

5-2017

# Clinician Support to Caregivers of Children with a Mental Health Disorder

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## Recommended Citation

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## Clinician Support to Caregivers of Children with a Mental Health Disorder

by

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MSW Clinical Research Paper

Presented to the Faculty of the  
School of Social Work  
St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota  
in Partial fulfillment of the Requirements for the Degree of

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**

The type of support clinicians' offer and provide to caregivers whose children have mental health disorder is an important topic for mental health professionals to consider in their own practice. The purpose of this qualitative research study was to gain insight in to how clinicians' support caregivers of children with mental health needs initially and over the course of their child's treatment. The researcher audio recorded a semi-structured interview with four mental health professionals. The researcher transcribed the interviews and conducted a qualitative analysis on the results. The researcher and research chair identified five major themes from the data analysis: intervention strategies, clinician skills to support caregivers, caregiver stigma, emotional impact, and family needs. Additionally, the following categories from the overarching themes emerged from the data analysis: identify the client, psycho-education, check-ins, tools to use, evidence-based practice, validation, empowerment, engagement, frustration, overwhelmed, relief, grief, emotional needs, and financial and basic needs. The researcher found several similarities and differences between the study's findings and the current literature in children's mental health. The findings from this study expand on the research documented in the literature and provide valuable insights to mental health professionals, especially social workers, working with caregivers of children with mental health needs.

*Keywords: caregivers, children, mental health, clinician, support*

### **Acknowledgments**

I would like to thank my clinical research chair, Renee Hepperlen, for your guidance and support throughout my research endeavor on this project. I would also like to express my sincere gratitude to my clinical research committee members, Michelle Suarez, MS, ED, LAMFT and Eric Hansen, Ed. D, LICSW, LMFT, for your feedback, guidance, and support. I am grateful for the time and commitment you have put into helping me critically think about this topic. Lastly, I would like to thank my family, friends, and classmates for your support throughout my academic journey. To all those who have supported me throughout my graduate school journey, thank you!

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### **Clinician Support to Caregivers of Children with a Mental Health Disorder**

Mental health disorders develop throughout the course of childhood, identified by serious changes in learning, behavior, or emotions (Center for Disease and Control [CDC], 2013). These disorders range in severity across a spectrum and can be considered acute or chronic. Mental Health disorders diagnosed in early childhood include various neurodevelopmental disorders such as autism spectrum disorder, attention deficit hyperactivity disorder (ADHD), and tic disorders (American Psychiatric Association, 2013). One study reports mental health disorders occur in preschool children 2 to 5 years of age that include diagnoses of serious emotional disturbance, attention deficit/hyperactivity disorder, depression, anxiety, and post-traumatic stress disorder (Egger & Angold, 2006, p. 320). Additionally, researchers Brauner and Stephens (2006) estimate that 9% to 14% of children ages birth to five years old have an emotional or behavioral disorder.

However, the typical onset of mental illness occurs during adolescence or young adulthood. Mental health disorders affecting children in their adolescent to young adulthood years include anxiety disorders, depressive disorders, eating disorders, bipolar related disorders, schizophrenia spectrum and other psychotic disorders, and disruptive, impulse control, and conduct disorders (American Psychiatric Association, 2013). The National Institute of Mental Health concludes from their research that at least half of mental illnesses develop onset before a child is 14 years of age (National Institute of Mental Health, 2005). Research on childhood mental health estimates that mental health disorders affect between 13% to 30% of children, or one in five children are impacted by mental illness (CDC, 2013). Additionally, severe and persistent mental illness affects four million children under the age of 18 (National Alliance on Mental Illness [NAMI], 2015).

Childhood mental illness significantly impacts children and their caregivers. Research on parents caring for an adult child with schizophrenia found that those who witnessed their child's psychotic symptoms were at an increased risk for subjective burden (e.g. feeling guilty or stressed) (Ghosh & Greenberg, 2012). The parents of mentally ill children experience prominent feelings of being alone, helpless, ashamed, or as if they were experiencing their child's illness (Shpigner, Possick, & Buchbinder, 2013). Research regarding parents self-blame for their child's mental health disorder found a vast majority of parents blamed themselves for their child's illness due to parenting techniques, failure to seek intervention, genetic components, or living in an unsafe environment (Moses, 2010; Richardson, Cobham, McDermott, & Murray, 2013). Additionally, Suiter and Heflinger (2011) found siblings of children with a mental illness lack the skills needed to cope with their sibling's disorder and their caregivers are often unavailable to attend to their needs. Thus, research has shown caregivers of children with mental health needs take on challenging and demanding roles within the context of their family.

The existing body of research on children's mental health has been established in the areas of parenting with a mental illness and providing early intervention to children (Boursnell, 2012; Carr, 2014; Levy-Frank, Hasson-Ohayon, Kravetz, & Roe, 2012; Loon, Ven, Doesum, Hoseman, & Witteman, 2015). However, there is a lack of research pertaining to how clinicians are supporting caregivers of children who have a mental health disorder. Additionally, gaps continue to exist in how clinical social workers can provide effective services to caregivers during this challenging time. Therefore, the purpose of this qualitative research study is to understand in what ways do clinicians support caregivers whose children have a mental health disorder and how do their supports change over the course of their child's treatment. In order to gain further knowledge on this research topic, this study seeks to conduct interviews with

clinicians who primarily work with families and children with a mental health disorder. Grounded theory techniques will be used to gain a comprehensive understanding of the challenges families endure while adjusting to their child's mental health disorder.

## **Literature Review**

### **Pediatric Mental Health**

**Healthy development.** The foundation for a child's healthy development is rooted in the quality of interactions children have with their primary caregivers early on in life (Van der Kolk, 2014). Secure attachments emerge when caregivers are able to attune emotionally to their child's needs. Caregivers show attunement to their children by engaging in playful back and forth imitation and connecting with their child on an emotional level. A child develops a secure attachment to their caregiver once they have established a trusting relationship and are able to view their caregiver as a responsive source of comfort when distressed (Geraity, 2009). A secure attachment is typically formed with a primary caregiver in the first seven months of a child's life (Main, 2000). Infants with a secure attachment will stay relatively close to their caregiver when exploring new situations and seek out their caregiver for comfort when feeling overwhelmed (as cited in Main, 2000; Siegel, 1999). The National Scientific Council on the Developing Child (2012) reports that children who experience a nurturing and stable relationship with their caregiver build a healthy foundation for their future development. It is also of importance to highlight that research on children with autism spectrum disorder has found significant links to autism stemming from components of a child's genetic makeup (Colvert et al., 2015), rather than autism spectrum disorder stemming from a child's attachment security or insecurity to their caregiver.



Researchers established the benefits of secure attachment in childhood in the literature (Allen, Fonagy, Bateman, 2007; Cooper, Shaver, Collins, 1998; Howard & Medway, 2004; Nakash-Eisikovits, Dutra, & Westen, 2002; Taca, Ritchie, & Balfour, 2011). A study conducted by Copper et al. (1998) found securely attached children are less likely to drink, use drugs, or have sex with a stranger during their adolescent years when compared to children with insecure attachments. Another study conducted on attachment style and coping under stress reports securely attached adolescents communicate more with family members and engage less in negative coping such as drinking, smoking, or becoming angry when stressed (Howard & Medway, 2004). Research shows children who form secure attachments are better able to identify their feelings and interpret emotional cues from others (Allen et al., 2007; Taca, Ritchie, & Balfour, 2011). Studies also indicate secure attachments are associated with fewer mental health concerns such as depression, anxiety, personality disorders, and behavioral problems, (Cooper et al., 1998; Nakash-Eisikovits, Dutra, & Westen, 2002; Papini & Roggman, 1992). Papini and Roggman (1992) report adolescents with secure attachments to their caregivers are more likely to have positive feelings regarding their self-worth and self-competence. It is evident that children who develop secure attachments with their primary caregivers demonstrate greater abilities to regulate emotionally and engage in positive coping skills.

**Abnormal development.** In contrast, disruptions in healthy development can be understood in the absence of a secure and nurturing environment. Children who have caregivers that are not readily available to address their needs will develop an anxious-ambivalent attachment style (Van der Kolk, 2014). Anxious children often make many attempts to catch their caregiver's attention by crying or remaining very close to them; however, the anxious child does not find comfort in their caregiver's attempts to soothe them. Whereas, children who have

caregivers that ignore their needs will develop an avoidant attachment style. Children with an avoidant attachment style typically avoid interacting with their caregiver and are always in a state of constant distress. Additionally, children who have not learned how to engage with their caregivers develop a disorganized attachment style. Children with a disorganized attachment perceive their caregivers to be scary or frightening. According to Hesse and Main (2000) children with a disorganized attachment are likely to experience maltreatment, role inversion, and dissociation. Children with insecure or disorganized attachment styles face many disadvantages when compared to securely attached children.

Researchers established the negative effects of insecure and disorganized attachments on children in the attachment literature (Bekker & Croon, 2010; Brumariu, Kerns, & Seibert, 2012; Cooper, Shaver, & Collin, 1998; Howard & Medway, 2004; Lessard & Moretti, 1998; Nakash-Eisikovits, Dutra, & Westen, 2002; Sund & Wichstrom, 2002). One study found children with a disorganized attachment style to have more symptoms of anxiety, more trouble problem solving, and a difficult time identifying their emotions (Brumariu, Kerns, Seibert, 2012). Another study found anxious-ambivalent adolescents to have higher levels of depression and delinquent behavior, lower grades in school, and are more likely to engage in risk-taking behavior such as using alcohol, drugs, or engage in sex with a stranger (Cooper, Shaver, & Collins, 1998). In contrast, adolescents with an avoidant attachment style are reported to have better grades and are less likely to engage in delinquent or risk taking behavior when compared to adolescents with an anxious-ambivalent attachment style. Additionally, adolescents with an avoidant attachment style are reported to be less likely to engage in risk taking behavior such as having sex with a stranger and using substances when compared to securely attached adolescents.

Howard and Medway (2004) found adolescents with avoidant, anxious-ambivalent, and disorganized attachment styles are more likely to cope with stress in negative ways. Additionally, researchers Sund and Wichstrom (2002) report adolescents with insecure attachments are more likely to develop symptoms of depression. A study conducted on suicidal ideation and attachment patterns found adolescents with a disorganized and anxious-ambivalent attachment style had more thoughts of suicidal ideation when compared to secure and avoidant attachments (Lessard & Moretti, 1998). Disorganized adolescents are also more likely to develop a personality disorder (Nakash-Eisikovits, Dutra, Westen, 2002). Lastly, anxious-ambivalent individuals are more likely to have low self-awareness and are more sensitive to others (Bekker & Croon, 2010).

### **Impact of Pediatric Mental Health on Caregivers**

**Acceptance.** Research indicates the initial diagnosis of a child's mental illness evokes mixed responses of acceptance among family members (Richardson et al., 2013; Shpigner, Possick, & Buchbinder, 2013). The impact of a child's diagnosis is difficult to conceptualize while to some it provides a sense of relief (Richardson et al., 2013). Shpigner et al. (2013) reported parents acknowledged their child's illness by observing changes in their behavior or by receiving a diagnosis from a mental health professional. Several parents reported they were caught off guard by the diagnosis and describe "the [initial] outbreak of the illness as a sudden, traumatic event that forces them [to] acknowledge the seriousness of the child's condition and to change their inner schema of the child and their relationship with him/her" (Shpigner et al., 2013, p. 543). Two qualitative studies reported parents experience "immense sorrow" and changes in their "hopes, dreams, and expectations for their child" upon receiving their child's initial mental health diagnosis (Richardson et al., 2013, p. 727; Shpigner et al., 2013, p. 546). The literature

provides insight into the hardships parents endure when initially learning of their child's diagnosis of a mental health disorder.

**Family life.** The literature regarding the challenges in family life while caring for a child with a mental illness is well established (Delaney & Engels-Scianna, 1996; Oruche, Gerkenmeyer, Stephan, Wheeler, & Hanna, 2012; Richardson et al., 2013). A qualitative study found mentally ill children put great restraints on their parents' social life that impacted their ability to spend time with family or participate in activities they enjoy (Richardson et al., 2013). Another study found caregivers felt overwhelmed caring for their mentally ill child while maintaining other household commitments (Oruche et al., 2012). Additionally, caregivers report not feeling supported by their significant others. Research findings indicate being satisfied in one's marriage increases psychological well-being while decreasing feelings of burden and symptoms of depression (Ghosh & Greenberg, 2012). Lastly, researcher Delaney (1996) found caregivers struggle with dividing their time between everyone in the family. For example, "Parents worried about how the siblings were affected by the constant discord and tension in the home. They worried that the siblings may be neglected because of the other child's time-consuming problems or that they may be in actual danger" (p. 23). Caring for a child with a mental illness appears to affect family members ability to balance everyone's needs.

**Emotional impact.** A review of the literature pertaining to the emotional impact families endure while caring for a child with a mental illness is discussed in the research (Moses, 2010; Oruche et al., 2012; Richardson et al., 2013; Shpigner et al., 2013). Shpigner et al. (2013) conducted a qualitative study that found parents of mentally ill children experienced prominent feelings of being alone, helpless, ashamed, or as if they were experiencing their child's illness. A study conducted by Moses (2010) found parents of adolescent children with a mental health

disorder placed blame on themselves for four reasons "... (a) bad parenting; (b) ineffective parental oversight of child's mental health in terms of failure to identify problems, seek help early, and just do more in general; (c) hereditary transmission and other biological assaults on the child; and (d) negative family environment" (p. 109). Additionally, caregivers of children with a mental illness report feeling ashamed of their child's illness because family members and school staff members judged their child's unpredictable behavior as a reflection of their parenting skills (Richardson et al., 2013). Conversely, parents who had been in a longer caregiving position were able to separate self-blame from their initial emotions of anger and helplessness (Moses, 2010). One study reported parental concern for their safety, fear of child's behavior, and being psychologically exhausted by their child's demands (Oruche et al., 2012). Additionally, a qualitative study conducted on parental loss and grief found parents felt a sense of loss for their previous child and grieved over their ongoing adjustment (Richardson et al., 2013). It is clear caring for a child with a mental illness greatly affects a caregiver's sense of emotional wellbeing.

**Employment and finances.** Researchers considered the employment and financial challenges families encounter while their child is receiving mental health treatment (Oruche et al., 2012; Richardson et al., 2013; Rosenzweig, Brennan, & Ogilvie, 2002; Song, Mailick, Greenberg, 2014). A qualitative study on parents caring for children with a diagnosed emotional or behavioral disorder found parents often sought employment opportunities that did not align with their professional goals or educational background in order to provide adequate childcare; hiring a caretaker to provide a respite service was unlikely to be a financial option (Rosenzweig et al., 2002). Several studies report on the ongoing demands parents face to drop work in order to attend appointments, school meetings, or crisis situations to ensure their child is receiving adequate care and not harming others (Richardson et al., 2013; Rosenzweig et al., 2002).

Research concludes working for a company without flexibility under these high demands has a negative impact on health when compared to parents of non-mentally ill children (Song et al., 2014). In severe cases parents quit their jobs to provide care for their children with mental health needs; this can be especially draining and costly (Oruche et al., 2012). Lastly, research from the Urban Institute found that treating children's mental health conditions is a costly practice nationwide totaling \$8.9 billion dollars per year, which is considered the most expensive illness for families to treat (McMorrow & Howell, 2010).

### **Supports and Interventions for Caregivers**

**Peer-led psychoeducation.** Research pertaining to peer-led interventions for caregivers has been established in the literature (Brister, Cavaleri, Olin, Shen, Burns, & Hoagwood, 2012; Hoagwood, Cavaleri, Olin, Burns, Slaton, Gruttadaro, & Hughes, 2010; Koroloff, Elliott, Koren, & Friesen, 1996; Kutash, Duchnowski, Green, & Ferron, 2011, 2013). Peer-led psychoeducational programs are led by caregivers who have gone through similar experiences of raising a child with a mental illness. These caregivers offer guidance and support to caregivers who are currently raising a child with a mental illness. Caregivers often seek help from peers with similar experiences because they can clarify information, decrease stress levels, and encourage caregivers to become involved in their child's treatment (Hoagwood et al., 2010, p. 18). A recent study review by Hoagwood et al. (2010) found peer-led interventions facilitate more discussions regarding caregiver experiences and focus on providing caregivers with tools to manage stress, anger, and self-care (p. 19). Additionally, caregivers in peer led interventions are more likely to converse about systemic barriers to care. Research conducted on the Family Associates peer-led intervention program found low-income caregivers who had access to a family associate or paraprofessional showed an increase in empowerment relating to family

dynamics and accessing services for their child (Koroloff et al., 1996). A study conducted on the impact of a free twelve-week peer led program, NAMI Basics, found caregivers increased their self-care and sense of empowerment (Brister et al., 2012). Researchers Kutash et al. (2011; 2013) found caregivers of children with emotional and behavioral disorders to be more engaged in their child's treatment and felt more empowered after receiving support from families who have had similar experiences raising a child with an emotional disturbance.

**Clinician-led psychoeducation.** Researchers considered the impact of clinician-led psycho-education for caregivers of children with a mental health disorder (Hoagwood et al., 2010; Leffler, Fristad, & Klaus, 2010; Levy-Frank et al., 2012; MacPherson, Mackinaw-Koons, Leffler, & Fristad, 2016; Mendenhall, Fristad, & Early, 2009; Ong & Caron, 2008). Clinician-led psycho-educational programs allow caregivers of children with a mental health disorder to “make informed treatment decisions with the patient; reduce anxiety about the illness; and help families and patients cope with the illness and its complications” (Ong & Caron, 2008, p. 811).

A review by Hoagwood et al. (2010) found clinician led interventions utilized behavioral and cognitive behavioral theories to help caregivers gain skills to support their child. Additionally, clinician led interventions helped parents manage their own mental health concerns in order to better support their children in treatment. A study found caregivers who received psycho-education from a clinician felt more informed to make better changes in their life (Levy-Frank et al., 2012). For example, “The therapist handed out information sheets and sat with us and explained everything, virtually, for the first time in our lives” (p. 273).

In addition, caregivers who attended the psycho-educational group were able to apply the knowledge and advice they received from the group into their lives. A recent study of caregivers who utilized multifamily psycho-educational psychotherapy found caregivers increased their

knowledge of mood disorders while their children with bi-polar disorder noticed a reduction in their symptoms following the intervention (MacPherson et al., 2016). A similar study that employed the family psycho-education method found caregivers enjoyed being involved in treatment and noticed improvements in their parent-child relationship when compared to a control group who did not receive any psycho-education (Ong & Caron, 2008).

Mendenhall, Fristad, and Early (2009) found caregivers of children with mood disorders who utilized multifamily psycho-educational groups as an intervention strategy increased their usage of mental health services. While Leffler et al. (2010) found that caregivers and children with bipolar disorder who utilized psycho-educational psychotherapy increased family functioning, stress management, and communication with school staff members. It is evident clinician-led psycho-education helps caregivers of children with a mental health disorder become more informed about their child's disorder and appropriate courses of treatment.

**Therapeutic interventions.** A wide variety of psychotherapies are available for caregivers and children, but this paper only considers several of the most promising interventions. One form of psychotherapy is called Functional Family Therapy (FFT) that aims to treat adolescents with behavioral problems (as cited in Hartnett, Carr, & Sexton, 2016). A study conducted on the effectiveness of FFT for adolescents and their caregivers found a significant increase in family functioning, family adjustment, and a decrease in child's behavioral problems (Hartnett, Carr, & Sexton, 2016).

Another popular psychotherapy method used in family therapy is cognitive-behavioral therapy (CBT) that aims to reorganize the brain to think in positive and more adaptable ways. A study conducted on CBT with families of children with an anxiety disorder reported CBT successfully treated 70.3% of children with anxiety and 95.6% of children who received CBT



treatment and an added component of family management (Barrett, Rapee, & Dadds, 1996).

Similarly, a study conducted on family cognitive-behavioral therapy (FCBT) for children with an anxiety disorder found an increase in the family's ability to relate to one another (Jongerden & Bogels, 2015).

Narrative therapy is a form of psychotherapy clinicians often use when working with families. This method of intervention guides each member of the family in sharing their story while clinicians identify strengths and help clients externalize their experiences (Body-Franklin, Cleek, Wofsy, & Mundy, 2013). According to researchers Body-Franklin et al. (2013) narrative therapy "... reframes the situation. The client is not the problem; the family is not the problem. The problem is the mental illness or the ADHD and the client and the family can work together to learn to address it and minimize its effects" (p. 200). McLuckie (2005) found that utilizing narrative family therapy with family members of children with an anxiety disorder was effective in addressing stress, education, and family challenges.

A popular psychotherapy recommended for young children and their caregivers is Parent-Child Interaction Therapy (PCIT). This form of therapy is an evidence-based intervention that targets caregivers and young children with disruptive behavioral disorders to learn skills that will improve the parent-child relationship. Recent studies showed that PCIT decreases young children's externalizing behaviors (Kohlhoff & Morgan, 2014; Lyon & Budd, 2010; Schuhman, Foote, Eyberg, Boggs, & Algina, 1998; Ward, Theule, & Cheung, 2016) and increases caregiver's ability to positively communicate with their child (Kohlhoff & Morgan, 2014; Lyon & Budd, 2010; Schuhman et al., 1998). Similarly, a study that utilized PCIT as an intervention with children on the autism spectrum with co-occurring behaviors and their caregivers found a decrease in behavioral problems and an increase in their caregiver's positive communication

skills (Masse, McNeil, Wagner, & Quetsch, 2016). Additionally, research indicates caregivers who receive PCIT as an intervention for their family have lower levels of stress (Eisenstadt, Eyberg, McNeil, Newcomb, & Funderbunk, 1993; Kohlhoff & Morgan, 2014; Schuhman et al., 1998). Research studies report a high level of satisfaction from caregivers who have utilized PCIT interventions for their family (Eisenstadt et al., 1993; Kohlohoff & Morgan, 2014; Masse et al., 2016; Schuhman et al., 1998).

**Stages of intervention.** Research indicates family members arrive at therapy at different readiness levels to implement change into their lives (Boyd-Franklin et al., 2013). Clinicians often utilize the theoretical model, stages of change, to determine a family members stage of readiness to engage in the therapy process. According to Norcross, Krebs, and Prochaska (2011) there are five stages of change that family members can reside during the therapy process that includes pre-contemplation, contemplation, preparation, action, and maintenance. The first step towards changing, pre-contemplation, involves family members who have no desire to engage in therapy or see a change in behaviors at the time. The second phase, contemplation, entails family members thinking about engaging in therapy or making a change but have yet to reach out for help. The third action, preparation, requires family members to have a plan to seek help. The fourth level of change, action, means family members are engaged in therapy and actively seeking ways to change behavior for a positive outcome. Lastly, the fifth and final stage, maintenance, occurs after change has been made and family members are working together to create a stable environment. According to Boyd-Franklin et al. (2001) “The therapist’s role is to assess where the family members are in this process of change and to engage them in treatment by meeting them where they are in this process” (p. 183). It is important for clinicians to identify a family members level of readiness to engage in the therapeutic process.

Similarly, research indicates that families arrive to therapy at various stages of the grieving process (Penzo & Harvey, 2008). A crisis frequently activates the grief cycle for caregivers of children with mental illness and follows five phases that include denial, anger, bargaining, depression, and acceptance. Initially, caregivers may be in denial about their child's behavior to safeguard their feelings about the situation. Caregivers may then experience feelings of anger towards themselves, their child, or clinicians due to the frustrations of their child's behavior. The third phase of the grief cycle involves the caregiver finding ways to manage responsibilities among family members and make decisions about their child's treatment moving forward. The fourth element of the grief cycle is depression, where a caregiver may feel bogged down by their negative thoughts of the situation not getting better. Lastly, the fifth stage is acceptance where caregivers tend to make plans on how to move forward with their child's best interest in mind. It is important for clinicians to recognize the cycle of grief in all of their clients to offer the best form of guidance in the treatment process.

**Psychotropic medication.** Caregivers often turn to psychotropic medication to regulate and alleviate their child's mental health symptoms (Hansen & Hansen, 2006; Rappaport & Chubinsky, 2000; Scholtes, 2001; Waters, 2000). A qualitative study conducted by Hansen & Hansen (2006) found medication improved family dynamics and reduced parenting stress. One caregiver illustrated the impact medication had, "... I can't imagine having gone through that for any longer than I did. I mean, everyday was a real struggle before he got on the proper medication" (p. 1274). One study reports that caregivers are often relieved when their child is prescribed medication because it proves how difficult it is to manage their child's mental health symptoms (Rappaport & Chubinsky, 2000). Studies also suggest caregivers feel less self-critical

and nervous if a child's symptoms decrease with medication treatment (Scholtes, 2001; Rappaport & Chubinsky, 2000).

Conversely, some caregivers and mental health professionals feel conflicted about providing children with psychotropic medication due to many unknown and negative side effects (Hansen & Hansen, 2006; Lazaratou et al., 2007; Waters, 2000). One study found many children experienced negative side effects while taking psychotropic medications such as a reduction in appetite, trouble sleeping, and an increase in anxious behaviors (Hansen & Hansen, 2006). A research study conducted by Ninan, Stewart, Theall, Katuwapitiya, & Kam (2014) found children with multiple mental health diagnoses and unpredictable behaviors were more likely to experience adverse side effects of psychotropic medication. Lazaratou et al., (2007) conducted a study regarding caregiver attitudes of child psychotropic medication and found the majority of caregivers fear psychotropic medication more than other types of medication and believe psychotropic medication can lead to addiction. The National Scientific Council on the Developing Child (2012) reports that there has been an increase in health care professionals prescribing psychotropic medications to young children, despite the lack of knowledge known about their side effects (p. 7). Similarly, Waters (2000) reports there is a lack of research pertaining to psychotropic medication for children across diagnoses that has led some caregivers to feel skeptical of medication interventions.

### **Social Work Practice**

Childhood mental illness greatly impacts the overall functioning of caregivers. The literature on children's mental health is well established in areas of caregiving experiences and mental health interventions for children and families. However, research continues to provide gaps in how clinicians provide direct interventions initially and over time, to the caregivers of

their young clients who are seeking treatment for their mental health. This qualitative study seeks to address the role of the social worker and other mental health professionals by examining five research questions.

- 1) In what ways do clinician's directly support caregivers whose children have a mental health disorder?
- 2) How do clinician's support caregivers in adjusting to their child's mental health disorder initially and over time as treatment progresses?
- 3) What are supports that clinician's implement throughout treatment to help positively impact caregivers during this adjustment period?
- 4) What has not been addressed as far as the support caregivers received during the adjustment period?
- 5) What supports have been helpful for caregivers during this adjustment period?

### **Conceptual Framework**

The theoretical framework that will guide this clinical research project is the strengths perspective. The strengths perspective is an approach that provides clinicians with a lens to discover positive attributes and qualities in clients (Miley, O'Melia, & DeBois, 2011). Clinicians who incorporate the strengths perspective into their practice are in a better position to key in on what clients do well and utilize these strengths as a source of intervention. Many caregivers of children with a mental illness experience a variety of challenges that are difficult to manage without adequate support. The strengths perspective can help clinicians validate the various adversities caregivers endure while shedding light on the strengths that helped them get through difficult times.

An important element of the strengths perspective is to focus on the client's strengths instead of their pathology or risk factors. Clinicians who simply diagnosis clients and provide a list of treatment options greatly stigmatize the client and miss the opportunity to partner with them in their treatment journey. Miley, O'Melia, & DeBois (2011) stated, "... pejorative labels and stereotypes assign categorical meanings, block visions of potential, and constrict plans for service delivery and social policy" (p. 76). A study conducted on clinician's perceptions of their clients found the majority of clinicians described their client's situations in a negative light (Saint-Jacques, Turcotte, & Pouliot, 2009). This type of thinking can be problematic for clinicians because it becomes harder to maintain hope for the client's situation to get better. Additionally, clinicians often fail to recognize the needs of caregivers as part of the treatment process (Penzo & Harvey, 2008). Typically clinicians who treat children with a mental health disorder leave out their caregivers. It is important to include caregivers in their child's treatment process and help address their needs as well. The ultimate goal for clinicians is to partner with the client and caregiver to help them find healthy solutions to manage and take charge of their life again.

An essential component of the strengths perspective is to recognize the resilience factors in caregivers and children with mental health concerns. Too often clinicians fail to recognize and address what is going well in a family that is struggling to overcome adversities of living with a child that has a mental illness. An overwhelming amount of research suggests children's mental health greatly impacts caregivers. While there are a variety of resources available from psycho-educational groups to family therapy sessions, there is still a lack of research on how clinicians are directly supporting the caregivers of their young clients. This research study intends to

provide insight into how clinicians, especially clinical social workers, integrate the strengths perspective into their direct practice with caregivers and children with a mental health disorder.

## **Method**

### **Respondents**

The respondents invited to participate in this research study were required to have experience working with caregivers of children with mental health needs. Additionally, clinicians needed to have a master's degree or higher with a professional licensure in clinical social work, marriage and family therapy, counseling psychology, or psychology. The researcher made several attempts to contact mental health professionals working in a children's mental health setting through snowball sampling. Methods used to attract potential participants included emailing mental health professionals, placing a message on a social media group for mental health professionals in the Twin Cities, and networking with professionals from previous internship sites and graduate school classes. The researcher interviewed four mental health professionals who met the research study's inclusion criteria. The respondents all reported experience working with children and families in settings such as foster care, day treatment, residential treatment, in home, and outpatient clinics providing individual and family therapy.

Prior to the interview, the respondents were briefed on the consent form (see Appendix A) and encouraged to ask any initial questions before the interview began. The respondents were briefed on the research question and the reasoning behind why he or she was chosen for the study. Participants were informed that the interview would take 60 minutes, and that he or she could skip any question, or withdraw from the interview at any time. The researcher informed the respondents that there were no direct risks or benefits to being a participant in this research study. Additionally, the researcher reviewed the confidentiality policy with the respondents

stating that the audio recording and transcript would be kept on a password-protected computer and uploaded to One Drive. The researcher and research chair would be the only individuals with access to the interview transcript. The findings will be presented to the public on May 15, 2017 and a written report will be submitted to the research chair and published online through St. Catherine University. All transcripts and data files will be destroyed by June 1, 2020. The respondents were instructed to contact Dr. Renee Hepperlen or the University of St. Thomas Institutional Review Board with any further questions, comments, or concerns. Once the respondents were briefed in all areas regarding the consent form both parties signed the document of informed consent.

### **Data Collection**

The collection of data occurred after the respondents agreed to participate in the research study. The researcher audio recorded the interview on her password-protected computer. The interviews followed a semi-structured format and were guided by a deductive set of questions pertaining to the respondent's employment and the overarching research questions (see Appendix B). The interview questions sought to further explore research documented in the literature regarding the direct support clinicians provide to caregivers of children with a mental health disorder. The interview questions followed a deductive model by first investigating the role of the mental health professional working with caregivers and children with a mental health disorder. Next, questions were asked about the prominent feelings caregivers experience throughout their child's care. Then questions explored treatment interventions clinicians are utilizing to support caregivers who are having a difficult time managing their needs while providing ongoing care to a child with a mental health disorder. Further questions addressed the clinician's experience identifying stages of change and grief in caregivers. Lastly, the



researcher's questions concluded with asking about the challenges caregivers endure throughout their child's care.

The researcher delivered the interview questions in an objective manner to encourage honest feedback from the respondent. The respondents provided feedback to all 13-interview questions with relevant information pertaining to working with caregivers of children with mental health needs. The interviews with the respondents lasted approximately 60 minutes and were saved to the researcher's password-protected computer for later transcription. After completion of the interview, the audio recordings were transcribed in full on a word document within one week following each interview with a respondent. The transcription of data was uploaded to One Drive to ensure confidentiality. Additionally, the researcher coded the interview transcriptions to identify themes from all four respondents in the study. A copy of the interview transcription was reviewed by the researcher's committee chair to ensure reliability of the themes.

### **Setting**

The researcher allowed the respondents to pick a location to meet that accommodated their schedule. The researcher met with respondents at the University of St. Thomas-St. Catherine University and at a local coffee shop. All settings had two chairs and a table for the researcher and respondent to sit at while conducting the interview. The conversation with each of the respondents was professional and informative for the research study.

### **Analysis**

The researcher noticed several reoccurring themes in the literature regarding the methods clinicians use to support caregivers of children with mental health needs. The researcher used the major themes of attachment, child mental health, and popular methods of support for caregivers

to inform and develop interview questions for this qualitative research study. A grounded theory methodology was used to interpret the data analysis through inductive coding of the data (Padgett, 2008). The data emerged from the researcher's interviews with the respondents and was transcribed from the audio recordings. The researcher coded all four transcripts in full and compiled reoccurring codes into themes. The researcher and research committee chair met to review the researcher's coding of themes and to identify major themes and categories from the interviews that appeared essential to highlight in this research study.

### **Findings**

The researcher initially identified four major themes after coding the transcriptions from all four respondents: clinician intervention strategies, emotional impact, family needs, and financial impact. The researcher's committee chair reviewed the researcher's codes and identified five reoccurring themes from the transcription: intervention strategies, skills to support parents, therapist skills to support parents, stigma of diagnosis and treatment, and family needs. The researcher noticed good inter-rater reliability between the themes she coded and the ones addressed by her research chair. The coding exchange between the researcher and research chair revealed five themes: intervention strategies, therapist skills to support caregivers, caregiver stigma, emotional impact, and family needs.

### **Intervention Strategies**

The respondents identified several intervention strategies clinician's use while working with caregivers of children with mental health needs. The researcher identified five categories relating to this overarching theme. The first category and intervention all four of the respondents spoke about was to identify who the primary client is in therapy. The clinician is able to provide support to both the child and caregiver; however, a clinician's primary focus usually resides with

one or the other. The second category that emerged from three of the respondents was to provide caregivers with psycho-education about their child's mental health disorder. The third category addressed by all four respondents was to check-in with a child's caregiver to see how they are doing. The fourth category all four of the respondents commented on was the tools they use to support caregivers. Clinicians offer tools of support to help caregivers co-regulate with their child, connect with their child during their daily routines, and process their own personal history. Lastly, the fifth category that emerged from the data analysis was the use of cognitive-behavioral therapy as an evidence-based practice to address caregiver needs.

**Identify the client.** The respondents noted the importance of identifying who the primary client is in therapy. The respondents mentioned that they are able to work with children and family members in a number of different ways; however, typically their primary focus would be on a child coming in for treatment services. The respondents agreed that they are able to provide supportive services to a child's caregiver through check-ins after session, individual meetings, or by providing phone or e-mail communication outside of session. The following quote depicts a respondent's intervention strategy of meeting individually with a child's caregiver:

*A lot of times what we'll do if parents are feeling really stressed out is maybe we will meet with just the parent or caregiver, without the child. So they really do feel comfortable in voicing what's going on and their concerns.*

The respondent recognized caregivers often feel stressed out by their child's ongoing needs. This respondent also made an attempt to reach out to caregivers to see if they are interested in meeting individually without their child present. The respondent brought attention to the importance of connecting with a caregiver on the individual level, without the caregivers' child present, to get an honest appraisal of how their child's mental health needs are impacting

them. Additionally, the respondents mentioned they felt caregivers can benefit from their own therapy and often refer a child's caregiver to another clinician to receive therapeutic support. The following quotes illustrate three respondents' remarks:

*So what we often did was if I had a child client that I was working with and based on my interaction with the caregiver thought that the caregiver was struggling and could use their own support. I would refer to them to one of my colleagues and vice versa. Like sometimes we'd be working with a family and they'd all come at the same time. One of us would be working with the kid and one of us would see the parent.*

*I've referred out for families to also see their own therapist. When we start services in the clinic our goal here is to do ASD all the way and our client is the child. But if I'm seeing that some of these needs are not being met or they're struggling with something in these areas it's my role to refer out and address it but not take it on directly.*

*I do refer out. So in all of my work I highly suggest that the parents receive their own therapy because they have their own experience along side their child's... parents need their own validation and own support going through that process.*

The respondents' illuminated a caregiver's need to receive their own therapeutic support that is separate from their child's treatment. A caregiver who has a child with mental health needs may need their own space to process their experience with mental health, parenting hardships, or their own upbringing. Additionally, the first respondent spoke to accommodating the caregivers schedule to meet with a different therapist at the same time as their child. Many caregivers have busy schedules that are based on strict time constraints. Caregivers need their own space to receive validation and support regarding their experience parenting a child with a mental health need. The category, identify the client, was developed as an intervention strategy

from multiple codes the researcher and research chair found within the transcription to determine who the primary client is seeking therapy services.

**Psycho-education.** The respondents agreed that there is great value in providing education to caregivers regarding their child's mental health diagnosis and treatment. The respondents acknowledged caregivers should be informed about their child's diagnosis and learn how their child's mental health disorder impacts their everyday functioning. The following quote from a respondent highlights that psycho-education is a helpful intervention to use with caregivers:

*“Just really giving them an explanation of why they meet a diagnosis based on the criteria and working that through with them is usually really helpful in their understanding.”*

This respondent noted that caregivers find it helpful when clinicians take time to explain what their child's mental health diagnosis means and discuss the impact it may have on their family. A clinician who is able to process this experience with a caregiver can provide a lot of good information to help a caregiver better understand their child's needs. The following quote captures the importance of providing psycho-education to caregivers around their child's trauma and stressors:

*“In terms of kiddos that have trauma or experience a lot of stressors there's always psycho-education around that as well. How that impacts children's mental health and how it impacts the brain and how it impacts their ability to function.”*

It is essential for clinicians to provide caregivers with psycho-education on how trauma impacts a child's brain and ability to function. The respondent highlighted the importance of caregivers learning tools to respond to their child if their trauma is triggered. Another respondent mentioned the value of normalizing a child's mental health disorder to a caregiver:

*If the particular mental illness that the child is struggling with is one of the more common ones. Some of that psycho-education of just data about how common this is. And again... just letting people know how common it really is and just across the life span how many people would seek help... And also letting people know that you can manage this.*

The respondent acknowledged caregiver's have the right to know the facts about their child's mental health diagnosis. The respondent spoke about normalizing the details of a child's mental health diagnosis to caregivers when it is appropriate. Additionally, the respondent pointed out the importance of validating caregivers in their ability to help their child manage their mental health symptoms. Psycho-education developed as a category of intervention strategies from multiple codes found within the researcher's transcription of the data. The subtheme of psycho-education was chosen because it illustrates an essential intervention strategy for clinicians to use while supporting caregivers in understanding their child's needs.

**Check-Ins.** All four respondents provided input on staying in consistent contact with the caregivers of the children they work with. The respondents identified this subtheme as an important aspect of developing a therapeutic relationship with a child's caregiver. One respondent spoke about engaging a child's caregiver in the last ten minutes of session to check in and get a sense of how everything is going for them. The following quote highlights a respondent's method of engaging caregivers in conversation:

*Yeah they're [caregiver] coming into the play therapy room or wherever we are. We [therapist and child] are telling them what we did and these are the things that we worked on. Even if they're just sort of listening and saying okay so what did you do? Just trying to use that as an opportunity to check in with them. How are you doing? What are you seeing at home? Even if it's about the child only, the only thing I can get them to*

*engage in a discussion on... So I'll try to start there and really to try to build a connection with them. To try to hope they will open up and reach out if they feel like they need support.*

The respondent made a point to include the child's caregiver in the last part of session. The respondent highlighted that it is important to engage caregivers in what the child worked on and learned during a therapy session. Clinicians who provide a check-in with a child's caregiver also get the opportunity to build an alliance with the caregiver. The clinician is able to ask the child's caregiver if they have any questions or concerns about their child's treatment. It is also valuable to check-in with caregivers to update them on their child's progress in treatment. The following quote illustrates how one respondent maintains consistent check-ins with caregivers:

*I think consistent contact with the families. So that's providing updates on how they are doing with their peers and their social interactions. With their use of coping skills, how they're doing in individual therapy. Not to go into too much detail because you still want to maintain your client's confidentiality even though they are minors. You want to ensure the parents that you're actually addressing the needs in the treatment plan goals. You want to also bring in too if there's any issues at home. You want to follow up on that.*

Caregivers want to know what clinicians are doing to address their child's individual needs. The respondent spoke about checking-in with caregivers on their child's interactions with peers, use of coping skills, and engagement in individual therapy. The respondent highlighted the clinician's responsibility to maintain confidentiality with their client; however, noted the value providing caregivers with enough information on how their child is doing in treatment.

Additionally, the respondent spoke to situations where she would be checking-in with caregivers

right away following a session with a child. The following quote captures situations where a respondent prioritizes connecting with a child's caregiver:

*So any suicidal thoughts or self-injurious behavior. Or anything like that, that was disclosed, then I would be calling. Or if there was potentially a break through in their trauma work, where I thought they could go home and present as irritable or isolate. Then I want the parents to watch those things and I'm calling right away.*

The respondent acknowledged there are times when a clinician should prioritize checking-in with a child's caregiver. It is important for caregivers to know if their child is having suicidal ideations or taking part in self-injurious behaviors. Additionally, the respondent emphasized connecting with caregivers on successes in their trauma work. However, there are times when it can be difficult to reach caregivers. The following quote captures what one respondent does to check-in with caregivers who are not as involved in their child's treatment:

*I have some families where it is really hard to set up times to meet and you can tell that they're not necessarily ready for the work. I think in those circumstances it's working with the child individually and being in contact with the caregiver on a regular basis. And eventually work to a place where they are able to work with the child. And a lot of times that means helping the caregiver with their own mental health because I think a lot of times that's what gets in the way of wanting to be in services with the child.*

The respondent mentions it can be challenging to always check-in with caregivers because they might not be comfortable engaging in their child's treatment. Clinicians should continue to make attempts to remain in regular contact with their client's caregiver. The respondent pointed out that caregivers who are distant from their child's treatment may be dealing with their own mental health issues. Conversely, there are some caregivers who want to



receive frequent updates from their child's clinician. The following quote captures a respondent's method of setting boundaries around checking-in with caregivers:

*So I would say I maintain consistent communication through the whole process. I guess... in the beginning of treatment services parents are generally more involved. Where they're calling more, emailing me more, and needing more updates. As their anxiety starts to reduce and they start to feel more comfortable with you as their provider, their need for that immediate communication decreases and then I can move into more weekly communication. There are still some parents that struggle with that immediate need for communication and so it's really important for me to set boundaries at the beginning of our relationship about how our communication is going to work and what they can expect from me as far as responses to e-mails, phone calls, what information I will share with them, and how it will be shared.*

The respondent acknowledged there are caregivers who are actively involved in their child's treatment. The respondent incorporates a discussion around boundaries as an intervention strategy for caregivers. The respondent makes it clear to caregivers what they can expect from her and what information she will be able to provide to them in regards to communicating about their child. Clinician check-ins developed as a category of intervention strategies from multiple codes the researcher and research chair identified within the transcription.

**Tools to Use.** The respondents all commented on the importance of providing caregivers with tools to utilize with their child outside of treatment and various ways to manage their own challenges with parenting. One respondent highlighted the value of providing caregivers with tools to use with their child:

*...I think as you go overtime you have to be giving. Parents have to feel like they're getting some tools for dealing with this. Otherwise, when you're talking about long term, not only are the children getting tools but the parents are getting tools for dealing with it.*

The respondent points out clinicians should be providing caregivers with tools continuously over the course of their child's treatment. The respondent mentions clinicians should not only be providing tools for the child to use but to the caregiver as well. It is important for caregivers to learn the skills their child is using and learn ways to manage their own emotions around parenting a child with mental health needs. The following quote captures the tools a respondent teaches caregivers to help them attune to their child:

*I think one of the main things... is co-regulation and helping the parent to be able to realize the child's cues and being able to respond to them. I think a lot of times, especially with young children, a lot of the issues come from the child miscuing the parent and the parent not knowing how to respond to the child's cues. And so [there's] a lot of work around... noticing that for the parent. And then in terms of that co-regulation piece helping parents try to understand that this child can't do it on their own. I think a lot of parents have this view that 'this kid if four, they should be able to do this on their own.' Or they just don't really understand child development. And really helping the parent to know when this child is having an upset, they need you to be in with them. I think, understandably so, it's really frustrating and hard for parents when their child is upset and their first go to is to kind of walk away or yell. And so helping parents to realize the importance of really sitting with a child's feeling and to be able to validate that feeling for the child and help them to work through it.*

The respondent vocalized the value of helping caregivers learn how to recognize their child's cues and respond to them in a helpful manner. Additionally, the respondent highlighted that caregivers need to partner with their child when they are upset to model how to regulate their emotions. Another respondent mentioned that caregivers want to learn tools that they can utilize in their every day routines. The following quote illustrates the respondent's remarks:

*...In my experience and in my opinion the treatments that have been most effective in supporting caregivers are the treatments that we can easily generalize and bring into the home, work into our natural environment, and bring into our natural routines throughout the day... So it does not feel like it's an additional thing you have to do in your day... what are those natural routines, and how can I maximize on those learning opportunities, and find those teachable moments where I can get into my child's spot light and teach. Or have that social connection or make that one social exchange.*

Caregivers want to learn tools in session that can be easily applied to their home setting. The respondent teaches caregivers how to transfer the tools they have learned into their daily routines. There is a lot of value in being able to step into your child's spotlight and connect with them on a more meaningful level without having to devote an extended amount of time to it. Another respondent highlighted how encouraging family wellness can be a great tool to get caregivers connecting positively with their children:

*I really like to talk with families about family wellness as a whole and all over wellness. So sticking with the anxiety example. We need make sure there is regular exercise, eating healthy food. A really unhealthy diet or lack of exercise can contribute to anxiety, so these are things that we need to be doing. I always tell families this is something that we should all be doing, even if we don't have a diagnosis of anxiety. So certainly*

*encouraging parents to do these things with their kids and to do things as a family because then they normalize it for their child and it also helps the family too... I just tell them don't feel like you have to have an hour to do that everyday. Just do your best. Even if it's 'we've been cooped up in the house all day, let's take five minutes and do some stretching.' You know just letting them know there are really simple things they can do... Some of the strategies for a young kid with anxiety or ADHD would be telling them to get their wiggles out. Where you get just them to stand up, wiggle, and shake their sillies out. We would tell that to the parents and tell them to do it with them. Not that that's going to be enough exercise but it's kind of silly and you're laughing. And if you're laughing with your kid who you struggle with a lot, that feels good. It helps with their connection...*

Caregivers can incorporate a family wellness plan into their daily routine that can help establish better exercise and eating habits for everyone. The respondent recommended that caregivers join their children in eating healthy foods and exercising to normalize the experience for them. Additionally, the respondent pointed out that caregivers do not need to schedule in a certain amount of time per day to exercise. A family's wellness plan can be as simple as dancing to a song or stretching together. Lastly, caregivers often need help processing their own experience of raising a child with mental health needs. The following quotes illustrate respondents helping caregivers' process their own history:

*So a lot of processing with caregivers about their own history, their own mental health, and how that impacts the child. For most parents there's at least a sense of anxiety or fear of what's going to happen to my child. So even if it's not a significant mental health issue there's still some anxiety or fear around what's going to happen. Or for families*

*that do have significant mental health problems just really helping them to see that it's not their fault.*

*I think the biggest thing is being direct and helping the parents look outside of themselves- what their past experiences was, how they were brought up, how they felt as a child or even as an adult, and how it's different than their current child and the child's circumstances vary compared to what their parent is. And having them refocus more on their child and not so much on themselves.*

The respondents acknowledged the value of speaking with caregivers about their own childhood experiences and how that may be impacting their role as a parent now. The respondents identify that giving caregivers the opportunity to talk about their personal background can improve their ability to focus on their child's needs. This category was developed from multiple codes the researcher and the research chair found within the transcription relating to tools clinician's use to support caregivers of children with mental health needs.

**Evidence-based practice.** One respondent spoke about utilizing cognitive-behavioral therapy (CBT) as an evidence-based practice to support caregivers of children with mental health needs. The respondent mentioned using CBT as an intervention with caregivers because they often have negative thoughts regarding treatment. The following quote captures why a respondent utilizes CBT as an intervention strategy with caregivers:

*I use a lot of CBT, even with parents. The reason why is a lot of times they're engaging in different thought distortions. So really challenging those thought distortions around the treatment or previous treatment history. And how things have worked or haven't worked... even as treatment progresses. I really challenge them on the way they're*

*thinking. As well as for them to identify their feelings... share their feelings and their thoughts in an effective manner. So not placing blame or criticizing, but using more of those I statements and sharing their feelings with their kids.*

This respondent intentionally uses CBT with caregivers to help them identify negative thought patterns and distortions. Additionally, the respondent engages caregivers in conversations regarding their perceptions of treatment and personal experience with treatment. The respondent teaches caregivers how to express their emotions to others without placing blame on others. Only one respondent mentioned evidence-based practices in the transcription of data; however, the researcher and research chair found it to be a valuable intervention to draw attention to while working with caregivers of children with mental health needs.

### **Clinician Skills to Support Caregivers**

The second theme respondents frequently brought up throughout the interviews were the skills clinician's utilize in order to support caregivers of children with mental health needs. The researcher identified three categories of this major theme. The first category included three of the four respondents' remarks about validating caregivers in their parenting journey. The second category that emerged from the data focused on three of the respondents' efforts to empower caregivers. Lastly, the third category that emerged from the data analysis incorporated ways to engage caregivers in their child's treatment.

**Validation.** The respondents provided remarks on the importance of validating caregiver experiences of parenting children who have complex mental health needs. The respondents noted caregivers want to feel accepted and not judged by their child's clinician. The following quote illustrates how one respondent provides validation:

*Parents need a lot of validation that what they are doing is helpful or not helpful. And to validate their experience in the process of their child receiving treatment. So parents will seek that out. They don't ask for validation but they'll go into how hard of a time they're having and that's their way of using me to get that.*

The respondent acknowledged that many caregivers seek out validation from clinicians by expressing the challenges they face while parenting a child with mental health needs. Caregivers want to receive reassurance that what they are doing to support their child is helpful. Additionally, the respondents agreed that caregivers need a space to be heard. The following quotes illustrate how respondents validate caregivers through active listening:

*Yeah, validate for them... really listening. Just really listening to them so they feel that they're being heard. So in terms of treatments or clinical skills. A lot of that listening, validating, reflecting back to people. Not necessarily the mental illness of the child but normalizing their experience of it being difficult.*

*So it starts initially but then it continues. I think if they have a clinician that they feel really listens to them, hears them, and validates for them that this is really hard. Like it is really hard to be a parent of a child struggling with this. So even though the child might be the client, if they feel like okay it's acknowledged that I'm really dealing with something really difficult here. So I think that has to happen initially and then I think it needs to be maintained throughout.*

The respondents both recognized the value of actively listening to the challenges caregivers experience while raising a child with a mental health disorder. It can be comforting for caregivers to receive validation from clinicians regarding their child's complex needs and pointing out that they are doing the best they can. Validation was developed as a category of

clinician skills used to support caregivers through the researcher and research chair's coding of themes found within the transcription.

**Empowerment.** The respondents made several comments about utilizing empowerment as a skill to help support caregivers in connecting with their children. The respondents mentioned that empowerment can help caregivers feel more confident in their parenting skills. Clinicians can help caregivers realize that they can manage their child's needs. The following quote illustrates how one respondent used an empowerment strategy with a caregiver:

*But also empowering caregivers to know that they can handle it. So again if we're talking anxiety and if we're helping a little kid make a tool kit of strategies to deal with anxiety. Then letting the parent know what those are and empowering the parent to remind the child of those strategies. So helping the parent be more competent in their capacity to deal with it.*

This respondent used empowerment as a skill to build up a caregiver's confidence. The respondent helped build up the caregiver's sense of self by providing messages that they can manage what their child is going through and learn how to use relaxation strategies with their child. Another respondent used empowerment as a means to help caregivers' teach their partner the skills learned in their child's session. The following quote captures the respondent's remarks:

*Usually when I see families it's mom coming in by herself because another parent is working or they are separated. I try to use that family system or those opportunities to empower the one parent that comes in to be a teacher for the other parent.*

It is common for one caregiver to attend a meeting regarding their child's needs. This respondent used empowerment to encourage one caregiver to teach their partner and other members of the family the new skills learned in their child's treatment. The respondent



acknowledged the value of getting all members of the family on board to learn the tools needed to respond effectively to their child who has a mental health disorder. Lastly, one respondent empowers caregivers through encouragement to participate in their child's therapy. The following quote captures how the respondent provides empowerment to support caregivers:

*... just empowering them [caregivers] to just participate because it's the only way they're going to see progress. That's the only way they're going to feel competent and achieved. Just teaching them how to be their child's number one. Just giving them the tools and being the teacher for the one hour so they have the tools for the rest of their lives. In relationships like this I've found it helpful to be the supportive teacher versus the therapist that knows everything about mental health.*

This respondent used empowerment to encourage caregivers to become participants in their child's treatment. It's important for caregivers to take part in their child's treatment because this is a big predictor of a child's success. The respondent highlighted that caregivers are going to feel more confident and competent in their abilities to respond to their child's needs through active engagement. The category of empowerment was developed through the researcher and research chair's coding of themes found within the transcription of data. Clinicians play an important role in empowering caregivers to be their child's number one through difficult moments.

**Engagement.** The respondents spoke about the importance of getting caregivers incorporated in their child's treatment. One respondent mentioned caregiver involvement is one of the top priorities for children six-years-old and under. The following quote captures the value of caregiver engagement in children's mental health treatment services:

*I think first off at the beginning of the assessment process we really talk with families about how important it is for kiddos six and under to have that work happen with the parent. So I think we set it up at the very beginning that this is going to be a family thing and that you're going to need to be involved because we know and research tells us that especially for kids who are really young the way that they're going to get better is for their parents to be involved in therapy. So I think that kind of the first step.*

The respondent highlighted the value of caregivers being involved in their child's treatment since children have a better chance of improving their mental health symptoms. This respondent is very transparent with the caregivers she works with about their need to be engagement in their child's treatment services. Another respondent acknowledged that it can be difficult to provide mental health services to a child whose caregivers are not involved. The following quote illustrates the need for caregivers to be engaged in their child's mental health treatment:

*Yeah you want to make sure the parent's perspective is being heard. The child is always going to be my client and I make that very clear to them that I'm going to focus on them and they are my number one priority, but without them I can't do anything. I need their perspective on things.*

This respondent acknowledged it is essential to receive a caregiver's perspective on their child. The child may be the primary client in treatment; however, the clinician still needs the caregiver to be engaged to provide input and insight on their child. However, one respondent admits that it is not always possible for caregivers to be involved in their child's treatment. The following quote illustrates how one respondent attempts to reach out to caregivers who may not be as involved in their child's treatment:

*I think for the most part [is for] you to have all caregivers that are important to the child involved in therapy, but I think a lot times it's also not possible, especially with things like scheduling issues and parents that work different schedules and things like that. I think it's really seeking out caregivers and trying to get them involved in services, even if they aren't seeing it as an important part of the change process. There are parents that are also, you know like you were saying earlier, just like want that quick fix. It's really talking with the parents about this is along process and it's not going to change in a day. A lot of the times a little snippet of information we give parents is that it takes 2,000 times for the brain to rewire. So it's going to take 2,000 of doing this over and over. Like if it's something like a child has a really hard time when a parent sets limits or when a parent says no. It's going to take 2,000 times of following through and supporting the child in that for their brain to rewire and do that. So again part of that is the psycho-education piece.*

This respondent attempts to reach out to caregivers who lack engagement in their child's treatment. The respondent highlighted the importance of caregiver involvement and wants caregivers to understand that progress will not take place in a day. A child's progress will take place over time as caregivers learn how to adapt their skills to meet the individual needs of their child. Conversely, one respondent questions if caregivers are ready for their child to partake in treatment services if they are not willing to engage in the therapeutic process. The following quotes depict a respondent's belief that caregivers may not be ready for treatment if they lack involvement:

*I think it's super, super, important to not forget the parent in the journey of their child and their journey of getting treatment. Focus on the well being of the parent. If the parent*

*is not well, not ready to support their child, not ready to bring therapy into the home, and discuss the hard stuff then we're not ready to help the child as a team.*

*Also, just discussing the importance of their participation and engagement is so important right off the bat. And if parents are not ready for that and parents are not ready to commit sometimes I might ask them again if they're ready for treatment for their child, and if they're not, they're not, and that's okay. I do ask for a commitment from families and reiterate the fact that they have to be very involved for this to benefit their child. And it's okay if you're not. So we can try again another time in your life.*

This respondent sets the tone for caregiver engagement at the beginning of the treatment process. The respondent notes if a caregiver is not in a place to be involved in their child's treatment it may not be an appropriate time to start services. Additionally, the respondent acknowledges that it is okay for caregivers to not be ready to participate in their child's treatment and ensures therapy services can be started at another point in time. Conversely, one respondent brought up the importance of clinicians addressing their own judgments about why a caregiver may not be as involved in their child's treatment. The following quote illustrates a respondent's message to clinicians about reflecting on their own biases regarding caregiver engagement:

*I think it's important for clinicians to address their own preconceived notions on parents or their own judgments. And to really self-reflect on is a parent really being needy or are they anxious? And if you were that parent how else would you feel? Because parents engage in treatment differently. Some parents are helicopter parents where they need to know everything, they're in constant communication, and they're highly anxious. Or they're very judgmental of what you're doing. There's other parents who you really have to work hard to get them bought in to the program and they're just kind of like will you*

*fix it and are hands off. So I think it's really important for clinicians to self-reflect on their own emotions and the counter-transference that's going on.*

This respondent identified the value of clinicians addressing their own biases about caregiver engagement in their child's mental health treatment. There are caregivers who occupy both sides of the involvement spectrum. The respondent identifies the importance of clinicians reflecting on how their own counter-transference impacts the judgments they make about caregivers who have children enrolled in treatment for their mental health needs. Caregiver engagement was developed as a subtheme of clinician skills to support caregivers by the researcher and the research chair while coding the transcription of data. Engagement was chosen as a category because it was a common topic brought up by respondents in the study.

### **Caregiver Stigma**

The third theme that emerged from the data analysis was caregiver stigma. This theme developed from multiple respondents addressing the impact stigma has on a caregiver's ability to address their child's needs and accept their child's mental health diagnosis. One respondent spoke about the general impact stigma has on caregivers of children with mental health needs:

*I think mental health stigma for just in the children I work with but also the parents is huge because it's deemed as more of a problem or issue that is wrong with the person itself versus the organ of the brain. And how people who have heart problems can receive help and their not stigmatized as the same way they are with their brain.*

Caregivers struggle with understanding the complexities of mental health in children. The respondent highlighted the strong stigma attached to children receiving treatment for mental health when compared to being treated for a physical illness. The respondents also noted that some mental health diagnoses have more stigma attached to them than others. The following

quotes highlight the impact stigma has on caregivers' accepting their child's mental health diagnosis:

*... I think sometimes a lot of the parents I see have a hard time coming to terms or accepting it. I know a lot of times when we do outcome measures and there's a question that asks 'does your child have a disability either mental or physical?' they'll say no even though they've gotten a diagnosis.*

*"Also I think... sometimes people decide to home school and they know their child is atypical and want to avoid a diagnosis being told to their child."*

*... if it's pointed out to them that we're actually talking about something other than anxiety. Maybe there's anxiety there too but there's something else that maybe has a lot more stigma attached to it. Or something that the parent isn't ready to accept. Or in a lot of denial about. Then they stop coming for services.*

*I would also say another one would be when children are starting to exhibit personality traits. So there starting to look into more borderline personality. That's a hard one for people to swallow because we can manage those symptoms but there's not full relief from those. So that's a lot harder than when kids are given depression or anxiety where hopefully you can do a complete symptom reduction over time.*

Caregivers have a broad spectrum of reactions when it comes to learning about their child's mental health diagnosis. The respondents spoke about caregivers associating stigma with certain diagnoses such as autism and personality disorders. Additionally, the respondents spoke about the ramifications that can occur if a caregiver is in disagreement about their child's mental health diagnosis. Caregivers also associate a stigma towards psychotropic medication. The following quote speaks to a respondent's experience providing psychiatry referrals to children:

*“I will see push back when I make a referral for medication management. For psychiatry referrals you’ll see more of a hesitancy to have their children medicated.”*

Caregivers often want to try other alternatives before resorting to medication for their child. The respondent expressed the push back she often receives from caregivers for providing psychiatry referrals to children. Caregivers appear to experience a lot of ambivalence about their child taking psychotropic medication for their mental health needs. Additionally, caregivers appear to experience difficulties in seeking out services for their own support. The following quote addresses a respondent’s view on caregivers seeking out assistance:

*I think it’s hard for people to ask for support for themselves. You know for dealing with their child... It’s hard for people to accept oh yeah maybe I could use some support or a support group would be really good for me to meet other parents whose children have similar mental health issues.*

Caregivers find it difficult to ask for their own support while raising a child with mental health needs. Caregiver stigma developed as a theme from various codes found within the transcription of data by the researcher and research chair regarding the stigma caregivers associate with children’s mental health and receiving their own support.

### **Emotional Impact**

The fourth theme that emerged from the data analysis was emotional impact. This theme developed from all of the respondents speaking to the emotional hardships caregivers endure while raising a child with a mental health disorder. The respondents addressed several feelings relating to the caregiver experience of raising a child who has mental health needs. The first category addresses caregivers’ feelings of frustration. While the second category speaks to the overwhelming feelings caregivers experience parenting a child with a mental health need. The

third category identifies the relief caregivers experience as they learn about their child's diagnosis. Lastly, the fourth category encompasses the grief caregivers' encounter as a result of their child's mental health diagnosis and ongoing needs.

**Frustration.** The respondents noted an array of frustrations caregiver experience while parenting a child with mental health needs. One respondent spoke to the frustrations caregivers experience about feeling helpless and not in control. The following quote from a respondent illustrates caregiver frustration:

*I also think they can feel really frustrated and sometimes at a loss. Often times people are not very proactive when it comes to mental well being and thinking oh this is just a phase my child is going through. My child will grow out of it. Or I'll be able to deal with it. Yes my child feels down, but I'll be able to deal with it. And just when it gets to the point where it feels like I have no idea what to do anymore. I've tried everything I can think of and I don't know what to do. That's when people come in.*

The respondent acknowledged that caregivers of children with mental health needs are not always proactive when it comes to their own wellbeing. Caregivers often let their frustration build up until they run out of resources to use with their child. Another respondent spoke about a caregiver's frustration with previous services not being effective in helping their child:

*I often see frustration and anger. And they're frustrated as to why previous services didn't work for their kid or why current services are taking so long and they're not seeing the benefit. We also see frustrations from collaboration with other professionals working in the child's life.*

This respondent spoke to the frustrations caregivers experience when they feel services are not working for their child. Caregivers want to know that the time, money, and effort they are



investing in their child participating in mental health services is benefiting their child. The respondent also expressed that caregivers want professionals to collaborate for effectively with each other. Lastly, a respondent spoke to a caregiver's frustration with doing all the right things for an adopted child but still seeing emotional and behavioral problems surface in their adolescent years. The following quote captures the respondent's remarks:

*We were really hoping this wasn't going to happen. We knew that that was there but you still think it's not going to happen to you and then it did. So that was really tough for those parents to then see that come about because we knew that that was a risk but really we did everything right. That's what the family was saying. So you know it's a risk when you get into it but you think it's not going to happen. Or maybe we're going to be one of the ones that are going to protect her from that.*

Caregivers can be caught off guard when a child's mental health needs emerge and it can take a toll on the entire family. This respondent highlighted the frustration one family experienced while raising an adoptive child who developed emotional and behavioral problems in their adolescent years. Frustration developed as a category of emotional impact through multiple codes identified by the researcher and research chair in the transcription of data.

**Overwhelmed.** The respondents addressed the overwhelming feelings caregivers experience while parenting a child with mental health needs. Two respondents spoke about the overwhelming pressures caregivers face to learn new parenting skills. The following quotes capture the respondents' comments:

*Also, I think they [caregivers] are so much more overwhelmed and they have way fewer resources. So both financially in terms of how to deal with things but also their energy just because of what they're dealing with in the lives and multiple system involvement can*

*often be like “so now I have to completely change how I parent?” So I think that is often something that I think people would say. So really we need to work with families in delicate way.*

*I first see a lot of these families in the very beginning when they’re just diagnosed.*

*There’s just so much to learn and understand. It’s this whole new world that you’d never expect that you’d enter while your pregnant and have your child. So it almost feels like you have to relearn how to do life.*

It can be extremely overwhelming for caregivers of children with mental health needs to learn new ways of parenting and interacting with their child. One respondent emphasized the importance of working with caregivers in a delicate way. Another respondent pointed out that caregivers often feel overwhelmed because they have reached their limit. The following quote illustrates the overwhelming emotions caregivers have:

*“I think people can feel exhausted, frustrated, kind of at their limit. Then they come into therapy just like ‘I don’t know what to do anymore.’ Then they unload everything and say ‘here’s the child, help me!’”*

The respondent highlights how overwhelmed caregivers can get once they have reached their limit. Caregivers often seek out services when they reach a point where they don’t know what to do anymore. Overwhelmed was developed as a category of emotional impact from multiple codes found within the data by the researcher and research chair.

**Relief.** Caregivers experience relief in a variety of ways regarding their child’s mental health diagnosis. All four of the respondents agreed that caregivers experience a degree of relief when receiving a diagnosis and learning about what the diagnosis means for their child. The following quotes illustrate the relief some caregivers’ experience:

*That initial acceptance is hard to hear. It's like okay this is PTSD. That is what's going on, okay. So there is some sort of relief and acceptance with just getting the yes this is what it is. And so that, I think, even though it's not the news they wanted it's kind of the news they knew was there. So just that acceptance I think helps them adjust. It's like once you know then you can say okay how are we going to move forward.*

*Sometimes I think too it's just parents are kind of excited, well not excited, but are happy to know like what's going on to have a name to put to it because I think a lot of times parents are like I don't understand what is happening? I don't understand why my child is acting like this. So to have some information around what's going on with them can also be helpful.*

*I think sometimes it's very relieving for parents because there's an answer. And then they're like 'oh, okay this makes sense!' So relieving and they're happy that there's an explanation and reasoning to what has been going on. Some are excited to receive services and to be getting help.*

Caregivers can experience a sense of relief once they have information on what's going on with their child. One respondent spoke about the initial acceptance piece being difficult but acknowledging that it provides caregivers with a roadmap on how to move forward. Another respondent brought up the value in putting a name to the emotions and behaviors their child displays at home. Additionally, a respondent brought up the relief caregivers' experience when they have more information on their child's diagnosis. The following quote highlights how one respondent normalizes a child's diagnosis:

*... I think the positive can come even as early as the first session. If the clinician is able to normalize for the parents. You know parents love to hear the stats on anxiety like it's the*

*most common. So they're like really? That many kids struggle with anxiety! So it just normalizes it a little bit. So I think there can be some relief once they're maybe getting going.*

This respondent attempts to normalize the facts on mental health for caregivers. The respondent mentions relief can come as early of the first session if the information regarding their child's diagnosis can be normalized to the general population. Additionally, one respondent spoke to caregiver's feeling relieved once they start to see improvements in their relationship. The following quote illustrates the respondent's remarks:

*"Usually at the end we see more relief and happiness because we've been able to subdue some of those symptoms for the child and change their behaviors. So the relationship between the parent and the child just improves."*

Caregivers gain a sense of relief once their child's symptoms improve and they make progress towards their goals. The respondent highlighted that relief and happiness are possible for caregivers to experience. The category, relief, was established because it was identified multiple times throughout the transcription of data by the researcher and research chair.

**Grief.** The respondents mentioned the grief caregivers experience while parenting a child with mental health needs. Some caregivers experience grief over the relationship they envisioned having with their child. While others experience grief over the etiology of their child's disorder and question if they played a role in their child's mental health. The following quote captures the emotional impact grief has on caregivers:

*I was thinking of a recent client, he is a six year old who was recently diagnosed with autism and I think a lot of times especially with that diagnosis but other ones as well parents feel this sense of grief of kind of, like this parent described it as they were*

*grieving the child they kind of had hoped for and expected that child to be. And so there comes some grief with it because they are mourning the loss of what they thought their child would be like.*

This respondent highlighted the impact grief had on a caregiver whose child received an autism diagnosis. The caregiver went through a grieving process about the child they had envisioned. Additionally, a respondent mentioned caregivers feel a sense of grief over what caused their child's mental health disorder. The following quote illustrates the respondent's remarks:

*"But I think there is also some sadness and hurt related to "did I cause this?" Or "am I the one continuing my kids mental health symptoms from not getting better. So I think sadness is the underlying one."*

This respondent recognized that caregivers experience grief and sadness around the impact they might have had on their child's mental health. Caregivers are very sensitive about the role they have in their child's health. One respondent mentioned that some caregivers may even take on their child's hurt or pain. The following quote illustrates a respondent's comment on caregiver pain:

*"I think the biggest one that they feel is some sort of hurt or pain. And it can be their taking on their child's hurt and their emotions from their struggles."*

The respondent illustrates the feelings of hurt and pain associated with the grieving cycle. Caregivers can feel pain, sadness, hurt, and doubt as part of the grieving process around their child's needs. Grief developed as a category of emotional support because multiple codes emerged from the researcher and research chair's transcription of the data.

### **Family Needs**

The fifth theme that emerged from the data was family needs. The researcher and research chair identified two categories of this overarching theme. The first category that appeared from the data was emotional needs from caregiver's family and friends. The second category that emerged from the transcription of data was financial and basic needs support from a child's clinician.

**Emotional needs.** It is important for caregivers of children with mental health needs to receive emotional support from their family and friends. One respondent commented on the isolation caregivers can experience from their friends who cannot relate to their situation. The following quote from a respondent depicts a caregiver's need for emotional support:

*It's so isolating and then not having friends who understand. You know you're going out to lunch with friends and they're all talking about how their child made the football team or their child made the honor role. Parents are very judgmental and Facebook is the worst. Everyone just puts how wonderful their kid is. It doesn't mean those kids don't have anxiety. You're just not talking about it on Facebook. So it's really the perceptions and dealing with the lack of support. It can be very isolating.*

This respondent recognized that caregivers often feel isolated from their friends. Caregivers want to feel supported from their friends; however, it can be challenging for other people to relate to their experience. The respondent also highlighted the image people portray on social media may not be the reality of many families. Additionally, several respondents commented on the desire to feel supported and accepted by their family members. The following quotes from respondents' illustrate the need for caregivers to have supportive family members:

*“...Initially when we started therapy they [caregivers] had a lot of trouble accepting the diagnosis, understanding it, telling friends and family about it, teaching friends and family about it, and having friends and family understand and accept it too...”*

*“Stigma and negative judgments from others who don’t understand. I think when that comes within the family that’s the hardest...”*

The respondents highlighted that caregivers want emotional support from their immediate and extended family members. The respondents also mentioned that it can be devastating for caregivers to have family members who are not accepting or supportive of their circumstances. Additionally, caregivers want to feel emotionally supported by their child’s clinician. The following quotes capture two respondent’s remarks:

*I think some of our caregivers really see that their child’s issues really put a whole burden on the family in general. So a lot of them are looking for services that help with the whole family whether it’s between the parent-child-relationship or between siblings. And so I think caregivers are really concerned with what this is doing to my family and family’s wellbeing. The dynamics of family.*

*... This mom reached out to me and asked what can you do for us? She had asked for this certain kiddo to have some time away from the clinic. They were planning to just get away and take some time away from everything. She had asked me if he could miss two weeks of treatment in order for them to just refocus and cope...*

Clinicians should be checking in about a caregiver’s emotional needs throughout their child’s treatment. One respondent noted that families are looking for services that can help improve family dynamics. Another respondent highlighted that caregivers want to feel emotionally supported by their child’s clinician. Emotional needs was developed was a category

of emotional impact by the researcher and research chair through multiple codes found throughout the transcription of data.

**Financial and basic needs.** The respondents expressed caregivers of children with mental health needs often seek out services to receive support in meeting their financial and basic needs. Two respondents commented on their ability to provide referrals to case managers within their organization to help caregivers meet these needs:

*I do a lot of referring to case managers who can take that role on. So I would say parents come to me more about financial needs out of the most and their basic needs. I think they both go hand in hand.*

*“As far as finances and basic needs... I would work with a case manager to support that.”*

*So a lot of that is just me referring out and providing them [caregivers] with different resources or hooking them up with different agencies to get those basic needs met because a lot of times that's where their focus is. Then the behavior issues or the emotional problems that their child are having is kind of second nature because I have to make sure there is food on the table, that there's a roof, that there's clothing, and that they're safe...*

The respondents made note that their primary role is to connect caregivers to case managers to support their financial or basic needs. However, one respondent highlighted that she has to make this connection a priority because she cannot be effective in her work if a family's basic needs are not being met. Financial and basic needs was created as a category of family needs because the researcher and research chair found several codes regarding this topic in the data analysis.



## **Discussion**

The purpose of this research study was to explore the various ways mental health professionals support caregivers of children with mental health needs initially and over the course of their child's treatment. The findings from this study reveal several similarities and differences from the literature documented on this topic. The following section will discuss the interpretation of the research study's findings on the five themes and their corresponding categories found within the transcription of data.

### **Intervention Strategies**

The researcher identified two similarities between the research study's findings and the current literature on this topic. The first similarity the literature spoke to was peer-led and clinician-led psycho-education being a valuable intervention strategy for caregivers of children with mental health needs to receive support and gain a better understanding of their child's diagnosis and treatment (Brister et al., 2012; Hoagwood et al., 2012; Koroloff et al., 1996; Kutash et al., 2011, 2013; Leffler et al., 2010; Levy-Frank et al., 2012; MacPherson et al., 2016; Mendenhall et al., 2009; Ong & Caron, 2008). The findings of this research study also suggest clinician psycho-education is a powerful intervention strategy to use with caregivers of children with a mental health diagnosis. The respondents addressed the value of teaching caregivers about their child's diagnosis, treatment options, and how mental health may impact their child's everyday functioning. The second similarity found within the literature is the use of CBT to help caregivers relate in more adaptable ways to their child who has a mental health disorder (Barrett et al., 1996; Jongerden & Bogels, 2015). A similar finding on using CBT with caregivers was mentioned by a respondent in the research study. The respondent utilizes CBT with caregivers to identify thought distortions about mental health treatment and teach caregivers how to express

their feelings to their children. Lastly, the findings from this study also provided new insights into identifying who the client is in therapy, checking-in with the child's caregiver on a regular basis, and teaching caregivers tools to practice using with their child outside of treatment.

### **Clinician Skills to Support Caregivers**

Respondents in this research study provided new insights into the skills clinicians utilize to support caregivers of children with mental health needs. The respondents addressed the value of validating the challenging experiences caregivers have endured while parenting a child with a mental health disorder. Additionally, the respondents identified that clinician empowerment is an essential skill to use with caregivers. Caregivers want to learn skills to feel more competent as a parent and rebuild the parent-child relationship. Lastly, the respondents expressed the importance of regularly reaching out to caregivers to connect about their child's treatment and address personal biases about caregiver engagement in their child's treatment.

### **Caregiver Stigma**

The respondents in the research study discussed the impact stigma has on a caregiver's ability to accept their child's mental health diagnosis. The current literature on this topic did not directly address caregiver stigma; however, the literature does address that caregivers experience a wide range of emotions regarding their child's mental health diagnosis from difficult to comprehend to relieved (Richardson et al., 2013). Additionally, a similarity found in the research study and current literature was the stigma attached to prescribing psychotropic medications to children. The current literature on caregiver perceptions of prescribing psychotropic medication to children for a mental health disorder is mixed (Hansen & Hansen, 2006; Lazaratou et al., 2007; Ninan et al., 2014; Rappaport & Chubinsky, 2000; Scholtes, 2001; Waters, 2000). However, the literature on this topic did address caregiver concerns about the negative side

effects psychotropic medication can have on children (Hansen & Hansen, 2006; Lazaratou et al., 2007; Ninan et al., 2014), which coincides with a finding in the research study that caregivers are typically hesitant to have their child medicated. Conversely, the current literature acknowledges that caregivers are often caught off guard by their child's mental health diagnosis but are able to adapt to their child's needs. Whereas, respondents from the research study pointed out that caregivers may decide to home school their children to avoid a diagnosis or terminate treatment services early due to the stigma children's mental health carries.

### **Emotional Impact**

Respondents in the study addressed that caregivers experience a wide range of emotions. The research study found caregivers experience a sense of frustration because they feel helpless or not in control. Similarly, the current literature identified that caregivers feel helpless and alone (Shpigner et al., 2013). The research study also spoke to caregivers feeling frustrated because previous services did not work or have been taking too long. Another similarity between the research study and current literature is the grief caregivers experience over their child's mental health needs. The literature addressed caregivers experience grief over the child they expected to raise and ongoing adjustment to their child's needs (Richardson et al., 2013; Shpigner et al., 2013). Additionally, the literature spoke to the various stages of grief caregivers may be experiencing about their child's mental health needs (Penzo & Harvey, 2008). While the research study also identified that caregivers experience grief over the child they envisioned and feeling a sense of sadness about the impact they have on their child's mental health. Conversely, the research study and current literature acknowledged that caregivers do experience relief learning about their child's mental health disorder and how to move forward (Richardson et al., 2013). Lastly, new insights were gained from the research study on the overwhelming feelings

caregivers experience when they have reached their limit and expectation to learn new parenting skills.

### **Family Needs**

There are several similarities between the researcher's findings and the current literature on caregiver needs. The research study found that caregivers want to receive emotional support from their family, friends, and child's clinician. The respondents spoke to the importance of caregivers receiving support from their significant other and extended family members. While similarly the literature addressed that caregivers are concerned about the lack of quality time they spend with their family and participating in their hobbies (Delaney, 1996; Richardson et al., 2013). Additionally, the literature and research study both address that caregivers of children with mental health needs often experience a lack of support from their significant other (Oruche et al., 2012). The research findings also pointed out that caregivers want to feel accepted by others and supported by their child's clinician. Lastly, the research study and the current literature addressed helping caregivers get their financial and basic needs met. The literature addressed the challenges caregivers endure to keep a job that aligns with their educational background and expectation to be available to support their child at all times (Richardson et al., 2013; Rosenzweig et al., 2002). Whereas, the research study's findings addressed the importance of providing referrals for caregivers to connect with case managers to get their financial and basic needs met. The respondents highlighted that providing referrals to caregivers should be a clinician's priority because work cannot be achieved in a child's therapy if their basic needs are not being met.

### **Limitations**

The researcher noticed several limitations that may have impacted this qualitative research study. First, the qualitative research design limits the external validity of the study's findings because of the study's small sample size and respondents were not selected at random. Additionally, the study's participants have worked in a broad range of settings that serve children and families, which may reflect different perceptions, reactions and treatment recommendations. Lastly, the four respondents were interviewed from a pool of mental health professionals in the Twin Cities metro; therefore drawing from a small geographic area. However, this qualitative research study has provided valuable insights into how clinicians support caregivers whose children receive treatment for their mental health needs. Additionally, the current research study contributes to the existing research that has been documented in the literature regarding children's mental health.

### **Implications**

It is important for mental health providers to have a knowledge base on the impact children's mental health has on families, especially caregivers. The researcher's interpretation of the findings has drawn four implications from this qualitative study. The first implication suggests that caregivers need to feel supported by their child's clinician. It is important for clinicians to give caregivers tools to help their child outside of treatment and teach caregivers about their child's diagnosis. The second implication from the findings emphasizes the importance of clinicians validating and empowering caregivers who have children with a mental health disorder. Social workers should focus on the strengths caregivers possess and bring these strengths to light. Additionally, the findings show that caregiver engagement is an essential component to a child's success in treatment and caregiver well-being. Social workers must find ways to connect with caregivers about their child's treatment and check-in to provide support.

The third implication from the research study's findings addresses the need for social workers to advocate and reduce the stigma associated with mental health services, especially for children and families. Lastly, the fourth implication of the study highlights the need for children and families to receive early intervention. Social workers should focus on providing mental health services to children and make a point to incorporate their caregiver in the treatment process.

Furthermore, research is still needed in the area of children's mental health, specifically in regards to how mental health professionals can best support caregivers of children with mental health needs. Future research should consider exploring the best evidence-based practices clinicians should use to support caregivers who are parenting a child with a mental health disorder. Additionally, researchers should conduct a qualitative study looking at the impact clinician support has on a caregiver's physical and mental well-being. Lastly, researchers should continue to explore the barriers caregivers experience in regards to seeking out services for themselves.

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## Appendix A. Informed Consent Form

**Consent Form****[977192-1] *A Clinician's Role: Addressing Caregiver Adjustment Concerns to Families of Children with a Mental Health Disorder***

You are invited to participate in a research study about how clinicians support caregivers of children with a mental health disorder. I invite you to participate in this research. You were selected as a possible participant because you work in a setting that provides mental health services to children and families. You are eligible to participate in this study because you are a licensed mental health professional with a master's degree or doctoral degree in clinical social work, marriage and family therapy, counseling psychology, or psychology. The following information is provided in order to help you make an informed decision whether or not you would like to participate. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Lauren Gavin, a graduate student at the University of St. Thomas and supervised by her research chair Dr. Renee Hepperlen. The Institutional Review Board at the University of St. Thomas approved this study.

**Background Information**

The purpose of this study is to understand how clinicians support caregivers of children who are receiving treatment for their mental health needs. Grounded theory techniques will be used to gain a comprehensive understanding of the challenges families endure while caring for a child with a mental health disorder.

**Procedures**

If you agree to participate in this study, I will ask you to do the following things: participate in a semi-structured interview at the University of St. Thomas or your place of employment for 60 minutes, allow me to audio record our interview on my password protected computer, allow my research chair to view the transcription of the data, and permit me to present the aggregated findings of this study to peers and colleagues in my seminar class and to the public on May 15, 2017. I estimate that a total of eight participants will take part in this research study. I do not intend to follow up with any participants after completion of the 60 minutes interview.

**Risks and Benefits of Being in the Study**

The study has risks. There is a possibility that a breach of data confidentiality may occur. In order to minimize the risk of a breach of data confidentiality, I will transcribe my interviews with participants within one week of the interview. The computer used to audio record the interview session will be saved to my password protected to ensure the confidentiality of participant's information. Additionally, I will upload all interview transcriptions into One Drive, which requires a password and is encrypted to ensure participant confidentiality.



There are no direct benefits for participating in this study.

### **Privacy**

Your privacy will be protected while you participate in this study. The researcher and participant will agree on a location before meeting to complete the interview. Additionally, the researcher will keep a visual timer on her computer to ensure the interview does not exceed 60 minutes. The audio recording of the interview and paper documents will only be shared with the researcher's chair.

### **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. The types of records I will create include audio recordings, transcripts, and computer records. All audio recordings, transcripts, and computer records will be stored on the researcher's password protected computer and uploaded to a password protected and encrypted online software, One Drive. My research chair will review the interview transcripts, but will not know who you are. I will delete identifying information from the transcript. I will keep my computer in my possession while traveling and in a locked room while not in use. The findings from the transcript will be presented to my peers and colleagues and to the public on May 15, 2017. The audio recording and transcript will be destroyed by June 15, 2020. All signed consent forms will be kept for a minimum of three years upon completion of the study. Institutional Review Board officials at the University of St. Thomas reserve the right to inspect all research records to ensure compliance.

### **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 me or the University of St. Thomas. There are no penalties or consequences if you choose not to participate. If you decide to participate, you are free to withdraw at any time without penalty or loss of any benefits to which you are otherwise entitled. Should you decide to withdraw, data collected about you will not be used in this study. You can withdraw by stating at anytime that you would like to be done with interview questions at this time. You are also free to skip any questions I may ask by stating that you would like to skip this particular question and move on to the next one.

### **Contacts and Questions**

My name is Lauren Gavin. You may ask any questions you have now and any time during or after the research procedures. If you have questions later, you may contact me at (651) 783-2968 and gavi0033@stthomas.edu. Specific questions or comments may be addressed by my research chair, Renee Hepperlen at (651) 962-5802. You may also contact the University of St. Thomas Institutional Review Board at 651-962-6035 or muen0526@stthomas.edu with any questions or concerns.

**Statement of Consent**

I have had a conversation with the researcher about this study and 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. I give my permission to be audio recorded during this study.

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

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**Signature of Study Participant****Date**

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**Print Name of Study Participant**

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**Signature of Researcher****Date**

## Appendix B. Interview Guide

1. Tell me about your educational background and what your role is as a clinician at [place of interview].
2. What are the demographics of the clients you serve at this agency?
  - e.g age, race, gender, socioeconomic status
3. What types of childhood or adolescent mental illnesses are referred to you?
4. What is your role as a clinician in providing services to caregivers' of children with a mental illness?
5. What are the prominent feelings that emerge for caregivers who have a child with a mental illness? Please explain.
6. As a clinician what are some ways you've seen a caregiver come to terms or accept their child's mental illness? Please provide examples.
7. In your opinion what treatments are the most effective for supporting caregivers in adjusting to their child's mental illness initially and over time?
8. What treatments work best for supporting caregivers in reducing their level of stress?
9. What are your thoughts on reaching out to a caregiver if they do not directly seek out your assistance?
10. How do you work with and support caregivers who are at different stages of implementing change.
11. What do you see caregivers seek the most assistance with in regards to their spirituality, culture, family, finances, basic needs, and emotional, social, and physical wellbeing? Please provide a few examples.

12. In your opinion what are the biggest challenges a caregiver will endure throughout their child's care?

13. Is there anything else you'd like to share with me about working with caregivers of children with mental health concerns?