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Acceptance Experience of Parents of Children with Mental Illness

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Running head: PARENT EXPERIENCE

Acceptance Experience of Parents of Children with Mental Illness

by

Brienne A. Gallaway

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

This study seeks to identify the grief and acceptance experiences of parents of children who have been diagnosed with a mental illness. In particular, the study compares the experiences of parents whose children have been diagnosed with a ‘socially acceptable’ diagnosis to parents whose children have been diagnosed with a ‘non-socially acceptable’ diagnosis. The study involved 29 parents who were recruited through the method of snowball sampling. A qualitative survey was distributed to parents, with descriptive statistics analyzed through frequency distributions. Qualitative questions were analyzed through content analysis, with responses transcribed and coded by the researcher. The research found that there were not many distinctions among experiences of parents of children with ‘socially acceptable’ and ‘non-socially acceptable’ diagnoses. Experiences appeared to be quite varied and individual for all parents. Both parent’s supports and time since a child’s diagnosis did emerge as factors that could impact a parent’s experience and acceptance of their child. Implications of this research suggests the benefits to social workers educating parents and professionals, as well as encouraging parents to deal with the emotions and responses they face regarding their child’s diagnosis.

Keywords: child mental illness, acceptance, grief, parent experience

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Acceptance Experiences of Parents of Children with Mental Illness

Diagnosing mental illness involves great complexity and affects not only that person, but also the many people and systems around him or her. The National Institute of Mental Health reports, “1 in 5 children, either currently or at some point during their life, have had a seriously debilitating mental disorder” (“Any Disorder Among Children”, 2010). This prevalence may indicate that a large amount of the population has been touched by a child with a mental illness, highlighting the importance of understanding these diagnoses. When a child is diagnosed with a mental health disorder, the child’s family is likely the system that is most affected. Following a diagnosis, both child and family are involved in the treatment and support moving forward (Marsh & Johnson, 1997). It is important to not overlook how the family may experience their child’s diagnosis.

Understanding a parent’s experience after their child’s mental health diagnosis, specifically the grief experienced, is important to the field of social work and working with children and families who have been diagnosed (Godress, Ozgul, Owen, & Foley-Evans, 2005; Richardson et al., 2012). Gaining insight as to how parents experience this journey is especially helpful to better understand how parents are able to accept their child following a diagnosis (Boulter & Rickwood, 2013; Wachtel & Carter, 2008). Some parents compare this grieving process to the grief of a death (MacGregor, 1994; Penzo & Harvey, 2008; Wiens & Daniluk, 2009). Once parents are able to grieve losses, they are better able to move forward and attune with their child’s needs (Wachtel & Carter, 2008). A parent’s acceptance of their child and of their child’s diagnosis can in turn affect both the emotional and practical support that a parent is able to share with their child (Wachtel

& Carter, 2008). In Rando's six stages of grief, an important step to grieving is accepting losses and moving into new relationships (Patricelli, 2006). The purpose of this study is to understand the grieving and acceptance experience of parents of children diagnosed with mental illness, and what the differences are in accepting a 'socially acceptable' diagnosis versus a 'non-socially acceptable' diagnosis.

Literature Review

Parent Reactions to Diagnosis

A large amount of research has studied how parents react when their child is diagnosed with a mental illness diagnosis (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2011). Ahmann (2013) interviewed parents to understand their experience of "making meaning" of their child's diagnosis (p.1). Moses (2011) conducted a similar study, looking at how parents conceptualize their child's mental health. Studies have found that some emotions are commonly experienced in association with a child's mental health diagnosis including helplessness, devastation, sadness, loneliness, guilt, anxiety, and grief (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2010; Moses, 2011). These emotions may overlap; for example, feelings of helplessness may lead parents to feel increasingly devastated or increased difficulty in processing grief (Mendenhall & Mount, 2011; Moses, 2011). The intensity of emotions that a family experiences when their child is diagnosed with a mental illness, such as the guilt they feel for their possible role in the diagnosis, may be affected by a parent's understanding of mental health (MacGregor, 1994; Moses, 2010). Understanding how these emotions play out for parents can be helpful to better understanding a parent's experience when a child is diagnosed with mental illness.

Helplessness is a very common feeling for parents whose child is diagnosed with a mental illness (Ahmann, 2013; MacGregor, 1994). Parents of children with a mental illness report feelings of helplessness around keeping their child from struggling either emotionally or behaviorally (Ahmann, 2013). Additionally, parents may feel helpless in creating safety or calm as they experience their child's outbursts and receive negative reports from teachers or other adults. Parents also may feel helpless to stop their child from being ostracized or excluded in school or other social contexts (Ahmann, 2013; Mendenhall & Mount, 2011). Often, a child's mental illness symptoms can have an impact on their social interactions. Parents may have some control over their child's friendships or social opportunities at home, but it may become more difficult as a child grows older. Helplessness is often created as parents feel a lack of control in their child's academics and social interactions.

Similar to a parent's experience of helplessness may be a sense of devastation or sadness (Ahmann, 2013). Devastation and sadness are often linked to realizing that a child is losing friendships or having increased difficulty in making friends (Ahmann, 2013; Mendenhall & Mount, 2011; Moses 2011). Parents may feel increasingly devastated or sad when comparing their child to other children and noticing differences (Moses, 2011). One key difference parents sometimes note is a child's inattentiveness or aggressive behaviors, which may be external symptoms of a mental illness (Ahmann, 2013). Sadness can lead to grief as a parent realizes their child may not be able to control their energy or may never interact with peers the same way others do. Additionally, a parent may lose hope for what they had dreamed or expected for their child's future (Marsh & Johnson, 1997; Mendenhall & Mount, 2011).

Having a child diagnosed with a mental illness can be a very lonely experience (Ahmann, 2013). Parents feel less able to relate to other parents and often feel alone in their difficult emotions – such as helplessness or devastation (Ahmann, 2013). This loneliness can be accentuated by having less time to spend with friends due to therapy appointments, meetings at school, or other increased activities to meet their child’s needs (Mendenhall & Mount, 2011; Suiter & Heflinger, 2011). Parents may also feel a transition with their friends as friends gain an understanding of the diagnosis and respond in various ways to the family (Mendenhall & Mount, 2011).

It is not uncommon for parents to assume responsibility for their child’s mental illness (MacGregor, 1994; Moses, 2011). Parents may experience a sense of guilt, feeling that they did not do enough to prevent their child’s mental illness or fearing that they took too long to get their child help (MacGregor, 1994; Moses, 2010; Wiens & Daniluk, 2009). Parents may even blame themselves for ‘causing’ the development of a mental illness, attributing it to a poor home environment or their lack of support for their child (Moses, 2010). This may lead to a parent contemplating what they could have done differently or how they could have prevented stressors that they may associate to the ‘cause’ of their child’s mental illness. If mental illness runs in the family, a parent may feel guilty for the role that heredity plays in the child’s life (Moses, 2010).

Studies have found that anxiety and stress are emotions often experienced by parents of children diagnosed with a mental illness (Mendenhall & Mount, 2011; Suiter & Heflinger, 2011). Anxiety comes from uncertainty of the future. Merriam-Webster defines anxiety as “painful or apprehensive uneasiness of mind usually over an impending or anticipated ill” (Merriam-Webster online dictionary, n.d.) Parents of a

child with mental illness may be anxious over their child making friends, over how other adults view their child, or about feelings of loneliness (Ahmann, 2013; Mendenhall & Mount, 2011; Moses 2011). Research has found that anxiety in parents often specifically links to their child's behavior problems (Mendenhall & Mount, 2011). Parents may even be anxious about safety for their child or family when violent behavior is a symptom of their child's mental illness (Suiter & Heflinger, 2011). Mendenhall and Mount (2011) also identify anxiety over their child's future as one of the main points of anxiety for parents.

Families may experience a mental health disorder diagnosis as a burden (Hinshaw, 2005; Mendenhall & Mount, 2011; Suiter & Heflinger, 2011). This is often referred to as caregiver strain or as objective and subjective burdens (Hinshaw, 2005; Marsh & Johnson, 1997; Suiter & Heflinger, 2011). Marsh and Johnson (1997) define an objective burden as the "caregiving responsibilities" and "limitations of the service delivery system" (p. 230). Another big aspect of the objective burden of raising a child with a mental illness is the financial burden (Hinshaw, 2005; Suiter & Heflinger, 2011). The subjective burden can be understood as the "psychological pain, embarrassment, and mental anguish related to caring for the family member" (Hinshaw, 2005, p. 720). Mendenhall and Mount (2011) highlight how the stress associated with caregiver strain, "can impact multiple areas of the parents' lives, including their own mental/emotional state, physical health, employment, social life, and family relationships" (p. 184). The objective burden of having a child with a mental illness was found to be easier for families to deal with than the subjective burden (Hinshaw, 2005).

Parent responses to a mental illness diagnosis vary by family, but common

emotions experienced by a parent include helplessness, sadness, loneliness, guilt, and anxiety (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2010; Moses, 2011; Suiter & Heflinger, 2011). Many of these emotions are not experienced alone, but overlap with others, and the same is true for a parent's experience with grief (Mendenhall & Mount, 2011). Understanding a parent's full experience can help to gain an insight into what leads to an acceptance of their child's diagnosis.

Socially and Non-socially Acceptable

Even within the category of childhood mental illness, there is a wide range in the level of stigma attached, based on the type of diagnosis (Giannakopoulos et al., 2014; Griffiths et al., 2014; Hinshaw & Stier, 2008; Perry, 2011). For the purposes of this study, a 'socially acceptable' diagnosis is one that has fewer stigmas attached to it, while a 'non-socially acceptable' diagnosis is often viewed with more stigma and discrimination. As Cormack and Furnham noted, "individuals with more severe, bizarre, and perceptible symptoms of mental illness are more likely to experience and perceive rejection" (as cited in Perry, 2011, p. 2). Anxiety, depression, attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD), and adjustment disorder are diagnoses with higher prevalence and tend to be viewed as less serious diagnoses (Giannakopoulos et al., 2014; Perou et al., 2013; Perry, 2011). Childhood disorders that have more stigma attached and are seen as 'serious mental illness' include major depression, schizophrenia, autism, and bipolar disorder (Griffiths et al., 2014; Hinshaw & Stier, 2008; Perry, 2011).

Factors of Parent's Reactions

A child and family's experience of mental illness is often shaped by their

knowledge of mental illness, their family demographics, social stigma, and by the impact of available supports (Boulter & Rickwood, 2013; Mukolo, Heflinger, & Wallston, 2010; Moses, 2010). A parent's understanding of mental illness impacts the way they begin to conceptualize a child's diagnosis. More specifically, this includes what a parent believes the cause of mental illness to be (Boulter & Rickwood, 2013). Boulter and Rickwood (2013) identify that parents more often seek help when they believe that the mental illness is unique to their child's internal self and that it would not change without intervention. Parents who receive or have received intervention for their own mental illness are also more likely to seek help for their child (Boulter & Rickwood, 2013; Moses, 2011).

A parent's understanding of mental illness may also be linked to their demographics. Moses (2011) found that Caucasian parents were significantly more likely to experience self-blame regarding their child's diagnosis than parents of a different race. In this same study, parents of a female child were more likely to self-blame than parents of a male child. Boulter and Rickwood (2013) found that Caucasian parents were more likely to seek help than minority parents. Other studies have found no significant difference based on demographics, although this could be a lack of participation of diverse populations in the studies (Crowe & Lyness; 2013).

The social stigma that is associated with mental illness often results in the difficult emotions associated with diagnosis to be experienced alone, and maybe even experienced more painfully (Hinshaw, 2005; Moses, 2010). Stigma often leads to the isolation that families experience, as parents are hesitant to be around or to allow their children to interact with a child with a mental illness (Mendenhall & Mount, 2011;

Mukolo et al., 2010). This social stigma and isolation from friends can be linked to the loneliness that parents experience following their child's mental health diagnosis (Mendenhall & Mount, 2011). Stigma and misunderstandings of mental illness can also contribute to friends, family, or society assuming that the family has contributed to the mental illness, on top of self-blame that families may already be experiencing (Richardson, Cobham, McDermott, & Murray, 2012). However, parents often are more resilient to a child's diagnosis when they can rely on the support of friends and family (Judge, 1998).

A fourth impact on family reactions that is very present in research is support, or lack of support, that parents receive (Boulter & Rickwood, 2013). Moses (2010) identifies the importance of social supports for families, as they work against the self-blame that parents take on themselves and against the stigma of society. Research has found that extended families may be unsupportive of parent's help seeking, which leads to one more factor on the list contributing to the complexity of dealing with a mental illness diagnosis (Boulter & Rickwood, 2013). MacGregor (1994) and Wiens and Daniluk (2009) highlight the experience of working with professionals who often overlook support for parents. Not only are social supports linked to fighting self-blame and stigma, they are correlated with good family coping and family resilience (Judge, 1998). Supports available for families can have a large impact on the way that parent's experience the diagnosis of a child with mental illness.

Grief

Grief may be one of the most complicated emotions that a family experiences with their child's mental illness diagnosis (Godress et al., 2005; Richardson et al., 2012).

Grief can be defined as “sorrow, emotion, and confusion that comes from losing someone or something important to you” (“How to deal,” 2001, p.1). One way to measure grief is through the Impact of Event Scale, which gages grief through “intrusively experienced thoughts and feelings” and “consciously recognized avoidance of thoughts, feelings, and situations related to a specific event” (Godress et al., 2005, p. 89). Grief, as with other emotions related to the diagnosis of a child’s mental illness, is experienced at different intensities for every family (MacGregor, 1994; Wiens & Daniluk, 2009). Even within a family, parents often grieve a diagnosis differently, which can be difficult for a parent who is grieving and may feel increasingly lonely in his/her grief (MacGregor, 1994). Additionally, a parent may be hesitant to admit grief, due to stigma or the complications of loss while his/her child is still physically present (MacGregor, 1994). At the same time, research supports that grief and loss are typical experiences for a family who has a child diagnosed with a mental illness (Godress et al., 2005; MacGregor, 1994; Richardson et al., 2012). Godress et al. (2005) found that parents with higher grief “also reported greater levels of emotional distress and lower levels of psychological well-being and health status” (p. 92).

The grief and loss that comes with a child being diagnosed with a mental illness appears to have some similarities to grieving a death of a loved one (MacGregor, 1994; Wiens & Daniluk, 2009). The grief of this loss can be understood in the context of a cycle of grief for death or another similar framework (Penzo & Harvey, 2008). The Kubler-Ross cycle of grief was initially applied to the loss of a loved one, but is now applied more broadly to grief of other losses (Patricelli, 2006). One parent of a child diagnosed with a mental illness expressed the great loss in comparison to his loss of close

loved ones, “The death of my father, the death of my mother, other deaths I’ve experienced—I’ve never felt like I did when my child was diagnosed with schizophrenia” (Wiens & Daniluk, 2009, p. 344). A unique experience associated with grieving a child diagnosed with mental illness is that this grief can ebb and flow with the milestones a child reaches (Richardson, Cobham, McDermott, & Murray, 2012). Sometimes the grief can be experienced even more intensely as the losses become more evident rather than at the time of diagnosis (Richardson et al., 2010; Richardson et al., 2012).

In understanding a parent’s experience with grief and this impact on acceptance of their child, it is helpful to understand what losses a parent is grieving. Parents may grieve many losses, including losses specific to their child and their own losses as a parent (MacGregor, 1994; Marsh & Johnson, 1997; Richardson et al., 2012). When a parent grieves a loss of their child, it often involves the loss of who they knew their child to be (Richardson et al., 2010; Richardson et al., 2012). The presence of mental illness symptoms affects a child and may change personality or characteristics (MacGregor, 1994). On top of that is the understanding that their child may continue to change or may never be the same (Richardson et al., 2010). As parents understand the implications of a mental illness, they may begin to experience their emotions of fear and anxiety over their child’s future (Richardson et al., 2012). At this time, or in the future when their child begins to reach the age of typical milestones, a parent may grieve losses of their child’s future; potentially including marriage, a career, or more (MacGregor, 1994; Richardson et al., 2010; Richardson et al., 2012). As a result, a parent may begin to grieve a loss of hope for their child’s “potential, talents, and competence” (MacGregor, 1994, p. 163). Beyond grieving losses of their child, a parent may grieve over the loss of the existing

family system or feeling a loss of capability as a parent (MacGregor, 1994; Richardson et al., 2010; Richardson et al., 2012). Stigma and a family's isolation may lead to a sense of loss regarding supports and relationships (Richardson et al., 2012). In regards to the objective burden that parents experience, a parent may experience a loss of freedom in time or finances (Hinshaw, 2005; MacGregor, 1994; Marsh & Johnson, 1997; Richardson et al., 2012).

Though grief of a child diagnosed with a mental illness is not a tangible loss, it could be viewed as a "complex, unending loss" for parents (Richardson et al., 2010, p. 34). The way that grief shows up in families may differ, but there are losses that are commonly experienced for parents of child with a diagnosis (Richardson et al., 2012; Wiens & Daniluk, 2009). This may include the loss of the child they knew, their child's future, or loss of the family's current way of functioning (MacGregor, 1994; Marsh & Johnson, 1997; Richardson et al., 2012). Understanding what and how a family grieves is helpful to beginning to understand a parent's journey to supporting their child.

Ability to Attune to Child's Needs

A parent plays a vital role in the life of a child who is diagnosed with a mental illness (Boulter & Rickwood, 2013; Suiter & Heflinger, 2011). Parents are important advocates for children getting the help and support they need to be successful (Suiter & Heflinger, 2011). Additionally, Boulter and Rickwood (2013) reason, "children and adolescents are necessarily dependent on adults to take responsibility for their mental health care needs, as they generally do not have the autonomy or the means to seek help for themselves" (p. 131). Beyond these needs, children need emotional support from their parents (Wachtel & Carter, 2008). Wachtel and Carter (2008) found that "parents

who are unable to emotionally accept their family's situation may have more difficulty becoming attuned to their children's needs" (p. 590).

There are factors that research has found that increase likelihood of parents utilizing services for their child's mental health (Boulter & Rickwood, 2013; Richardson et al., 2012). One of these factors is the "worsening of their child's symptoms" (Richardson et al., 2012, p. 725). Boulter and Rickwood (2013) also found that parents sought help following an increase in their child's behaviors or seeing greater affects on the entire family system.

Acceptance and Resolution

Understanding a parent's ability to attune to their child's needs can be linked to the parent's resolution or acceptance of the diagnosis (Milshtein, Yirmiya, Oppenheim, Koren-Karie, & Levi, 2010; Wachtel & Carter, 2008). Resolution is the concept of "coming to terms with and accepting the diagnosis and its implications" (Milshtein et al., 2010, p. 89). According to Pianta and Marvin, resolution can be viewed as "accepting the diagnosis, incorporating the diagnosis into one's reality, and resisting self-blame" (as cited in Wachtel & Carter, 2008, p. 576). Additionally, Bowlby explains the idea of acceptance in his final stage as "accepting the irreversible nature of the loss, working through and discarding old patterns of thinking, feeling, and acting, and a gradual acceptance that the loss is permanent and that life must be shaped anew" (Feniger-Schaal & Oppenheim, 2013, p. 307). Accepting new norms and relationships is the final stage in Rando's theory of grieving (Patricelli, 2006). Milshtein et al. (2010) and Feniger-Schaal and Oppenheim (2013) did not find links between characteristics of a child's diagnosis and the parent's state of resolution. Studies on resolution have also not found a link

between parent's resolution and family demographics (Kearney, Britner, Farrell, & Robinson, 2011; Riper, 2007). Studies on parent resolution status have found that between 1/3 and 1/2 of parents would be considered to be resolved (Feniger-Schaal & Oppenheim, 2013; Kearney et al., 2011; Milshtein et al., 2010).

Wachtel and Carter (2008) found that "emotional resolution" scores from an emotional resolution inventory are "significantly related to both PCIRS cognitive and supportive engagement", PCIRS being a rating scale of parent support and interactions (p. 16). This finding suggests that a parents' resolution of grief can be linked to their ability to support their child. Additionally, Milshtein et al. (2010) found that mothers who were not resolved tended to have "more negative perceptions regarding their child and the influence that raising the child has on the family" (p. 98). Feniger-Schaal and Oppenheim (2013) found that a parent's state of resolution might have an effect on their sensitivity toward their child.

A variety of factors have been linked to a parent's state of resolution (Feniger-Schaal & Oppenheim, 2013; Kearney et al., 2011; Riper, 2007). Riper (2007) found that significant factors linked to resolution included "family demands, family resources, and family problem-solving communication" (p. 124). Kearney et al. (2011) also found that with mothers, depression, various stressors affecting the mother, and stress of child rearing could have impacts on state of resolution. A state of resolution is an important piece of the process toward acceptance for parents whose children have been diagnosed with mental illness (Milshtein et al., 2010; Wachtel & Carter, 2008).

Conceptual Framework

The two grief frameworks that are being used to drive this research include the Kubler-Ross grief cycle and Rando's Six R's of grief (Patricelli, 2006). Though these both were originally geared to grief of a death, I am applying these frameworks and concepts to the losses that come from having a child diagnosed with mental illness. The Kubler-Ross model has five stages, including "denial", "anger", "bargaining", "depression", and "acceptance" (Axelrod, 2006). Rando's six stages of grief include the steps of "recognize", "react", "recollect", "relinquish", "readjust", and "reinvest" of these relationships (Patricelli, 2006). Rando's second step, 'react' includes experiencing and acknowledging all the emotions that are related to the loss, such as the child's prior behavior or child's future (Patricelli, 2006). Beginning to feel these emotions and losses is a necessary step in the grieving process for parents, before coming to terms with the loss, or in this case, the diagnosis and involved losses (MacGregor, 1994; Richardson et al., 2012).

The last stage of both the Kubler-Ross model and Rando's model is the stage of acceptance (Axelrod, 2006; Patricelli, 2006). In the literature, the grief and acceptance experiences of parents of children diagnosed with a mental illness appear to fit with these stages of grief (Richardson et al., 2010; Richardson et al., 2012; MacGregor, 1994; Wachtel & Carter, 2008; Wiens & Daniluk, 2009). In this research, I am specifically interested in what moves parents to the acceptance stage, and how they are able to support their child. Through the literature, I believe that what is best for children diagnosed with mental illness is for their parents to reach the stage of acceptance, as this allows for the most successful and supported life for a child (Milshtein et al., 2010; Wachtel & Carter, 2008). A limitation to these models is that they do not incorporate a

systems perspective or look at the family as part of an environment. A systems perspective is helpful in understanding how formal and informal supports are impacting a parent's grief and acceptance experience ("Concepts: System Perspective", 2011).

Methods

Based on the literature around the experiences of parents whose children have been diagnosed with mental illness, my research question is "What is the acceptance experience of parents of children diagnosed with a 'socially acceptable' diagnosis versus a 'non-socially acceptable' diagnosis of mental illness". To gain insight into how parents experience this diagnosis, I conducted qualitative surveys online. This included both open-ended and closed-ended questions that allowed parents to describe their experiences, emotions, and potential processes in moving toward acceptance of their child's diagnosis.

Subject

I interviewed parents of children diagnosed with mental illness for this qualitative research project. The respondents were found through an organization called NAMI (National Alliance on Mental Illness). NAMI provides support, advocacy, and spreads awareness of mental illness. Participants were found through posting on the 'research opportunities' section of NAMI's website. Participation was sought from approximately 8-10 parents. Qualitative surveys allowed the opportunity to gain good insight to a parent's experience of the process following their child's diagnosis with mental illness. Participants seeking out participation in research opportunities through NAMI were likely to have begun the process of accepting their child's diagnosis, as they

would be expressing a desire to participate in this study. Parents of children up to age 16 were sought for participation in this study.

Protection of Human Subjects

Participation in this study was voluntary and there was implied consent of participants (see Appendix A). Surveys were completed online, which allowed for anonymity of participants involved in this study. The study was reviewed by the St. Catherine University Institutional Review Board prior to the survey being administered. Surveys were transcribed and coded, then partner coded by a fellow classmate, who signed a confidentiality agreement. Confidentiality was discussed with respondents, including the portion being transcribed and reviewed with a partner.

Data Collection

Data for this qualitative research was gathered through an online quantitative and qualitative survey. The survey included both closed-ended and open-ended questions, with the list of questions approved by this researcher's committee prior to posting the survey. The questions for this study were developed following research of the literature regarding parents of children diagnosed with a mental illness (see Appendix B). Closed-ended questions involved questions related to family demographics and characteristics related to the child's diagnosis. Open-ended questions focused on the emotions that parents have experienced since the initial diagnosis, as the literature suggests a wide range of emotions may be experienced by parents (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2010). Questions involved how parents view the concept of acceptance of their child's diagnosis, and where they feel they are at in the

acceptance process. This also involved how the parent has shifted expectations of their child and how they are able to support their child.

The surveys were listed on the NAMI website, under Research Opportunities. Surveys were completed from a link on the NAMI posting, which people could find through voluntarily visiting the Research section of NAMI. NAMI posted surveys on their Research Opportunities section following review by the organization's medical director, documentation of IRB approval, and determining relevancy to NAMI members. Parents had the opportunity to read a little bit about the survey, and contact me with questions if applicable. Surveys were approximately 15 minutes in length, and respondents were able to complete this on their own schedule. Surveys were created through the web survey tool called Qualtrics.

Data Analysis

Sample. My sample was analyzed through questions to determine demographics of the population that I was researching. Demographic questions included questions regarding the child's gender, age, and diagnosis. A question was also asked to determine who is filling out the survey, and what their relationship is to the child. A frequency distribution was run on the child's gender and age. The purpose of this analysis was to draw some conclusions about the parents who completed the survey.

Research question. To answer the question "What is the acceptance experience of parents of children diagnosed with a 'socially acceptable' diagnosis versus a 'non-socially acceptable' diagnosis of mental illness", a content analysis was completed on the qualitative portion from the surveys of parents of children diagnosed with mental illness. In this method, researchers created codes and themes through the data. These themes are

created through grouping similar codes found in the research (Monette, Sullivan, & DeJong, 2011; Padgett, 2008). Themes were identified that were related to the research question of how parents experience the grief and acceptance of their children diagnosed with mental illness. My hypothesis was that there would be a difference between acceptance experiences among parents of children with ‘socially acceptable’ diagnoses and parents of children diagnosed with ‘non-socially acceptable’ diagnoses.

To analyze the demographics of respondents on these surveys, frequency distributions and measures of central tendency and dispersion were run on the descriptive statistics. Frequency distributions were done on the nominal level variables, including child’s gender, diagnosis, and relationship to child. Central tendency and dispersion were used to measure child’s age and time since diagnosis.

To support the reliability of the coding done in this research process, a partner coder was utilized for partner reliability. This involved both researcher and partner analyzing and coding the same data for codes and themes, then discussing the findings (Monette et al., 2011). The researcher transcribed the surveys, then coded and themed on her own. Her partner received blank copies of the same transcription of surveys, then created codes and themes on her own, prior to discussion. This process of accountability is an additional guard against bias by the researcher (Monette et al., 2011).

Strengths and Limitations

A strength to content analysis is that it allows for finding themes among words, phrases, or even behaviors (Monette et al., 2011). Another strength is that themes are drawn out as a result of codes and patterns that are found, rather than finding portions of the data to fit into a predetermined theme (Padgett, 2008). A limitation of using content

analysis for research is that bias can impact a researcher's coding and theming, but this can be reduced through the use of a partner coder (Monette et al., 2011). With the use of partner coding and overlaps found among codes, reliability could be a strength for this way of analyzing research. Another limitation to content analysis is the use of interpretation for the data, which is less objective than other modes of research (Monette et al., 2011).

Conclusion

This research on the experiences of parents of children diagnosed with mental illness is important for guiding social work practice with these parents and families. It is beneficial for both parents and professionals to better understand this process of acceptance and the supports that are needed. An online qualitative survey allowed parents to respond on their own time and share as much detail as they feel comfortable with. It also allowed the research to involve a range of parents in a variety of settings.

Findings

Introduction

This purpose of this research study is to understand the acceptance experiences of parents of children diagnosed with a mental illness. This study asked parents about their reactions and emotions following diagnosis, as well as how that changed over time. It then asked parents to list what they gave up or how they felt they had to sacrifice for their child's diagnosis. Parents were given opportunity to discuss supports in their life and their perspective on how acceptance can be defined. Finally, respondents were asked to identify ways in which they support their child.

Some aspects of this study varied from the methods section regarding how the survey was completed. When the researcher emailed NAMI with this study, they responded that they were merging their site with another and would no longer be posting research studies. The researcher then resubmitted a proposal to the IRB proposing the method of snowball sampling as a means of gathering participants. The number of participants sought was 25 parents. The researcher received 29, with 26 being fully completed surveys. The study was aimed at parents of children under the age of 16, however, 3 participants had children over the age of 16. Cerebral palsy and developmental delay were also listed as diagnoses by some of the respondents. These diagnoses were added to the findings, despite not being listed in the categories of expected diagnoses. Due to the symptoms of this child's diagnosis, the researcher categorized this diagnosis into 'non-socially acceptable' diagnosis for the purpose of this study. The surveys maintained the same questions as the researcher intended in the initial proposal. Surveys were created through Qualtrics and included both open and closed-ended questions. The researcher did not have a partner coder for this study, so the researcher created codes and themes for the findings.

Sample

Surveys were conducted with parents of children diagnosed with a mental illness to answer the research question, "What is the acceptance experience of parents of children diagnosed with a 'socially acceptable' diagnosis versus a 'non-socially acceptable' diagnosis of mental illness". Parents were recruited through snowball sampling and completed surveys anonymously.

Descriptive Statistics

The first descriptive statistic measured the gender of the respondent's child. This variable is operationalized through the research question: What is your child's gender?

This nominal variable was analyzed through a frequency distribution and bar chart. The frequency distribution in Table 1 represents the gender of respondent's children, with (1) Male and (2) Female.

Table 1. *Child's Gender*

What is your child's gender?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	21	72.4	72.4	72.4
	Female	8	27.6	27.6	100.0
	Total	29	100.0	100.0	

Table 1 shows that of the 29 participants, 21 respondents (72.4%) have a male child who has been diagnosed with a mental illness and 8 respondents (27.6%) have a female child who has been diagnosed with a mental illness.

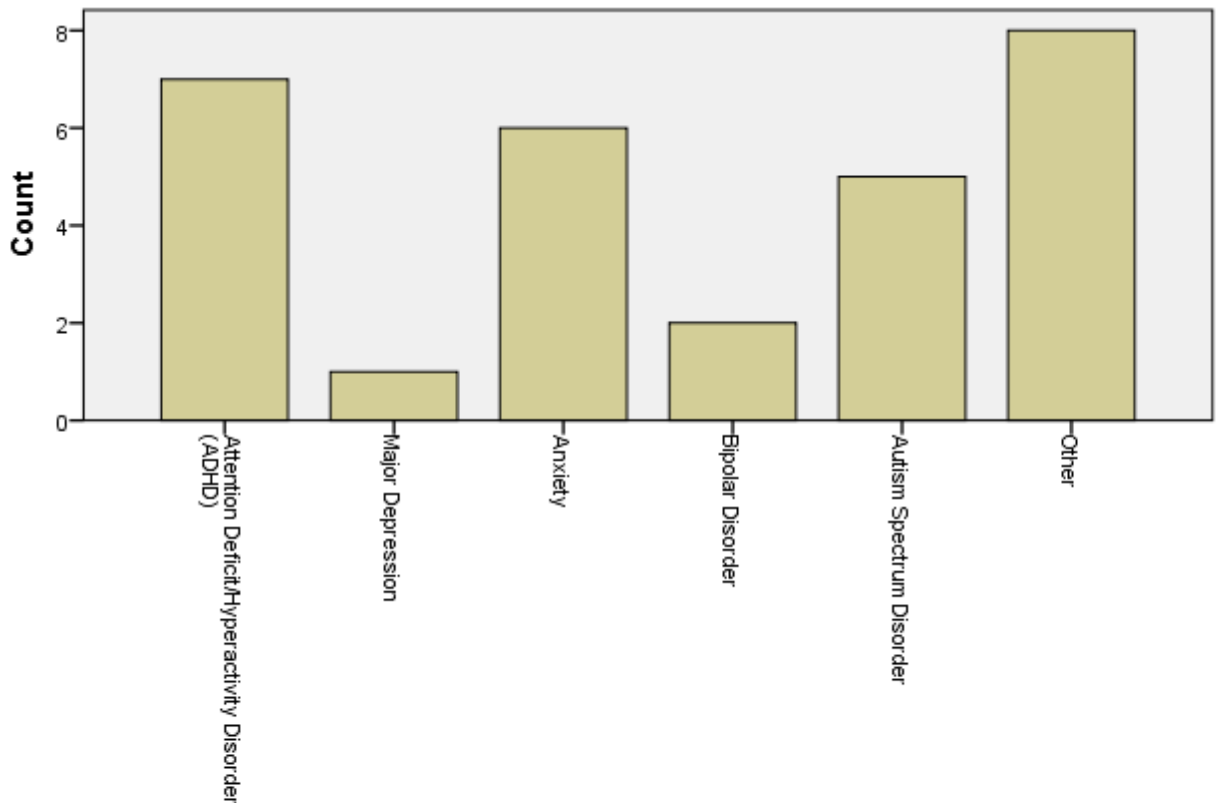
The second descriptive statistic measured the mental health diagnosis of the respondent's child. This is operationalized by the question: To the best of your knowledge, what is your child's diagnosis? This nominal variable was measured through a frequency distribution and bar chart. The frequency distribution in Table 2 represents the diagnoses of respondent's children.

Table 2. *Child's Diagnosis*

To the best of your knowledge, what is your child's diagnosis?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Attention Deficit/Hyperactivity Disorder (ADHD)	7	24.1	24.1	24.1

Major Depression	1	3.4	3.4	27.6
Anxiety	6	20.7	20.7	48.3
Bipolar Disorder	2	6.9	6.9	55.2
Autism Spectrum Disorder	5	17.2	17.2	72.4
Other	8	27.6	27.6	100.0
Total	29	100.0	100.0	

Table 2 shows that of the 29 respondents, 7 respondents (24.1%) have a child diagnosed with Attention Deficit/Hyperactivity Disorder, 1 respondent (3.4%) has a child diagnosed with Major Depression, 6 respondents (20.7%) have a child diagnosed with Anxiety, 2 respondents (6.9%) have a child diagnosed with Bipolar Disorder, 5 respondents (17.2%) have a child diagnosed with Autism Spectrum Disorder, and 8 respondents (27.6%) have a child diagnosed with a diagnosis other than these. The 8 respondents who listed other identified their child's diagnosis as (1) 'Developmental Cognitive Delay (mental retardation) and Anxiety', (2) 'Down Syndrome', (3) 'Sensory issues', (4) 'ADHD, Depression and ASD', (5) 'Mild Autism and ADD', (6) 'OCD, Hoarding, PTSD, and ADHD', (7) 'Asperger with anxiety and possible ADHD', and (8) Cerebral Palsy. Participant responses are shown in the frequency distribution below (Figure 2).



To the best of your knowledge, what is your child's diagnosis?

Figure 2. Diagnosis Distribution

1= ADHD, 2= Depression, 3= Major Depression, 4=Anxiety, 5=Bipolar Disorder, 6= Autism Spectrum Disorder, 7= Schizophrenia, 8= Oppositional Defiant Disorder, 9= Adjustment Disorder, 10= Eating Disorder, 11= Other

Figure 2 visually demonstrates that the majority of respondents fell into ‘Other’, as their child did not fit just one of the diagnoses. This visual also shows that there was not an extreme distribution to any one of the diagnoses.

The third descriptive statistic measured the respondent’s relationship to the child they were completing the survey regarding. This is operationalized through the research question: What is your relationship to the child you are completing this survey about? This nominal variable was analyzed through a frequency distribution. The frequency distribution in Table 3 represents the relationship of respondents to their child.

Table 3. *Relationship to Child*

What is your relationship to the child you are completing this survey about?

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Mother	25	86.2	86.2	86.2
Father	4	13.8	13.8	100.0
Total	29	100.0	100.0	

Table 3 shows that of the 29 participants, 25 respondents (86.2%) were mothers and 4 respondents (13.8%) were fathers.

The fourth descriptive statistic measured the age of the respondent's child. This is operationalized through the question: What is your child's age? This interval level of data was measured through a frequency distribution. The response scores ranged from the minimum of 3 to the maximum of 26.

Table 4. *Child's Age*

What is your child's age?				
	Frequency	Percent	Valid Percent	Cumulative Percent
Valid	1	3.4	3.4	3.4
3	1	3.4	3.4	72.4
4	1	3.4	3.4	75.9
6	1	3.4	3.4	79.3
7	4	13.8	13.8	93.1
8	1	3.4	3.4	96.6
9	1	3.4	3.4	100.0
10	1	3.4	3.4	6.9
11	5	17.2	17.2	24.1
12	1	3.4	3.4	27.6
13	3	10.3	10.3	37.9
14	1	3.4	3.4	41.4
15	5	17.2	17.2	58.6
21	1	3.4	3.4	62.1

26	2	6.9	6.9	69.0
Total	29	100.0	100.0	

The findings in table 4 show that 1 respondent (3.4%) had a child age 3, 1 respondent (3.4%) had a child age 4, 1 respondent (3.4%) had a child age 5, 1 respondent (3.4%) had a child age 6, 4 respondents (13.8%) had a child age 7, 1 respondent (3.4%) had a child age 8, 1 respondent (3.4%) had a child age 9, 1 respondent (3.4%) had a child age 10, 5 respondents (17.2%) had a child age 11, 1 respondent (3.4%) had a child age 12, 3 respondents (10.3%) had a child age 13, 1 respondent (3.4%) had a child age 14, 5 respondents (17.2%) had a child age 15, 1 respondent (3.4%) had a child age 21, and 2 respondents (6.9%) had a child age 26. This indicates that the ages were fairly spread out, with some clusters at a few of the ages.

The fifth descriptive statistic measured the length of time since the respondent’s child received his/her diagnosis. This is operationalized through the question: What is the length of time since your child received his/her diagnosis? This ordinal statistic was measured the measures a frequency distribution and displayed in a bar chart. Response options included (1) 6 months – year, (2) 1-3 years, (3) 3-5 years, and (4) 5+ years.

Table 5. *Length of Time Since Child’s Diagnosis*

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 6 months - 1 year	5	17.2	17.2	17.2
1-3 years	5	17.2	17.2	34.5
3-5 years	9	31.0	31.0	65.5
5+ years	10	34.5	34.5	100.0
Total	29	100.0	100.0	

Table 5 shows that out of the 29 participants, 5 respondents (17.2%) had a child who had been diagnosed 6 months- 1 year, 5 respondents (17.2%) had a child who had been

diagnosed for 1-3 years, 9 respondents (31%) had a child who had been diagnosed 3-5 years, and 10 respondents (34.5%) had a child who had been diagnosed for over 5 years.

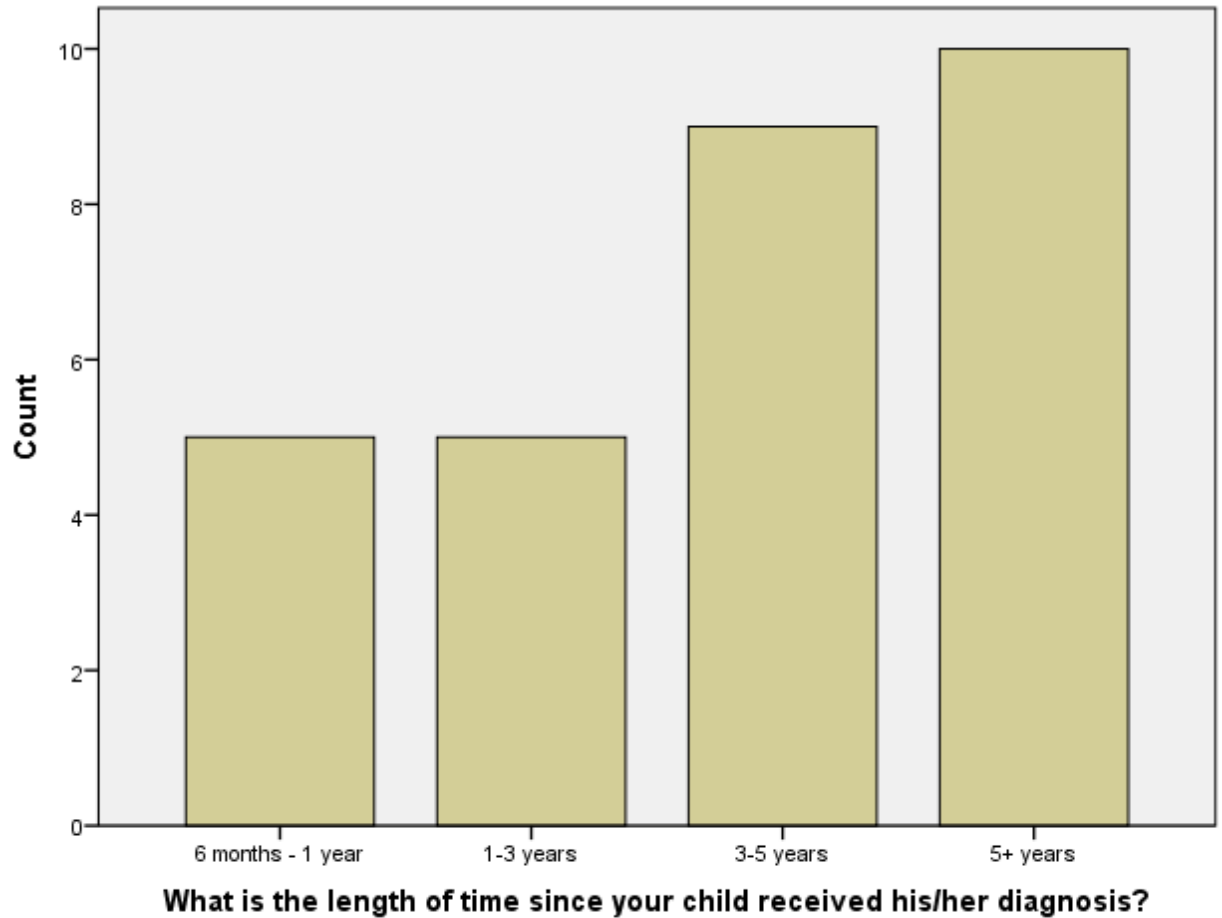


Figure 5. Length of Time Since Diagnosis

Figure 5 visually demonstrates that the majority of respondents have children who have been diagnosed with a mental illness over 5 years. The histogram indicates a negative skewness, because the tail goes to the left and more of the participant's responses fall on the right of the mean.

Qualitative Analysis

Themes were identified in respondent's answers to the qualitative survey questions through coding by the researcher. The researcher was hoping to gain insight into the experiences of parents of children diagnosed with a mental illness. This included the emotions that parents experience once their child is diagnosed and what the process looks like for a parent to grieve and then move to a place of accepting their child. Ultimately, the researcher was interested in understanding how a parent's ability to accept their child allows them to support their child.

Initial reactions to diagnosis.

The first question in this survey was stated as: List your initial reactions to learning that your child was diagnosed with a mental illness. The researcher identified two themes from this question, which included positive reactions and negative reactions. The variety of negative emotions and reactions listed was far more extensive than the list of positive emotions and reactions.

Positive emotions.

The first theme that was identified was positive emotions and reactions following a child's diagnosis. These emotions included feelings of relief and parents focusing on solution finding after diagnosis. This theme is supported by the following quotes:

- "I was glad, because we had a diagnosis and we could get him the help he needed."
- "I was okay with it- felt like I had a path to move forward on."
- "Relieved to have confirmation of my suspicions."

The theme was found by the researcher as ‘positive emotions’, from the subthemes of ‘solution-focused’ and ‘relief’. Of the 27 respondents, 14 identified one of these subthemes in their responses.

Negative emotions.

The second theme that came out of respondents answers to this question was the theme of negative emotions or reactions. There was a much wider range of emotions that fell into this theme. Some of these emotions included guilt, anger, denial, shame, sadness, helplessness, worry, fear, and loneliness. This theme of negative emotions is found in the following quotes:

- “The early years were filled with a combination of guilt, fear, anger (a lot of anger), embarrassment and loneliness.”
- It was really hard to hear. Although I knew something was different about him, I had to come to terms with the fact that his life would/could be very different than I had imagined it would be. It felt like grieving the loss of something.”
- “Helpless. Once we exhausted all possibilities with psychiatrists, psychologist, etc.”
- “Anger, sadness, denial, shame.”

This theme was coded by the researcher as ‘negative emotions’. The theme came from codes including ‘guilt’, ‘helplessness’, ‘shame’, ‘worry’, ‘fear’, ‘anger’, ‘denial’, ‘sadness’, and ‘grief’. Twenty-one of the 27 responses included at least one of these codes.

How emotions have changed since initial diagnosis.

This question was stated as: How have your emotions/response changed since initial diagnosis? The researcher identified four themes from this question, including, similar emotions or no change since initial diagnosis; some change, but some similar emotions; accepted as reality/challenge recognized; and hope with being better equipped and in seeing child's growth. Overall, there appeared to be quite a wide range of emotions for parents in the time since diagnosis. Responses indicated that change in emotions was related to a child's growth and progress, available treatments, and parent's place in grieving the diagnosis.

Similar emotions or no change since initial diagnosis.

The first theme that was identified in the data was the theme of similar emotions or no change in emotions. The following quotes support this as a theme:

- *“I haven't seen much change or improve, so I think my mood has changed now to some helpless/hopelessness.”*
- *“No, not really.”*
- *“Overall not really. I did find some relief from the concern about the adhd when a different doctor explained that is was pretty typical for children born premature.”*

This theme was found by the researcher as similar emotions or no change since initial diagnosis, simply from the codes of 'no change' and 'similar emotions'. Out of the 29 respondents, 26 participants answered this question and 7 identified similar emotions or no change in their emotions/response since initial diagnosis.

Some change, but some similar emotions.

The second theme that was identified in the research was the theme of some change in emotions, but some similar emotions. Though parents have worked through some of those responses, there are still periods or emotions that are difficult for parents to deal with. The following quotes support this as a theme:

- *“Still in partial denial since he is still young and not positive the diagnosis is correct... Less shame now, but the looks and judgment from other adults (known and unknown) makes that waver from day-to-day.”*
- *“They have been all over the spectrum of emotions at different times along the way.”*
- *“Yes, but it is a rollercoaster of emotions with good times and challenging ones.”*
- *“We have learned to cope with his mood swings. However, I am still baffled, bewildered, confused, and frustrated to some of his responses to everyday situations. I can’t understand his thought process and I feel I don’t know my own baby boy.”*
- *“Still sad, but not in denial.”*

The theme was identified by the researcher as ‘some change, but still difficult’, but then was reworded to incorporate the idea that some parents felt they still experienced some of the same emotions. This theme included codes of ‘some change, still difficult’ and ‘rollercoaster’. Out of the 26 participants who responded to this question, 12 had a response that fit with this theme.

Accepted as reality; challenge recognized.

The third theme that came from this survey question is the theme that parents accepted their new reality and recognized the challenges they face. Some of the parents who completed the survey identified coming to terms with the diagnosis, though this does not necessarily eliminate the emotions that parents feel. This theme was identified through the following quotes:

- *“Now I’ve accepted that not everything is “fixable”, but I still feel helpless sometimes.”*
- *“It is still a challenge to find the best combination of treatment. I think I now know this will be a challenge that she will likely carry with her for her whole life and I’m glad she is learning to deal with it now.”*
- *“With the comorbidity of depression, I have more fear. Trapped in the permanence.”*
- *“I’ve arrived at more of a place of acceptance, although some days it’s still hard.”*

This third theme was identified by the researcher as ‘accepted as reality; challenge recognized’. It was coded from the themes ‘resolved with challenge’ and ‘acceptance of reality’. Out of the 26 responses, 9 responses included an experience of accepting the reality of the diagnosis or recognizing the challenges.

Hope and child’s growth.

The final theme identified in the survey question of how parent’s emotions changed since diagnosis is ‘hope with being better equipped and in seeing child’s growth’. Parents identified more hopeful or appreciative views of their child’s diagnosis

over time, often through learning more about their child's diagnosis or seeing growth in their child. The following quotes support this theme:

- *“I have described this process over the years as phases that have included the fear/anger/embarrassment phase to acceptance/coping to appreciation. We are in the appreciation phase now and can see that my son's diagnosis has shaped the other members of our family into better human beings. I fully believe that his siblings are the best that they can be because they have learned to appreciate life in ways that sometimes people don't understand until their later years.”*
- *“I've learned about his uniqueness and come to see how although his life may not ever be like mine is now, he has potential for a great life full of love and meaning. I guess I feel more hopeful about his future.”*
- *“I have gained more info and feel more in control of my responses to behavior – also I feel my responses are much more productive.”*

This theme was identified as 'hope with being better equipped and in seeing child's growth'. This theme included broader themes of gained understanding, hopeful/happy, growth in child, better able to meet child's needs (prepared), and acceptance. Thirteen of the 26 responses for this question involved a response that is a part of this theme.

What was sacrificed after child's diagnosis.

This question was stated in the survey as: List some things you sacrificed or gave up following your child's diagnosis. The researcher identified four themes through the responses to this question. The four overall themes include sacrificing nothing,

sacrificing own lifestyle, sacrificing time, and sacrificing everything. Responses varied greatly on what parents felt they needed to give up things in their life based on their child's diagnosis, likely based on the level of need of their child's diagnosis. Responses seemed to be impacted by the time, attention, and support that is required by a respondent's child.

Nothing.

The first theme that was identified through responses to what parent's sacrificed or gave up following their child's diagnosis was 'none'. Some of the responses simply consisted of the word 'nothing', so the reason for their life not changing is not made known. Based on some of the parent's responses, the reason for not making sacrifices could have been related to the severity of the diagnosis. The severity of diagnosis and symptoms may not require a large amount of adaptation in these parent's lives. This theme of nothing sacrificed is seen in these quotes:

- *"Nothing really. His diagnosis wasn't very life changing."*
- *"Nothing changed in this regard."*

This theme was identified as 'nothing' being sacrificed by some parents. Out of the 27 respondents who answered this question, 5 parents listed this as their response. 4 of these 5 parents had a child who was diagnosed with a 'socially-acceptable' mental illness.

Own Lifestyle.

The second theme, 'own lifestyle' was identified as a predominant response listed by parents. Within these responses, lifestyle includes work, exercise/own health, and no childcare. It also includes a sub-theme of time with family and friends, which many

parents report having to give up after their child was diagnosed with a mental illness.

The following quotes support this theme:

- *“Friends and free time. I didn’t feel that anyone should have to have the responsibility for caring for my son unless I was at work as the burden was too great.”*
- *“As parents we had to be willing to get to extra doctor appointments and it has taken away from the time I might otherwise dedicate to my own health or recreation. I don’t take time to go to the gym. I have to set aside more time and energy to be available. Both my husband and I still work full-time.”*
- *“Less time with friends, less time with older 2 children due to all the medical appointments, sleep.”*
- *“It took a toll on many friendships. I just didn’t have as much time to spend and we often both needed to be home to help deal with him in those toughest times. Routine exercise definitely fell to the wayside.”*

This theme was found by the researcher as a respondent’s ‘own lifestyle’ being sacrificed following their child’s diagnosis with a mental illness. This theme was created with the codes of friends, other children, exercise and own health, no childcare, and work. The researcher found the subtheme of friends as being significant, with 11 respondents specifically listing this loss.

Time.

Another common theme that was identified in what parents sacrificed following their child’s diagnosis was time. Parents quantify time in multiple forms, but there was

an overall theme that there was greater need for time to be devoted to their child with a diagnosis. These quotes support this theme of sacrificing time:

- *“Time...by far the biggest change. Appointments, driving, & dealing with insurance companies...so, so time consuming!”*
- *“Initially, more time had to go into helping him adjust, learn skills that don’t come naturally to him, networking with teachers, doctors etc.”*
- *“I did not give up much, other than time...”*

This theme was found by the researcher as time, being sacrificed in a variety of areas. The theme, ‘time’ was created through the codes of appointments, driving, and insurance. Of the 27 respondents who answered this question, 9 identified an aspect of time as something they sacrificed.

Everything.

A final theme that was found in response to this question was the theme of everything being sacrificed or given up. Depending on the severity of the mental illness, parents sometimes have to adjust all areas of their life to be able to care for their child the best that they can. This theme is found in the following quotes:

- *“We spend much less time with friends or going out because we never know how this child might react. We have had to change schools, to adjust to the support he needs. Most everything in life has changed because of this child’s diagnosis.”*
- *“Well, our lives are on hold...”*
- *“Our son has become the focus of our family to the detriment of our other 3 children. All hobbies have been forgone...”*

The theme ‘everything’ was identified out of these quotes, as families expressed giving up so many aspects of their previous ways of doing life. Though some parents categorized this as everything, the majority of families did respond with more specific areas of what they sacrificed or gave up following their child’s diagnosis.

Did this change at 6 and 12 months.

This question was stated in the survey as: Did that change at 6 months? 12 months? This question was a follow-up from the previous question: List some things you sacrificed or gave up following your child’s diagnosis. The researcher found 2 themes in response to this question, including ‘no’ and ‘fewer sacrifices and new norms’.

No.

The predominant theme found in response to this question was that sacrifices did not change after time had passed since the time of diagnosis. Many parents found that they still devoted the same amount of time and energy to their child. Other parents initially responded that they did not feel they had to make sacrifices, and that stayed consistent as time went on. This theme of time is found in the following quotes:

- *“No, he’s 13 and it still hasn’t changed.”*
- *“Not really, since it is something that is on-going. A couple summers ago we had weekly appointments for a while to work through a tough period.”*
- *“I still feel the same. I haven’t had to give up too much. I have had to give up time to bring her to therapy appointments and pick up her ADD medication from the pharmacy.”*

This theme was identified as no changes by the researcher. Twenty-six of the 29 participants responded to this question, and 15 of those respondents answered that there were no changes in what they sacrificed after 6 or 12 months.

Fewer sacrifices and new norms.

The second theme that was found in this research is that some respondents felt that over 6 or 12 months time, they made fewer sacrifices than they did in the beginning, or by then had become accustomed to new norms. This theme can be seen through the following quotes:

- *“Time...interventions have lessened and have also helped with his mood and behavior, so there has been greater opportunity to be away from him. This gives a chance for more relationships and activities outside of our home.”*
- *“Yes. We got support in the home to help with all of us. Less pressure on me.”*
- *“He has become more competent and self-sufficient.”*
- *“I have mellowed out about her issues, and work to prepare her more than the environment. But I still avoid certain activities such as sporting events and noisy restaurants.”*

This theme was identified by the research as fewer sacrifices made by the respondents. This theme came from the codes ‘fewer sacrifices’ and ‘changed the nature of outings’. Of the 26 responses, 8 respondents identified this being their experiencing.

Helpful supports and difficulties.

This question was stated as: What supports have you had or what has been helpful in grieving or coming to terms with your child's diagnosis? What has been difficult?

Through coding, the researcher identified four themes from respondents. These themes include informal supports, formal supports, day-to-day difficulties, and isolation and supports lacking understanding.

Informal supports.

The first theme that emerged from the responses was the helpfulness of informal supports on grieving a child's diagnosis. These informal supports can include family, friends, support groups, and faith community. Respondents particularly identified support coming from parents and families who had been through a similar life experience or who had a child who had also been diagnosed with a mental illness. This specific support was found to be a sub-theme of informal supports. The following quotes support this as a theme:

- *“I'm a social worker and a mom. Most of my friends are social workers and moms, so I am fortunate to have an amazing network of people who are willing to listen. More importantly to note, my friends are people who have been people who have welcomed all of our family into their homes and stood by us.”*
- *“The most helpful thing has been finding friends that are interested in entering into the difficult like with you – not just saying, “I'm sorry”, but actually coming over, providing respite care, spending time with the child.”*

- *“Talking with other parents/friends that have gone through the same situations.”*
- *“Parent support group has been extremely helpful; met/communicated with other parents of children with Down syndrome.”*
- *“God has been my main support, along with family and friends who also have kids with special needs or health or mental issues.”*

This theme was identified by the researcher as informal supports being helpful for grieving a child’s diagnosis, with codes of ‘faith’, ‘support groups’, and ‘friends/family’. There was a sub-theme found within this theme that was coded as ‘families with similar situations’. Fifteen of the 26 respondents identified at least one informal support being helpful to the grieving experience.

Formal supports.

Formal supports were the second theme that was found through parent’s responses. Formal supports include doctors, teachers and therapists. Often, these professionals are supportive of the parents too, not just the child. The following quotes reflect this theme:

- *“Having a therapist for my child has been helpful because I talk to them just as much as she does.”*
- *“We had a wonderful doctor, who was very encouraging. She was also careful and reserved in her prescription of meds.”*
- *“A team that truly understands and can work together in an integrated way.”*

- *“Just good communication with doctors and teachers. I have no problem communicating my concerns with them because I want my son to succeed.”*

This theme was identified as formal supports. This theme was formed through codes of ‘professionals’ including doctors and teachers and ‘therapists’. Of the 26 respondents, 10 identified professionals as being an important support to their grieving.

Day-to-day difficulties.

A theme that was found to be difficult in grieving or coming to terms with a child’s diagnosis is the day-to-day difficulties. This encompasses a child forgetting to take his medication, kids teasing a child at school because of his mental illness, or the overall adjustments needed for daily life. This theme is supported by these quotes:

- *“It’s difficult when he still struggles to remember to get things done. I feel bad for him, but also get frustrated.”*
- *“Difficulties have included trying to make sure he takes his medication. Staying on top of that daily.”*
- *“It’s difficult to see my child hurting from being teased at school for having poor social skills and few friends though.”*

This theme was identified by the researcher as day-to-day difficulties. This theme was found through codes of ‘forgetting’, ‘meds’, and ‘teasing’. Five of the 26 respondents found that the day-to-day difficulties made grieving and coming to terms with their child’s diagnosis more difficult.

Isolation and supports lacking understanding.

Isolation and supports lacking understanding is the last theme that was identified from the respondents. Where informal supports were identified by over half of the respondents as being helpful supports, the lack of these informal supports has been identified as being a difficult part of grieving a child's diagnosis. This can be seen through the following quotes:

- *“Difficult were the early years. There was not much social networking and I was isolated. I wish I had known how to reach out for support.”*
- *“Finding support has been a huge challenge. It's a very lonely place to be as a parent.”*
- *“I literally do not have any supports at this time...The most difficulty I have had has been with one of my daughter's teachers. No matter how often I talk with her or how much information I give her, she constantly fans the fire and makes my daughter more anxious.”*
- *“None. No support, in fact it was a frequent source of marital strife.”*
- *“Difficulties have been talking about it with others who do not understand our situation.”*

The researcher identified this final theme as isolation and supports lacking understanding. The theme included more general codes of 'isolation', 'no support', and 'people not understanding'. This theme was the most prevalent difficulty that parents noted in their responses.

Defining acceptance.

This question was stated as: How do you define acceptance? The researcher identified two main themes through parent's responses. These themes include 'resolved

and coping' and 'unconditional love and celebrating uniqueness'. These two themes summarize the majority of parent's responses.

Resolved and coping.

The first theme that was noted in respondent's definitions of acceptance was the idea of being resolved and coping. This could also be understood as coming to terms with what will not change or what this new reality looks like. The theme of being resolved and coping comes out in the following quotes:

- *"I think it means accepting the unique challenges that are part of your life and knowing you can't control them."*
- *"Coming to terms with what cannot be changed."*
- *"Knowing that this is just what is. Taking the value judgments out, but still working toward a better life for him."*
- *"Stopping the struggle against the issue and to start working with it."*

This theme was found by the researcher as 'resolved and coping', which came from parents responses that involved coming to terms with life circumstances and coping with where they are at. Fourteen of the 24 respondents expressed viewing acceptance as being resolved and coping.

Unconditional love and celebrating uniqueness.

Unconditional love and celebrating a child's uniqueness was the second theme that was found in the respondent's definitions of acceptance. Parents identified loving their child for who they are and appreciating their unique qualities. This theme is supported in the following quotes:

- *“For me, acceptance goes beyond just acknowledging someone with special needs. I believe that to fully accept someone you need to appreciate all of the qualities that they have.”*
- *“Belief that every child is special and has their own unique characteristics, and every child should be celebrated.”*
- *“Loving and standing beside someone in spite of differences or difficulties.”*
- *“When someone fully understands who they are, and what they have to give to the world and they choose that as their gift to the world.”*
- *“Being and feeling loved, for exactly who you are. Openness to just be you.”*

This theme was identified as ‘unconditional love and celebrating uniqueness’. It came from the codes of ‘being loved for you’, ‘unconditional love’, ‘appreciating qualities’, and ‘celebrating uniqueness’. Of the 24 respondents, 9 included this theme in their definition of acceptance.

Views of child changed.

This question was stated as: How have your views or expectations of your child changed over time? It was coded and themed by the researcher, producing three themes. The three identified themes are ‘better understanding of capabilities and limitations’, ‘adjusted expectations’, and ‘loving and valuing child’.

Better understanding of capabilities and limitations.

The first theme that the researcher found was the theme of respondents better understanding their child's capabilities and limitations over time, which has an impact on their view of their child. These quotes support this theme:

- *“There are still some frustrations, but I understand his condition better and do our best to have patience.”*
- *“I now have insight into her little brain :) It's so much easier to understand who she is and why she does things. I have lower expectations in some areas and higher in others. I know when she is in need of extra time, extra love, or just a chat and I can read that better now and offer it to her.”*
- *“I understand the reasons behind his behavior and that helps guide my response to it.”*

This theme was identified as ‘better understanding of capabilities and limitations’, through the codes of ‘better understanding’, ‘insight’, ‘knowing needs’, and ‘understanding abilities’.

Adjusted expectations.

The second theme that was identified in the research was the theme of adjusted expectations of the respondent's child, including both current expectations and future expectations. Some parents identified this as being more realistic. This theme can be found in the following quotes:

- *“Maybe they have become more realistic. I think I have a pretty clear understanding of his present capabilities and limitations.”*

- *“I used to expect my child to one day become ‘normal’. Now I’ve realized that we can expect certain things of him but they are never going to be what we would expect of our other children.”*
- *“I have lowered many of my expectations for my child, as far as dreams that I had for her to do well in school or at sports. But I’ve also had to raise expectations for her so that I am sure to follow through with consequences for things that we are trying to change about her behavior.”*
- *“I am more realistic. My wife and I are both highly educated and driven people. We have stopped assuming that our daughter will be of a similar bent.”*

Adjusted expectations is the second theme, which came from quotes similar to those above. This theme came from the codes ‘realistic’, ‘adjusted expectations’ and ‘future expectations’. Some of these expectations resulted from the previous theme of better understanding one’s child.

Loving and valuing child.

Loving and valuing a child is a third theme that came from the respondent’s answers, of an important way they now view their child. These quotes support this theme:

- *“The things that haven’t changed are probably the most important things: I love him. He is a valued and unique member of our family. I will always support him and challenge him to be the best he can be.”*
- *“I love him for who he is and I am thankful for any progress he makes, however slow.”*

- *“Love him more, feel more blessed to have him every day.”*

This third theme the researcher found was the theme of loving and valuing one's child. Respondents did not necessarily identify this as being a change in their view of their child, but as being an important part of the way they view their child.

Supporting child.

This final question was stated as: What are some of the ways in which you support your child?" The researcher found four themes in the respondent's answers.

These three themes include emotional support, accommodate and structure life based on child's needs, and time – appointments and practicing skills.

Emotional support.

The first theme that the researcher identified from these respondents is the theme of emotional support. This theme includes loving, comforting, and encouraging a child as a form of supporting him/her. The following quotes support this theme:

- *“Often, I just have to keep an eye out and check in often. Instead of telling her to care more about school and other responsibilities, I find myself telling her to relax and let things be imperfect. She worries enough on her own.”*
- *“We are always there for him. He has been dealt a lot over the last six years, and he has NEVER had to face anything alone. We are there for him if he wants, or we give him the space and time he needs.”*
- *“We pray every night and ask God to calm her brain and take away any specific worries. Bed time is very hard for her and her brain, so we often*

think of funny things to think about to divert her brain ie. A chicken roller skating, or a monkey playing video games.”

- *“Not pressuring her or putting her in situations that make her anxious. Letting her know we understand and want to help her be more comfortable.”*

This theme was found as the researcher to be emotional support. The theme was created from the codes of comfort, soothe, encourage, and love. Twelve of the 26 parents who responded identified this as being at least one of the ways that they support their child.

Accommodate and structure life based on child’s needs.

The next theme found in the responses of the way the respondent supports his/her child was through accommodating and structuring life based on the child’s needs. Parents do this through creating routines, knowing the limitations of their child, and making other accommodations as needed. This theme is found in the following quotes:

- *“We talk through the situations before we encounter them. We help her to map out her days, so that she avoids the unexpected.”*
- *“Planning – a lot of planning. Routines are important as well.”*
- *“Clean house. Trying to de-clutter so he can think better. A routine. A structure.”*
- *“Adapt and accommodate his daily needs.”*

This second theme was identified as accommodate and structure life based on child’s needs. This theme was made from the codes know limitations/needs, accommodate, and structure/routine.

Time.

The third theme that the researcher found in responses was that many of the parents support their child through time. This includes both appointments and practicing learned skills. This theme is identified through the following quotes:

- *“He can also become very emotionally defeated. I remind him of coping strategies and help soothe him when necessary.”*
- *“He attends a different school that can support him (from our other children). He attends Occupational Therapy. We receive parent coaching so that we can be a better parent to him. We try to interact with him in therapeutic manners.”*
- *“Listening to her frustrations and reminding her of the tools she has learned in therapy.”*
- *“Many ADL’s, teaching life skills (PT/OT/Speech), feeding, organizing therapies.”*

This final theme was summarized by the researcher as time. This overall theme was made from the codes time, appointments, and practicing learned skills. Twenty of the 26 respondents identified supporting their child in this way.

Discussion

The purpose of this study was to better understand the grieving and acceptance experience of parents of children diagnosed with a ‘socially acceptable’ diagnosis versus a ‘non-socially acceptable’ diagnosis of mental illness.

Interpretation of Findings

The themes found in this research can lead to better understanding the experience of parents of children diagnosed with mental illness. A primary focus of the study was to compare experiences of parents whose children were diagnosed with a socially acceptable diagnosis to children diagnosed with a non-socially acceptable diagnosis. The findings indicated many similarities among parents of children with both socially acceptable and non-socially acceptable diagnoses. There were some smaller differences that were noted as well. Other influences, such as time and supports, did appear to correlate to a parents' acceptance of their child following their diagnosis.

My hypothesis was that there would be a difference between acceptance experiences of parents whose children were diagnosed with a socially acceptable diagnosis and parents of children diagnosed with a non-socially acceptable diagnosis. Based on the data collected from respondents, socially acceptable and non-socially acceptable diagnoses did not appear to be strongly related to parents' acceptance or experiences. There was a mix of positive and negative responses for both sets of parents. Similarly, there was no consensus among the sacrifices that parents made following their child's diagnosis. Responses fluctuated from sacrificing 'nothing' to 'everything' following a child's diagnosis, and this was the same among socially and non-socially acceptable diagnoses. The variety of responses indicates the unique and individual experience of a parent when their child is diagnosed with a mental illness. Parents' views of acceptance, expectations of their child, and means of supporting their child were similar among all levels of diagnoses, which was an unexpected find. In parents' grief and acceptance experiences at large, the social acceptance of a diagnosis did not appear to impact responses. In both categories, parents were scattered in their experiences of

emotions, sacrifices, and supports, which signifies the role that other factors may play in the grief and acceptance experiences of parents.

There were, however, small areas of difference among parents of children with socially acceptable and non-socially acceptable diagnoses. When parents were asked to list how their emotions regarding child's diagnosis had changed over time, all five parents who listed a response coded as 'acceptance' were parents of children who had been diagnosed with a non-socially acceptable diagnosis. This may indicate that it took more time or that parents had to be more purposeful in accepting the new reality of their child's diagnosis with a diagnosis that was less accepted by others. Another interesting finding was the responses of parents who felt they sacrificed friends or time with friends following their child's diagnosis. Nine of 12 parents who had a child with a non-socially acceptable diagnosis listed this as a response, while only 2 of 15 parents of child with a socially acceptable diagnosis reported this sacrifice. The next difference in responses was found in parents' views of acceptance. All four parents who described acceptance as celebrating their child's uniqueness had a child who was diagnosed with a non-socially acceptable diagnosis. This response seems to indicate an importance for parents to appreciate differences in their child who has symptoms that are less socially appropriate or accepted by others. This makes sense as a common step for parents in the process of moving to a place of acceptance of their child and his/her diagnosis. A final difference that was noted is found in the ways that parents support their children. A popular theme among parents of children diagnosed with a non-socially acceptable diagnosis was supporting one's child through providing routine and structure. Six of seven parents listing this response were parents of children with a non-socially acceptable diagnosis.

This could likely be linked to the symptoms or behaviors diagnosed with the diagnosis, or the severity of a diagnosis on a child's level of social functioning.

While a few themes appeared to be linked to the presumed social acceptability of a child's diagnosis, there were other factors that seemed to impact parents across both groups. This includes both the level of supports available to a parent and length of time since a child's diagnosis. Overwhelmingly, parents indicated that having informal and formal supports was a necessary piece to grieving and coming to terms with a diagnosis. This was found in 23 of 26 responses. Parents indicated that isolation made grieving and accepting their child more difficult. The importance of professionals, friends, and supports with similar experiences played a large role in many parents' experiences of grief and acceptance. Length of time since a child's diagnosis was found to impact all parents, independent of the child's type of diagnosis. This was especially seen in parents' reactions of their child, acceptance of their child, and views of their child changing over time. When asked how their reactions changed over time, 15 of 26 parents noted that they grew in acceptance, understanding, or feelings of empowerment. Six additional parents stated that they remained positive in their emotions. This means that a majority of parents felt similarly positive or more positive after time passed since their child's diagnosis. Findings were similar with parent's acceptance experiences. All of the parents who named celebrating their child's uniqueness as an important element to acceptance also identified that this view of acceptance had changed over time. This indicates that parents grew to view acceptance in this light after time with a child diagnosed with a mental illness. Three of the four parents who described acceptance as unconditional love also acknowledged that their views of acceptance had changed over

time. This finding is noteworthy, in that these parents altered their view of acceptance after experiences with their child who was diagnosed with a mental illness. To further support this, parents were asked how they saw their view of their child changing over time. The majority of parents identified that they had grown in understanding of their child and/or had adjusted expectations of their child. This indicates that time is necessary for parents to see and appreciate their child for who he/she is. It is also important to note the link over time of parents growing in positive emotions regarding their child's diagnosis, while growing in acceptance of their child's uniqueness, and also better understanding their child and appropriate expectations. Parents are often simultaneously growing and learning in all of these areas. Time was even seen to play a role in the sacrifices that parents made related to their child's diagnosis. All of the parents who listed that they now made fewer sacrifices had children who had been diagnosed for over five years. It seems that parents may have been able to create new norms over time, but this can take years for families. Time appeared to be a link to parents beginning to manage future expectations of their child. All parents who listed this response had a child diagnosed for over three years. It appears that as time progresses, parents grow in their realizations of the long-term impacts of their child's diagnosis. Over years, children reach more milestones and parents would understandably be working to manage future expectations for their child's life. It is interesting to note that over 1/3 of respondents in this study had a child who had been diagnosed with a mental illness for over five years. This longer duration of these diagnoses may have provided helpful insight for this study. In all children's mental health diagnoses, both having supports and the role of time appear to be significant in a parent's grief and acceptance experience of their child.

Findings from Literature

Research in literature has found that parents often experience a variety of emotions after their child is diagnosed with a mental illness (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2011). Responses from this research study found that parents did identify experiencing many of the emotions listed in the literature. Some of these emotions include helplessness, grief, loneliness, sadness, and guilt (Ahmann, 2013; MacGregor, 1994; Mendenhall & Mount, 2011; Moses, 2010; Moses, 2011). Over half of the parents in this study noted feeling relief or being solution-focused following their child's diagnosis. Neither of these reactions were stated previously in this literature.

Respondents were then asked how their responses and emotions regarding their child's diagnosis had changed since the initial diagnosis. As the theme 'hope and child's growth' indicates, some of the respondents identified a positive change in emotions and response as a result of better understanding their child's diagnosis. Others identified that better understanding the diagnosis helped them be better prepared to deal with it. This seems to support what literature found of knowledge of mental illness shaping parent's reactions to, and experience of, mental illness (Boulter & Rickwood, 2013).

Findings from the literature identified how both social stigma and availability of supports can impact a parent or family's experience with mental illness (Boulter & Rickwood, 2013; Hinshaw, 2005; Moses, 2010). Respondents answered the question regarding what supports have been helpful for grieving their child's diagnosis and what had been difficult. There appeared to similarities among responses from parents of both socially acceptable and non-socially acceptable diagnoses. The two themes that parents

identified as being important supports included informal and formal supports. The majority of respondents depended on friends, family, faith, and professionals (teachers, doctors, and therapists) for their support system, to grieve or come to terms with their child's diagnosis. The lack of supports or supports that lacked understanding regarding mental illness was identified as contributing to difficulty in grieving their child's diagnosis. Some respondents also noted that a lack of understanding could lead to blaming parents for mental illness and contributed to isolation for parents. All of the respondents who listed no supports or having supports who lacked understanding had listed that they had no change in emotions or some similar emotions since initial diagnosis. This finding supports the literature that found both social stigma and support for parents impacting a parent's experience and emotions/reactions around their child's diagnosis (Boulter & Rickwood, 2013; Hinshaw, 2005; Moses, 2010). The second theme identified as adding difficulty to the grief and acceptance process is the theme of day-to-day difficulties. Of the five parents who listed day-to-day difficulties, four were parents of children with a socially acceptable diagnosis.

The next question in this survey asked parents to define how they view acceptance. In the grief frameworks noted, acceptance is often the last stage of grieving and involves accepting the loss (Patricelli, 2006). In the literature, resolution is understood as an acceptance and coming to terms with a diagnosis (Milshtein et al., 2010). There was a good amount of overlap in the responses found in this survey, which led to two themes to summarize responses. These two themes are resolved and coping, and unconditional love and celebrating uniqueness. Four parents had responses that fit the code of celebrating their child's uniqueness or qualities, and all four parents had

children diagnosed with a non-socially acceptable diagnosis. Of the 24 respondents in this survey, 14 indicated being resolved and coping with their child's diagnosis.

Respondents were asked how their views or expectations of their child changed over time. Three themes came from these responses, including better understanding of capabilities and limitations, adjusted expectations, and loving/valuing one's child. As was found in the literature, some of the respondents discussed grieving their child's future or grieving as their child reached new milestones (MacGregor, 1994; Richardson et al., 2012). One of the parents said in response to this question, "They constantly evolve. We're in a very bad way right now with depression, all because the world we'd hoped for after graduation really doesn't exist." Five of the six parents who identified their views changing with better understanding of their child had a child who was diagnosed with a socially acceptable diagnosis. Four respondents included loving and valuing their child as part of the view of their child, and all four respondents had a child who had been diagnosed with a non-socially acceptable diagnosis.

The final question in this survey asked parents about some of the ways they support their child. One of the themes that was found was that parents provided emotional support for their child, including comforting, soothing, loving, encouraging, and listening to their child. The literature identified that support from parents is very important to a child diagnosed with a mental illness (Boulter & Rickwood, 2013; Suiter & Heflinger, 2011). Wachtel and Carter (2008) highlight the need for parents to support their child emotionally and categorize this as a way of being attuned to their child's needs. Another theme found from these responses included that parents support their children through routine/structure. Six of the seven respondents who identified

routine/structure as being an important way to support their child had a child who was diagnosed with a non-socially acceptable diagnosis.

Limitations

This study has a few limitations for this field of research. The first would be the limited number of respondents, as research could benefit from a greater pool of parents. A second limitation was having respondents with children with a few particular diagnoses, but limited parents with children of other diagnoses (schizophrenia, major depression, or bipolar). It would be interesting to compare the experiences of parents of children with these diagnoses. A third limitation is the skewed data, which includes having more respondents being mothers (86.2%) and only 13.8% of respondents being fathers. The nature of responses could vary based on the relationship of the parent to the child. A fourth limitation of this study is that the study did not necessarily account for dual diagnosis. Some respondents had children diagnosed with both socially acceptable and non-socially acceptable diagnoses, which may even add another category of parent experiences, beyond 'acceptable' or 'non-socially acceptable' diagnosis categories. Additionally, experiencing the impact of multiple diagnoses might impact a parent's grieving and acceptance experience in different ways than a single diagnosis, which this study did not account for.

Implications

This study has implications for further research and for social work practice. As the limitations suggest, this research could be even more insightful with a larger pool of respondents. The research was compiled through snowball sampling, but with a small sample, it is likely that many of the respondents were affiliated. Further research on this

topic could be broadened to a less connected group of respondents and an increased diversity in respondents.

A more qualitative or quantitative approach to this topic of research could be beneficial for future research. Qualitative interviews of parents could be helpful for gaining more in-depth answers and for discussing parents' reasons and thoughts behind each answer. Fully quantitative studies could be beneficial for understanding specific correlations between reactions and levels of acceptance. It could also allow parents to rank emotions or helpfulness of specific supports, while limiting answers to compare certain variables. Both methods of research could be helpful for further research of the experiences of parents of children diagnosed with mental illness.

As this research identified, further research could be advantageous when studying the impact of other factors that might play a role on parent's experiences with grief and acceptance of their child and his/her diagnosis. Specifically, research focused on helpful supports and the role they play could be helpful for encouraging parents in seeking out important supports that could benefit both them and their child. Further research on the role of time in a parent's grief and acceptance experience could also be useful research. This research could study the length of time that involves the most change in parent's views of their child.

This study also has helpful implications for current social work practice. As the findings suggested, supports are an important part of the acceptance experience. This includes both formal and informal supports. For social workers, this suggests the importance of encouraging parents to seek out support groups, helping them identify helpful supports currently in their lives, and recommending formal resources that could

be valuable to parents. Time was another important factor in parent's experiences of grieving and accepting their child and his/her diagnosis. For social workers, understanding this role of time is important for understanding the typical experience of parents. Educating parents on what this grieving process typically looks like can help parents manage expectations and maintain hope. Education is also important for normalizing the experience for parents and helping them know what to expect. Parents can be encouraged in the existence of both positive and negative reactions related to a diagnosis, with hope of change over time. Social workers can specifically help parents in their identification of sacrifices that they may make following their child's diagnosis and encourage them in their own self-care. Parents can be encouraged to both access their supports and look for ways their own physical or mental health may be being neglected.

Through this study, it was also made evident that there is not one standard experience for parents following a child's mental illness diagnosis. Social workers and parents can be encouraged that each experience is unique and may include very diverse emotions. Understanding each parent's experience is important for social workers to employ best practices.

Answers from respondents in this study can be helpful for social work practice and for assisting parents in dealing with some of these emotions and responses. One parent explained that it was difficult that her son's disability was not visible, when they were in public. Many mental health disorders do not include noticeable physical features, so this can be a common experience for parents. As social workers, it can be helpful to discuss with parents possible scenarios and responses (both verbal and internal) to people's reactions to their child. Multiple respondents also pointed out how their child

notices being judged or treated differently. Social workers can work with both children and parents to give them a safe place to process this and combat potential thinking distortions. Respondents noted a lack of understanding about mental illness not only by friends and family, but also by some professionals. Teachers are an example that was identified in a response. Social workers can assist families by advocating for accommodations for a child's education. They can also help by educating teachers on the symptoms and impacts of mental illness. Social workers can work with the team of professionals involved in a child's life to support both the child and family.

Ultimately, the research found that there were no largely noticeable differences between experiences of parents whose children were diagnosed with a socially acceptable diagnosis and parents of children with a non-socially acceptable diagnosis. This was surprising, as I anticipated there being a difference for parents grieving and accepting their child based on the stigma of others or the prevalence of their child's diagnosis. These categories of diagnoses did not appear to impact parents' sacrificing, accepting, or overall reactions to their child. Many parents did have emotions, views of their child, and means of supporting their child that were expected, as they seemed to line up with much of the literature. Additionally, loving one's child for who they are and celebrating their unique qualities appeared to be an important piece of acceptance that allowed parents to support their child well.

Conclusion

The purpose of this study was to answer the question, "What is the acceptance experience of parents of children diagnosed with a 'socially acceptable' diagnosis versus a 'non-socially acceptable' diagnosis of mental illness". There did not appear to be many

links between the social acceptability of a child's diagnosis and a parent's experience of emotions, sacrifices, or ways of supporting their child. A parent's availability of supports did appear to impact a parent's experience. The length of time that had passed since a child's diagnosis also linked to a parent's ways of accepting his/her child. Finally, this study suggested the importance of understanding each parent's unique experience of grief and acceptance related to their child's diagnosis.

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Appendix A

Acceptance Experiences Among Parents of Children Diagnosed with a Socially Acceptable Diagnosis Versus a Non-Socially Acceptable Diagnosis of Mental Illness.**INFORMATION AND CONSENT FORM****Introduction:**

You are invited to participate in a research study investigating the acceptance experiences of parents of children diagnosed with mental illness. This study is being conducted by Brienne Gallaway, a graduate student at St. Catherine University under the supervision of Sarah Ferguson, a faculty member in the Department of Social Work. You were selected as a possible participant in this research because of your experience as a parent of a child diagnosed with mental illness. Please read this form and ask questions before you agree to be in the study. You can contact me at gall7666@stthomas.edu, or Sarah, my faculty advisor at smferguson@stkate.edu or 651-690-7739.

Background Information:

The purpose of this study is to understand how parents view acceptance of their child diagnosed with a mental illness, and what the differences are in accepting a 'socially acceptable' diagnosis, versus a 'non-socially acceptable' diagnosis. Approximately 25 people are expected to participate in this research.

Procedures:

If you decide to participate, you will be asked to complete the following online survey, including all questions that you feel comfortable answering. This survey includes both closed-ended and open-ended questions. This study will take approximately 15-20 minutes.

Risks and Benefits of being in the study:

The study has a risk. Participating in this study may trigger emotions, such as grief, sadness, helplessness, or shame. A list of resources for supports will be given to parents at the end of the survey, in case the study does prompt an emotional trigger for you. This will include a list of supports by state through NAMI and a list of National Crisis Hotlines.

Though this study has no direct benefits, there are other benefits for participating in this study. Understanding the acceptance experiences from the perspective of parents is important for clinicians working with families where a child has been diagnosed with a mental illness. This research can assist clinicians in knowing what support is missing for parents and in being more aware of the challenges that are present for parents. The research can also be helpful for parents, to realize similar experiences of other parents, as well as to be aware of the ways that they view acceptance of their own child. Hopefully, this research will lead to increased supports for parents, and ultimately to parents who are able to support their children in their mental illness.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable and only group data will be presented.

I will keep the research results in a password protected computer folder and only I and my advisor will have access to the records while I work on this project. I will finish analyzing the

data by May 18, 2015. I will then destroy all original reports and identifying information that can be linked back to you.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with St. Catherine University or NAMI in any way. If you decide to participate, you are free to stop at any time without affecting these relationships.

Contacts and questions:

If you have any questions, please feel free to contact me at gall7666@stthomas.edu, or my faculty advisor at smferguson@stkate.edu or 651-690-7739. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

Participation in this study is your implied consent. Even after beginning this survey, you may withdraw at anytime from the study.

Appendix B

Qualitative Survey Questions

To the best of your knowledge, what is your child's diagnosis?
(Using drop down options)

What is the length of time since your child received his/her diagnosis?
(Using drop down options)

What is your child's age?

What is your child's gender?
(Using drop down options)

What is your relationship to the child you are completing this survey about?
(Using drop down options)

List your initial reactions to learning that your child was being diagnosed with a mental illness:
(I.e. Anger, Shame, Denial, Guilt/shame, Business-mode/ solution focused, Helpless, Lonely)

How have your emotions/response changed since initial diagnosis?

List some things you sacrificed or gave up following your child's diagnosis?
(I.e. Did you quit your job? Did you quit any hobbies? Did you spend less time with friends?)

Did that change at 6 months? At 12 months?

What supports have you had or what has been helpful in grieving or coming to terms with your child's diagnosis? What has been difficult?

How do you define acceptance?

Has that changed over time?

How have your views or expectations of your child changed over time?

What are some of the ways in which you support your child?