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The Caregiver Experience: Raising a Child with a Mental Health Condition

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Running Head: The Caregiver Experience: HOW MENTAL HEALTH CONDITIONS
IN CHILDREN IMPACT THE ENTIRE FAMILY

The Caregiver Experience: Raising a Child with a Mental Health Condition

By

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MSW Clinical Research Paper

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Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

Caring for a child with a diagnosed mental health condition not only affects the child, but impacts the caregivers of these children in a variety of ways. The purpose of this project was to explore caregivers' experiences raising a child with a diagnosed mental health condition, specifically looking at what supports and services are available to them, how these services and supports are utilized, and what challenges and barriers they encounter. Using a qualitative design, six participants (five professional and one familiar caregiver) were interviewed regarding their experience assisting in or raising a child with a mental health condition. Data were analyzed using both inductive and deductive approaches in which categories were first developed from the interview responses and were then linked to related literature. The findings indicated that in fact there are supports and services available to these caregivers; however, there are often barriers in reaching these supports and services. Caregivers spoke to both challenges and rewards identified in raising children with a mental health condition. These findings suggest ways that mental health professionals can assist and support these familial caregivers, identify barriers and reduce stigma surrounding children's mental health conditions, and finally ways that supports and services can be made more accessible.

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Mental health conditions in children not only affects the child, but the entire family, and in particular the caregivers of these children. While care giving alone can be challenging, being the care giver to a child with a persistent mental health condition can encompass a whole realm of difficulties. “Recent studies indicate an alarmingly high prevalence rate, with approximately 1 in 5 children having a diagnosable mental disorder and 1 in 10 youths having a serious emotional or behavioral disorder that is severe enough to cause substantial impairment in functioning at home, at school, or in the community” (Huang, Stroul, Friedman, Mrazek, Friesen, Pires, Mayberg, 2005). Mental illness can be defined as, “significant and persistent distress and impairment of functioning, with causes that are psychological or pschyo-physical” (Laylard & Clark, p. 36, 2014). It is estimated that around 3% of children suffer from anxiety disorders, 1-2 % suffer from ADHD, while less than 1% suffer from depression. The largest percentage of children suffer from conduct disorder, which affects around 5% and 1 in 150 children are born on the autism spectrum” (Laylard & Clark, p. 215, 2014). “Some estimates of children with autism in the United States are even higher. The Center for Disease and Control and Prevention estimates that around 1 in every 68 children born in the United States have been identified with autism spectrum disorder (ASD)”.

<http://www.cdc.gov/ncbddd/autism/data.html>

Given this prevalence rate, many children diagnosed with mental health conditions are not receiving proper treatment. “It is estimated that 75% of children with emotional and behavioral disorders do not receive specialty mental health services” (Huang, Stroul, Friedman, Mrazek, Friesen, Pires, Mayberg, 2005, p. 615). Policy studies that have been done on children’s mental health services yielded findings that

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signify, “(a) that children were not getting needed mental health services; (b) that those served were often in excessively restrictive settings; (c) that services were limited to outpatient, inpatient, and residential treatment, with a few intermediate-care, community-based options available; and (d) that the coordination among child-serving systems responsible for mental health needs was weak” (Huang, Stroul, Friedman, Mrazek, Friesen, Pires, Mayberg, 2005, p.616). Given these findings, it is imperative for mental health clinicians to provide effective and efficient treatment to these children suffering from mental health conditions.

While it is important for children with mental health conditions to receive proper treatment, it is also essential to look at the caregiver’s experience of raising a child with a mental health condition. These parents “may face challenges such as financial burden, sibling rivalry, stigma, self-doubt and blame, marital stress, and difficulty receiving services, in addition to dealing with the symptoms their child is experiencing” (Mendenhall, Mount, 2011, p. 183). Caregivers often feel a sense of strain and burden as a result of their child’s mental health condition. “Although many factors can influence the effects of caregiver strain, child behavior is the strongest predictive factor associated with caregiver strain” (Brannan & Heflinger, 2002). It is important to note that caregiver strain can profoundly impact child well-being and treatment. Often times these parents also experience self-blame and guilt towards their child’s condition. “Even when accepting the idea that their children’s disorders have a biological underpinning, some parents continue to ‘self-blame’. Moreover, parents of diagnosed children are sometimes regarded with suspicion for problems by family, friends, spouses/partners, mental health professionals, and the community” (Moses, 2010, p.104).

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It is also important to note that many caregivers suffer in their own health, social life, work and family environment as a result of their child's mental health condition. "A study on the care giver experience of parents of children with disabilities found that 41% of the caregivers reported worsening of their own health state over the past year, and they attributed this decline to their lack of time and control and a decrease in psychosocial energy" (Mendenhall, Mount, 2011, p.184). Parents also report distress in their own social lives. One study found that, "Parent caregivers identify social activities and hobbies are one of their most neglected areas" (Mendenhall, Mount, 2011, p.185). Not only those areas, but another affected area is the caregiver's work and profession. Rosenzweig, Brennan & Ogilivie conducted "A qualitative study investigating the work-family fit for parents of children with mental illness and found that there is often spillover and conflict between the work-family areas of life, making it necessary for parents to adjust their employment status" (2002). Family environment and family culture is another affected area. "Parents of children with mental illness reported family life was strained in these areas: effects on the siblings; parents' ability to spend time away from children; amount of attention parents provided to other children; family's relationship with extended family, friends, and neighbors; the family's ability to participate in social activities as a family; and the parent's relationship with their spouse" (Mendenhall, Mount, 2011, p.185).

It is imperative for social workers and other mental health professionals to better support these types of caregivers. "Understanding the processes of family involvement can lead to the development of new interventions for engaging families in services and deeper understanding of how and why interventions are effective" (Hoagwood, 2005,

p.690). Collaboration between families and mental health professionals is essential for the well being of the child and the adult. “Providing parent caregiver’s with emotional support and an outlet for their stress that is separate from their child’s treatment may help to decrease mental health and emotional strain and strengthen the self-concept of parents” (Mendhall & Mount, 2011, p.186).

This study looked at the caregivers’ experiences raising a child with a mental health condition, and looked at what supports are available to these caregivers and in which ways these caregivers can be better supported by mental health professionals. Qualitative interviews were conducted, specifically asking questions regarding caregivers’ experience, what supports these caregivers utilize, and how caregivers can be better supported by mental health professionals. The purpose of the interviews was to gain a sense for what is working for these adults, and to find out what areas of support are in need that can better support these caregivers and their families.

Literature Review

Research done on children’s mental health conditions has focused primarily on the child; the impact it has on the child’s life and successful interventions and medications used to treat these disorders. While it is important to look at children’s mental health conditions, it is also imperative to look at how these disorders impact the caregivers of these children and ways to better support them. Key topics will be discussed in this literature review, including the prevalence and significance of children’s mental health conditions, the caregiver’s experience, current support systems for caregivers and families, and barriers to support for these families.

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Children's Mental Health

Mental health conditions among children are on the rise, and at a significant rate. The World Health Organization (WHO) speculates that by the year 2020, childhood neuropsychiatric disorders will increase by more than 50 percent internationally to become one of the five most common causes of mortality, morbidity, and disability among children (LeCroy, 2011). According to the Center for Disease Control and Prevention (CDC, 2013), mental health disorders affect children of all ethnicities/race, age and regions of the country (CDC, 2013). Interestingly, the CDC also indicates that the number of children with a mental health disorder increase with age (CDC, 2013). Gender differences exist as well with “boys being most likely to have most of the conditions reviewed compared to girls, including ADHD, behavioral or conduct problems, autism spectrum disorders, anxiety, Tourette syndrome, and cigarette dependence, while girls are more likely to suffer from alcohol use disorder and depression” (CDC, 2013).

Research indicates that one in every five children have a diagnosable mental health disorder and one in 10 youths have a serious emotional or behavioral disorder that impacts the child's functioning substantially in the child's functioning at school, at home and in the community (Huang, Stroul, Friedman, Mrazek, Friesen, Pires, Mayberg, 2005). “The National Institute of Mental Health's National Advisory Mental Health Council, Workgroup on Child and Adolescent Mental Health (2001) concluded that no other illness damages so many children so seriously” (Huang, Stroul, Friedman, Mrazek, Friesen, Pires, Mayberg, 2011, p.1). Among the most prevalent children's mental health disorders, mood disorders are persistent and recurrent. In the United States,

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epidemiological studies propose that up to 2.5% of children and up to 8.3% of adolescents suffer from major depression (Ong, Caron, 2008). Major depression also has a high relapse rate, which can be up to 70% at 5 years; and follow up studies done on depression indicate that childhood and adolescent depression often returns in adulthood (Ong, Caron, 2008).

Given this information on children's mental health conditions and how they affect such a large proportion of the population, it is essential to note that children's mental health not only affects the child, but the entire family as well. Caregivers caring for these children face numerous obstacles and are in need of support informally and formally; for example by mental health professionals. It is vital to look at the caregiver's experience to better understand the needs of these caregivers and the impact caregiving has on them and their families. It is also essential to look at what is currently available to these caregivers and families, to better understand what is helping these families and what could offer better support.

Caregivers' Experiences

Understanding the caregiver's experience caring for children living with a mental health condition is critical because the child's mental health can impact the entire family unit. Often times, these caregivers invest so much time, resources and energy into supporting and finding effective treatments for their child, they often neglect their own psychological and physical well being. The health and psychological well being of the caregivers is important because it affects how they cope with and support their children.

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For the purpose of this review, the term “caregiver” will be defined as an adult living with or caring for a child diagnosed with a mental health disorder.

Strain and Burden

A prominent theme in the literature referring to a caregiver caring for a child with a mental health disorder is caregiver strain. Caregiver strain can encompass several different aspects, but the most common areas of caregiver strain can include guilt, sadness, parenting stress, interruption of family relationships, restrictions on their personal time and freedom, financial strain, disrupted social life and interruptions at work (Brannan, Heflinger, 2006). There has been literature suggesting that differing life experiences and socio economic status can affect caregiver strain. For instance, a caregiver’s employment status and educational level have been found to be connected with caregiver strain (Brannan, Heflinger, 2006). It is also important to note that strain of the caregiver can impact the types of services the child receives.

In a study done by Brannan and Heflinger, these authors looked at caregiver strain in two child mental health service systems. They investigated both caregivers’ objective strain and subjective strain in a managed care setting compared to a fee for service setting. In this study, objective strain referred to the observable interferences and negative experiences that result from children’s emotional and behavioral disorders (Brannan, Heflinger, 2006). In both samples, they found that the child’s symptoms resulting from their mental health condition and the impairment the disorder had on their psychosocial functioning increased objective strain in both samples (Brannan, Heflinger, 2006). Also, in both samples caregiver strain was amplified by time and location barriers

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of which the services operated. One major difference in the samples to note was that in the managed care group, the more pleased caregivers were with their family life, the less strain they experienced (Brannan, Heflinger, 2006).

This study also looked at subjective strain among caregivers. Subjective strain relates to the caregivers' noticeable negative feelings surrounding their children's problems such as embarrassment, resentment and anger (Brannan, Heflinger, 2006). In both of the fee for service and managed care samples, the child's age and outward problems were positively related to caregiver subjective strain (Brannan, Heflinger, 2006). The major findings of this study were that as the more barriers towards payer/provider increased, families in the managed care system experienced more objective strain than did the fee-for-service families and as children aged five to 17.

Another study done by the same authors demonstrated the difference in strain amongst caregivers caring for youth with substance abuse disorder and families of youth with mental health problems. Strain among caregiver's has been found to be related to, "entering mental health treatment, receiving more restrictive services, having longer lengths of stay, having more gaps in care, and incurring higher costs of care" (Heflinger, Brannan, 2006, p.85). This study also compared and contrasted the idea of objective strain and internalized strain. The important findings of this study indicated that both groups reported higher subjective internalized strain than other forms of strain. This study also indicated that the more depressive symptoms the caregiver possessed, the more objective strain the caregivers tended to account for (Heflinger, Brannan, 2006). This is essential because it describes that between two different samples of caregivers, the objective strain the caregivers report for is significant.

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It is also important to look at how diverse types of caregivers report strain differently. A study done on caregiver strain for those who care for children with emotional and behavioral disorders demonstrates this phenomenon. This study looked at two different caregiver groups: Medicaid caregivers versus military caregivers. This study done by Taylor-Richardson, Heflinger and Brown indicated that Medicaid caregivers reported high levels of objective strain, whereas military caregivers scored higher on the subjective internalized and externalized subscales of Caregiver Strain Questionnaire (CGSQ) (2006). This study also looked at how other relatives report strain versus primary caregivers. The authors found that relatives of children with mental health disorders report less experience of strain than those directly caring for these children (Taylor-Richardson, Heflinger, Brown, 2006). This is important because it demonstrates that while relatives of children with emotional behavioral disorders do report some types of strain, it is often not in the same level of severity of the primary caregivers (such as parents).

Looking at how social connections affect the caregiver, child and family well being are also essential. How caregivers utilize their social supports not only affects them as caregivers, but it impacts in how they care for their child. In a study done by Munsell, Kilmer, Cook and Reeve (2012), the authors discuss caregiver strain as it relates to social supports and family well being. The caregivers in this study reported high levels of strain as their child displayed more challenging and oppositional behaviors. They also found that caregiver social connections and caregiver strain were considerably connected with caregiver well-being (Munsell et al., 2012). These results point out that when caregivers are more strained, the children they care for and their families suffer.

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Burden, Loss and Grief

Burden is another experience of caregivers caring for a child with a mental health condition. Feelings of burden again not only affect the caregiver, but also the child and even the course of their illness. Two studies on parental burden highlights two different kinds of burden: objective burden and subjective burden. These two concepts were defined as, “objective burden being the disruption of tangible aspects of a caregiver’s life, while subjective burden is the extent to which caregivers perceives care responsibilities to be overly demanding and stressful” (Liu, Lambert & Lambert, 2007, p.87).

A study done with Chinese parents (fathers = 49, mothers n=48) caring for a child with mental illness involved giving three instruments to parents in order to determine the level of burden they faced. They included the Social Demographics Questionnaire, Coping Health Inventory for Parents, the Caregiver Burden Scale. The findings indicated that the parents suffered from high levels of care giver burden, especially subjective burden (Lio, Lambert & Lambert, 2007). Most caregivers reported increased pressures in their life, with nearly all of them expressing increased anxiety. Most parents of this study reported never using a coping strategy that they could name to deal with their feelings of burden.

Burden can also impact how and when parents seek help for their children with a mental health condition. In a study done by a public school system in North Carolina, parents were given the Child Behavior Checklist, which asks about a child’s behavioral problems, and then were randomly selected to participate in the study. The parent and child were interviewed separately about the status of the child’s psychiatric status, using

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the Child and Adolescent Psychiatric Assessment (Angold et al., 1998). The most frequent individual burden expressed by the caregivers was the effect on personal well-being, restrictions on personal activities, and stigma. The results also showed that when a child displayed a diagnosis and impairment, the perceived burden was associated with a three times higher likelihood of a parent seeking a specialist in mental health services (Angold et al., 1998). A sense of burden is another significant experience that caregivers face when raising a child with a mental health condition.

The experience of grief among caregivers whose child has a mental health condition is another prominent theme in the literature. Grief can encompass symptoms such as intrusive thoughts and emotions, avoidance and preoccupation with mental illness (Richardson, Cobham, McDermott, Murray, 2013). In many circumstances, grief is often not recognized by mental health professionals and the surrounding community of caregivers. In Richardson et al.'s study, the questions for caregivers were geared towards the parent's cognitive, behavioral and emotional experiences. The measure also investigated the parent's social supports and coping styles. The study found that participants sustained a number of losses associated with their child's mental illness (Richardson, Cobham, McDermott, Murray, 2013). "Losses included loss of their child's former or idealized personality, dashed expectations, loss of certainty about their youth's future, loss of parental confidence and control, loss of financial stability, limited chances to engaged with other children, missed opportunities to socialize and loss of self" (Richardson, Cobham, McDermott, Murray, p. 730, 2013). Participants also described feelings consistent with grief; sadness, numbness, worry, denial, self-blame and shock. A focus group found similar findings surrounding guilt. These parents reported similar

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feelings of grief, such as being overwhelmed, fear of the future for their child, anguish and exhaustion (Mendenhall, Mount, 2011).

However, in a different study done by Godress, Ozgul, Owen, Foley-Evans (2004), the authors concluded that while parents experience high levels of grief characterized by intrusive feelings and thoughts, and difficulties adapting to the illness, parental grief appears to diminish over time. This usually occurred after experiencing an extended period of grief over the illness. Increased parental grief was linked to health status and psychological well-being, as well as negative affective parent-child relationship (Godress, Ozgul, Owen, Fole-Evans, 2004). This finding suggests that given the significant amount of grief parents can experience, it may lessen over time as parents become more familiar with and accustomed to their child's mental illness.

Looking at caregivers' experience of raising a child with a mental health condition is necessary in assessing what kinds of supports are available and effective to these caregivers. Their experience is so vital because they do the primary care-taking of these young individuals and often coordinate their care. Often times these caregivers serve as parent, therapist, case manager, school advocate and much more. These caregivers need and deserve valuable support from the mental health community. The next part of this review will explore what kinds of supports are currently available for these caregivers and their families.

Caregiver and Family Support

Looking at what is currently available to caregivers' and families is relevant because it gives mental health professionals knowledge about what supports are working.

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“Parents have identified the following needs when seeking treatment: education about mental illness and community resources, development of problem-solving and stress-management skills, and learning to cope with their child’s symptoms” (Mendenhall, Mount, 2011, p. 186). Similarly, Mendenhall and Mount (2011) looked at several different types of interventions that support caregivers. The first support group they examined is psychoeducational psychotherapy. Otherwise known as PEP, this intervention combines psychotherapeutic and educational techniques to inform both the family and patient to reach better outcomes for the whole family (Mendenhall, Mount, 2011). PEP also provides families with prognosis of the illness, information about symptoms and services, and teaches coping and communication skills. In a study done on outcomes of this type of intervention, “parents reported greater satisfaction with treatment and more positive functioning and relationships than controls who did not receive psychoeducation over a 6-month period” (Mendenhall, Mount, 2011, p.187). Such groups are often offered by national organizations such as NAMI.

These findings corroborate with other findings in a study by Ong and Caron on family-based psychoeducation for children and adolescent caregivers. These authors spoke to the finding that family-focused psychoeducation was found to be of higher quality than individual focused psychoeducation. They emphasized that psychoeducation has the benefit of adding to sharing support among various families and improving their coping skills (Ong & Caron, 2008).

The next intervention they looked at was psychotherapies, which typically involve therapeutic interventions done with the child and often times can be done with the parent or caregiver as well. Family therapy has been demonstrated to be a productive

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intervention for several different mental health issues, and is often used concurrently with parent management training (Mendenhall, Mount, 2011). The benefit of a caregiver doing psychotherapy with their child is that it gives the parent a safe space to talk with the child about their own needs with the support of the therapist. Families who have done psychotherapy in the past have reported a decline in PTSD symptoms for both parent and child, as well as a decline in anxiety and depressive symptoms for the child (Mendenhall & Mount, 2011).

Parent management training is another successful and useful intervention used. Otherwise known as PMT, in parent management training parents are taught methods to help deal with challenging behaviors in children, such as tantrums, medication compliance, and help in encouraging a child's cooperation in following directions from parents. (Mendenhall, Mount, 2011). "A study of 94 parents of children diagnosed with oppositional defiant disorder showed that this PMT program is an effective intervention for public health care settings; results indicated reductions in behavior problems as well as improvements in comorbid conditions" (Mendenhall & Mount, 2011, p.187).

The last intervention this study evaluated is technology-based interventions. Otherwise known as tele-mental health, this kind of intervention includes mental health interventions via videoconferencing, e-mail, internet, virtual reality simulators and the telephone (Mendenhall & Mount, 2011). This kind of intervention can be beneficial when caregivers and parents are living in rural areas and do not have means and access to needed support. The potential drawback of this intervention is being able to keep the caregiver and child's attention throughout the session. Some recent studies of technology

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based interventions have reported high client approval for various populations

(Mendenhall & Mount, 2011).

Hoagwood et al., compiled and compared over 50 programs that are available to caregivers in forms of support. They looked at family led, clinician led, and team based delivery models (Hoagwood et al., 2010). They defined family support services as those directed at “meeting the needs of parents or caregivers of children with mental health needs with the explicit purpose of helping parents/caregivers (a) clarify their own needs or concerns; (b) reduce their sense of isolation, stress, or self-blame; (c) provide education or information; (d) teach skills; and (e) empower and activate them, so that they can more effectively address the needs of their families” (Hoagwood et al., 2010, p.3).

Eleven of the programs they looked at were family-led programs. These programs are led by parents who have children with a mental health disorder. One major component of family-led programs is advocacy, and all of the programs included this element of support. Instructional and informational types of support were almost commonly represented in all these family-led programs, and a key component of these programs was to connect and link families to community resources (Hoagwood et al., 2010). However, “the evidence base for family-led support programs is thin, and the findings suggest that family support may be particularly beneficial for families who are less empowered, such as low-income families” (Hoagwood et al., 2010, p. 9).

Clinician-led programs were the next program studied. Two-thirds of the programs evaluated in this study were clinician-led, and programs were led by one or

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more clinicians, whom held a master's or doctoral degree (Hoagwood et al., 2010).

These types of support groups were often led by a psychologist, and their main focus was on behavior parent training (BPT) using strategies such as positive reinforcement, time out, praise and planned ignoring (Hoagwood et al., 2010). The theoretical premise of behavior parent training is that negative relations between parent and child reinforce problematic child behaviors (Hoagwood et al., 2010). It is also noted that several of the BPT training encompassed other caregiver issues such as, "stress, social supports, marital discord, anger management, communication skills, and problem-solving skills" (Hoagwood et al., p. 10, 2010) Another clinician-led program was Cognitive Behavioral Therapy, which focused more on helping caregivers identify their anxiety and modeled ways to reduce their anxiety for parenting their child (Hoagwood et al., 2010).

These programs focused on, "building parenting skills and addressing the caregiver's own symptoms of anxiety or distress through cognitive behavioral techniques such as cognitive restructuring and relaxation strategies. Additional instructional support skills focused on enhancing the caregiver's problem-solving, communication and/or coping skills" (Hoagwood et al., 2010, p. 11). Almost all of the clinician-led programs focused upon diminished symptoms displayed by the child or expansion in functioning (Hoagwood et al., 2010). Overall, programs that consisted of caregiver support as part of the child treatment plan resulted in positive advantages for the child, caregiver and service-related outcomes.

Team-led programs were the next type of support this study examined. Team-led programs encompass a program that is led by a clinician and family member. The clinician in these programs was usually a social worker or psychologist and collaborated

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with a family member (Hoagwood et al., 2010). Of this type of program, emotional support was the most important factor of team-led programs (Hoagwood et al., 2010).

“Overall, team-led parent support programs showed positive benefits on caregiver-related outcomes related to self-efficacy, symptoms, and perceived social supports and skills” (Hoagwood et al., 2010, p. 18).

Empowering caregivers and parents is another key component in support services. Caregivers that feel empowered are more likely to be better involved with their child’s care, and how to properly navigate through the mental health system (Hoagwood, 2005). Empowerment can be defined as, “a process through which people become more able to influence those people and organizations that affect their lives and the lives of those they care about” (Hoagwood, 2005, p. 701). In this study parents received knowledge and information about mental health services and systems, and were also trained in how to better communicate, goal setting, problem solving, assertiveness, and how to find community resources. “The results indicated that one year and two months after the training, the group had more self-efficacy than the control group” (Hoagwood, 2005, p. 701).

It is evident that there are models of supports for caregivers whose children have a diagnosed mental health condition. The literature suggests that these supports are needed among caregivers, and often utilized. While it is essential for the child to have supports, it also is vital that these caregivers feel supported and connected by mental health professionals.

Barriers to support and interventions

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Although there are many supports and interventions available to caregivers and families raising a child with a mental health condition, it is also important to look at the barriers these caregivers come into contact with. If mental health professionals can identify barriers to support, they can better equip these caregivers to accessing supports and interventions for their child, and for themselves. It is important to point out that, “The mental health care system for children is complex and fragmented, with separate mental health services having different points of entry and funding streams. Also, unlike physical health conditions and health services, there is a stigma associated with mental health and mental health service utilization that can result in denial of mental health problems and reluctance to use services” (Owens et al., 2002, p.732).

Owens et al., (2002) pointed to three distinct barriers to treatment and mental health interventions for children and their families. These barriers include, “(1) structural barriers; such as lack of availability of providers, long waiting lists, lack of insurance or inadequate insurance coverage, transportation problems, inconvenient services, (2) barriers related to perceptions about mental health problems; such as parents’, teachers’, and medical care providers’ inability to identify children’s need for mental health services, (3) barriers related to perceptions about mental health services; such as lack of trust in or negative experience with mental health providers, lack of children’s desire to receive help, and stigma related to receiving help” (Owens et al., 2002, p.732).

It is potentially valuable to look at what parents and caregivers report surrounding barriers to accessing mental health services for their child and to get support themselves. In this study by Owens et al., the authors found that approximately 35% of parents reported a barrier to mental health services for their child with mental health needs

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(2002). An interesting finding in this study was that parents who reported barriers recognized more difficulties with parenting their child compared with parents who did not report any barriers (Owens et al., 2002). Parents who also reported barriers were those who experienced three or more parent stressors, those who had schedule constraints and those who were divorced (Owens et al., 2002). Another vital point that this study made was that, “Additional responsibilities related to attendance at meetings was associated with structural barriers, and difficulties with parenting were related to all types of barriers. Parents may be too overwhelmed by their child’s psychosocial problems and lack resources and knowledge about mental health and health services to be able to care for their child and overcome barriers to mental health care” (Owens et al., 2002, p. 735).

While many caregivers and families feel that services and supports are valuable, it is common that families are not receiving adequate supports. Many caregivers and parents strive to have their child living in the home, and in their care. For this to be possible, children with persistent mental illness often need wrap around services. Wrap around services are, “the comprehensive range of services and supports needed to maintain a child with a serious mental illness in a community setting. Many of these intense services were formerly offered by residential treatment programs, but are now individually tailored to the child’s and family’s needs to make it possible for children with serious mental illnesses to receive intensive services while remaining in their homes and communities” (NAMI, 1999, p. 16). A national survey of parents and other caregivers living with a child with mental illness reported that there seems to be a common breach between services with few flexible treatments options available to these families. For instance, based on a survey the authors conducted, they concluded that of

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the 83% of families who were not receiving wrap-around services, 59% felt that they were of significant value (NAMI, 1999). These families expressed that they felt other services were valuable to them, such as respite care for their child, however, of the parents surveyed, only 16% of families reported that they were receiving such a service (NAMI, 1999).

The study concluded that on an individual level, parents often felt frustrated, blamed and unsupported by family, professionals, friends and schools (NAMI, 1999). Parents identified needing services like family support services, wrap around services and respite care for their child. These parents also expressed wanting more support from mental health professionals about their child's mental illness and wanted earlier intervention services for their child (NAMI, 1999).

While there are supports available in some larger settings for parents and caregivers, there is still a high need for these caregivers to get the appropriate types of support and for mental health professionals to make these supports more accessible. Caregiver's of children with mental health problems often face significant challenges, and they are often in need of different support programs and interventions so that they can attune to the needs of their child. It is also essential for the family unit as a whole to have support when living with a child with a mental health condition. It is evident that when caregivers and families feel supported and know where to turn to in the mental health system, it is not only better for themselves, their children, but the whole community as well. This study inquired as to what supports caregivers utilize and may still need, at the level of detail qualitative interviews afford, with the goal of better supporting these adults and diminishing the associated burdens.

Conceptual Framework

This study will be understood through the framework of the ecological perspective. There were three major contributors to this perspective: Robert Park, Rachel Carlson and Caryl Germain. This perspective allows social workers to look at the nature and consequences of transactions between humans and their physical and social environments (Germain, 1979). More specifically, ecological social workers, “direct their practice efforts towards improving the transaction between people and environments, nurturing human development within particular environments, and improving environments so that they support the expression of client systems’ positive dispositions and potentials” (Forte, 2007, p. 118). Caryl Germain stressed the importance of understanding the person, the environment, and the transactions that occur between the person and their environment.

Understanding how people interact with their environment is essential for social work practice. The ecological perspective uses a holistic view of people in their environments. Germain and Gitterman explained this as, “From a holistic view, people and physical and social environments can be fully understood only in the context of the relationship between and among them, in which individuals, families and groups and physical/social environments continually influence the operations of the other” (1996, p.6). This being said, the ecological perspective emphasizes that people and their environment are whole; they cannot be understood as interdependent of one another. It is important to point out that people are in constant interaction with the world around them, and these transactions affects how people navigate through their environment.

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It is important to note that the environment includes varying levels of systems.

Urie Bronfenbrenner was an ecological theorist who proposed that all human development must be understood in a “development in context” (Forte, 2007) He thought that, “Because there are many different environmental contexts, there must be many ways to develop as a person” (Forte, 2007, p. 134). The two of Bronfenbrenner’s (1979) ideas that will be highlighted in this study are the importance of the immediate setting, and the mesosystem. The immediate setting “includes systems such as the home, the classroom, and the neighborhood in which the person develops. This setting is a specific place or life space with identifiable physical features where developing persons participate in specific activities for a particular time” (Forte, 2007, p. 136). He defines the mesosystem as, “a system of relationships between two or more immediate settings” (2007, p. 136). Bronfenbrenner later urged ecological developmental scientists to study the connections between the family and the school, the family and the peer group, and the family and the support systems such as the neighborhood and daycare (Forte, 2007).

Recognizing that parents and caregivers have to navigate through their environment to utilize services for their child and themselves is key to understanding the transactions they experience. The transaction that caregivers encounter through their environment often perpetuates how much help and support they will seek out for their child and themselves. Using the ecological perspective as a framework, parent experiences in their environment were transcribed and coded after interviewing them. The researcher looked for themes and codes that spoke to how the caregiver’s environment and service utilization affect each other. The ecological perspective will be used in the way that the researcher looked for themes that spoke to what caregivers utilize

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from their immediate environment and at what relationships emerge between two or more settings. Looking at caregivers' experience through this lens allowed me to identify what caregivers still need from their environments; and how better improving their transactions will lead to better services and supports.

Methodology

Research Design

The research design for this study utilized qualitative interviews. The purpose of this study was to collect information in order to explore the caregivers' experience in raising children who have a diagnosed mental health condition. This study looked what services and supports these caregivers utilize, and how these services and supports can be improved. The literature on this subject highlights what supports and services are available to these caregivers, and what barriers to support these caregivers often encounter. In order to begin measuring the quality of the services these caregivers utilize, caregivers and professionals in the mental health field across disciplines who are assisting parents and caregivers had the opportunity to talk about their experience, and their recommendations for better service and support utilization.

Population and Sample

The sample invited to participate in this study included a group of parents or other familial caregivers who are currently or recently had a primary role in raising a child with a diagnosed mental health condition, or professionals in the mental health field who work with caregivers. Ideally, the sample would have consisted of four professionals and four caregivers. These interviews could be potentially be utilized as a needs assessment. The

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interview sample was selected through a variety of agencies such as a local school district, a local association for children's mental health, and a private behavioral consulting firm. This firm provides services and support to people with varying disabilities who exhibit difficult behaviors. They provide services to the individual and as well as other support people, including the family.

Participants were selected through a combination of purposive sampling and snowball sampling. Purposive sampling is defined as, "The investigators use their judgment and prior knowledge to choose for the sample people who best serve the purposes of the study" (Monette, Sullivan, Dejong, 2011, p.153). All participants were selected on the basis of either being a caregiver themselves, or a professional in the mental health field who has or currently is assisting caregivers whose child has a diagnosed mental health disorder. In order to narrow down a potential pool of mental health professionals and obtain a study sample, snowball sampling was used. Potential interviewees were requested from the researcher's committee members, individuals employed in the mental health field, and other professional acquaintances. The researcher attempted to request potential participants from those who agreed to participate in the study until eight interviews were scheduled, however, only six participants responded to the study.

Protection of Human Participants

In order to ensure protection of human participants, informed consent forms were created using a template provided by the University of St Thomas. These consent forms were reviewed with each participant prior to beginning the interview that further

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explained the purpose of the study, the voluntary nature of the study, and the measures that will be used to ensure confidentiality (Please refer to Appendix B). The form was reviewed and approved by the chair of the researcher project prior to the interviews. The participants of this study were adults and the focus was on their experience versus that of their children, and so in consultation with the IRB chair, an expedited review was conducted by the IRB. The sensitive nature of the interview questions being asked was explained to the participants and therefore the risks involved in taking part. The interview questions were only completed by adult caregivers, and professionals in the mental health field. I did give professionals interviewed a half sheet of paper (Appendix A) explaining my study to pass along to other professionals if they feel they would be a beneficial candidate to interview. Additionally, if a participant was interviewed and passed the interest of my study along to another person, I did not follow up with that professional who made the referral to ensure no coercion of participants. The questions in the interview did not ask any identifiable information, such as names, addresses or phone numbers. Participation of this survey was completely voluntary, and if participants decided to not continue with the interview, the interview would conclude. Participants were also given the choice to not answer particular questions, if they wished.

Data Collection

The interviews were conducted in person, audio taped and later transcribed by the researcher. The questions used were semi-structured, with eight prepared questions. I did ask the interviewee if their child has a mental health condition; what kinds of services they currently utilize in regard to their child's mental health, what services might be better utilized, what kinds of informal and formal supports they find helpful, what

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challenges and rewards are associated with care giving, what aspects of their life are impacted by their child's mental health condition, what barriers they feel impact their service utilization, and what their recommendations are for better access to services and supports. If the interviewee was a professional, I was asking what their professional experience is in assisting caregivers, what services they find helpful to caregivers, what barriers they feel impact caregivers, and what their suggestions are to better assist these caregivers. The interview questions, themselves, are attached as Appendix C & D.

The audio tape interviews were transcribed and all records will be kept confidential. Transcripts and tapes will be kept in a locked file at the residence of the interviewer. Any potentially highly identifying information will be removed from the transcripts to ensure the confidentiality of the participants (such as names, locations, workplace, etc.). Once the audio parts of the interview have been transcribed, all audio recordings from the interview will be digitally deleted by May 31st, 2015. I will keep the written transcripts in my home, in a locked file cabinet.

Data Analysis

The interview questions were developed based on themes that were presented in the literature. The first theme noted in the literature was the caregiver's experience and related feelings. The first common theme was caregiver strain and burden (Brannan & Heflinger, 2006). A subsequent theme in the literature also notes the caregiver's social connections related to child and family well being (Munsell, Kilmer, Cook and Reeve, 2012). A second theme noted in the literature was caregiver and family support, and

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what types of services are utilized (Mendenhall & Mount, 2011). The third theme in the literature addresses the barriers to support and services (Owens et al., 2002).

Once each interview was completed, the audio of the interview was transcribed. Once transcribed, the researcher looked for themes described by the participant. The transcriptions were also reviewed for codes (such as recurring words, phrases and ideas) present in the data. The data were organized into themes (ideas that recur at a greater level of abstraction), and then further studied for sub-themes as well other themes that may be missed in the initial review.

The validity of this research will depend in part of the caregivers and professionals who completed the interview. Their unique experience as being a caregiver or professional who assist these caregivers will add to the depth of the study which is striving to uncover what families need in the form of support.

Strengths/Limitations

One of the strengths of this study is that participants will be given a chance to use their own voice and life experiences to describe their caregiver experience in raising a child with a diagnosed mental health disorder. Another strength of this study is that participants will be able to identify what services and supports are available to them and which services they use the most and find helpful. Participants were asked what they feel can be improved in utilizing these types of services, and how they can better access services in the mental health system. There are some potential limitations to this study. One potential limitation of this study would be that going through a limited number of organizations only reflects responses from those participants, and does not give a wide

variety of caregivers' experiences. Another possible limitation includes what types of mental health conditions are represented in the sample.

Results

The current study had the following research questions: What is the experience of a caregiver raising a child with a diagnosed mental health condition? What services and supports are available to these caregivers, and what are the barriers to obtaining services and supports, from their point of view? And finally, what are the common needs and challenges of caregivers raising a child with a diagnosed mental health condition? By using an ecological perspective, this study hoped to understand and identify how caregivers utilize and interact with their environment to get their needs met for themselves, their child and family. The method used for recruiting caregivers and professionals who work with caregivers used both purposive and snowball sampling through recommendations from the researcher's committee members, and three agencies: a school district, an advocacy group and a consulting firm, recruitment letters were sent to possible interviewees. Recruitment letters were also sent by email to professionals working with caregivers and who have had worked with caregivers, and these professionals were asked to pass on a separate recruitment letter to caregivers and other professionals that would potentially be interested in the study. Five professionals responded to the recruitment letter, and one caregiver responded and agreed to an approximately thirty minute audio taped interview.

The sample included six participants; five were females and one participant was male. Five of the respondents were professionals who worked with caregivers and families, and one was a caregiver to a child with a diagnosed mental health condition.

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Two of the professionals worked in a private practice setting, one doing individual psychotherapy and one working as a consultant to families whose child has a diagnosed mental health condition. Two of the professionals worked in a school setting, one being a school social worker, and the other providing school based mental health therapy. The other professional was a project director of an agency providing services to parents and caregivers.

Data were gathered through transcribed audio taped interviews. Themes were then discovered through inductive methods. The transcripts were investigated in an inductive manner, seeing what themes were present on their own and how these themes related back to what was present in the existing literature.

Five major themes emerged when the data were explored inductively. These themes were: caregiver challenges: internal challenges and external challenges, stigma associated with mental health, systemic issues regarding access and navigation through the mental health system, and supports: what caregivers need and what supports are beneficial to caregivers, and lastly, what rewards are experienced by caregivers. The themes that emerged inductively in these areas can be seen in Figure 1.

Themes

Figure 1: Themes

Caregiver Challenges	Internal Challenges: feelings of isolation, exhaustion, worry, self-blame and guilt. External Challenges: Interference with
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	profession, financial constraints, transportation issues, time constraints, priority of family members.
Stigma	Shame surrounding mental health diagnosis.
Systemic Issues	Accessing and navigating mental health system
Supports	What caregivers utilize, and what caregivers need and benefit from.
Rewards	Feelings of reward and success in relation to children with a mental health condition.

Theme of Caregiver Challenges: Internal and External Challenges

Participants were asked to reflect upon their experience working with caregivers and caregivers raising a child with a diagnosed mental health condition. Two sub-themes emerged within participants' answers to questions regarding what caregivers common needs are and what area's of a caregiver's life is most impacted, and what challenges arises from parenting a child with a diagnosed mental health condition. The first sub-theme most commonly identified by professionals and caregivers were internal challenges, such as feelings of isolation, exhaustion, worry, self-blame and guilt surrounding the child's mental health condition. The second sub-theme most commonly identified by professionals and caregivers were external challenges, such as conflicts with

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caregiver's profession, financial constraints, transportation issues, time constraints and priority of family members.

Theme #1: The caregiver's challenges raising a child with a diagnosed mental health condition

The first and most identified theme that emerged from professionals and caregivers' responses was the caregiver's challenges raising a child with a diagnosed mental health condition. There were two sub-themes to this theme: internal challenges and external challenges.

Subtheme #1: Internal Challenges experienced by a caregiver

The internal challenges a caregiver experiences raising a child with a diagnosed mental health condition was very prominent in the responses. One of the internal challenges experienced by caregivers is the feelings of isolation and loneliness:

I hear a lot of parents talk about how they feel lonely, isolated, that their friends and other family might have typically developing kids and they just feel alone.

Another participant shared her experience working with parents and caregivers and the feelings of isolation they experience from immediate or extended family members:

I work with caregivers who have difficulty connecting with their extended family, I mean I'm thinking we just got through the holidays and there are families that spent the holiday at home or they had to separate their immediate family, for instance having a sibling or parent go to larger family function or church while another parent or caregiver had to stay home just because their child with a diagnosis can't handle it. Some children aren't welcome at other immediate family homes, and it really affects the parents and caregivers because they have lost a piece of that.

Another internal challenge that was present in the data was the feeling of exhaustion experienced by parents and caregivers. Often times, parents and caregivers

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become exhausted and overwhelmed by the amount of effort they have to put into a child with a diagnosed mental health condition. One professional explained:

So as far as personal needs of parents, when I'm working in family homes, a lot of times you can see that parents are just exhausted, so there is that simple getting enough hours in the day to get in some sleep. Often we are running into kiddos who are up during the night and that parent's responsibility to get up every day and attend to that child and when their child has to go to school then they have to go to work, so their just simply not getting enough rest.

Another internal challenge that came up in the data was caregiver feelings of shame and self-blame surrounding their child's diagnosed mental health condition. Professionals stressed that often times, parents and caregivers blame themselves for their child's mental health condition. Caregivers and parents often experience shame and guilt associated with their child's mental health condition. This shame can be associated with how society views mental health conditions, and how sometimes professionals and people in the community blame the parents and caregivers for their child's mental health condition. One professional said:

They feel ashamed and guilty, like what did I do wrong?

Another professional commented:

I think parents are scared, blame themselves and don't see the facts of mental illness.

A parent described her experience of self-blame and worry about how her experience was affecting others:

I probably became a burden to my friends and family because all I would talk about and cry and worry about was him. You do feel like you're the only parent out

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there, and you always see all these perfect children and you know all these perfect parents and all these perfect children and why isn't my kid like that?

Subtheme #2: External challenges experienced by caregiver.

The second sub-theme of challenges parents and caregiver's experience surrounding their child's mental health condition is external factors, such as: interferences with profession, financial constraints, transportation issues, time constraints and priority of family members. Participants described several times how external factors can affect parents and caregivers in relation to dealing with their child's mental health condition.

The first external factor that came up the most throughout the interviews was how the child's mental health condition affected the caregiver's or parents job or profession. Often times, parents and caregivers whose child has a diagnosed mental health condition have to leave their job early, attend meetings during the day, take their child to appointments during the day, and have flexibility surrounding their work schedule to accommodate their child's needs. One professional noted:

I think that one thing that, in my role at the school the one thing that comes to mind is work life, professional life, they are having to give out those sick days, and days of work to come pick up their kids and go to doctor's appointments, and that's a huge stress. Parents are afraid of losing their jobs, taking that time off to go to all those meetings and talk to people, pick their kid up from school if their having a bad day.

A parent talked about her experience with her life being impacted by her son's mental health condition and the impact it had on her job:

You know, work is affected just because I had to attend IEP meetings, I would get frequent phone calls from school, many times I would have to go pick him up because he was too upset. They wanted him to be picked up from school, so it did affect work as my unexpectedly having to leave work sometimes.

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The second external factor that came up repeatedly in the interviews was the financial burden and amount of money surrounding the services and fees for a child's mental health condition. Often times, insurance does not cover all of services needed by the child to have comprehensive services related to their mental health condition. Parents and caregiver's often are put in the position where they have to decide whether or not they can accord the services and supports for themselves and their child.

One professional noted:

Parents have to decide if they can pay directly for services, or if they have enough money for gas to get there, insurance is another thing, if they can't afford the co pay or equipment needed for the child.

Another professional commented on the financial constraint in relation to a burden caregiver's experience:

Off the top of my head, I would say sometimes it's financial; I think that, even if services have a sliding scale or fee, I think the fear of and the stress of having to pay extra.

The other external factor that came up quite frequently is the issue of transportation. Some parents and caregivers simply do not have their own transportation, can't afford to pay for gas to go everywhere for their child, or face issues with deciding who to transport within their family and who gets priority over that. One professional commented on the issue of transportation:

Some other barriers, I think if there are other siblings involved, it can be hard to manage just the needs of the child, physically manage that like whom am I going to drive today? Some parents don't have any transportation like if they don't have a vehicle or if their vehicle isn't working or isn't safe enough to transport a child.

Another therapist commented:

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I would say at least one third of my parent does not drive or has an issue with mobility. And that makes it really difficult to get to and access services.

The last external factor that often conflicts with parents and caregiver is the lack of time and the amount of time needed to be able to access services and supports. This came up in relation to time for parents and caregivers for themselves, and for their children with the mental health condition. Often times, parents and caregivers have little or no time for themselves, and they also have to manage their child, which takes a lot of time. For instance, getting their child to appointments and services takes away time they would have to get themselves to a support group or education class surrounding their child's mental health.

One professional commented on the amount of effort and time required by parents and caregivers:

There are legitimate things that get in the way, sometimes parents, there is reasons why they are giving up or why they can't get to services, they try so hard, it requires a whole lot of effort on their part and time to do their own work on top of their kids work.

Theme # 2: Stigma experienced with a mental health diagnosis

The second major theme revealed in the data was the stigma that is experienced with a caregiver of a child with a diagnosed mental health disorder. Professionals described the experience of stigma through caregivers in many different situations. Ultimately, there is a strong sense of stigma from surrounding society and culture regarding mental illness. Some professionals spoke of caregivers and parents feeling stigma from other professionals in the mental health and medical field. Stigma affects caregivers and parents in a way that it becomes a barrier to reaching out to services.

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Stigma mental illnesses are also prominent in other cultures, as many other cultures view these conditions as a weakness or sign of insanity. In some cultures, there is not describing words or even language surrounding mental health. Some of the professionals in this study spoke to the idea that the way around stigma is through continued education and support for the field of mental health.

One professional described a common need for parents and caregivers as:

I think a big need is education, I think there aren't a lot of resources out there, and there is just huge stigma around mental illness that there is just not a lot of fact based support out there.

Another professional described stigma as being a barrier to receiving support and services:

Another barrier for parents is that they just do not want to go into the system, just the stigma is another huge one, isolation and shame, they think "oh there's something wrong with my kid, I'm defective, and I did this. I'm a bad parent."

Other professionals talked about the different cultural ideas surrounding mental health and how that can impact reaching out to services. The idea of stigma in other cultures is very real and can hinder how those cultures deal with and identify mental illness.

One professional described this situation of different cultures having different meanings for mental illness:

But I think, there are different cultural ideas about mental health, not even mental health but how the brain works and maybe feelings and everything else. Not even a physiological thing, like if it's an issue with trauma or depression and anxiety, it becomes something else or a sign of weakness. But I also think that it's a protective thing, like when you have people coming from the outside looking at your family and you have a healthy reason to distrust outside services. There's also shame but there is a protective piece to it. To accept and look at something in a different way might mean that I have to all these different changes (referring to families).

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Another professional interviewed was asked specifically about stigma and if she believed it was still a problem, she replied:

Oh yes, some parents I work with are refugees; and stigma can be huge with them. Parents I've trained and parents that are new to our system are the Somalia population, that's one thing we talk about. In their native language there are only two words for mental health – sane or insane, and so they don't understand that whole continuum of mental health and the different language we use to describe the different conditions. So educating is really important and helping them to understand that it's okay to get help and even to hear from other Somali parents that have gone through the system and gotten their children on IEP's and to the doctor to get medication, that helps them to overcome the stigma and get help for their child.

Theme # 3: Systemic issues in accessing and navigating the mental health system

The next major theme discovered in the data was systemic issues that arise while trying to access and navigate through the mental health system. Several of the professionals interviewed spoke to this idea that parents and caregivers become overwhelmed by the amount of paper work that needs to be filled out, how to access services properly and what to do when a crisis situations occurs. The mental health system is very vast and it takes a lot of knowledge and thoroughness to be able to navigate and access services. Parents and caregivers often get frustrated and exhausted knowing where to turn for help not only for their child, but for themselves as well.

One professional spoke of her experience with parents and caregivers directly relating to accessing the system:

I think it is tiring to fill out paper work and tell that story over and over again and get through all of it. And I will say it's a confusing system, they'll talk to the school, talk to a mental health provider, they'll end up in the hospital, the kid will be in the hospital and then the parents are like now what? What am I supposed to do? I have really heard parents confused by the system and how do you find really good help and then some consistency, there is rarely consistency. It takes a lot of savviness to navigate the system,

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so if their smart enough to do that and have the patience to do that, that's great, if not, I try really hard to get people a mental health case worker just to help them navigate this.

When speaking to one professional about what the biggest challenges parents and caregiver's face, she spoke to this:

I think finding quality mental health providers are difficult, and that is huge.

Another professional agreed with this, and commented on how parents don't know where to begin with the system. She also stated how sometimes children don't qualify for certain services because of the severity of their diagnosis and symptoms:

I think sometimes they don't exactly know where to start. Some other barriers would be just the amount of paper work that can be difficult for some families. I think it's just tough when a student or child has a mental health diagnosis but they are fairly high functioning and don't qualify for a lot of services, so then in turn parents aren't seeking out a lot of help for themselves because they've been told that there's not much help out there. So I think when parents get that answer, that they don't qualify for services or right now they don't qualify for something, I think that is a dead end that parents are hurdling.

This same professional also emphasized the importance of having a county case worker to help parents navigate through the system:

I think that most services are for the child but once families has good connections with their school or a county case worker and have someone to help guide them through a process

A parent of a child who had a diagnosed mental health condition spoke of her experience how her son's school was very supportive, but it would have been nice to have more a mental health team:

The IEP team was so focused on his education, just school, so it would have been nice if that could be expanded or even if there was a separate mental health team. His IEP was physical therapy, occupational therapy, a school counselor and things like that but not really about the mental health. So that would have been helpful, I would have liked that.

Subtheme # 1: What to do in a crisis situation

A few of the professionals interviewed discussed how parents and caregivers often times do not know who to call or what to do when a crisis with their child ensues.

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Often times when there is a crisis and children are brought to the hospital; they are often released quickly, as programs are full or not available for that child. Then, parents are left feeling helpless and not knowing where to turn. Since the system is so confusing, parents often take their child home and hope that a crisis doesn't happen again, however, often times it does and they are not sure with how to proceed.

One professional discussing need of parents and caregivers emphasized this point:

Sometimes an emergency will happen in a family home and parents really sometimes have a tough time knowing who to call and sometimes a dangerous situation happens in a home because a family member either did not know who to call or was nervous about making a call. There's some families will call and utilize hospital services, but that's always tough because it's always short term, and it kind of diverts the crisis and doesn't give a long time support so I think that's another need, families that are finding themselves in crisis, how do they utilize more follow up support.

Another professional highlighted the importance of people relating to these children who have a diagnosed mental health condition and what to do when a crisis situation does happen:

Sometimes they face the challenge of a crisis situation where they have to call for crisis intervention; sometimes they end up with juvenile justice issues, when the people relating to them don't understand the mental health issues so they treat it as a negative behavior.

Theme # 4: Support: The Importance of Mental Health Collaboration

The fourth major theme discovered in the data was the emphasis of mental health provider's collaboration with one another. Several of the professionals interviewed discussed the different types of supports and services out there, and stressed the importance of how mental health care needs to be cohesive and collaborative for the best success. Many of the professionals mentioned the connection with school and how important and helpful it can be to get support from the school. A few of the therapists

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talked about a wrap around model, which is a model that supports having services continuous and in collaboration with each other to ensure best outcomes for families. One professional really stressed the importance of making sure the parents and caregivers have support from themselves and how she encourages them to get help. Another service that came up several times is support groups for families and how helpful that can be for caregivers.

One professional talked about his experience being a school based therapist and how he feels that school integrated services could be more helpful than school based programs:

I really think school integrated services instead of school based services like I'm here in this school but where it's really should be the kids needs are being attended to by a whole team of people, more a holistic way of how we support these kids, that would be huge.

Another school social therapist talked about she really thinks the wrap around model is so important and can really be helpful for families:

I really like the wrap around model, so a model that doesn't involve just therapy, not just psychiatry but has somebody that is really helping collaborate, providers talking with one another, any way to streamline any intervention that is offered.

The last service that some professionals and a parent commented on that was helpful throughout was being a part of a support group, and how helpful that can be to connect with other families.

One professional who assists parents and caregivers becoming certified family peer specialists stressed the importance of having someone who has already gone through the system that can of help to other families:

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We are also training parents that have gone through the system and are good advocates and knowledgeable about systems of care, training them to be able to support and mentor other parents.

Another professional commented on how helpful and supportive it can be for parents to be a part of groups where they know someone else has gone through the same thing and how helpful that can be for families:

Parents really like support groups and fundraisers, like I'm thinking of the Autism Walk because it helps them to feel like a community and meet other parents. I've worked with some moms who have a child diagnosed with autism and they meet other moms in a support group and they kind of grow up together and stay connected. That's really important, especially for mom's, it's really important for them to know other moms who are in the same situation.

Lastly, a parent whose child grew up with a diagnosed mental health condition talked specifically about her experience being involved with a support group and how beneficial that was for her:

I did go to a parent support group for children with ADHD, and that was just so helpful and so, you feel like you're the only parent out there.

Theme 5: Rewards and Successes Experienced

The last theme that was noted in the data was the reward and success parents and caregivers experience while raising a child with a diagnosed mental health condition. Several of the professionals noted rewards and experiences that parents and caregivers can experience themselves and for their child. Some professionals commented on how getting the right kind of help can feel like a success.

One professional noted in relation to getting their child help, also engages the parents to get their own help:

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I'm a big believer in parallel process, and I've seen engaging kids in this stuff through talking to parents, causes them to look at their own lives differently. They get services themselves or they are working on certain skills with their kids and they are also working on skills for themselves.

Another professional commented on how when parents can relate to other parents experiencing the same thing, it helps them to feel validated:

I think they get validation from knowing that they are not alone, knowing that what they experienced is real, I think when they find the right help, and they get the validation that their child can heal, is very rewarding.

One professional made the comment on how once the caregiver or parents reprioritize their family life and see their kids get better, that then parents and caregivers are able to get better themselves:

Rewards are seeing the family change and do better, it really, I will say they prioritize, the best families or the ones that really just head into it straight on and take it as a challenge, they learn to reprioritize their lives and their kid gets to come first and that is really to watch that happen. They get so much better, they get better themselves, after the kid gets better, they also get to learn the very most important parenting stuff, like their job isn't to create a perfect human being, it's just they need to feel worthy of love.

In conclusion, the five major themes discovered in the data were: caregiver challenges, internal challenges and external challenges; stigma surrounding mental health diagnosis; systemic issues in navigating the mental health system; supports available to families; and finally, the rewards experienced by caregivers and children. These themes emerged consistently throughout the interviews, by professionals and the parent that described her experience. It is important to note that while there are several challenges and barriers in accessing and navigating the mental health system, as well as stigma associated with mental health, there are rewards and moments of success experienced by this population.

Discussion

The purpose of this study was to gain insight into the experience of caregiver's raising a child with a mental health condition, and how caregiver's can be better supported. These findings are consistent with the assertions found in the literature that caregivers lives are very much impacted by their child's mental health condition in a variety of ways (Mendenhall, Mount, 2011). This section will review how this study's findings compared to the literature regarding caregiver challenges, both internal and external; stigma surrounding mental health conditions; systemic issues in navigating and accessing the mental health system; supports utilized by caregivers and what they still need; and lastly, rewards and success experienced by caregivers in relation to their child's mental health condition. Implications for practice, policy, and recommendations for future research will also be discussed.

Caregiver Challenges: Internal and External

All of the participants interviewed in this study readily identified that caregiver's caring a child with a diagnosed mental health condition experience challenges in their daily living. These challenges can be broken down into two categories: internal and external. Internal challenges are described as feelings of isolation, exhaustion, worry, self-blame and guilt. External challenges are described as interference with a caregiver's profession, financial constraints, transportation issues, time constraints, and priority of family members. Internal challenges described by participants are consistent with the findings from a study by Brannan & Heflinger (2006) noting that caregiver strain can encompass several different aspects, but most commonly include guilt, sadness,

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parenting stress, interruption of family relationships, restrictions on their personal time and freedom, disrupted social life and interruptions at work.

Another internal challenge noted by the participants that is consistent with the literature is the feelings of self-blame, guilt and grief that is associated with raising a child with a diagnosed mental health condition. In a study done by Richardson et al. (2013), parents raising a child with a mental health condition reported consistent feelings of sadness, numbness, worry, denial, self-blame and shock.

External challenges were also readily identified by professionals and the caregiver interviewed. These external challenges they reported are often associated with barriers to receiving mental health services for their child, or supports and services for themselves. These findings are consistent with findings from a study by Owens et al. (2002) noting that the more parent stressors and schedule constraints the caregiver experiences, barriers to services are more evident in these cases. These findings are also consistent with the idea stemming from the person and environment context that explained that, "From a holistic view, people and physical and social environments can be fully understood only in the context of the relationship between and among them, in which individuals, families and groups and physical/social environments continually influence the operations of the other" (Germain & Gitterman, 1996, p.6). This idea supports the finding that when caregiver's experience external challenges in their environment, it effects how much they will continue to try and reach out for services. Many caregivers' get overwhelmed and feel defeated by these barriers, and eventually give up trying to get services for their child and themselves.

Stigma

This study confirmed that caregivers raising a child with a diagnosed mental health condition experience stigma in relation to their child's diagnosis. In this study, stigma can be defined as the shame surrounding a mental health diagnosis. Professionals consistently reported that often times, caregiver's experience a strong sense of stigma from other professionals in the mental health and medical field. Participants commented on how stigma surrounding mental health can often times interfere with caregiver's obtaining services for their child and themselves. These findings are consistent with the literature in the way that caregiver's often experience stigma as a type of burden associated with their child's mental health. These findings are congruent with the findings from a study done by Angold et al. (1998), where the authors found that the most frequent individual burden expressed by caregivers were stigma, personal well-being, and restrictions on personal activities. The participants in this study stressed that it is essential for the mental health community to continue to provide education and support to these caregivers so that the stigma surrounding mental health is reduced and families can seek the services that they need.

Systemic Issues: Accessing and Navigating Mental Health System

All participants spoke to a reoccurring theme that caregivers often times do not know where to turn or begin the process of seeking help in the mental health system. They all identified that parents and caregivers often get frustrated and overwhelmed in trying to navigate the system properly. Many of the participants noted that caregivers often don't know where to start to get services not only for their child, but for themselves

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as well. The literature identifies that once parents know where to turn, there are many programs and services that can help caregivers and parents with understanding and coping with their child's mental health condition. In a study done by Hoagwood et al. (2005), the authors here identify different programs that have been of help to caregivers and parents. They identified these programs as: family-led programs, clinician-led programs, and team-led programs. The authors of this study also spoke to empowering caregivers and parents as another essential piece in support services, noting that if caregivers feel more empowered, they are more likely to be better involved with their child's care and how to properly navigate through the mental health system.

Supports Utilized

All participants interviewed in this study stressed the importance of utilizing supports for caregivers raising a child with a mental health condition. They also emphasized the significance of having collaboration between members of the mental health team. A theme that came up amongst professionals was the importance of the wrap around model, which is a model that supports having services be continuous and collaborative to ensure best outcomes for families. This kind of service not only ensures quality mental health services for the child, but also supports the caregiver in the way that they feel supported and connected with mental health professionals in regards to their child's condition.

The literature in this study spoke to the importance of different types of supports and services available to caregivers and families. Mendenhall & Mount (2011) identified specific areas in which caregivers identified as needs in regards to their child's mental

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health. Those areas include: education about mental illness and community resources, development of problem-solving and stress management skills, and learning to cope with their child's symptoms. The supports and services most identified within the literature that encompassed a wrap-around model component were psycho-educational programs, psycho-therapies, parent management trainings, family-led programs, and clinician-led programs (Hoagwood et al., 2010).

One of the most prominent and identified programs by participants was a family support group, which are often led by a caregiver who has experience raising a child with a diagnosed mental health condition. One interview participant stressed the importance of caregivers attending this kind of group, who can get support and advice in how to navigate the system and can identify with feelings of struggle raising a child with a mental health condition. This is consistent with the literature in regards to family-led programs. Hoagwood et al. (2010), identify that a key component in these kinds of programs is to connect and link families to community resources.

One theme discovered through the participants that was not necessarily identified in the literature was the importance of having a county case worker. Many of the participants interviewed stressed the significance of the amount of help a case worker can bring to the family in regards to having someone navigate and find resources not only for the child but for the caregiver as well. Having a case worker can help alleviate the stress a caregiver can experience, by having someone knowledgeable of the mental health system in helping to connect with services, supports and providers.

Rewards Experienced by Caregivers

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The last theme discovered in the interviews was a sense of reward and success felt by caregivers raising a child with a mental health condition. It is essential to point out that while caring for a child with a mental health condition does encompass struggles for the caregiver and family, it also encompasses a sense of compassion and success. It was evident in the interviews that once the child starts to show improvement or the caregiver finds the right kind of help, the negative aspects of care giving are diminished.

Caregivers can start to feel success in regards to their child's mental health, which in turn affects their own psychological well being. This finding is consistent with the findings in a study done by Godress, Ozgul & Foley-Evans (2004) who found that over time, the amount of grief parents can experience often lessen as parents become more familiar with and accustomed to their child's mental health condition.

Implications for Practice

Clinical social workers and other mental health professionals can use the information from this study to better understand the experience and needs of caregivers raising a child with a diagnosed mental health condition. They may be more equipped to provide education and support surrounding children's mental health conditions, and how these conditions can impact the entire family. While much of the children's mental health intervention is focused on the child, it is necessary that attention is given to these caregivers so they can not only benefit psychologically themselves, but obtain vital services for their child.

While it is imperative for clinical social workers to be able to identify and educate families about symptoms of mental health conditions, it is also necessary for them to be

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able to acknowledge and educate families about how mental health conditions can impact the entire family. Many of the participants involved in this study stressed all the different areas of a caregiver's life that are impacted by their child's mental health condition. With that information, it is imperative for social workers to be able to address those areas and offer support and solutions to better alleviate those stressors.

All participants involved in this study spoke to how important and helpful it is for caregivers to be involved with a support group, or a family-led program where they can meet other caregiver's who have had similar experiences. It is essential that social workers are knowledgeable of these groups and resources, so that they can refer caregivers to these types of supports. Not only is support offered at these groups, but it also gives caregiver's an opportunity to network with other caregiver's about available community resources. It is a place for caregiver's to feel connected and supported, and that is ideally what many caregivers are seeking, a place to feel that they are not alone.

Several participants also spoke to the idea that it is so important to have someone guiding caregivers and being able to help them navigate the mental health system. Often times, caregivers and parents raising a child with a diagnosed mental health condition don't know where to start, and get overwhelmed by trying to access services. Social workers must ensure that if the family is eligible for a county case worker or a mental health case worker, that they are connecting caregivers with this resource. This can alleviate the stress and feelings of being helpless for many caregivers. It was also noted through the participants that once caregivers feel a sense of comfort that their child is receiving proper services, that they can then address their needs and get help for themselves.

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The last important part where social workers can be involved is helping to reduce the stigma surrounding mental health conditions. Many participants spoke to the stigma and how debilitating it can be for caregivers to seek help because of the stigma that surrounds mental health. A couple of participants also noted that there is a need for culturally sensitive material in regards to helping other communities understand and find resources for mental health. Social workers can be a vehicle for change in this regard, as they can help educate other cultures and help assist in understanding the resources available for mental health conditions.

Implications for Research

Further research is necessary to corroborate the value of support services and programs available for caregiver's raising a child with a diagnosed mental health condition. Continuing to do program evaluations for existing programs is also necessary, as that can determine what is working with these existing programs, and what the limitations still exist within these programs.

Through the literature and findings through the interviews, it was apparent that family-led programs and connecting with other caregiver's who have had similar experiences is extremely comforting and beneficial to these caregivers. Continuing to research what the benefits and possible limitations to these kinds of support would be valuable, as they offer support to caregivers that professionals in the mental health field are unable to provide.

Finances were mentioned several times as a barrier to reaching out to supports and services. Often times, parents and caregivers spend much of their finances

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surrounding the child and their treatment, and there is then little left for them to get their own support. Research surrounding the Affordable Care Act and how that will change services surrounding mental health and those caring for someone with a mental health condition would be beneficial to this population.

Strengths and Limitations

Choosing to do qualitative interviews was a strength of this study, as it gave participants an opportunity to use their own voice and speak to their personal experiences surrounding the topic. Because the interviews were done in person, the researcher was able to follow non-verbal behaviors among the participants, and ask necessary follow up questions to gain clarification to any answers provided.

The major limitation of this study was sample size, and the distribution between professionals and caregivers. One of the limitations of this study was in that snow ball sampling was used as a way to recruit participants. In doing this type of recruitment, the researcher hoped to complete eight interviews, however, only six participants responded to the letter asking for participation. The other limitation of this study was that the researcher had hoped to get an even distribution between professionals and caregivers. Only one caregiver responded to the recruitment tool.

Suggestions for Future Studies

Many of the participants in this study spoke to the idea that parents often become overwhelmed and confused by how to navigate through the mental health system. Future studies that would be helpful to this population are how to navigate and obtain services

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through the mental health system. Many respondents reported that once caregiver's know that their child is receiving beneficial services, that then they feel like they can get help for themselves. Many caregivers feel better and supported when they feel like their child is being supported, so really getting children with a mental health condition to receive proper services is essential for the entire family.

Conclusion

Social workers who work with caregivers and parents of a child with a diagnosed mental health condition can support and help them in finding resources not only for the child, but for the caregivers as well. With the challenges that arise in caring for a child with a mental health condition, it is essential that caregivers and parents feel empowered and supported by professionals in the mental health field. Often times, parents and caregivers do not know where to turn to feel supported and connected, and the assistance of social workers could be extremely beneficial.

This study's findings are consistent with previous research indicating that there are often some available supports and services for caregivers raising a child with a mental health condition. In addition, this study confirms that, for many, there are rewards and feelings of success raising a child with a mental health condition. However, it is evident that there are also burdens associated with raising a child with a mental health condition, and there are several barriers for caregivers in trying to access services and supports for themselves.

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Appendix A

Sample Letter Sent to Potential Participants

The Caregiver Experience: How Children's Mental Health Conditions Impact the Entire
Family

A Qualitative Research Study

University of St. Thomas/St. Catherine University

By: Kelly Mwei

My name is Kelly Mwei and I am a Social Work Graduate student at The University of St. Thomas. I am conducting a study about the caregivers' experience raising a child with a mental health condition. I am looking for caregivers who have raised a child with a mental health condition, or a professional who has worked with caregiver's whose child has a mental health condition. I am conducting in person interviews that will take approximately 45-60 minutes. The interview questions that I will be asking are surrounding what types of services and supports these caregivers utilize, what barriers are to service utilization, and how these services and supports can be improved. If you are interested in participating in this study, please call me at 612-916-1912 or you can email me at Mwei8869@stthomas.edu. Your participation in this study is greatly appreciated, and I look forward to meeting with you.

Appendix B

CONSENT FORM

UNIVERSITY OF ST. THOMAS

GRSW 682 CLINICAL RESEARCH PROJECT

**The Caregiver Experience: How mental health conditions in children
impact the entire family**

I am conducting a study about caregivers' experiences raising a child with a mental health condition. I invite you to participate in this research. You were selected as a possible participant because of your experience being a caregiver or your professional experience in assisting caregivers whose child has a mental health condition. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Kelly Mwei, a graduate student at the School of Social Work, St. Catherine University/University of St. Thomas and supervised by David Roseborough, *Ph. D., LICSW*.

Background Information:

The purpose of this study is to collect information in order to explore the caregivers' experience in raising children who have a diagnosed mental health condition. This study will look what services and supports these caregivers utilize, and how these services and supports can be improved. The method used to collect data will be in person interviews with either a present caregiver, or a professional who has assisted caregivers raising a child with a mental health condition. A potential benefit to this study is that caregivers and professionals will have the opportunity to talk about their experience, and give their recommendations for better service and support utilization.

Procedures:

If you agree to participate in this study, I will ask you to do the following things:

1. Complete a 45-60 minute interview about your experience either raising a child with a mental health condition, or your experience assisting caregivers who are raising a child with a mental health condition.
2. The interview will be audio taped and will be transcribed and coded by myself.

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3. The findings of my project will be presented in my clinical research paper and will be disseminated during an oral presentation in May, 2015. Your name or organization will not be shared in the paper or presentation.

4. The findings of my project will be published in my clinical research paper. Quotes may be used but will not be linked to your name.

Risks and Benefits of Being in the Study:

There is no known risk. The study has no known direct benefits. As a caregiver, I am inviting you to reflect on experiences in relation to a child or family member. This may understandably involve some emotion. I will be asking about your experiences more generally and not about specifics related to the child for whom you are a caregiver.

Confidentiality:

The records of this study will be kept confidential. In any sort of report I publish, I will not include information that will make it possible to identify you in any way. The types of records I will create include transcripts and will be stored at my home in a locked file cabinet. I will also keep the electronic copy of the transcript file on my password-protected computer indefinitely, but will destroy the audio file of the interview by deleting it off my audio recorder. The audio recordings will be kept in a locked storage area, and will be digitally deleted on June 1, 2015.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with any cooperating agencies or institutions or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until May 15, 2015. Should you decide to withdraw data collected about you will not be used in this study. If you decide this, I would ask that you let me know by email within a week after the interview. You are also free to skip any questions I may ask.

Contacts and Questions

My name is Kelly Mwei. You may ask any questions you have now. If you have questions later, you may contact me at 612-916-1912. My research chair is David Roseborough, and his phone number is 651-962-5804. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

You will be given a copy of this form to keep for your records.

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. *[If additional permissions are*

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needed (e.g. audio or video recording, accessing private student or medical records), include these here.]

Signature of Study Participant

Date

Print Name of Study Participant

Signature of Researcher

Date

Print Name of Researcher

Date

Appendix C

Interview Questions for Professional

1. Can you briefly describe the agency you work in and your role as a professional?
2. In your experience, what are the most common needs of parents/caregivers whose child has a diagnosed mental health condition?
3. In your experience, what areas of a caregiver's life are most impacted by their child's mental health condition? (i.e. Does this vary by diagnosis or do you see "common trends"?)
4. What do you feel are the most utilized supports and services available to these caregivers?
5. What do you think are some common barriers that these caregivers run into when trying to access supports and services?
6. How do you feel that these caregivers and parents could overcome these barriers to gain better access?
7. In your experience working with parents and caregiver's, what are some common challenges they face? What are some rewards they experience?
8. What do you feel are some promising models that are helpful to these parents and caregivers? (For instance: parent trainings, parent support groups, individual therapy, family led programs, clinician led programs?)

Appendix D

Interview Questions for Caregiver

1. Which services have been most helpful in regards to your child's mental health?
2. Which of these services might be better utilized more in delivering mental health services to your child?
3. What do you as a caregiver rely on as far as informal supports? (For example: family, friends, community members, relatives, colleagues, etc.)
4. What are some rewards to being a caregiver to a child with a mental health condition?
5. What are some challenges being a caregiver to a child with a mental health condition?
6. What areas of your life have been impacted by your child's mental health? (For example: social life, work, family environment)
7. What barriers do you experience when trying to utilize services and supports? (For example: transportation, cost of services, accessibility,)
8. What barriers do you think other families in similar situations to yourself experience?
9. What could help you and your family better access services and supports?

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10. Do you find it helpful or supportive to connect with other caregivers in similar situation to yourself? If so, in what ways?

11. What do you feel are some promising models that are helpful to people in a similar situation to your family? (Such as parent training, psycho education psychotherapy/classes, family led programs, clinician led programs)

12. Is there anything I haven't thought to ask that you'd like to add?

Appendix E

Resources

- **Walk-in-Counseling Center**

Address: 2421 Chicago Ave, Minneapolis MN 55404

- **Contact your Employee Assistance Program**

Free counseling options may be available to you

- **The Crisis Connection**

Phone: 612-379-6363 free 24/7 phone counseling

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