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Parenting as Occupation: Occupational Therapists' Perspectives on Working with Parents in Mental Health

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Parenting as Occupation: Occupational therapists' perspectives on working with parents in
mental health

A Master's Thesis presented to the
Faculty of the Graduate Program in Occupational Therapy Ithaca College

In partial fulfillment of the requirements for the degree of Master of Science

by
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August 2020

Ithaca College
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CERTIFICATE OF APPROVAL

This is to certify that the thesis of
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submitted in partial fulfillment of the requirements of the degree of Master of Science in the
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Abstract

Millions of Americans suffer from mental illness in the United States and of those, a large percentage are parents. There is a lack of research in the literature about occupational therapy interventions related to parenting for clients in acute phases of mental illness. The purpose of this study was to understand the practice patterns of occupational therapists providing services to parents with mental health illness, as well as the barriers and facilitators associated with the ability to address parenting in mental health practice. This study was a phenomenological qualitative design utilizing two phone interviews per participant. Four participants working in inpatient mental health settings from three different facilities participated. Six themes were identified from the data analysis. Themes related to barriers included parenting is secondary, lack of familiarity, and lack of access. Themes related to supports included supports vary and relevant skills. An overall theme related to practice patterns emerged: a desire for change. The results showed there are multiple barriers that must be overcome in order to provide interventions on parenting in an inpatient mental health setting and that the resources occupational therapists have vary greatly based on the facility. The implications for occupational therapy include the need to identify parenting as a goal, more education on the topic in occupational therapy programs and continuing education courses, and creative solutions to overcome lack of access to children and families. More research is needed to further understand the clinical reasoning behind decision making with a broader range of participants and to understand occupational therapy's role in working with the children of parents with mental illness to address their concerns.

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Chapter One: Introduction

Background

Millions of people across the United States suffer from mental illness and many receive occupational therapy services (Stambaugh et al., 2016). According to the National Survey of Drug Use and Health in 2016, 12.8 million parents suffered from mental illness (Stambaugh et al., 2016). Children of a mentally ill parent are more likely to have negative outcomes such as anxiety, loneliness, hopelessness, increased risk of mental illness, financial distress, and increased responsibility (Laletas, Reupert, & Goodyear, 2017; Oskouie, Zeighami, & Joolae, 2011).

Living with a parent with mental illness in conjunction with an absence of other support systems can cause toxic stress, which changes how neural networks in the brain respond to stress, leading to difficulty in occupational performance. Toxic stress in children is defined as “chronic or cumulative traumas that the child experiences without the available support of a loving caregiver” (Gronski et al., 2006, p. 149). A child experiencing toxic stress may have difficulty focusing in school, frequent illnesses, increased anxiety, and mood swings, and on a larger level it can affect how their neural networks respond to stress in the future (Franke, 2014). Continued research in this area has been suggested (Franke, 2014; Gronski et al., 2006). With children’s healthy development at risk it seems imperative that intervention occur prior to reaching the point of toxic stress. There has been little information disseminated on how to minimize trauma, such as how to provide parenting skills training to mentally ill parents and

caregivers. While the purpose of this study was not to investigate toxic stress in children, parenting interventions may aid both the parent and the child.

There is evidence that parenting programs can have an impact on the well-being of their children based on positive outcomes after intervention (Substance Abuse and Mental Health Services [SAMHS], 2009). In a report to Congress in 2007, the United States Department of Health and Human Services outlined the benefits of parenting and early intervention programs to prevent substance abuse in children. For example, the Nurse-Family Partnership paired expectant, first-time, low-income mothers with a nurse who makes home visits through the first two years of a child's life (SAMHS, 2009). The intervention process targeted health, environment, social support, parental roles, and major life events. In a follow-up to the study started in the 1990s, the Nurse-Family Partnership program resulted in a 79% reduction in child abuse and neglect, 44% reduction in maternal behavior problems, 69% reduction in maternal arrest rates, and 54% fewer arrests among the now 15 year old adolescents who were in the program as infants compared to the control group (SAMHS, 2009). Each of the domains created by the Nurse-Family Partnership (health, environment, social supports, parenting, and major life events) align with areas of practice for occupational therapists and could be areas of focus for practicing occupational therapists (American Occupational Therapy Association [AOTA], 2014).

The Occupational Therapy Practice Framework identified instrumental activities of daily living (IADLs) that are more complex than activities of daily living (ADLs). One of these IADLs is 'child rearing,' defined as "providing care and supervision to support the

developmental needs of a child” (AOTA, 2014, p. S19). Occupational therapists work with adults and children with mental illness in schools, hospitals, and community-based settings such as homeless shelters, community clinics, after-school programs, senior centers, and more, focusing on ADLs and increasing independence and autonomy (Castaneda, Olson, & Cargill Radley, 2013). Occupational therapists use a variety of techniques to address social and psychological factors such as therapeutic use of self, active listening, facilitating problem solving, role modeling, and psychoeducational groups (Kannenberg, Amini, & Hartmann, 2012). Like any occupations such as grocery shopping, managing, and paying bills, and running a household, parenting is an occupation that may be important to an adult with mental illness that can be addressed under the scope of occupational therapy.

Not only is parenting an occupation, but it is a larger role that needs to be fulfilled, making it more complex than just one occupation. A role is a “set of behaviors expected by society and shaped by culture and context” (AOTA, 2014, p. S8). The role of parent can consist of many occupations- care of others, child rearing, meal preparation, driving and community mobility, home management, safety and emergency maintenance, and shopping (AOTA, 2014). Each parent-child relationship is different, as well as their resources and barriers, making the occupations they need to complete unique to the client.

According to one study about occupational therapists’ perceptions of parenting in the United Kingdom, participants identified that a client is a parent, but not addressing specific goals related to parenting or addressing the needs of the individual’s child

(Hackett & Cook, 2016). Given the unique skillset of occupational therapists, there is potential for creation of programs similar to the Nurse-Family Partnership but focused on role development and occupational engagement. Occupational therapists have the ability to focus on occupation in their treatment, use our activity analysis to identify and adapt the problem, and are trained across the lifespan to include infants and the adult parents (AOTA, 2014).

Research Problem and Significance

Although there is research focused on occupational therapy's role in adults and children with mental illness and identifying the negative outcomes of children with mentally ill parents (Oskouie et al., 2011; SAMHS, 2009; Hackett & Cook, 2016) there is limited research into the role of the occupational therapist in addressing parenting as an occupation. Research has shown decreased parenting skills negatively influence the children (Oskouie et al., 2011; Mayberry & Reupert, 2009). Given the approximately 12.8 million parents with mental illness in the United States, a large population is being overlooked in current occupational therapy research and practice (Hackett & Cook, 2016). The potential negative consequences of mental illness on parenting skills warrant more research into ways to limit these consequences through occupational therapy services.

Rationale/Need for Study

Research in this area could benefit the expansion of services for adults with mental illness, and indirectly, their children who may be affected. While parenting is listed as an IADL in the Occupational Therapy Practice Framework, there is little information on

whether it is or how it is being addressed within the United States (AOTA, 2014). Further research would clarify the need for programs and interventions targeting parenting as an occupation to contribute to understanding occupational therapists' role in minimizing the cycle of childhood toxic stress and mental illness.

Purpose of Study

The purpose of this study was to gain more detailed information from occupational therapists working in mental health settings about parenting as a targeted occupation. How practitioners identified clients as parents as well as deficits in parenting skills, setting goals, and providing interventions in this IADL were explored. The ultimate goal in gathering this information was to gain knowledge to inform practice and expand the role of occupational therapy in parenting and mental health.

Research Questions

In order to explore the practices of occupational therapists and the barriers and facilitators of providing occupational therapy services to this population, the questions that guided this research effort were:

1. What are the barriers and facilitators to providing occupational therapy services, specifically addressing parenting, to this population?
2. What are the experiences and practice patterns of occupational therapists working with clients with mental illness who are parents?

Chapter Two: Literature Review

There is a vast array of information on parenting, occupational therapy, and mental illness, but very little on the intersection of all three. This section will summarize parenting as occupation, various facets of mental illness, occupational therapy's role in mental health, and what little information there is on occupational therapy's role in working with parents with mental illness.

Parenting as Occupation

Occupation is the basis of occupational therapy and is “the everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do” (World Federation of Occupational Therapists [WFOT], 2012, p. 2) Parenting can be defined as “the process of raising children and providing them with protection and care in order to ensure their healthy development into adulthood” (Kretchmar-Hendricks, 2017, p. 1). While child rearing is defined in the Occupational Therapy Practice Framework as “providing care and supervision to support the developmental needs of a child,” there is a lack of literature from the occupational therapy profession on parenting, therefore, most of the literature in this section derives from other disciplines (AOTA, 2014, p. S19).

Raising a child requires providing the basic human needs such as food, shelter, and clothing, as well as more advanced needs like love and emotional support (Kretchmar-Hendricks, 2017). Advanced needs can also include health and physical safety, emotional and behavioral competence to support the child's mental health, cognitive competence to

succeed in school and the world, and social competence to be able to develop healthy relationships with family and peers (National Academies of Science, Engineering, and Medicine [NASEM], 2016). The needs of the child also change across the lifespan. Infants and children require more care with frequent feedings, diaper changes, and close supervision. The American Psychological Association [APA] (2009) places emphasis on forming a close attachment for a warm and open relationship, clear boundaries, and explaining reasoning for rules during this life stage. In adolescence children become more independent, detach from the current family bonds, and instead bond more with peers (APA, 2009). In this life stage, a warm communicative relationship with reasoning behind parenting results in higher rates of social competence, less experimentation with drugs, and lower rates of anxiety and depression (APA, 2009). Adolescents may require less immediate supervision and instead a focus on preparing for adulthood and the next phase of their life, with guidance from their parents. Whereas an infant may need diaper changes, physical contact, and frequent feedings, an adolescent may need to be driven to their part-time job, advised on college applications, or counseled through new relationships. Children in between those ages have their own variety of needs that are vastly different than other life stages. Those could include teaching right from wrong, help with schoolwork, learning to dress and feed themselves, involvement in extracurricular activities, navigating new friendships, and more (APA, 2009).

Parenting may be provided by people who might be the primary mother and father in a nuclear family, grandparents as primary caregivers, foster caregivers, or any other combination of caregiver and child in which the adult is providing care and protection for

the minor. The available research is not inclusive of same sex or non-binary couples, limiting the definition of a nuclear family to one mother and one father. In the United States, approximately 73 million adults identify as parents, a broad category of individuals with varying family structures (United States Census Bureau, 2016). The family structures may consist of a child living with two parents (50.7 million), with only the mother (17.2 million), or the father (3 million) or with no primary parent present (2.8 million), such as in foster care (United States Census Bureau, 2016). In a two-parent (one mother, one father) household, studies have shown parental positive affect and marital quality impact parenting style and characteristics (Planalp, Van Hulle, & Goldsmith, 2019). Parents who display satisfaction with their marriage and general happiness are more sensitive to their children, which in turn leads to better parent-child relationships (Planalp et al., 2019).

When a child lives with divorced parents, the custody agreement can be influenced by the child's level of development and age. In older literature, when custody is being determined for an infant, the emphasis is placed on the infant-mother relationship to secure that bond, although research has shown that can have negative effects on the child's relationship with the father (Kelly & Lamb, 2000). Now, however, research supports that the custody arrangement has less effect on the child than the level of hostility between the two parents and whether the child feels stuck in the middle (Canada Department of Justice, 2015).

In addition to family structure, there are several other factors that influence parenting including socioeconomic status and cultural ties. A longitudinal study by Park and Lau

analyzed data across 27 years, including 90 countries reporting, found ties between socioeconomic status and values of independence or obedience (2016). In this study, countries with higher levels of wealth and more education promoted child independence, while low income countries promoted obedience to parental figures as more important (Park & Lau, 2016). On an individual family scale, middle class families were more likely to have their children participate in organized activities, such as sports teams, which cultivates independence and self-regulation, whereas working class families focused more on direct instructions leading to obedience and deference to the adult (Park & Lau, 2016).

Culture is another important aspect that affects parenting. “Culture” is a widely used word that traditionally means the customs and beliefs of a group of people and can include values, attitudes, roles, communication, and physical objects (Li & Karakowsky, 2001). More recent occupational therapy based research has shown culture is a phenomenon including many parts: culture is alive, has visible and invisible expressions, shares meaning between members, uses a sense of belongingness to differentiate, and has power (Castro, Dahlin-Ivanoff, & Martensson, 2014). Parents who have strong cultural ties and incorporate those in family life can strengthen their child’s identity, which is a protective factor against high risk behavior (Perron, 2018). This can be a protective factor, but can also cause conflict if, for instance, the child of an immigrant family assimilates to their new culture more quickly. For example in some cases, there is a difference in Western culture that the child is growing up in which focuses on individual success and the Eastern culture of the family that focuses on what is best for the

collective (Perron, 2018). Whether there is conflict or not, establishing family rituals, such as family mealtime, provides an opportunity for bonding and a chance for parents to be involved and know what is happening in their childrens' lives (APA, 2009).

As there are a variety of parent characteristics and family structures, there are a variety of styles of parenting, all of which have an effect on a child's development. Researchers frequently identify two main dimensions of parenting style to be parental support and parental control (Kuppens & Ceulemans, 2019; Smetana, 2017). Parental support includes all the ways a parent shows involvement and support, such as being available, showing emotion, involvement in activities, and being responsive and accepting (Kuppens & Ceulemans, 2019). Parental control consists of behavioral control such as discipline strategies, punishment and reward, and supervision, as well as psychological control in which a parent attempts to control the child's thoughts and feelings (Kuppens & Ceulemans, 2019). Research has shown different styles have different effects on children (Smetana, 2017). Heavy emphasis on psychological and behavioral control with parental monitoring has been shown to cause detrimental effects such as overcontrol, maladjustment, and feelings of guilt and shame (Smetana, 2017). On the other hand, focus on positive aspects of parenting using parental support, such as praise for positive behavior, family bonding times, or family dinners, can strengthen the parent-child bond and improve positive outcomes such as preventing substance abuse and deviancy (Kuppens & Ceulemans, 2019). Parents must find a combination of strategies to form their own parenting style in pursuit of positive outcomes for their own children, while matching the child's stage of development.

Lived Experiences of Individuals with Mental Illness

There is a large body of research (Stambaugh et al., 2016; Mayberry & Reupert, 2009; SAMHSA, 2019) on adults with mental illness in the United States with approximately 47.6 million adults having been diagnosed with any mental illness (AMI) in 2018 (SAMHSA, 2019). This equates to 19.1% of the adult population according to the National Survey on Drug Use and Health (SAMHSA, 2019). In addition to this statistic, approximately 9.2 million adults with AMI have a co-occurring substance use disorder (SAMHSA, 2019).

Individuals with AMI face a variety of challenges due to the pervasive nature of mental illness. Many individuals report feelings of isolation, powerlessness, and hopelessness due to their mental illness (Kaite, Karanikola, Merkouris, & Papathanassogou, 2015). A recurring theme in research on adults with mental illness is the loss of identity and struggle to accept their illness as a part of them (Kaite, Karanikola, Merkouris, & Papathanassogou, 2015; Jones et al., 2016). Their identity as a healthy, self-sufficient adult may be challenged by having new cycles of symptoms, hospitalizations, frequent medication, and a new identity of *sickness*.

In addition to personal factors, individuals may have a variety of reasons for not accessing mental health services. According to research from Kaite, Karanikola, Merkouris, & Papathanassogou they may feel they have inadequate access to mental health services and community resources, be unaware of options, or have fear of utilizing the system due to stigma (2015). Only 68.5% of adults with mental illness will seek services for their symptoms and frequently there is an average delay of five years from

the time symptoms begin to the time an individual seeks help (Latzman, et al., 2019).

Research suggests there are a few main reasons people do not seek services: lack of knowledge about mental illness, ignorance of how to find resources, stigma and prejudice, and expectations of discrimination (Henderson, Evans-Lacko, & Thornicroft, 2013).

Symptoms. The nature of mental illness involves a cycle of illness symptoms that can cause chaos and derail individuals' lives and progress. There are many types of mental illness which are categorized into broader groups including mood disorders, anxiety disorders, personality disorders, psychotic disorders, eating disorders, trauma-related disorders, and substance use disorders (American Psychiatric Association, 2013).

Mood disorders include diagnoses such as depression and bipolar disorder (National Alliance on Mental Illness [NAMI], 2020). The most common features are feelings of emptiness, low self-esteem, loss of interest in activities, sleep disturbances, decreased energy, trouble concentrating, physical complaints, irritability, hostility, and aggression (NAMI, 2020). Anxiety disorders, such as Generalized Anxiety Disorder (GAD) or obsessive-compulsive disorder (OCD) feature symptoms of difficulty sleeping, feeling weak or tired, gastrointestinal problems, poor concentration, and increased heart rate (Mayo Clinic Staff, 2018). Personality disorders can include a variety of diagnoses such as Borderline Personality Disorder or Paranoid Personality Disorder and has symptoms involving dissociative feelings, inappropriate affect, unstable relationships, and impulsive behaviors (Mind, 2020). Eating disorders may have unique symptoms, but center around disordered views of food and exercise, which may include excessive exercise, calorie

limiting, and bingeing/purging (NAMI, 2020). Trauma-related disorders are diagnosed after a traumatic event and can include flashbacks to the distressing event, avoidance, anxiety, and extreme arousal symptoms (Barnhill, 2018). Substance use disorders involve frequent overuse of substances such as alcohol and drugs that negatively influence an individual's daily life (NAMI, 2020).

Symptoms may be categorized into different clusters such as cognitive, physical, and emotional. Cognition allows individuals to receive and understand information from their environment, then use it in a functional way to accomplish tasks (Mental Health Coordinating Council Inc., 2015). When cognition is impaired, the ability to accomplish ADLs and IADLs is impaired. Symptoms of impaired cognition could look like difficulty remembering information, losing the ability to respond quickly, challenges initiating speech, and inability to sustain attention (Mental Health Coordinating Council Inc., 2015).

In addition to cognition, mental illness is well-known to impact physical health. Individuals living with mental illness, on average, have a life span that is ten to twenty years shorter than those without mental illness (USC Nursing, 2019). Increased risks of cancer, heart disease, and death from respiratory illness are associated with mental illness, as well as the likelihood of receiving substandard healthcare for those problems (Hert et al., 2011).

Lack of sleep can affect the cognitive and physical symptoms and individuals with mental illness are more likely to be suffer from lack of sleep than those without, affecting approximately 80% of individuals with mental illness (Faulkner & Bee, 2016).

Pharmacological treatments for psychiatric disorders may affect sleep, in turn making the mental illness more difficult to manage or triggering new symptoms (Krystal, 2013).

Generalized Anxiety Disorder, for example, has sleep disturbance as a symptom, but increased sleep disturbances can manifest new and more severe anxiety disorders at two times the rate of healthy individuals (Krystal, 2013). It is clear sleep management is important to control the current mental illness and prevent subsequent diagnoses.

Symptoms involving emotion, such as affect, mood changes, and grandiosity, can be a telling sign of a person experiencing a mental illness ([APA], 2009). Symptoms such as these can affect daily life. For example, grandiosity might make someone think they can open a new business, take out a loan, and make millions, when in reality they are not likely to make any money. Another example would be a person with severe mood changes having difficulty maintaining a romantic relationship because of the constant back and forth mood swings. The symptoms a person with mental illness experiences greatly affects their day to day life and the occupations in which they successfully participate (American Psychological Association, 2009).

Medication. Symptoms of mental illness vary in severity from person to person and diagnoses to diagnoses; however, all these symptoms can negatively influence an individual's daily life (Kaite et al., 2015). Seeking treatment for chronic mental illness may include a combination of medication and behavioral strategies to minimize the impact symptoms have on daily life.

While medication to limit symptoms is the most frequently used strategy by healthcare providers, there is a risk of negative side effects. For example, Sertraline and

Fluoxetine are common antidepressant medications with potential side effects listed as nausea, vomiting, weight gain, sleepiness, and sexual problems (National Institute of Mental Health [NIMH], 2016). Antipsychotic medications, such as haloperidol and risperidone, have more serious possible side effects including low numbers of white blood cells, muscle rigidity, persistent muscle spasms, and tremors, drowsiness, dizziness, nausea, vomiting, weight gain, and dry mouth (NIMH, 2016). The medications are needed to limit the symptoms of mental illness but bring about a new set of symptoms that could impede daily life.

Hospitalization. Individuals with severe mental illness may require a hospitalization due to the nature of their symptoms. Hospitalization is often required when the person is a danger to themselves or other, whether the individual is voluntarily admitted or not. In 2006, 1.7 million Americans were hospitalized primarily due to a mental health condition, and one out of every five hospital stays has some form of mental illness as a comorbidity (Saba, Levit, & Elixhauser, 2008).

The average length of stay (LOS) for an individual with a mental illness is longer than for individuals with physical conditions with no mental illness co-morbidities. The average stay in 1994 was 9.6 days for a mental health condition which had decreased to 8.2 days in 2006 (Saba et al., 2008; Tulloch, Fearon & David, 2011). Inpatient hospital stays account for 16% of mental health spending in the United States (Tulloch, Fearon, & David, 2011).

In a study on LOS for individuals with mental illness, researchers found a longer stay was linked to female individuals, symptoms of psychosis, and larger hospital systems,

whereas, a shorter stay is linked to married individuals, leaving against medical advice, and a prospective payment healthcare system (Tulloch, Fearon, & David, 2011). The shorter hospital stays that focus on getting an individual back to a non-crisis point may contribute to re-admission rates that leave individuals in a cycle of illness, hospitalization, release, and illness again (Tulloch, Fearon, & David, 2011). While it is important to focus on symptoms to get to a more stable place, without focusing on more long-term parts of life that affect mental illness, such as parenting or other complex IADLs, it is easy to slip back in to another cycle of hospitalization.

Stigma. Difficulty facing stigma is commonly reported by individuals with mental illness (Shor, Kalivatz, Amir, Aldor, & Lipot, 2015; Henderson, Evans-Lacko, & Thornicroft, 2013; Krupa, 2008). Finding a new identity and navigating life with mental illness can be difficult; adding stigma and loss of social support can make it even more challenging. Individuals report losing social status after revealing their illness due to stigma and ostracization adding to the feelings of isolation and hopelessness that plague their lives (Kaite et al., 2015).

There are societal beliefs that individuals with mental illness are dangerous to themselves and others and are more violent than a typical person (Parcesepe & Cabassa, 2013). These negative perceptions have increased over time, from 1950 to 1996, particularly for those who have psychosis or diagnoses of schizophrenia, depression, or alcohol dependence. Although the public widely holds these beliefs, one study reported that seeking treatment is seen positively and those numbers are improving over time (Parcesepe & Cabassa, 2013). Even with improving views of seeking help, the

stigmatizing thoughts and actions towards individuals with mental illness continues to limit the support and resources they are willing to seek (Parcesepe & Cabassa, 2013).

Parenting with Mental Illness

It is difficult to find exact numbers of how many adults with mental illness are parents, but according to a study which gathered data from 2008-2014, 2.7 million parents had a serious mental illness (SMI) and 12.8 million parents had AMI (Stambaugh et al., 2016). Stambaugh and colleagues indicated that as many as 18.2% of adults who are parents may experience mental illness.

Parents living with mental illness may experience a variety of negative emotions, including anxiety, feeling overwhelmed, and feeling increased stress due to the increased responsibility and pressure of raising children (Hackett & Cook, 2016). People with mental illness might experience lack of self-esteem and insecurity in their role as a parent. They might feel guilt for possibly being a burden to their children. Not knowing how to explain their illness to their children is another stresser (Shor et al., 2015). In one study of support groups for parents with mental illness, parents often reported they were not equipped to explain their illness in an appropriate way and sought help from professionals and peers in the group to face the challenge (Shor et al., 2015). This study also found that remaining connected to the child through hospitalizations and cycles of illness was a primary concern (Shor et al., 2015). The effects of these emotions and their illness may make it difficult for a parent to fulfill their roles. The ability to apply knowledge, read and solve problems, learn new skills, or follow multi-step directions are vital to navigating daily life and being a parent. When those skills are impaired, parenting

may be affected (Bromfield, Parker, Lamont, & Horsfall, 2010).

In addition to the emotional aspect and stressors, parents with mental illness can face a variety of barriers that parents without mental illness do not. Parents with mental illness may have difficulty adhering to their treatment and dealing with side effects and symptoms from their medication, as well as facing the cyclical nature of many mental illnesses (Reupert & Mayberry, 2007). Mental illness can go through periods of highs and lows with symptoms, which can make it difficult to provide a stable home. The current approach to treating mental illness with medication requires a ‘trial and error’ method, meaning the doctor prescribes a variety of combinations of medicine until the client finds one that works. During this time of trial and error, the individual with mental illness is trying to manage the symptoms they feel with their role as a parent, which can be difficult. Another possibility is that medicines may stop being as effective after long-term use, so the trial and error method continues to seemingly never end. These cycles can put the parent in a constant state of trying to maintain their mental health while fulfilling their roles as a parent (Reupert & Mayberry, 2007).

Another barrier for parents with mental illness is the constant fear of losing custody of their children, either to the state or the other parent in the case of divorce. Mothers with mental illnesses are three times as likely to have involvement with the child welfare system (Van der Ende, Van Vusschbach, Nicholson, Korevaar, & Van Weeghel, 2016). This involvement, while it is intended to be supportive, can be distressing to the parent, as 28% feel they are discriminated against in their role as a parent by the child welfare system (Van der Ende et al., 2016). When there is involvement from the government, an

assessment of the parent's caretaking capability may be requested. Parents with mental illness are three times as likely to lose custody at some point and the chances of losing your child increases if you have lost custody previously (Ostler, 2010). The child welfare system assessment looks for circumstances that are known to be more likely for children of parents with mental illness including domestic violence, poverty, substance use, single parent status, poor social supports, and high stress situations (Ostler, 2010).

The fear of not having custody of their children, whether by the welfare system or to the other parent, has been reported. In a pilot study of 20 mothers with severe mental illness that included 76 children, 22% of the children were with their mother full-time and 7% part-time (Sands, Koppelman, & Solomon, 2004). Of the children who were not in the custody of their mother with mental illness, 26.3% were in non-kinship foster care, meaning they lived with non-relatives through government foster care, and 43.4% lived with other family members (Sands et al., 2004). In addition, in the qualitative portion of the study, multiple mothers who had children not in their custody reported not knowing if they had been adopted or if they could get their children back. This study showcased the prevalence of children of parents with mental illness (COPMI) not living with their parents. Although dated, there is limited research on children residing outside of the family home and the confusion and difficulty mothers face navigating a complicated system while managing their illness.

A study by Benders-Hadi, Barber, & Alexander (2012) focused on whether clients are identified as parents during intake, on their own or by staff, and the demographics of their relationship with their children. The researchers found 40% of the female patients at a

suburban New York mental health facility identified as mothers and of those, 25% had contact with the child welfare system at some point and 33.3% were not the primary caretaker of their children (Benders-Hadi et al., 2012). This study noted a clear need for facilities and healthcare practitioners to identify parents using a protocol, as it was not consistent for the clients (Benders-Hadi et al., 2012). The results from this study emphasize that mothers are not always identified. When they are there is a likelihood of intervention from the welfare system or loss of custody.

The other major concern, when mothers with serious mental illness have custody, was what to do with their child if they are hospitalized, once or multiple times. Decisions about what to do with their children often have to be made when the parent is in the cycle of being ill, not when the parent is well and managing their illness (Basset, Lampe, & Lloyd, 2001). While this evidence is more than twenty years old, this article relates to the fear of losing custody to the other parent or the state, as well as the lack of social support to provide care for their child when they are unable.

There are also challenges in providing care to parents with mental illness from the perspective of the psychiatric providers. In a systematic review of barriers to providing care for parents with mental illness, Mayberry and Reupert (2009) found barriers within the agency and providers. From a policy standpoint, there is no policy to identify consumers as parents when they are using psychiatric resources. In addition to the lack of identification, the authors noted not enough funding to make the practice family-focused rather than individual-focused. Researchers also found that agencies do not collaborate and share information in order to make the continuum of care smooth and

accessible. Psychiatric service providers were also found to lack knowledge of family-centered care when focusing on parenting or family related issues, although they acknowledge it is an important focus (Mayberry & Reupert, 2009).

Effects of Parental Mental Illness on Children

Children of parents with mental illness (COPMI) can face a variety of negative consequences from growing up in an environment with parental mental illness, including impacts in social and economic domains, and in their own health and well-being. From a social standpoint, children may experience withdrawal and isolation, lack of communication, difficulty expressing their feelings, and decreased social support (Oskouie, et al., 2011; Rasic, Hajek, Alda, & Uher, 2014; Reupert & Mayberry, 2007). Foster (2010) interviewed adults who grew up with a parent with mental illness and found that as children, the participants were unsure of how they fit in their world. They often experienced loneliness and had difficulty relating to peers. In addition to fitting in with their peers, they found difficulty connecting with their mentally ill parents and maintaining parent/child roles and boundaries, further impeding their ability to bond (Foster, 2010). A secure parent-child attachment makes the infant or child feel safe and secure and helps build a sense of identity. Without this attachment, the child may be left with impairments in cognitive and emotional development and poor parent-child attachment can affect the relationships they have with others as they age (Reupert & Mayberry, 2007; Oskouie, et al., 2011). How children cope with stressful situations is also affected by parental mental illness. Commonly, when faced with recurrent hospital stays or the cycles of illness, the child learns to withdraw, avoid, or distance themselves

from their parent and the situation, rather than learning healthy coping strategies (Reupert & Mayberry, 2007).

In addition to social stressors, having a parent with mental illness can negatively influence financial security and stability within the home. A study by Luciano, Nicholson, and Meara found that employment rates for parents with serious mental illness (SMI) were for 38% full-time for mothers and for 60% full time for fathers, compared to 50% for full time for mothers and 85% for full time for fathers without SMI (2014). In addition, 30% of parents with SMI fell below poverty threshold compared to 17% without SMI and the study showed a decrease in likelihood of employment as severity of mental illness increased (Luciano, Nicholson, & Meara, 2014). According to the study, without financial stability, children of parents with mental illness face increased challenges compared to their peers with non-mentally ill parents and who have a stable socioeconomic situation.

COPMI have also reported an increase in role responsibility, such as caregiving for their ill parent or siblings and managing the household, cooking for the family, cleaning, and working (Oskouie et al., 2011). In addition to taking over physical tasks, some children may take emotional responsibility for the well-being of the family, which can be seen as positive by increasing independence and self-reliance, or negatively by feeling resentment for being put in this situation (Foster, 2010).

It is well-known that COPMI are more likely to be diagnosed with their own mental illness compared to peers raised by parents without AMI. The child of a parent with a SMI, including bipolar disorder, schizophrenia, or major depressive disorder, has a one in

three chance of developing SMI and a one in two chance of developing AMI (Rasic, et al. 2014). Approximately 50% of COPMI will develop AMI, a large statistic that can cause added fear and anxiety for children. Increased anxiety and feelings of guilt are also common in children for a variety of reasons, including their parents will relapse or have increased symptoms, uncertainty about the future, fear of marriage or passing on genes to their own offspring (Oskouie et al., 2014).

Another well-studied phenomenon is childhood toxic stress (Gronski et al 2013; Franke, 2014). Childhood toxic stress is “chronic or cumulative traumas that the child experiences without the available support of a loving caregiver” (Gronski et al, 2013, p. 149). A variety of traumatic events can add to toxic stress, such as natural disasters, abuse, parental mental illness, and caregiver substance abuse.

Childhood toxic stress affects the child’s development by causing damage to the cognitive, psychological, and physiological systems (Gronski et al., 2013, p. 149). When the child is exposed to the stressor, they have a neuro-endocrine immune response that triggers the fight-or-flight response (Franke, 2014). The more chronic and repetitive the events, such as a parent who is bipolar with recurring cycles of mania and depression, the more impact toxic stress has on the child. Another key aspect of childhood toxic stress described by Frank (2014) is a lack of positive supports. For a child living in poverty whose mom is repetitively hospitalized, the effect of toxic stress could be mitigated by a loving, involved, and supportive second parent. If the child lacks that support, the effects of toxic stress are more likely to negatively influence the child’s development (Franke, 2014). If the childhood toxic stress continues to build, the child is more likely to have

negative health outcomes later in life such as alcoholism, chronic obstructive pulmonary disease, depression, cancer, obesity, and heart disease (Franke, 2014).

Research supports a variety of negative outcomes for COPMI that must be taken into consideration when working with adults with mental illness. Addressing the role of parenting and increasing programs for them may in turn trickle down to positively influence their children and relieve guilt and stress the parent may feel.

Occupational Therapy, Occupational Science, & Clinical Reasoning

To study occupational therapy, it is important to understand the concept of occupational science. Occupational science is the study of the things people do every day, or the study of their occupations (Hocking & Wright-St. Claire, 2011). The purpose of occupational science is to continually learn new knowledge about how and why people do the things they do and, more importantly, why they do them and how they affect overall well-being (Hocking & Wright-St. Claire, 2011).

Occupational science allows occupational therapists to take the information they have learned about the occupations people engage in and use it to help clients return to doing the activities of daily living that are important and meaningful to them (Hocking & Wright-St. Clair, 2011). The basis of occupational therapy is to help individuals do the things they need and want to do through the therapeutic use of activities (AOTA, 2014). Occupational therapists strive to support independence and improve the quality of life of their clients.

The Occupational Therapy Practice Framework (AOTA, 2014), a document that outlines the way occupational therapy is practiced in any setting, guides occupational

therapists. It focuses on ADLs such as bathing and dressing, IADLs such as child rearing and household management, and client factors like values and beliefs. There are definitions and examples of body structures and functions, performance skills needed to complete occupations, and contexts and environments in which a person performs their needed occupations. The OTPF also focuses on the types of interventions that are planned and the outcomes occupational therapists work towards. The OTPF is a roadmap for working with clients, from evaluation (person, environment, and occupation) to intervention, and the eventual outcomes, and guides our scope of practice (AOTA, 2014).

When working with clients, occupational therapists use theory, in addition to the OTPF, to guide their practice. Clinical reasoning is one facet of theory that largely informs occupational therapists and the choices they make. Clinical reasoning is “the process used by practitioners to plan, direct, perform, and reflect on client care” (Marquez-Alvarez, Calvo-Arenillas, Talavera-Valverde, & Moruno-Millares, 2019). It is an individual process and no two occupational therapists will approach a situation in the same way, as they each have different clinical reasoning that guides their decision. Clinical reasoning comes from a variety of clinical experiences, the use of theoretical frameworks, personal life experiences, and education or experience.

Different aspects of reasoning may include scientific, diagnostic, procedural, narrative, pragmatic, ethical, interactive, and conditional (Marquez-Alvarez, Calvo-Arenillas, Talavera-Valverde, & Moruno-Millares, 2019). For example, an occupational therapist treating a patient after a stroke may use scientific reasoning to select a Task Oriented approach based on the available literature and outcomes that support its use in

practice, procedural reasoning to determine when and how often to implement that approach, and narrative reasoning to take into account the client's specific circumstances such as preferred activities, caregivers, or strengths and weaknesses. An occupational therapist working in mental health may specifically utilize narrative reasoning to understand the client's thoughts and feelings, pragmatic reasoning to choose a service delivery model (such as telehealth in the times of a pandemic) and interactive reasoning to build a rapport and decide which method elicits the best response from the client. Each therapist selects a method of clinical reasoning as they encounter new clients throughout their practice.

Occupational Therapy with Mental Illness

The roots of occupational therapy began in mental health in the 1800s and has transformed in the 200 years following (Newton, 2007). Although occupational therapy strayed from its' mental health beginnings for a time to a medical model focused on physical rehabilitation, occupational therapists now pride themselves as uniquely able to work in mental health through their training in sciences and psychology and use of occupation and theory (Champagne & Gray, 2016). According to the American Occupational Therapy Association, occupational therapists' can aid individuals in their mental health recovery at any phase of the process (2014). For example, it is within the scope of occupational therapy to assist in creating coping strategies, implementing healthy habits, and providing education and information on their illness. Additionally, occupational therapists can provide community resources and help with long-term life planning to meet their goals (Champagne & Gray, 2016). Occupational therapists can

work in a wide variety of mental health settings including acute care in hospitals, schools, private clinics, forensic settings, and community-based mental health clinics. Each of these settings has different goals. For example in acute care, the goal may be to manage the immediate crisis and discharge to the community. In a forensic setting, goals might include coping strategies to manage anger or compulsions (Champagne & Gray, 2016). Community-based settings may focus on broader IADLS, such as household management or care of pets (Champagne & Gray, 2016). Different settings can have a variety of goals that are meaningful, client-centered, and aid in mental health recovery.

In a meta-analysis of research into occupational therapy for individuals with mental illness (Ikiugu, Nissen, Bellar, Maassen, & Van Peurse, 2017), a medium effect size was found when measuring occupational performance after intervention and a small effect size when measuring patient well-being. When providing intervention for individuals with mental illness, the study showed that having the backing of specific theory is essential in improving occupational performance and well-being, as ambiguous theory leads to smaller effect sizes (Ikiugu, Nissen, Bellar, Maassen, & Van Peurse, 2017). Examples of specific theories that may be useful are the Model of Human Occupation (Kielhofner & Posatery Burke, 1980), Occupational Adaptation (Schkade & Schultz, 1992), the Canadian Model of Occupational Performance (Polatajko, Townsend, & Craik, 2007), Behavioral and Cognitive Behavioral theory, psychodynamic theory, and the Cognitive Disabilities model (Allen, 1992).

For young adults with mental illness, intervention is critical for obtaining positive outcomes (Read, Roush, & Downing, 2018). In a meta-analysis focused on adolescents

and young adults, four interventions were found to be most effective in treatment of mental illness. Cognitive remediation, cognitive-behavioral therapy, supportive employment, and family psychoeducation were found to improve and maintain occupational performance (Read, et al., 2018). These techniques can be used by occupational therapists, as well as other mental health professionals. Addressing cognition and thought processes through occupational engagement, such as supportive employment, can aid an individual early in their mental illness with social skills, abnormal thought processes, insight into illness, and with overall disease management (Read et al., 2018).

Focusing on engagement in occupation is crucial when providing intervention, as individuals with SMI engage more in solitary activity or sleeping than those without mental illness (Hohl, Moll, & Pfeifer, 2017). Occupational therapists can use a variety of techniques to address activity disruption caused by symptoms of mental illness, such as behavioral activation, supportive employment, time-use interventions, and exercise. Behavioral activation entails scheduling activities to fill their day rather than being solitary all day and using activities to avoid triggers for mental illness symptoms. Time-use intervention also aid in this by planning activities to gain occupational balance (Hohl, Moll, & Pfeifer, 2017).

When working with individuals with mental illness, there are several components that are important to remember in order to obtain positive outcomes and positively influence recovery. Individuals with mental illness find connectedness and belonging to a peer group as essential (Doroud, Fossey, & Fortune, 2015). This peer group may provide hope

and optimism that their condition and current situation can and will improve (Doroud et al., 2015). Identifying what is important to them and personal identity exploration are also important to help the individuals find meaning and purpose in their lives. Individuals find having some control over their life, such as choosing what activities to engage in and planning interventions with their occupational therapist, to be empowering and provide them with a sense of personal responsibility (Doroud et al., 2015). In addition, having a sense of accomplishment for completing a task as well as positive affirmation, from occupational therapists and peers, can encourage them to continue participation in groups and therapy activities (Milbourn, McNamara, & Buchanan, 2017).

Stigma is a common problem for this population and occupational therapists can help provide strategies for individuals to navigate stigma. There is limited literature on this topic, but a lecture by Krupa in 2008 introduced approaches of how to explain mental illness to their clients can help the client feel empowered to educate others (Krupa, 2008). For example, normalizing mental illness can be beneficial, but a common technique of comparing it to physical illness can have a negative influence by ignoring the unique challenges and stigma a mental illness presents. Instead, focusing on using occupation to have the person with mental illness integrate into the community, teaching advocacy, and having more shared activities and occupations can be more beneficial (Krupa, 2008).

Occupational Therapy with Parenting

The OTPF lists child rearing and care of others directly as an ADL, as well as driving and community mobility, financial management, home management, meal preparation, shopping, and social participation, all of which are indirectly involved in raising a child

(AOTA, 2014). Occupational therapists address client factors that include mental functions such as attention, memory, emotion, temperament and personality, energy and drive, and experiences of time and self (AOTA, 2014). These skills are important for parents as well as the for the individual when facing stigma, which may be increased for parents. Occupational therapists are qualified to address multiple aspects of parental mental illness and can use the OTPF to justify their scope of practice when addressing parenting.

There is a lack of literature on parenting from an occupational therapy lens. One study by Llewellyn in 1994 described parenting as “intensely personal and commonly experienced” classified it as a neglected occupation due to the lack of literature (Llewellyn, 1994, p. 173). In this early study, Llewellyn identified role strain and competing demands as the most common struggle for parents. Demands from being a parent and homemaker, as well as being a full-time employee, making time for oneself, and social demands can strain the relationships between parent and child (Llewellyn, 1994). The lack of current research about parenting viewed through an occupational lens exposes a gap in literature on how occupational therapy impacts parenting.

Occupational Therapy with Parenting and Mental Illness

In other countries around the world, information on addressing parenting for adults with mental illness is, while still lacking, more common than in the United States. For example, in Australia, programs such as the “Living with under-fives” model focuses on education about positive parenting skills and provides a support group (Basset, Lamp, & Lloyd, 2001). This program also holds simultaneous programs for children to have the

opportunity for developmentally appropriate play, and staff can monitor their development. Of the 34 parents who participated in this program over a two year period, positive outcomes included more freely discussing lifestyle changes they have made, becoming more responsive to their children and aware of their needs, forming relationships with peers, and experiencing fewer hospitalizations. Findings were gleaned from staff observations, self-reports, and readmission rates (Basset et al., 2001). While this program is from 2001, it provides rare information on a parenting program that address the parent and child. As previously discussed, there is a lack of this type of program and limited, updated research.

In some countries, focusing on preventative healthcare allows for positive changes before a child is born. For example, an occupational therapist in India focused on the role of preparing for motherhood by identifying and addressing possible challenges, planning for childcare with family, and education about parenting and childcare through educational materials and practice with dolls (Acharya, 2014). This preventative approach through occupational therapy has the potential to stop negative consequences for the child, as well as mitigate stressors for the parent so they can focus on managing their illness and caring for their new baby. In the United States, information on parenting programs run by occupational therapists is lacking, even though occupational therapists have the unique skillset to address the adults and children simultaneously or separately. Mental illness has clear impacts on many facets of life- physical, emotional, cognitive (Mental Health Coordinating Council Inc., 2015; Hert et al. 2011). What may not be obvious is the impact on COPMI and parenting skills. As the literature has shown,

occupational therapists have the skillset to address parenting with individuals with mental illness. A lack of research investigating links between mental illness and parenting, as well as the role of occupational therapy, provides an opportunity for new research to fill the gap.

Chapter Three: Methodology

Research Design

This study was a phenomenological qualitative design, as it identified the phenomenon, interviewed multiple participants, focused on the participants' lived experiences, and compiled the data into themes (Creswell, 2013). The phenomenon being studied was how occupational therapists address parenting with individuals with mental illness, including their practice patterns, barriers, and facilitators. The interview process consisted of 2 interviews, each 30-60 minutes in length. The first interview contained a set of broad, open-ended questions devised by the primary researcher and faculty advisor. The second interview was a follow-up interview to ask clarifying questions and gather more in-depth examples and stories. Four occupational therapists participated in this study, thus meeting the desired target based on the feasibility for the researcher and scope of the project.

Creswell, based on a study by Dukes, recommended interviewing 1-10 participants for up to two hours for a phenomenological qualitative study (Creswell, 2013). Interviews were selected as the research method in order to gather in-depth information from participants (Creswell, 2013).

Researcher Positionality

It is important to disclose that the primary researcher is a COPMI. This major life experience provided the inspiration and desire to pursue research in the area of parenting and mental health to see how occupational therapists can be of service to this population. While there is a risk of bias, the research team mitigated that by having two other researchers read transcripts and review to triangulate the data, then discuss their

impressions. Although it may add bias, the personal experience brought to the project provided passion and a unique lens to view the participants and their stories.

Participant Recruitment

Participants were recruited through contacts from the faculty advisor, Melinda Cozzolino, the American Occupational Therapy Association CommunOT forum, and the Facebook group “Mental Health Occupational Therapy Network.” A script was emailed to individual contacts and posted in each forum and Facebook group. Four participants responded and were pre-screened for qualification. The inclusion requirements were: being a registered and licensed occupational therapist, practicing in any mental health setting, and having clients who identified as parents. Exclusion criteria included being an occupational therapy assistant, working in other settings, and not having clients who identified as parents. After qualifying, each participant was sent an electronic informed consent to be signed and returned. After receiving the informed consent, the first interview was scheduled.

Each of the four participants were given a \$25 Amazon gift card for their participation. *Table 1* showcases important characteristics of the four participants. Of the four, Participants 2 and 4 worked at the same facility, although in different areas. All participants worked in inpatient rehabilitation, although their specific roles were different.

Table 1- Participant Characteristics

Participant	Years in Practice	Years in Mental Health	Setting	Geographic Location
1	2	1	Inpatient mental health at a large metropolitan hospital	Mid-Atlantic
2	8	8	Inpatient mental health and outpatient day program at a large metropolitan hospital	Mid-Atlantic
3	5 months	5 months	Inpatient mental health at a small city hospital	South
4	5	3	Inpatient mental health at a large metropolitan hospital	Mid-Atlantic

Researcher-Participant Relationship

The participants were recruited via online forums and responded in an email. The researchers did not know the participants and contact was limited to emails and the phone interviews, thus limiting the influence on the research process.

Data Collection & Analysis

Each interview was recorded on the primary researcher's password protected phone. After recording, it was sent to Temi to be transcribed using their encrypted and secure server. Each Temi transcription was then edited by the primary researcher for transcription errors and compiled into one document.

Once compiled, the primary researcher, faculty advisor, and committee member received a copy of the transcripts to begin analysis. Open coding was used to look through the material first and identify main ideas and assign loose labels to them, then axial coding was used to review the initial codes and begin to organize them into themes (Neuman, 2014). Selective coding began after going through the data multiple times in order to continue clarifying themes (Neuman, 2014). After each member of the research team reviewed the analysis and went through the coding process, the research team met to discuss the findings. Six themes emerged and serve as the main ideas and answers to the research questions. Some themes were divided into subthemes to provide greater detail.

Chapter Four: Results

In looking at the results, the research team went back to the research questions to identify the barriers, facilitators, and practice patterns. Six themes emerged from the data: Parenting is secondary, occupational therapists feel unequipped, lack of access, supports vary, relevant skills, and desire for change. Additional findings were identified that did not fit into the research questions, however, are important to note and have also been included.

Research Question 1: Barriers

There were three primary themes that emerged as barriers: parenting is secondary, OTs feel unequipped, and lack of access.

Parenting is Secondary

The first theme to emerge was that parenting was secondary to acute symptoms of the mental illness. Each participant worked in an inpatient setting (although some also worked in outpatient clinics), meaning the patients they saw were having symptoms that significantly disrupted their daily life, putting themselves or others in danger. In the inpatient setting, the participants noted that they had to focus on addressing the current symptoms first. Participant 2 stated “I think because the majority of our settings are inpatient, it’s really just trying to manage the illness, it becomes the focus because if they’re not managing the illness then they can’t do parenting.... so you’re starting far away from the actual parenting part of things.”

Instead of parenting, participants reported focusing on self-care, symptom management, and coping strategies. Another participant said “The roles of parenting

would probably come later because they're there for themselves and they have their own personal problems. They can't be an effective parent if they can't even take care of themselves." Participants noted this as one of the main barriers to addressing parenting as an occupational therapist in mental health and was mentioned by all participants at some point during their interviews.

Occupational Therapists' Feel Unequipped

The second theme to emerge was that occupational therapists feel unequipped to address parenting with their patients for a variety of reasons. This theme has been broken into subthemes to address the three most prevalent reports.

Lack of Training. The first subtheme is the lack of training on parenting, as reported by the participants. Each participant was asked questions regarding their graduate curriculum, specifically whether parenting was addressed. Participant 4 responded "Not at all. I think the closest that it maybe came to [it] was when you are doing like a pediatric class that talks like basically about how to help parents with facilitating like appropriate play... But none of it specifically addressed their role as a parent." Other participants said parenting was discussed in one of two ways: identifying 'parent' as a role or how to interact with parents in a pediatric practice setting. No participant identified that their curriculum discussed how to address parenting as an occupation.

In addition to graduate education, participants were asked about their experience with continuing education. Three of the four participants stated they had taken no classes specifically on parenting, but the skills they learned could be applicable to addressing parenting in mental health settings, such as using a family-based approach. Only

Participant 1 had taken a class that directly mentioned parenting with mental illness at the AOTA Mental Health Specialty Conference, although the focus was not specifically parenting. The lack of education in graduate curriculum and continuing education serve as barriers to providing service to parents with mental illness who need it.

Lack of Familiarity. The second subtheme was lack of familiarity with parenting. Participants who were not parents reported feeling they could not address parenting because they are not parents themselves. Participant 3 said:

My role is not to be able to know exactly what it feels like, but I feel like it's one of those things that maybe I would be able to help out better or say the right thing or, you know, be of more help... I get constantly asked here 'do you have kids?' And I say no. And then almost always a follow-up question is, well, when are you going to have kids?... why are they supposed to listen to me a 25-year-old spring chicken who doesn't have kids?

Only Participant 2 was a parent and did not report any feelings of unfamiliarity or that she could not help with parenting. She attributed this to being a parent and understanding the complexity involved.

Disparities. The third subtheme involved the disparity occupational therapists feel between themselves and their clients, which can make it difficult to relate to or understand the individual's circumstances. Participant 1 said:

Even with just worrying about saying the wrong thing. If somebody who might be using a substance or even, you're like interacting with a seven-foot dude from DC. That is totally different in every aspect than me. You know, I'm like, you know, average size, middle class white lady who grew up in the suburbs of Virginia. So I obviously grew up much differently than somebody who's in DC, people who are using cocaine and playing Russian roulette in their free time. So it's definitely something to learn as you go.

Another participant discussed her upbringing and how her parents parented her in contrast to the client population she works within a low socioeconomic status area with

high rates of drug abuse. The differences in her experiences with parenting presented challenges in how to navigate a different style of parenting with different resources and challenges.

Lack of Access

The third theme to emerge is lack of access to the COPMI. Within this theme, there were two subthemes: loss of custody and partners/family visiting hours.

Loss of Custody. The first subtheme is the parent having lost custody of their child. As mentioned in the literature review, parents with mental illness, specifically mothers, are more likely to have a history of being involved with the child welfare system, as is evident in the stories from participants. Participant 3 stated:

I have a lot of patients who have grief over being parents because their children have been taken away from them. They're in the foster care system now or another family member has custody over them because for whatever reason they were not able to be good parents.

Participant 2 told a story of helping a client in her outpatient program by aiding in finding a lawyer and doing mandatory drug tests in order to fulfill the requirements to regain custody of her children. If the parent does not have custody, the OT may be able to work on the process of regaining custody, but not the exact parenting skills.

Partners/Family and Visiting Hours. The second subtheme is limiting access to the children is the willingness of the partner or family to bring the child in and visiting hour guidelines. All four participants worked in a locked unit in an inpatient hospital setting, which can be intimidating for a child. Participant 2 stated “I mean typically if it's a parent that we're working with, their child [is] not coming to the locked unit.” Whoever is providing care for the child while the parent is in the hospital, whether it is a spouse,

other parent, or family, may not be willing to put the child in this situation, limiting access to address parenting with the parent and child.

The other difficulty limiting access is the time of visiting hours. Participant 3 said,

There are visitation hours a few times a week, but that is like later in the day and there are no groups scheduled during that time so that they can just spend time talking with their family. I never see the family members. Some people, some patients have people that come every visitation, some people have nobody that comes. It just depends, but I'm never a part of the groups, they're never a part of that.

Another participant said she sometimes preplans activities for the parent to do with their child when they visit, but cannot physically be there, to facilitate the activity and help foster the relationship. Participant 4 recalled that sometimes she sees the family for planning meetings during the day, but it is often older, adult children, no longer living with their parents, that attend.

Research Question 1: Facilitators

Supports Vary

The fourth theme is supports vary, meaning each participant has different supports within their facility to enhance their practice. These supports can be combined into three subthemes: OT supervisor, facility policies, and kitchen access.

OT Supervisor. The first subtheme is the most valued support was having an occupational therapist supervisor. Three of the four participants had an OT as their main supervisor or rehab director. Participant 1 said:

I have a great rehab director. She's an OT, so I think that helps a lot. I know rehab directors that are PTAs before. And our previous director was a speech language pathologist, so I think that's great. But I think having an OT as a rehab director is awesome because she's a great advocate for what I'm doing and things like that.

Similarly, Participant 4 said “My boss is really super and being involved and being willing to kind of be a mediator if we have any issues with the other multidisciplinary teams, which fortunately I'm very thankful to say doesn't happen all that frequently.”

The one participant who did not have an OT supervisor cited it as a barrier. Participant 3 reported feeling that she could ask the supervisor questions and that was helpful, but also said “I feel like I can't get across our value and what's important for our profession.”

Facility Policies. The second subtheme, facility policy, can be a great support for some participants, but a barrier for others. Participant 2 saw her facility policies as a support and said:

We have a nice outside area, we are able to do home assessments. We're able to go out to the community with our clients when appropriate. So we have a lot of ability to do lots of different stuff depending what their goals are.

In contrast, Participant 3 cited facility policies as a barrier that limited or banned outside time, what materials individuals could use, and even the clothes they can wear.

She said:

If I could change anything about the way my facility was set up, I would have it on a main floor that they had a courtyard or something so they'd be able to at least like go outside and get fresh air because like I can't imagine not being able to go outside for maybe a week at a time. Like that would be detrimental to my mental health. And it'd be really frustrating if I'm trying to get better, but I feel like stuck in a place they're not allowed to have any type of clothing that has buttons, zippers, strings, anything like that.

Each facility has their own set of policies to ensure the safety of the clients and staff, but whether those facilities are supports or barriers depends on the facility and occupational therapist.

Kitchen Access. The third subtheme was access to a kitchen for intervention sessions. Meal preparation is an activity that addresses many skills and can be completed in individual sessions or groups. Three of the four participants had access to a kitchen and reported using it frequently in their practice. Participant 4 stated:

We have on each of the unit floors there is a kitchen that we have access to, which is really nice because people aren't always able to leave the floor depending on the reason for their admission and safety and that sort of thing. So it's really awesome that we're able to integrate that especially because it's so occupation based and so hands on. But we also have a full kitchen on our OT floor, and I use that every Friday for my ED [eating disorder] patients and then every Thursday I cook with my young adult patients.

The one occupational therapist that did not have a kitchen cited that as a barrier instead. She recalled being taught to make fruit salad as an example intervention that does not require a kitchen, however, it could be demeaning to her patients. She said she strives to treat her patients how she would want to be treated and believed if she were in their position, she would be offended being asked to do something so simple. Instead, this participant chose to make use of the materials they do have, such as values inventories and routine making activities.

Research Question 2: Practice Patterns

Relevant Skills

After discussing the supports and barriers and seeing the challenge in addressing parenting, it was important to know what occupational therapists are doing to address parenting. The fifth theme is focused on the skills the participants are addressing that are relevant to parenting and can be broken into three subthemes: self-care and routines, values, and coping strategies.

Self-care and Routines. The first subtheme was self-care and daily routines. In this paper, self-care can include basic ADLs such as grooming as well as ADLs meant to promote mental health, such as taking thirty minutes a day to read by yourself or an hour of quiet time alone. As discussed in the first theme, managing the mental illness and taking care of the individual was the primary focus of the inpatient setting and part of that is learning or re-learning self-care routines. Participant 1 said:

I'll start with you know, we look at basic self-care and routines and we make sure those are good to go. So I have an activity with establishing a morning routine and afternoon routine, a sleep routine. So we can do a lot of work with identifying new routines and barriers to them and things like that.

Another participant spoke of the guilt her clients often feel when they are in the hospital, receiving treatment, and focusing on their own health and well-being. She said:

I just have to say self-care is important. You can't pour from an empty cup, right? You are here now for five days because we've neglected ourselves and you can't be a parent while you're in here. If you were just taking a little bit of time out of your day every day to make sure that you were taking care of your own physical and mental health. So a lot of it is just kind of coaching them through that guilt that they feel for taking care of themselves.

The occupational therapists' focus on the patients taking care of themselves and understanding their own needs so they can then go home and resume the caregiver role for another person, such as their child.

Values. The second subtheme was values exploration. Utilizing values exploration activities allows occupational therapists to aid their clients in developing insight into themselves and what matters to them. Participant 3 discussed a values exploration activity that she runs as a group:

I do a values clarification group. I explain to them that, you know, we all have different values. This is going to be based on our past experiences, the way we

were raised... I do that to help them understand that you do not need to make these huge big changes in order to do little things that help us live in line a little bit more with our values. And so I asked them to identify three of the values that they found were important to them.

In facilitating this activity, the client may identify parenting or being a good parent as an important value, which can lead to further insight about that role. While it may not directly address a parenting skill, it opens the door to identifying parenting as an important aspect of one's life and serve as a starting point for developing further skills.

Coping Strategies. The third subtheme was addressing coping strategies. Each participant identified coping strategies as an intervention they incorporate with their patients. Participant 1 said:

Then we talk about triggers, we talk about coping mechanisms and goals. I always make it related to their function, to what they need to be able to do personally, like for a patient to identify three triggers for anxiety or substance use in the work setting or in the home setting. And then the coping mechanisms, we'll decide three, kind of like you're just identifying and describing and then moving on to implementing them in their daily routines and things like that.

Coping strategies can be used to minimize triggering situations that could cause relapse in drug use, increased negative behaviors, or other negative symptoms (Champagne & Gray, 2016). As the participants were focused on the acute illness, identifying coping strategies is an important way for the clients to begin to manage their illness independently.

Additional Findings

Desire for Change

The final, and most pervasive, theme is the desire for change. Each participant, regardless of their various supports and barriers, identified the desire to change how they

address parenting. Each participant discussed their ideal way to address parenting was to involve family through family-based interventions and increasing familial involvement at the very least. Participant 3 stated:

So I guess ideally what I would like it to look like would be able to have an opportunity for them to resume that role in some practical way while in the hospital. Whether that be like having an opportunity to kind of parent their child a little bit, whether that be as far as like teaching them or having meals with them or having the kids come and visit and the other people who live visiting there with them, like actually give them some space to kind of have the same kind of interactions that they would at home.

Participant 2 said:

Maybe if we had a greater population that was well that their main goal was parenting, I would probably want to like create a group where the parent and child came in together and helped facilitate what it means to have a healthy relationship. Healthy boundaries and facilitate they have to work on something together. Maybe like going out and doing something with the patient and their child that they could then do independently without the therapist.

The participants identified various barriers that prevent them from being able to practice how they would change. When asked where they thought the change needed to occur, Participant 3 believed it was at the facility level to allow more access to children to be able to facilitate the parent-child bond. Regardless of the barriers or what specific part they thought needed to change, there was consensus among the participants that this change is necessary to allow them to fully address parenting with their patients.

Chapter Five: Discussion

This study investigated the barriers, facilitators, and practice patterns of occupational therapists' addressing parenting with clients with mental illness to better understand how this population is cared for. Six primary themes, each with subthemes, emerged to answer the research questions. The study revealed there were significant barriers to addressing parenting, including access to children, parenting being secondary to illness management, and lack of familiarity. The facilitators included varying supports such as OT supervisors, kitchen access, and facility policies, which varied from participant to participant. The overall understanding of practice patterns showed that working on relevant skills such as self-care, coping strategies, and values exploration were primary skills addressed, and further supporting that occupational therapists addressed parenting indirectly or secondarily.

Many of the findings were in accordance with the literature review. The first theme, parenting is secondary, supported the literature that the focus during an inpatient mental health setting is on managing the symptoms (Tulloch, Fearon, & David, 2011). As was discussed in the literature review, patients with mental illness can have a variety of symptoms, depending on their diagnosis, that impede function and prevents the focus from expanding to IADLs (American Psychiatric Association, 2013; Kaite et al., 2015). In this study, participants reported focusing on symptom management and frequent readmissions, which could be related to the length of stay and crisis focus as seen in the study by Tulloch, Fearon, & David (2011). From these two studies, a longer length of stay with more focus on ADLs and IADLs rather than just symptoms could be important

to lower readmission rates and improve the quality of life of individuals with mental illness.

The second theme focused on lack of familiarity with parenting as a barrier to providing treatment. After completing the study, a review of Accreditation Council for Occupational Therapy Education (ACOTE) requirements mandate “Explain the meaning and dynamics of occupation and activity, including the interaction of areas of occupation, performance skills, performance patterns, activity demands, context(s) and environments, and client factors” (ACOTE, 2019, p. 19). This is just one standard that mentions the importance of the client’s interaction of different areas in their life, which includes being a parent. Despite this, the participants in this study reported learning very little about parenting in their graduate curriculum and if they did, it was focused on interacting with parents when treating their child.

The lack of familiarity with addressing parenting could be due to OT programs omitting content about parenting or addressing the importance of more complex IADLs. Another important finding from this study was that the participants felt like they could not address parenting because they are not parents. One participant mentioned that her clients ask her personal questions, like when she is going to have kids, frequently because she was recently married. The participant continued to say she did not feel like she could address parenting with them, because she was not a parent. This apparent cultural taboo could play into why occupational therapy programs are not mentioning parenting in their curriculum. Alternatively, this could have been a missed opportunity to turn the question

back to the client and ask if they have children or what parenting is like for them, shifting the focus away from the occupational therapist and back to the client.

In a pop culture search on parenting, articles such as “Dear Non-Parents, Please Stop Giving Parenting Advice” (Baroni-Cook, 2015) and “Why People Without Children Shouldn’t Give Parenting Advice” (Milner, 2016) were among the top results. As occupational therapists, we are required to treat a variety of conditions we may not have, set goals for tasks we do not engage in, and understand the values and beliefs of clients that may not be the same as ours. Despite not identifying with clients in many areas, occupational therapists still treat them to the best of their ability and seek outside resources to gain knowledge. With parenting however, this is seen as taboo. This gap may cause occupational therapists to not feel equipped or like it is their role to ask about parenting and tackle what can be a touchy subject, but it is within the scope of occupational therapy through child rearing and other important and complex ADLs and IADLs that involve the care of a child (AOTA, 2014).

Lack of access is another theme that is well represented and in agreement with the literature. In this study, participants reported difficulty in working with the families and children because they were not brought in to visiting hours or the parent did not have custody. Mothers with mental illness are three times more likely to have involvement in the child welfare system, providing a role for occupational therapy intervention to assist with the process (Van der Ende et al., 2016). Each participant spoke to lack of access in some way and cited it as a barrier to their practice. Participant 2 recalled helping a client work through the legal system and regaining custody. Similarly, the participants of this

study frequently reported the distress of not having access to their children and the guilt they felt for being away. This is consistent with Gronski and colleagues that describes parents feeling distressed because they were not the primary caretaker of their children (2013). Occupational therapy can provide the bridge to caring for children and being involved in their lives, even while managing a mental illness in an inpatient setting.

In terms of the facilitators participants reported, it was interesting to note the differences in geographic regions in comparison to the amenities available and facility policies. Participant 3 lived in a southern state in a smaller city, while the other three lived in the Mid-Atlantic region in a large metropolitan city. Participant 3 had stricter facility policies, lack of outdoor space, and no kitchen, while the other participants reported more freedom and resources.

While the variances may not just be based on geography, Participant 3 also mentioned the increased negative attitude and stigma she felt from being in a rural setting. After attending graduate school in a larger metropolitan city still in the south, and moving to a rural practice setting, Participant 3 identified differences in attitudes related to racism, negative attitudes towards individuals with lower socioeconomic status, and increased stigma of mental illness. According to prior research, there is a societal belief that individuals with mental illness are dangerous to themselves and may be dangerous to others and that belief has increased over time (Parcesepe & Cabassa, 2013). The increased stigma, in addition to other discrimination, can add to feelings of hopelessness and isolation, already common symptoms of mental illness (Kaite et al., 2015). The

increased stigma and therefore increased symptoms add to the barriers that occupational therapists in a rural setting, like Participant 3, may experience.

The lack of familiarity and variances between therapist and patient based on factors such as race, mental health status, and socioeconomic status is unsurprising based on the demographics of healthcare professionals. In the United States, the general population is made up of approximately 13.2% African American, 17.% Hispanic, 1.2% American Indian and Native Alaskan, 5.4% Asian, and .2% Pacific Islander, while the population of healthcare professionals is 14.2% African American, 11.8% Hispanic, and 6% Asian (Hepworth & Schafer, 2016). While it may seem like small discrepancies to some, it symbolizes one part of a larger, more systemic problem of lack of racial diversity in the profession.

AOTA calls for greater diversity within the profession in the Centennial Vision, however, the statistics of the profession do not match, with 87% of occupational therapists being white, 5% African American, and 4% Hispanic (U.S. Department of Health and Human Services, 2014). The mismatch between the population of the United States and the demographics of the occupational therapy profession clearly show the differences in who occupational therapists treat and who occupational therapists are as a profession. Participant 1 brought this up when discussing how it was difficult at times relating to clients who were vastly different than her as a middle class, white woman. The lack of diversity and lack of training on diversity/inclusivity is a serious problem within the occupational therapy profession that needs to be addressed for parenting, the good of the profession, and for the clients' occupational therapists they work with.

Regarding the supports that participants mentioned, there is limited research other than anecdotal reports that having an occupational therapist as the Rehabilitation Director or Supervisor is beneficial. From a student's and soon to be new graduate perspective, it makes sense that having a supervisor who understands what occupational therapy is and the full scope of practice is beneficial. Occupational therapy is often misunderstood, confused with physical therapy, or limited to just the upper body (Langbein, 2019). With a supervisor who is an occupational therapist, the full scope, including addressing parenting, may be recognized and the occupational therapist supported.

Three of the four participants listed kitchen access and cooking interventions as a support and unlike the anecdotal evidence of having an occupational therapy supervisor, there is evidence to support this intervention. This is consistent with Farmer and colleagues' systematic review of studies that looked at the psychosocial benefits of cooking interventions in a rehabilitative setting, the results showed a positive influence on socialization, self-esteem, quality of life, and affect (2018). While these are not parenting specific, being able to cook for your child is an important occupation of a parent and a positive increase in the aforementioned characteristics can affect the quality of parenting and parent-child relationship.

As discussed in the literature review, other countries around the world have occupational therapists who address parenting. Programs like the "Living with under-fives" program (2001) or focus on preventative health in India (2014) involve the families of the client to address the holistic nature of human beings, but in the United States that is limited. As the participants reported, their strongest desire is to involve the

children and whole family in their interventions to increase positive outcomes that have been noted in previous studies (Basset, et al, 2001; Acharya, 2014).

Strengths & Limitations

As stated previously, the primary researcher is a COPMI and therefore brings the experience and potential bias of that role. Qualitative research is meant to deepen the understanding of the lived experiences of a group of people and having personal experience with the topic is a strength that adds investment in the research and a unique perspective.

There are several limitations to this study. The first is that, although the primary researcher has personal experience, they are a novice in qualitative research. The researcher has had multiple classes focused on research and read extensively in preparation for this project, however, this is still the first independent project.

Another limitation is the homogeneity of participants. Two of the participants are from the same facility, all participants worked in inpatient rehabilitation as their primary setting, and three of the four were in the Mid-Atlantic region, in large metropolitan cities. Originally, it was not a requirement or intended to be only with participants in inpatient settings, however, that became the only setting. Additionally, the similarity of geographic region and city was not intentional, but by chance. By having information from similar participants, it gives us a greater depth of understanding for that setting but limits the overall understanding of the mental health field. The relative inexperience of the occupational therapists is also important to note as the average years of experience was only 3.85 years, further limiting the range of information.

The third limitation is the short time frame of interaction with the participants. Due to the timeline and scope of this project, the interviews were limited to 30-60 minutes each, over the phone. Ideally, the interviews would have been longer, over more occasions to obtain a broader pool of information.

A fourth limitation is the way the questions were asked. At the end of the first interview, participants were asked what they would change about how occupational therapists interact and work with parents with mental illness. By asking this it could imply that there needs to be a change and skew their answer to coming up with an answer that indicates change, even if they previously would not have indicated a change.

Implications for Occupational Therapy

From this study, there are several implications for occupational therapy. More education is essential for occupational therapists to identify the need for setting goals focused on parenting. Adding class discussions on ‘child rearing’ and the other important IADLs focused on parenting will prepare occupational therapists to better serve a large population, in physical or mental health. In addition, the limited continuing education courses specific to parenting and occupational therapy makes it difficult for those who are interested in parenting and mental illness to learn more.

For occupational therapists who are currently treating parents with mental illness, creative solutions are needed to overcome the lack of access barrier. Ideally, facility policies and insurance coverage would change to allow family interventions to be more prevalent, however, until then options such as telehealth or electronic communications with families could fulfill that role. With the current Covid-19 global pandemic,

telehealth has become more important than ever for occupational therapy and has the potential to change the way occupational therapists involve families in their therapies. Telerehabilitation can be used for evaluation, to teach new skills, incorporate assistive technology, modify the environment, and create routines and habits (AOTA, 2018). Research has supported the use of telehealth for occupational therapy services for a variety of clients including children with Autism, home programs for children with Down Syndrome, hand therapy for adults, caregiver training for adults with dementia, amongst others (Nissen, Hersch, Tietze, & Chang, 2018; Wallisch, Little, Pope, & Dunn, 2019; Walker, Washington, Early, & Poskey 2020; Worboys, Brassington, Ward, & Cornwell, 2018). This appears to be a viable solution to overcome the access barrier.

Occupational therapists have a wide skill set that allows us to tackle a complex ADL, like parenting. Occupational therapists are skilled in activity analysis allow complex activities to be broken down into smaller pieces that can be addressed through interventions previously discussed, such as kitchen tasks, coping skills, and self-care routines. Although occupational therapists know we have this skillset, other professions may not. In addition to creative solutions, it is imperative that current and future practitioners advocate for the occupational therapy profession and the role of occupational therapy in mental health and parenting. Advocating within the workplace with other professionals, at the facility level, as well as state and national level through professional organizations like AOTA. It is up to current and future professionals to take action through research to learn more about addressing parenting and incorporate that knowledge into practice and advocacy.

Chapter Six: Summary, Conclusions, Recommendations

Summary

This graduate thesis was inspired by the researcher's personal life experiences as a COPMI who sought to understand the barriers, facilitators, and practice patterns of occupational therapists working with clients with mental illness. A phenomenological, qualitative design was used to gain an in-depth understanding of the participants background, daily lives in practice, and overall life experiences in regard to the topic. Of the four participants, three were located in the Mid-Atlantic region in a large, metropolitan city, while the other was located in the South in a small city. All participants were women with experience levels from five months to eight years in practice. Each interview took place over the phone and was from thirty to sixty minutes in length.

The results of the interviews, after analysis by the committee, showed six themes. The first three related to barriers: parenting is secondary, lack of access, and lack of familiarity. The fourth theme, supports vary, related to the facilitators occupational therapists experience that aid in their practice. The fifth theme, relevant skills, touched on the practice patterns and what the occupational therapists were focused on in regard to parenting. The final theme did not fit specifically into either of the research questions but reflected an overall desire to change how they practice by incorporating families in intervention to allow for a focus on parenting.

Overall, the findings from this study support previous findings in the literature despite the lack of an occupational lens. Shorter length of stay and frequent readmissions with the focus on illness management make it difficult to address IADLs, such as parenting,

rather than expanding to larger life skills. Additionally, the participants and primary researcher deny learning about parenting in their graduate curricula despite having an ACOTE standard that includes it. From this lack of familiarity or expertise, participants who were not parents felt uncomfortable or out of place due to the cultural taboo of nonparents giving parenting advice to parents. Other factors such as geography, facility policies, and stigma add to the barriers occupational therapists already experience. Focusing on the relevant skills that are part of occupational therapists' scope, like self-care and coping strategies, can allow occupational therapists to address parenting in a less direct, but possibly effective, way. A more direct way in which occupational therapists can address parenting is through helping their clients navigate custody challenges. The lack of access and loss of custody can be greatly distressing to clients and require creative solutions such as telehealth to overcome. Repeated by each participant is the desire to have more family-based interventions, specifically involving the COPMI, as seen to be successful based on studies in other countries.

Conclusion

1. Occupational therapists addressing parents in a mental health setting face a number of barriers including parenting is secondary to focusing on symptom management, lack of familiarity or education on parenting, and lack of access to children to address parenting due to loss of custody or problems with visitation.
2. The facilitators available to occupational therapist greatly depends on facility and geographic location, but can include things such as specific facility policies, kitchen access, and having a supervisor that is an occupational therapist.

3. Occupational therapists are utilizing interventions focused on coping strategies, self-care and routines, and values exploration to address parenting in an indirect way.
4. Family-based interventions are the ideal and most desirable way to address parenting with parent and child, as seen in other countries.
5. Creative solutions are needed to focus on parenting more pointedly, such as telehealth, to mitigate lack of access to children.

Recommendations for Future Research

Recommendations for future research to expand upon this study include:

1. Replicate this study with more varied participants and in multiple settings in order to understand the barriers, facilitators, and practice patterns. This study was limited to four participants, three of whom were in the same region of the country and two at the same facility. Adding more and diverse participants, such as different family structures, a variety of cultures, and those with differing abilities, will gather a larger breadth of information.
2. Develop a study to understand the role occupational therapists may have working with the COPMI, individually and with their parent. Establishing the role of occupational therapists in working with COPMI could mitigate negative outcomes for the children, as previously discussed they have greater financial instability, increased likelihood having their own mental illness, and increased feelings of responsibility or burden. This was the original inspiration for this study and could highlight a new and important role of occupational therapists.

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