness are linked to roles related to family life and leisure participation.

Importance of providing support. Another perception reflected in this study was the importance of providing support for occupational participation. For Paul and Margret this was seen as a part of the parenting role and included encouraging Ann to become an active participant in these types of family occupations as well as selecting occupations in which Ann is able to participate. The follow-up interview with Margret confirmed that this was intentional and specifically created to better meet Ann's needs because she and Paul do not want Ann to be left out of family occupations. Although encouragement is provided to all children, these parents were more purposeful in providing this to Ann due to her impaired performance capacity. This suggests that the family participation as a whole is designed to take into account Ann's performance capacity.

This idea of purposeful design and selection of both leisure and everyday occupations has been noted by a number of parents of children with disabilities (Downs, 2008; Larson, 2000; Segal, 2004), and has been found to improve children's ability to participate in family occupations. Thus, by encouraging Ann to participate in family occupations, the parents are once again reflecting the value of participating in these occupations. Law (2002) stresses the importance of participation to overall health and life satisfaction for individuals with disabilities. In this discussion, she credits the family as having power to impact participation and reduce the risks for lack of participation by providing positive support to family members with disabilities. The need for such support is also described by Yazdani, Jibril, and Kielhofner (2008) who found that relationship between family and friendship roles were associated with the highest-levels of well-being for college age students. Thus, by providing encouragement, the parents of this family are not only supporting family participation, but meeting individual participation needs as well.

The perception of the importance of support was also reflected as a part of habituation, more specifically through the creation of habits that enabled occupation participation, despite Brad and Ann's impaired performance capacities. Margret viewed these habits as necessary aspects of occupational participation as she described the habits as tasks that had to be done to better support the family's ability to participate in occupations. If Margret did not engage in these habits, such as avoiding overstimulating environments, engagement in occupations would not be successful. For example, Paul's described Brad's response to sensory stimulation as leading to Brad acting out and becoming disruptive. Thus, the entire family's participation in an occupation is negatively impacted due to Brad's behaviors. Created habits therefore not only provide a support for Brad and Ann, but for the entire family. This is consistent with previous research that reports occupations can be designed to provide a positive experience for children with disabilities (Downs, 2008; Segal, 2004). However, in this study, this purposeful design also benefits other members of the family as well.

Limits in occupational participation. Despite the efforts made to support participation, Paul and Margret did perceive ways in which accounting for the special needs of their children also limited the family's overall occupational participation. This limitation was due to the need be selective when choosing activities that would match the abilities of all family members. Thus, the family did perceive their overall occupational participation as being limited directly based upon the presence of disabilities. This view is not surprising given the results of previous studies which suggest that parents of children with disabilities face a greater number of demands each day related to the managing behaviors, appointments, schedules, finances, and stress, as well as the difficulty with maintaining positive family relationships despite a lack of support (Cashin, 2004; Hall & Graft, 2010; Ludlow, Skelly, & Rohleder, 2011). In addition, parents are also challenged to orchestrate family occupations not only to meet the needs and interests of the child with disabilities, but interests of other family members as well (Larson, 2000).

Thus, to meet such challenges, this family had to be selective in their overall occupational participation which included not participating in occupations that may be enjoyable for some members of the family. This is consistent with MOHO, which views environment as a dynamic influence on occupation as a whole (Kielhofner, 2008d). This model also suggests that the environment is a central aspect that influences how one experiences life with a disability (Kielhofner, 2008d). Therefore, it is not surprising that this family experienced a need to select environments based upon the presence of disabilities as well as personal interests. This concept is consistent with research related to disability studies, which views the social and environmental barriers experienced related to a disability as being a key source of impairment (Block et al., 2005; Kielhofner, 2005a).

However, it is also important to point out that for this particular family, the size of the family was also, at times, a limitation to occupational participation. Margret described activities as being more demanding based upon the number of children and need to supervise each child. This was included as a limitation to grocery shopping as a family. These demands were then magnified due to the presence of disabilities. For example, Margret perceived crowds to be a barrier to participation based upon the need to safely monitor all four children. However, additional demands were experienced due to the sensory needs of both Brad and Ann. Thus, as suggested in family-centered care, it is important to consider the individuality of each family as well as the presence of disabilities, as this family had unique needs that may not be experienced by other families who have children with similar diagnoses.

In addition, use of MOHO also provides a more in-depth understanding of these limitations through its emphasis on the interactions between the various components of occupation. According to Kielhofner (2008c), all four components (volition, habituation, performance capacity, and environment) must be present for occupation to occur, and therefore should be considered with equal value as a change in one area will directly influence an individual's emergent occupations. Thus, these components cannot be viewed in isolation, but come together to create occupation. Such interaction is seen in the limitations perceived by this family that related to multiple aspects of this theoretical model. Limitations related to performance capacity were experienced due to Ann and Brad's disabilities. Volitional limitations were imposed due to the struggle to meet the interests of multiple family members when planning activities. Environmental influences were also present, such the need to avoid loud, crowded environments, the family's lack of social support, and the overall size of the family. This illustrates Kielhofner's description of the dynamic nature of human occupation and the way in which all components interact to influence occupation, or more specifically for this study, occupational participation.

Impact of routines. Another perceived barrier to participation for the family was the lack of a daily routine. Many studies have reported the importance of a daily routine specifically for children with disabilities (Kellegrew, 2000; Koome, Hocking, & Sutton, 2012; Segal, 2004). Segal (2004) reported that a lack of routine may be associated with greater feelings of stress and less order within the family. Similarly, when working with families, daily routines are thought to be a way to organize daily patterns and provide a sense of normalcy, which can lead to feelings of distress when disrupted (Jaffe, Humphrey, & Case-Smith, 2010). Thus, a lack of routine may also impair overall daily occupational participation due to the inability organize daily occupations. In addition, routines are described as an important aspect of MOHO because they provide structure and, through the habits related to routines, also provide individuals with an effective means of managing the temporal context (Kielhofner, 2008e). Therefore, the importance of routines is not easily overlooked.

However, although routines are important for families of children with disabilities, establishing such routines can be challenging, as experienced by the family in this study. Margret expressed a desire to establish a daily routine, but felt that the unpredictable needs of the children prevented her creating one. Such challenges have been reported in previous literature and can lead to increased tension and stress (Koome, Hocking, & Sutton; 2004). Again, this demonstrates the importance of habituation as a key influence of occupational performance. A key influence that was impaired for the family participating in this study.

However, apart from the daily routine, children appeared more aware of the routines associated with leisure occupations. This is consistent with findings from Downs (2008) who suggested that the design and structure in leisure routines can contribute the family experience and well-being. Such findings may further explain why leisure occupations were perceived to be more enjoyable and valued aspects of occupational participation. Apart from the intrinsic appeal to children’s interests, there was also less chaos and unpredictability during the selected leisure activities as opposed to daily life as a whole. This also reinforces the concepts of family-centered care, as structured routines may not be necessary or helpful for all families. Such an idea is supported by DeGrace (2003) who suggested that routines will vary from family, and that the same routine will not be effective for all. Once again, this indicates the importance of viewing multiple components of occupation, as both volition and habituation must be considered when viewing the family's routines.

Impact of roles. Family perception of occupational participation also included the notion of clearly defined roles, a key component of habituation. As presented in the results, the clearly defined roles between Paul as the provider and Margret as the caregiver were recognized not only by the parents, but also by Brad and Cindy. Even Cindy's most valued occupation, helping her mother with the laundry, depicted the idea that Margret is the caregiver for the family. These roles reflect the occupational participation of the family because the roles dictate the ways in which different members of the family participate in occupations. Perception of the clearly defined roles also included an awareness the Paul was, at times, unable to participate in a number of family occupations because of involvement in work. Similar experiences have been expressed by other fathers of children with disabilities who experience work related demands (Carpenter & Towers, 2008). Paul's limited participation reinforces the value of the family being able to participate in leisure activities in which Paul can be an active participant. Previous research reports a positive connection between one's family and leisure roles with overall life satisfaction and happiness (Branholm & Fugl-Meyer, 1992; Yazdani, Jibril, &Kielhofner, 2008). In addition, because family, leisure, and worker roles are most likely to influence happiness (Branholm & Fugl-Meyer, 1992), the importance of leisure occupations is valuable not only to the family as a whole, but also Paul as an individual.

Sibling roles and interactions were also clearly defined within this family. Typical aspects of sibling interactions were present in this family, such as providing support for one another as well as having relationships that reflect both warmth and conflict (Deater-Deckard & Dunn, 2002). Yet, there was also a variance in sibling roles that may be related to the presence of disabilities. For example Cindy's role as a sibling to Ann was experienced as a mix of caregiving and playing. Although Cindy described activities in which she played with Ann and with the rest of her siblings, she did not describe individual interactions with Ann. In addition, in many of the observed exchanges between these two children Cindy's interactions with Ann were mainly focused on helping Ann with basic needs such as dressing and grooming. This is consistent with previous findings that report older children with disabilities do not necessary fill the roles associated with being older, but fill more subordinate sibling roles (Myers &Vipond, 2005; Stoneman, 2005).

Conversely, despite having a disability, Brad fulfilled roles typical of the older sibling and was viewed by Margret to be the ringleader of the children. This suggests that once again individual characteristics should be taken into account, to prevent broad generalizations from being misapplied to families. This is also consistent with findings that sibling interactions vary not only by diagnoses, but also fluctuate for children with the similar diagnoses (Stoneman, 2005). This is especially true considering findings reported in regards to how sibling relationships are experienced by children with ADHD. Mikami and Pfiffner (2008) reported that children with ADHD often have impaired social relationships with their siblings that can lead to increased dysfunction in sibling relationships, although warmth of relationships may remain unimpaired. Although Brad did engage in warm relationships with siblings and did report experiencing conflict with siblings, it did not appear that the family perceived this as causing dysfunctions in the sibling relationships.

In addition, although Margret perceived some sibling rivalries and jealousies, this is typical among siblings (Deater-Deckard & Dunn, 2002). Overall, Margret viewed the children has having positive participation related to fulfilling the sibling role. Despite findings that suggest it may be difficult for siblings with disabilities to bond with typically developing siblings (Moyson & Roeyers, 2010), Margret revealed that the closest bonds among siblings were between Brad and Cindy, and Ann and David. Though this could be associated with a number of factors, including the abilities of each child, it again speaks to the importance of understanding the unique structure of each family.

Overall perception of participation among siblings was also positive as reflected by both Margret and Brad. Although Brad expressed that sometimes his siblings were a source of frustration, he also said that he enjoyed having fun with them during the summers. The close bonds reflected by Margret as well as the positive views reflected by Brad suggest that despite the presence of disabilities, children still value sibling relationships. This finding is consistent with previous reports about the value of sibling interactions for typical siblings and siblings with disabilities (Moyers &Roeyers, 2010; Serdity & Burgman, 2010; Stoneman, 2005).

Summary of findings. The interaction of these findings and the influence of each subsystem is illustrated in Figure 1[1]. For this family, it was evident that each component of MOHO was influential in the perception of occupational participation. Beginning with volition, it became evident that the goal, or motivation, for occupation was related to the value of family interaction. Leisure occupations were more family-focused and were also found to be more enjoyable. Thus, the interest in the occupation, related to enjoyment and bond, was also a contributing factor in the motivation to engage in leisure-based occupations. However, the motivation for necessary occupations was more individually focused, leading to decreased enjoyment and bonding. Although volition influences the interest and enjoyment related to occupational participation, other areas of MOHO were influential in this experience as well. The presence of disability represents the influence of performance capacity, which in turn influences the types of occupations in which the family participates. Environmental aspects, such as the support provided by parents as well as demands and constraints also influenced the types of occupations in which the family participated. Finally, various aspects of habituation such as the lack of daily routine and clearly defined roles between Paul and Margret also contributed to the occupational participation by influencing the participation and experience of this participation. Thus, all factors are important in understanding what occupations the family was able to participate in and how this participation was perceived.

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[1] All Figures are located in Appendix F

Parent View of Co-occupation

When first developed, the intent of this research question was meant to focus on co-occupations that occurred between parents, thus targeting the marital relationship. Upon further review of co-occupation, the researcher for this study became aware that AOTA (2008) also classifies caregiving as a co-occupation. Although caregiving does fit the description of a co-occupation in that in that at least two individuals must participate in this activity (Zemke & Clark, 1996), the decision was made to include this occupation as a part of the individual views of occupation because much of the data gathered in this regard was from Margret and related to her own view of her parenting abilities. In addition, it is important to note the influence of family-centered care in also addressed through this research question. Although marriage is included in MOHO by looking at one's role of spouse and through the family relationships, or social groups, this model does not place as strong an emphasis on the interdependency of the family system as family-centered care. The family-centered care framework not only focuses on the dynamic interaction of the family unit (DeGrace, 2003), but also suggests that children are affected when there is stress within in the family (Rosenbaum et al., 1998). Thus, this model was used in conjunction with MOHO to examine the importance of participation in co-occupations as a part of the overall family dynamic.

Lack of participation in co-occupations. Results of this study indicate that the parents did not perceive themselves as participating in any co-occupations related to marriage. The parents did not view themselves as being a couple, but instead as two individuals who were co-existing. One of the major barriers to this participation perceived by Margret was a lack of time spent together as a couple. Although studies related to marital quality for parents of children's with disabilities present varied results, a lack of time spent together as a couple is consistent with findings reported by Hock, Timm, and Ramisch (2012). This study reported that parents of children with ASD were found to have less time and energy to devote to one another. The study also reported that finding more time to spend together as a couple established a deeper sense of intimacy as well as commitment.

A lack of participation in co-occupations was further expressed by Paul and Margret's division of roles. Such division did not provide these two with a sense of unity that is often experienced in co-occupations. For parents of children with ASD, establishing a sense of unity by working together as a team was described among couples who experienced higher marital satisfaction (Hock, Timm, &Ramisch, 2012). However for these parents, the divided roles experienced by Paul and Margret prevented them from engaging with one another as spouses.

Differing beliefs and response to behaviors. Margret also perceived the differing belief systems, referred to as personal convictions in MOHO, as a constraint to participating in these occupations. Use of the MOHO framework suggests that such differing beliefs not be overlooked because personal convictions, a part of volition, are used to define life matters and therefore influence not only what occupational choices an individual makes, but how one experiences the act of engaging in occupation (Kielhofner, 2008g). Margret felt that these differing beliefs were a barrier that prevented her and Paul from reaching an agreement and, as a result, caused tension. Margret expressed that she and Paul differed in beliefs related to Brad's behaviors and this lead to conflicting parenting styles. Margret felt that she was more involved in interacting and managing Brad's behaviors than Paul and also reflected that she had a better understanding of these behaviors. According to Baker (1994) behaviors related to ADHD create challenges for parents that can increase the experience of parenting stress, with mother's being slightly more susceptible to this stress. However, Barker points out that that reports of how such stress influences marriage are inconsistent. Therefore, the conflict between Paul and Margret related to managing Brad's behavior may be attributed to associated marital stress, but may also contribute to the lack of unity forged between them as a couple. This conflict may also be related to their lack of experiencing parenting as co-occupation, but instead as a more individual role.

Another study by Lifford, Harold, and Thapar (2008) reported that ADHD related behaviors were more likely to create negative impacts on the mother-child relationship than the father child relationship. However, Margret believed that Brad's behaviors had a greater negative effect on Paul and Brad's relationship. This view was not expressed by

Brad who desired to spend more time with Paul and valued the time the two had together. Brad was eager to share stories related to helping Paul and work, and also talked about how his dad allows the children to take turns going on evening golf cart rides. Although it is unclear whether this occupation was a part of Paul's work related duties, which the children were able to participate in, or a novel occupation designed to promote participation with his children, riding in the golf-cart was seen as a valued form or participation for Brad. If purposefully designed to spend time with his children, Paul's use of the golf-cart ride is consistent with findings that fathers of children with disabilities often make efforts to create meaningful occupations with their children to (Bonsal, 2013; Carpenter & Towers, 2008). Therefore, when considering Brad's perceptions and his interactions with Paul in addition to Margret's beliefs, Margret's own personal beliefs related to the impact of Brad's behaviors may have influenced her perception that these behaviors are the biggest challenge for the family, but this challenge may not be viewed the same way by Paul.

Influence on family occupations. This perception of co-occupations was also found to influence the ways in which Margret experiences participation in family occupations. First, this lack of co-occupation negatively influenced Margret's satisfaction with her marriage. As mentioned, she expressed that this is the one area of her life that she would like to change. Additionally, Margret also appears to perceive the limited participation in this area as having a negative effect on the family occupations because she does not perceive the family feeling whole or united. In the follow-up interview Margret stated that though there were times when leisure occupations helped her overlook this tear in the family, these did not have the same influence on the bond between parents. Rather, Margret saw the marital satisfaction as being a key factor in how satisfied she was with the outcome of family occupational participation because tension between her and Paul influenced how the occupation was experienced. This further reflects the interdependent nature of the family unit reflected by DeGrace (2003), through demonstration of the ways in which one aspect of occupational participation (the experience of co-occupation) influences the greater perception of family participation. In addition, this is reflective of the influence of interactive components of MOHO as Margret's experience in fulfilling the role of wife influenced her perception of the family.

Importance of perspective. In addition, it is important to note that although more positive interaction was observed between Paul and Margret during the occupation of swimming, consideration of Margret's perspective must be included. Her perception suggests that this brief experience of participation did not influence her overall view of participation in co-occupations or martial quality. Furthermore, Margret's view of the tear in her marriage suggests that at times she perceives a direct negative impact from their lack of participation in co-occupations. This finding supports the use of MOHO as a theoretical framework due to its focus on understanding individual client perspectives. Lee, Taylor, and Kielhofner (2009) reported that for most occupational therapists participating in their study, approximately 98%, an important consideration for using MOHO was its client-centered nature and holistic understanding of clients. Use of a holistic and client-centered model is consistent with family-centered care and the emphasis on the importance of each individual family member's perspective (Rosenbaum et al., 1998) as well as equality among the perspective between the professional and the family member (Hanna & Rodger, 2002; Lawlor & Mattingly, 1998; Rosenbaum et al., 1998).

Individual View

Views about individual participation were most clearly expressed by Paul, Margret, Brad, and Cindy. In some cases these individuals shared common views about their own participation, while in other cases, as expected, views were uniquely individual.

Lack of choice. For Paul and Margret, an awareness of a lack of choice was expressed in relation to occupational participation, which according to MOHO may influence their volition as choice and control influence one's self-efficacy (Kielhofner, 2008g).This lack of choice was however, expressed differently by each. For Paul, this lack of choice was associated with his defined role of caregiving. When explaining that he "had" to miss out on family occupations because of his work schedule, Paul appeared to reflect a "sense of obligation," defined by MOHO as "strong emotional dispositions to follow what are perceived as the right ways to act" (Kielhofner, 2008g, p. 47). Although

Paul desired to be able to participate in more family occupations outside of the home, his ability to do so was limited. For Paul, occupational participation was therefore impacted by his obligations to work, leading to a lack of ability to participate in a greater variety of occupations. In addition to once again emphasizing the importance of the worker and family member roles reported by Branholm and Fugl-Meyer (1992), this finding also serves to re-emphasis the interaction of the MOHO components, in this case volition (self efficacy) and habituation (roles).

For Margret, a lack of choice was associated with having children with disabilities. She stated that this is not the path she had envisioned for her life and not what she would have purposefully chosen. Margret felt limited in her ability to decide her own values, as she now has come to value occupations specifically related to the presence of disability. Thus, although Margret continues to participate in a number of occupations each day, these occupations are based upon the needs of her children and not on the activities that she would have necessary chosen for herself. This is also described in findings reported by Crowe, VanLeit, Berghmans and Mann (1997) who suggest that mothers of children with disabilities fulfill less non-parenting related roles than mothers of typically developing children. Thus, like Paul, her occupational choice was also dictated by circumstances beyond her control.

Influence of self-efficacy. Although according to MOHO framework a limitation in choice may impair self-efficacy (Kielhofner, 2008g), this was not apparent for Margret as she expressed a strong sense of her ability to affect change through the occupations and roles in which she participated. This shows that, despite her limited ability to choose to participate in occupations for herself as an individual, Margret has put for the effort to remain engaged in occupations that will help others. She expressed a strong sense of identity and success in her role as an advocate for her children, which according to Case-Smith (2004) may provide a greater source of parenting satisfaction. Similarly, Margret showed an awareness of the effort she puts into caring for her children and also promoting their occupational participation. Her ability to be successful in these occupations thus appears to have provided her with a stronger view of self-efficacy. Similar findings have been reported, suggesting that parents of children with disabilities may experience greater self-efficacy when the child is able to be included as a part of family occupations (Downs, 2008; Segal, 2004) and may also feel better able to cope with a child's disability after gaining knowledge through advocacy (Kuhaneck, Burroughs, Wright, Lemanczyk, &Darragh, 2010). Thus, the importance of her ability to participate as an advocate and support her children was an important aspect of Margret's individual occupational participation.

Influence of internalized roles. Margret also expressed that her ability to participate in occupations was impacted by her general role as a parent. Her conviction that as a parent her children should come first has led her to focus her energy in participating in caregiving, or "meeting the basic needs." For Margret, this included an inability to participate in individual occupations that would be of interest to her, due to the demands she faces in raising all for children. Initially, she hesitated when asked the types of activities in which she would like to participate if given the opportunity. This hesitation may be indicative of Margret's internalization of the parenting role. Internalized roles are defined in MOHO as, "the incorporation of a socially and/or personally defined status and a related cluster of attitudes or actions" (Kielhofner, 2008e, p. 59). Based on this description, it appears that both Paul and Margret appear to perceive themselves as having respectively internalized the provider and parenting roles. Thus, because internalization of roles includes action, these perceptions are also an influential piece of occupational participation. Although it is suggested that a lack of individual identities result when a child in the family has a disability (Stein, Foran, &Cermak, 2011), this family appears not to have lost identifies, but instead developed more defined roles to represent their new identities.

Influence of time constraints on parents. The environment was also found to be influential in perception of individual occupational participation, as reflected by perceived time constraints. In addition to constraints experienced by her caregiving role, Margret also felt that her occupational participation was limited due to a lack of time. This was discussed by Margret as a limitation not only in participating in co-occupations, but also in finding time for herself. This is consistent with previous findings that indicate that mothers of children with disabilities desire more alone time as well as a desire to share the caregiving load (Kuhaneck et al., 2010; Donovan, VanLeit, Crowe, & Keefe, 2005). Both she and Paul expressed a desire for more quiet time, suggesting that they are currently not able to participate in occupations that provide this time away

Parental satisfaction. However, despite all of these limitations, Margret also expressed overall satisfaction with her life. She stated her love for her children and her love for being a mother. This suggests that although Margret might have a desire to participate in more individual occupations, she is not unhappy with her participation as a parent. She also does not view her participation in parenting occupations as being unsuccessful. Although she would like to do better, she feels that she is doing the best she can with the circumstances she has been given. Although Larson (2000) reported an association between mothers' perceived well-being and the progress of their children, Margret did not appear to share this view. She expressed that she has difficulty managing Brad's behaviors and acknowledged her feelings that she could do better as a parent. However, it seems that her strong sense of self-efficacy has contributed to Margret feeling successful in, and satisfied with, her overall participation in parenting occupations. This is perhaps due in part to her value of the mothering role, as well as her focus on helping her children participate rather than perform, which was found to be a key focus in the some families of children with disabilities (Segal, 2004). Various studies have reported that parenting a child with a disability can be a positive experience (Case-Smith, 2004; Cashin, 2004; Ludlow et al., 2011). This once again illustrates how application of MOHO can be used to identify multiple factors of influence, as Margret's satisfaction was influenced by her volition (values) and habituation (role). This also illustrates the ways in which this model uncovers uniquely individual experiences such as, in this case, the experience of the parenting role.

An additional support for Margret's satisfaction that is captured in the MOHO framework is her religious beliefs, or convictions. Although Margret explained that she was not able to participate in organized worship services on a regular basis, she expressed that her belief in God was not dependent upon this participation. A decrease in public worship for mothers of children with disabilities was also reported by Parker, Mandleco, Olsen Roper, Freeborn, and Taylor (2011). Yet, these authors found that spirituality was still important to these mothers, as is the case with Margret. It should be noted that Margret was the only family member to express this belief, although this could be due to the large amount of time the researcher spent engaged in conversation with Margret as opposed to the rest of the family.

In addition it is also important to note that Margret viewed her acceptance of the children's disability as dynamic. She likened this acceptance to the stages of grief (Kübler-Ross & Kessler 2005), explaining that she cycles through these stages. Currently Margret is not experiencing bouts of depression, guilt, or grief, thus these emotions are not hindering her occupational performance at this time. However, it is possible that this may change and such emotions may later influence her participation. This is consistent with previous findings that suggest mothers of children with disabilities view grief as an ongoing process and suggested a desire to better manage emotions such as guilt, rejection, grief, and worry (Donovan et al., 2005). The dynamic nature of human occupation should also be considered in relation to these finding. According to Lee, Strauss, Wittman, Jackson, and Carstens (2002) understanding the roles parents fill outside of parenting is a key in addressing parents' ability to cope with feelings of sorrow. These authors reported that leisure roles enabled parents to better cope with sorrow. Thus, it is important to remember personal factors that may influence individual views of acceptance related for parents of children with disabilities as a means of keeping family-centered services truly focused on the family needs.

Children's limitations. Brad and Cindy also expressed limitations in the ability to participate in individual occupations of interest. The limitations cited by these children were more closely related to the environment, than areas of volition, habituation, or performance capacity. For Brad, this included a limitation in having time to himself. Moyson and Roeyers (2012) reported a similar finding for siblings of individuals with intellectual disabilities, in that these siblings desired private time that included having their own quiet space at home. However, Brad expressed that his time away was most often disrupted by Cindy, and was therefore not related to the presence of disability in the family. In addition, Brad's limited ability to participate in solitary occupations may be related the size of his family as well. Brad also expressed a desire to have more time to play ball. Brad explained that he was no longer able to participate in this task due to fighting. However, he engaged in the fight to defend Cindy, and therefore did not attribute this limitation with the presence of his disability. Although Brad did express an understanding of his difficulty in managing his anger, he also explained that he saw his “cool down routine” as an effective means to manage anger, thus this was not viewed as an impairment to his own participation.

Both of these children also identified a desire for more time to participate in valued occupations such as swimming and fishing, as well as more time to spend with their parents. This desire to have time alone with parents has also been reported by other children in families of children with disabilities (Moyson & Roeyers, 2010; Stoneman, 2005). In addition, Brad and Cindy also acknowledged the constraint of time as being the influential factor preventing them from having individual attention from their parents. This suggests that the burden of time was not only a limit for the parents but for children as well. Several studies have explored the constraints related to time use for parents of children with disabilities (Brotherson & Goldstein, 1992; Crowe & Florez, 2006; Crowe et al., 1997; VanLeit & Crowe, 2002), but there is a lack of research regarding the relationship between these time constraints and children.

Cindy, like Brad, did not identify any constraints to her own occupational participation due to the presence of disabilities, but rather a lack of resources. In addition to feeling limited by time, Cindy also felt that participation in fishing was limited due to her not having a fishing pole. Although this simple view maybe merely reflective of Cindy’s young age, it may also reflect her more positive adjustment to the presence of disabilities. Giallo and Gavidia-Payne (2006) found that typically developing children who had the opportunity to participate in family activities were better adjusted to the challenges associated with a sibling’s disabilities. Thus, it may be that Cindy’s view of her siblings’ disabilities and the impact of these disabilities on her own occupational participation is influenced by the overall family occupational participation. This again reflects the premise of interdependency stressed by DeGrace (2003) as a part of family-centered care.

***Perspectives related to Ann's participation*.** Although the third research question was meant to address individual view of occupational participation, a limited view was captured from Ann. Thus, other family members' views of Ann's individual participation are also included in this section. Margret suggested that Ann was not left out of activities because she often preferred to be by herself, as noted in observations. Although Brad viewed Ann as not being "with them" while swimming when she was sitting outside of the pool, he did not indicate any other views that suggested he felt Ann's occupational participation was limited, nor did he express this has having a negative impact on the sibling relationship.

Observations of Ann during dinner did not indicate that Ann viewed this as a pleasurable activity. Yet, during her individual interview, she indicated that this was an activity she enjoyed. This finding could be true for Ann, but might also reflect a lack of understanding of the interview instrument. Another explanation could be that Ann's participation in feeding and eating is inconsistent. However, this does speak to the importance of trying to better understand Ann's point of view as this cannot adequately be inferred based upon observation alone. This also reflects the MOHO premise that all components of occupation be considered, as Ann's volition (motivation) for meaningful occupational participation, including value and enjoyment of an activity, must not be overlooked.

In addition, it should be noted that caution should be taken when interpreting Ann's view of participation through the lens of others. Although her family knows her well, this does not mean that the view expressed by family members accurately represents how Ann feels. A study conducted by O'Brien, Begeron, Oliver, and St. Onge (2009) reported that parents' views of children's occupational participation were not congruent with the views expressed by their children. Thus, it is reasonable to assume that Ann's interpretation of her own occupational participation would be uniquely her own, and therefore different from the views expressed by others.

Implications for Occupational Therapy

A number of implications for the profession of occupational therapy can be drawn from the current study. First, this study provides support for DeGrace's (2003) premise that the profession should have a greater focus on family-centered care while addressing occupations that are meaningful to individual families. She urges professionals to consider the importance of family identity and the influence of this identity on overall health. The findings from this study indicate that occupational participation can play a role in establishing such an identity, as evident from this family's response to leisure activities. Therefore when considering how a family views their own identity, practitioners should also consider how occupational participation influences this view for the family as a whole. This is similar to the difference between "doing" and "being" discussed by DeGrace, who suggests that doing is focused more on performance while being encompasses how families gain meaning from daily participation in occupations. This current study also supports the importance of understanding the difference between these two perceptions, as many of the findings from the study relate to the "feeling" of being united as a family. Although at times families must "do" necessary occupations, this should not be the only focus of occupational therapists. Rather, these therapists should consider the family's view of participation to discover meaningful occupations which support the experience of "being" a family.

The results of this study also highlight other aspects of family-centered care. As demonstrated throughout the discussion, the results of this study depict the way an occupation-based, holistic framework such as MOHO can be utilized by practitioners to address the needs of the family as whole. This study emphasized the importance of gaining perspectives from individual family members as a means of supporting and encouraging all family members, as suggested by Rosenbaum et al. (1998). In addition, use of this holistic model was also beneficial in capturing the uniqueness of the individual family through an in-depth understanding of how multiple components of occupation are experienced by various family members. Occupational therapists who are using family-centered care need to be aware of the interaction between various components of occupation and how these components come together to influence the overall individual and family experience. Family-centered care also suggests that multiple influences should be considered when understanding families' priorities, including culture (Hanna & Rodger, 2002), environment (DeGrace, 2003; Lawlor & Mattingly, 1998), and beliefs

(DeGrace, 2003). Use of the MOHO framework allows practitioners to deepen this view. This framework can be used to organize and glean information related to all areas of occupations, with an emphasis on volition, habituation, performance capacity, and environment. These areas can then be related to the overall family needs.

Another aspect of family-centered care that is notable based upon the findings of this study is the importance of considering family resilience and individual family members' resilience. Family resilience is used to describe a family's ability to respond positively to change and is a dynamic process in which both the family's strengths and the environment influence this response (Abelenda & Helfrich, 2003). In addition, resiliency also includes a family's overall well-being and positive family functioning (Bayat, 2007), a concept that should be considered when providing family-centered care. Resiliency is relevant to the field of occupational therapy as Bayat (2007) identified family connectedness as a key factor associated with resiliency in families of children with disabilities. This idea, speaks to importance of participation in family occupations as a means to increase the family bond as suggested by DeGrace (2003) and as exhibited by the family in this study. Thus, it is important for occupational therapists to consider ways in which occupations might be used to create opportunities for family bonding as a means of increasing resiliency and connectedness.

In addition, family resilience also supports the importance of understanding each family as a unique unit because resiliency is a process that is unique for each individual family as well as individual family members (Abelenda & Helfrich, 2003). The importance of understanding individual family members' unique perspective also supports the use of MOHO as a means of better understanding individualized family resilience and needs. After applying MOHO as a framework to better understand resilience among families of individuals with mental illness, Abelenda and Helfrich (2003) suggested that family resilience can be enhanced through an individualized approach, in which family strengths and other positive family qualities are emphasized. Such an approach might be considered when viewing this study by relating the experience of leisure occupations versus necessary occupations to better understand how the family bond contributed to overall resilience.

However, it is important to remember that, as depicted in a family-centered approach, all families respond differently to life challenges and have individual environmental influences. It is also important to remember that some families are able to reach a high level of resilience on their own (Kielhofner, 2005a). Professionals should not assume that families with disabilities need assistance in achieving resiliency. For many families, the presence of disabilities often leads to growth and strength on a family and individual family member basis (Bayat, 2007). As demonstrated by the family in the current study, occupational participation in meaningful occupations is already a part of the family dynamic. As cautioned by DeGrace (2003), occupational therapists should not be focused on prescribing the same routine for every family, but instead look at the type of occupations that will be important and meaningful to the family. Thus, inclusion of meaningful evaluations and outcomes which consider the needs and preferences of the entire family as well as individual family context should be included when looking at family-centered care (Hanna & Rodger, 2002). This can be used to bolster family resiliency through creation of meaningful occupations.

Another consideration for occupational therapy is that practitioners should not assume a family will be defined by the presence of disability. According to disabilities studies literature, it is important not to consider a disability as the impairment, but instead focus of the environmental barriers that one experiences (Block et al., 2005; Kielhofner, 2005a). Similarly, because families will face a wide array of environmental barriers, one must be careful of drawing broad conclusions for all families based on the presence of a disability. The emphasis on the importance of environmental influences is also consistent with the family-centered care notion that family context, including cultural and environmental factors are unique to each family (Hanna & Rodgers, 2002; Lawlor & Mattingly, 1998). Such an idea is illustrated in the current study as several environmental factors, including supports and limitations, contributed to the family experience of an occupation. Thus, the presence of disabilities alone was not responsible creating challenges to occupational participation, but a combination of factors that included environmental influences. This is important to consider when providing occupational therapy services as one should ensure that environmental influences on occupational participation are not overlooked. In addition, it is important to focus not on impairment alone which might reinforce the notion of disability (Kielhofner, 2005a), but instead focus on individual family strengths and needs (Rosenbaum, et al., 1998). This again demonstrates the ways in which a theoretical framework, in this case MOHO, can be utilized to provide a structure for gathering a more holistic view, instead of focusing solely on impairments.

This study also speaks to the importance of using narrative reasoning in clinical practice. AOTA (2008) describes creation of an occupational profile as the first step in the occupational therapy process. Based upon the results of this study, this profile should take into account information from multiple family members. Although practitioners may face limitations and constraints when trying to find the time to gather such data, the use of interview with parents and other family members should not be overlooked or seen as an unimportant piece of the evaluation process. Other methods of gathering profile related information should also be considered such as brief questionnaires that can be filled out by all family members to provide a more complete view of overall family experiences.

In addition, this study suggests that because it is important to consider the entire family perspective, practitioners should also attempt to include multiple members of the family into interventions when appropriate or feasible. If a family need is expressed, it may be difficult to address this need through simulation in the clinic. Families therefore should be involved in this process, which may further promote family occupational participation. For example, Ann's siblings viewed her therapy as play and desired to be a part of this process. Why not include them?

This study also suggests that occupational therapists should focus on various facets of occupation. It is important to consider motivation, organization, performance, and the environment when designing interventions (Kielhofner & Forsyth, 2008). In addition, as suggested by Kielhofner & Forsyth (2008), it also important to remember that clients are a vital source of information throughout the therapy process. Although clinical observation is a valuable tool, as seen in the case of Ann, observation alone may not provide the complete picture**.** For example, mere observation of Ann might indicate that she is left-out of some family occupations and a goal to increase participation may be written. However, this process does not take into consideration that Ann is still satisfied with her own participation, and such a goal may not be meaningful to her or her family. This is not to suggest that clients will never have to work on skills that are seen more as necessary and less enjoyable, but brings the focus back to the importance of incorporating meaningful occupations into practice.

Finally, it is recognized that considering the family perspective, the client perspective, and the professional expertise is likely to require extra efforts on behalf of the occupational therapist. However, one must consider the overall benefit of this process based upon the richness of family occupation, the importance of client collaboration, and an emphasis on supporting social/emotional needs when addressing physical dysfunction. Practitioners should not just be focused on what the family does (DeGrace, 2003), but also how participation in occupation is experienced. Because occupational therapists should focus on providing occupation-based practice (AOTA, 2008), an emphasis on understanding the impact of a disability on the needs of the entire family unit needs to be incorporated into practice.

Limitations

There are several limitations that should be considered when interpreting the results of this study. One limitation is the temporal nature of the study. The study was conducted over a three month period and consisted of three separate visits with actual face to face interaction. During this time a little less than 14 hours were spent conducting observations and interviews. Although multiple forms of data collection were used, these data are all reflective of the family mindset at a particular time period. Because families are dynamic, it is likely that the views of occupational participation will change with time. Thus, the applications of this study are limited in generalization not only to other families, but also to this same family as time goes on. In addition, as is the nature of a qualitative case study, this data reflects the views of only one family. Because families are unique, these views are likely to differ from one family to another.

Although the study was designed to examine the perspective of all family members, the ability to equally represent all members of the family was limited. Much of the data in this study has been provided from Margret, which may have skewed the results to represent more of her opinion than the opinion of the family as a whole. Similarly, there was no opportunity to conduct an individual interview with Paul, as he and Margret participated in a joint interview. This may have further limited his ability to share more of his own, personal opinions. Similarly, little input was gathered from David due to his young age, which limits the ability of this study to capture the entire family view. Also, though attempts were made to gather data from Ann and David questions concerning the accuracy of the Smiley Face Data Sheet are applicable. Although this has been found to be a reliable tool with the social skills group at Eastern Kentucky University, this sheet may not have been fully understood by Ann and David. Ann showed a tendency to pick the smiling face, with one exception while David continually picked the neutral face and then made this face at the researcher. Thus, there are concerns related to the children's perspectives gathered by this instrument.

Another limitation in this study is lack of information regarding intimacy and sexual relations between the parents in this family. Although sexual intercourse is a co-occupation, this was not addressed in this study due to the researcher's preference to abstain from asking personal questions regarding this topic. However, this is an area that should be considered as a co-occupation related to marriage as well as occupational participation.

Finally, although attempts were made to limit the influence of the researcher's bias on the findings and implications of this study, these biases cannot be completely ignored. A researcher's journal was used to bracket such biases and this journal was reviewed throughout the data collection and analysis process. However, it is still reasonable to assume that biases are present and therefore this must be considered as a limitation to the study.

Recommendations

This study provides an overview of the interrelatedness of family occupational participation and suggestions about the importance of considering this concept when providing actual intervention. Future research may further this view in a number of ways. One way might be to consider viewpoints of multiple families rather than a single case.

Although it is difficult to make broad generalizations based upon the uniqueness of individual families, it is also important to gain an understanding of experiences that might be similar for each family. Future research involving the viewpoints of multiple families may provide a more substantiated framework to guide practitioners in understanding how occupational participation is experienced. A better understanding of this experience will help practitioners apply these concepts in practice because they will have evidence and knowledge regarding how to approach this topic.

In addition, one might consider examining the ways that this premise can be aptly applied throughout the occupational therapy process. Currently, this study has set forth evidence to suggest that understanding the family perspective is important during the initial stages of the occupational therapy process. However, by studying the impact of services on the family view of participation, future researcher may investigate the effectiveness of family-centered care on occupational therapy outcomes as well as family well-being. Future studies can also focus on the importance of understanding the families' views of occupational performance as it pertains to establishing and obtaining goals during occupational therapy intervention. Client-centered and family-centered care should not be a consideration only during evaluation but throughout the therapy process. Therefore, future research may provide more evidence on how family-centered care can be included in interventions and how this inclusion impacts the outcomes of services.

Finally, development of a comprehensive family based assessment should also be considered given the findings of this study. Although this study speaks to importance of gaining the perspective of the entire family, this is often a limitation in actual practice. Design of an assessment to assist practitioners with gaining this perspective should be considered for future research so that professionals are able to gather background information to support the design of family based intervention. Use of MOHO as a theoretical basis allows for occupational therapists to better understand and articulate the concept of occupational participation and would provide a framework for the design and interpretation of such an assessment. Furthermore, such an instrument would bolster the ability to provide services from a family-centered perspective and may include assessments of occupational participation as this relates to the meaning that is derived from engagement in family occupations.

Conclusion

The overall findings of this study suggest that the occupational participation of this family is impacted by the presence of disabilities. However, this impact varied based on the type of occupations well as on the perspective of the individual family members. This study allows provides an example of how a family's overall motivation (volition) to participate in an occupation influences the meaningfulness of such participation. This is important to consider when providing family-centered care, which should address occupations that are meaningful to the family and support family unity. In addition to underscoring the importance of volition, this study also demonstrates the importance of looking at all facets of occupation (volition, habituation, performance capacity, and environment), to more fully understand how occupational participation is experienced and therefore provides support for the use of theory to guide occupational therapy practice.

In addition, this study further supports family-centered care by illustrating the way in which individual family members experience of occupational participation impacts the family as a whole. Thus, this study shows the importance of taking into account all members of a family and also considering the unique impacts of volition, habituation, performance capacity, and environment, which will vary from family to family and even person to person. Similarly, the findings illustrate the importance of considering the interrelatedness of the family unit when viewing occupational participation. The findings from this study are applicable to the field of occupational therapy and the effort to provide family-centered care. Results suggest that an effort should be made to recognize the meaningfulness of occupational participation as it applies to various occupations and individual family members. Finally, this family-wide impact should be a consideration that is incorporated into practice by occupational therapists working with children and their families.

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APPENDIX A:

Table 3- Theoretical Basis for Parent Interviews

Table 3

Theoretical Basis for Parent Interviews

Theoretical basis	**OPHI-II Question(s)**
MOHO	1-16
Volition	1, 2, 5, 8, 12, 13, 14, 15
Habituation	3, 10, 11, 15, 16
Performance Capacity	6
Environment	3, 4, 7, 8, 9, 11
Family-Centered Care	8-16

APPENDIX B:

Table 4- Theoretical Basis for Child Interviews

Table 4

Theoretical Basis for Child Interviews

Theoretical basis	**COSA Questions**
MOHO	1-6
Volition	1, 2, 3, 5, 7
Habituation	2, 6, 7
Performance Capacity	4, 5
Environment	2, 3, 4
Family-Centered Care	2, 3, 4, 6

APPENDIX C:

Sample Interview Guide- Parents

Sample Interview Guide-Parents

Based on the OPHI-II (Kielhofner, 2004)

1. Do you get to do the things that are important to you?

2. Have you been able to choice the things in life that are important to you?

3. Is there anything that routinely interferes with what you want to do?

4. Do you feel you have enough time to do the things you enjoy?

5. Do you ever plan for your own future?

6. When you run into an obstacle or difficulty, how do you handle it?

7. What is the biggest challenge you are facing right now?
8. How have you adjusted?

9. Does having children with disabilities impact what activities you are able to do yourself?

10. Does having children with disabilities influence the activities you choose to do as a family?

11. What roles do you fill within the family?

12. Do you ever feel as if you are unable to fulfill all your roles? Explain.

13. Are there any activities you would like to do as a family, but are unable to do?

14. What activity do you most enjoy doing as a family? Why do you prefer this activity?

15. What activity do you least enjoy doing as a family? Why do you least prefer this activity?

16. Does having a child with a disability influence the activities you choose to participate in as a couple?

17. Do you think this has impacted your marriage?

APPENDIX D:

Sample Interview Guide- Children

Sample Interview Guide Children

Based on the COSA (Kielhofner, 2005b)

1. What is your favorite thing to do?

2. What is your favorite thing to do with your family?

3. What is your favorite thing to do with your mom?
    a. Dad?
    b. Siblings?

4. What things are hard to do as a family?

5. Are they things you want to do that you don’t get to do?

6. In what ways do you help your family?

7. What is your favorite part of the day?

APPENDIX E:

Interview Guide using the Smiley Face Data Sheet

Sample Interview using the Smiley Face Data Sheet

Modified from Wittman& Bundy, 2008

How do you feel about doing ______________________ with your family?



How do you feel about doing ______________________ with your family?



How do you feel about doing ______________________ with your family?



How do you feel about doing ______________________ with your family?



APPENDIX F:

Figure 1- The Family’s View of Occupational Participation

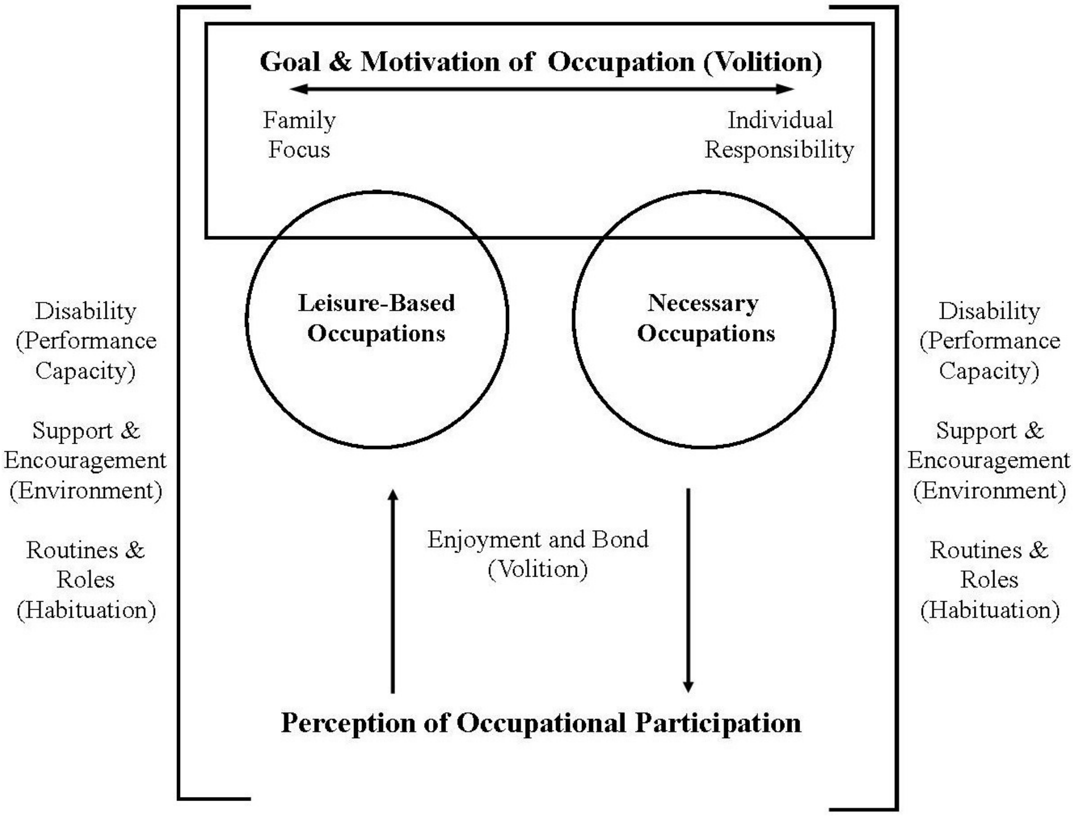

Figure 1: The Family's View of Occupational Participation