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Alissa Kaasa
St. Catherine University

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Grieving Mental Illness: Individual Experiences of Grief, Loss, and Growth

By

Alissa Kaasa

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Committee Members

Andrea Nesmith, Ph.D., MSW (Chair)

Diane Bauer, MSW, LICSW

Mandie Kender, M.A., CPRP

Abstract

The purpose of this study was to explore the grief experience of people who develop severe and persistent mental illnesses (SPMI). Group members and facilitators of a Grieving Mental Illness group that met at a suburban drop-in center were asked to voluntarily participant in semi-structured, qualitative, in-person interviews. Content analysis was used to find themes in the group member and facilitator interviews. The findings indicated that individuals with SPMI have a unique grief experience that is enhanced by many factors. Group participants expressed having cycling feelings of grief. These feeling were triggered by life events or reminders of the loss they experienced and were affected by outside factors, like negative reactions from family because of the mental illness. Group participants did not identify that they were grieving until they joined the Grieving Mental Illness group, but after addressing areas of grief they were able to accept themselves and their new reality. Facilitators identified the need for acknowledgement that mental illness exists and can cause grief. They also observed that gaining insight for ill individuals into the effects of having a mental illness can take time; connecting with other people can be an important healing component for grief; and feelings of grief cycle throughout a person's life. Further research as well as grief services for individuals with SPMI diagnosis' are needed to help individuals process areas of grief.

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Finally, I would like to thank the facilitators of the Grieving Mental Illness group for first introducing me to the idea that grief is a part of a person's experience when they develop a mental illness. They are pioneers in the mental health field when it comes to grief and their dedication to being a support for their clients inspires me to continue listening to the experiences my clients bring to the social work relationship.

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Introduction

In the United States, one in four adults experience mental health symptoms every year; that is 57.7 million people (National Alliance on Mental Illness, 2011). According to the National Alliance on Mental Illness (2011), approximately one in seventeen Americans live with a Severe and Persistent Mental Illness (SPMI). SPMI's include schizophrenia, bipolar disorder, major depression, and anxiety disorders. Mental illnesses greatly alter a person's life, abilities, and mental processing, which negatively affects their ability to engage in activities, care for themselves, and perceive what is going on around them. Symptoms that accompany SPMI diagnoses, such as psychosis and mania, can cause worldviews to shift, relationships to change, abilities or functioning to decrease, and support to disappear because of the presence of intrusive symptoms (Macias & Rodican, 1997). All of these factors are often unspoken and cause an unseen sense of loss for the ill individual.

According to National Alliance on Mental Illness (2011), about half of individuals with SPMIs develop the illness by age 14. Furthermore, three-quarters of mental health cases develop by age 24 (National Alliance on Mental Illness, 2011). Grief associated with an illness becomes more challenging when the ill individual loses an aspect of life that they had prior to the development of the illness (Simos, 1977). Knowing what life was like before the loss of functioning can greatly affect the struggle of trying to adapt to unwanted changes that accompany an illness.

Johnstone (2001) describes the effects of a mental illness as being on a continuum of dysfunction where cognitive, emotional, and behavioral aspects of a person are affected. The intensity of symptoms affects how their functioning and behaviors change (Johnstone, 2001). This change in functioning affects the person's work, household activities, relationships, school,

and self care. Essentially every aspect of a person's life can be affected by mental health symptoms (Lafond, 2002). For example, symptoms of depression can make it difficult for someone to get out of bed every day. Activities like going to work, caring for the house, and accomplishing the other many responsibilities in life are almost impossible if you cannot first get out of bed. Not only is the dysfunction debilitating, but it also interrupts the functioning of what society sees as a normal individual. The experience of losing functioning due to the development of a mental illness is unique and painful.

The experience of loss around developing a mental illness is ambiguous because losses are not clear or obvious to the individual and society (Worden, 2009). The loss around having a mental illness is also a form of disenfranchised grief, because it is not seen as a significant loss by society (Doka, 1989). Society oftentimes does not acknowledge that individuals with a mental illness experience and grieve significant losses that are connected to having an illness. The combination of the disruptiveness and life changing nature of mental health symptoms, along with the development of symptoms occurring later in life, creates a sense of loss and grief in the diagnosed individual, which can be unseen by both the individual and society.

Understanding grief and loss that is experienced by individuals who have a mental illness is essential for social workers. According to the National Association of Social Workers, around sixty percent of mental health professionals are clinical social workers (National Association of Social Workers, 2012). To be able to effectively help clients, social workers need to be trained in methods of addressing grief and loss with individuals who have a mental illness. For this population, grief is often under-addressed and unrecognized (Young et al., 2004). Even mental health providers can be unaware of the loss and pain someone with a mental illness experiences. Clients may need assistance with putting words to the loss they are feeling. Normalizing feelings

of grief related to the experience of developing a mental illness is another important aspect that social workers can provide for clients (Boss, 2010; Doka, 1989). Individuals can end up very isolated and feeling like no one understands their struggle when in reality millions of Americans struggle each year with mental health symptoms. Social workers, as well as society as a whole, need to be able to understand what a person with a mental illness experiences so that they can provide more support and acknowledgement around the grief experience.

Research around mental health related grief and loss is severely lacking. In 2004, Young, Bailey, and Rycroft published an article that included data from a Medline search which indicated 26 references appeared with the search criteria of "grief" and "mental illness". Only six articles appeared with grief in the title (Young et al., 2004). There has been a great deal of research regarding family's experience of grief when a family member is diagnosed with a mental illness, yet very few address the grief of the diagnosed individual. Past studies allude to the grief experience of people with a mental health diagnosis, which opens up speculation regarding the severity and magnitude of losses that accompany a mental health diagnosis. This study examined grief that was experienced by individuals after they develop a mental illness.

Literature Review

Everyone experiences grief during their lifetime. Some cases of grief can be unseen or unacknowledged by the griever as well as society. Doka (1989) labels this type of grief as being disenfranchised while Boss (2010) describes it as being a form of ambiguous loss. Both terms describe an experience of grief that is often seen as less important than more straightforward forms of loss (Boss, 2010; Doka, 1989). For example, having a loved one pass away from old age will often be less complicated than losing a loved one to Alzheimer's disease. The grief process holds no hope of resolution or a return to what life used to be and the griever can feel

stuck in the grief process (Boss & Couden, 2002). Individuals who have a mental illness are familiar with the ambiguity and pain associated with this type of grief. Stigma is a complicating factor that can expand the reach of grief, creating an incredibly challenging and painful journey for the ill individual as well as their friends and family.

Ambiguous Loss and Disenfranchised Grief

Boss (2010) outlines two types of ambiguous loss. The first involves the physical absence of a person. The bereaved individual lives in a state of limbo because they do not have physical proof that their loved one is gone (Boss, 2010; Walsh & McGoldrick, 2004). For example, if a loved one disappears and no body is found, the bereaved may hold some hope that the loved one is alive even though they are not physically present in day to day life. The second type of ambiguous loss occurs when the person is still physically present but is psychologically altered to the point where the original person seems to be lost (Boss, 2010; Walsh & McGoldrick, 2004). The ill person's physical body is intact yet their mind has changed significantly. They are "no longer as they once were" (Boss & Couden, 2002, p.1352). In these instances, the grief can be paralyzingly painful and lasts a lifetime.

Often, the grieving individual lacks socially accepted opportunities to grieve as well as an awareness that they are grieving because of the ambiguous nature of the loss (Young et al. 2004). Worden (2009) describes ambiguous forms of loss as being "socially negated" where society labels the experience as not involving an actual loss (p.3). The griever is left without a socially acknowledged "right, role, or capacity to grieve" and is left with few opportunities to work through the grief (Schweback, 1992, p.3). The griever themselves may not be aware that what they are feeling is grief related to the development of an illness (Young et al. 2004). For providers, it can be challenging to not misdiagnose the normal feelings of grief as mental health

symptoms. Misdiagnosis can cause further isolation and does not give the individual the opportunity to address grief (Young et al. 2004). Ambiguous loss and the grief that accompanies it are felt by individuals who suffer from a mental illness.

Losses Experienced with Mental Illness

There are many losses associated with the decline of mental functioning which can cause grief. The realization of loss when a mental illness occurs does not always happen right away because creating time to process what has been lost is often not the first concern. Often this happens once the individual accepts their new reality of having a mental illness (Young et al. 2004). Also, the rate of loss can be very rapid (Doka, 1983). Before the individual has time to consider what will be lost, numerous losses have already occurred. Identifying losses, especially in the early stages of illness development, often does not occur (Lafond, 2002). The multitude of changes along with the numerous immediate needs, like finding affective medications, can hinder the process of examining what has been lost. There are also secondary losses which result from the primary or main loss (Doka, 1983; Worden, 2009). In the case of mental health, the primary loss involves a decline in cognitive and emotional processing stemming from the onset of the illness (Wittmann & Keshavan, 2007). This loss of functioning causes several secondary losses which affect the individual's life.

Daily Functioning. Cognition, affect, and behavioral changes can alter the functioning ability of a person and provides extra challenges to daily tasks (Feldman & Crandall, 2007). When a psychological loss occurs, many aspects of daily life change or disappear (Doka, 1989). This loss of the ability to accomplish daily activities which were once second nature can be a traumatic experience (Wittmann & Keshaven, 2007). Activities that used to be common may not be possible or may be altered to decrease stress and to accommodate disruptive symptoms. For

example, a person may need to adjust their schedule on days when the act of getting out of bed is an obstacle. Johnstone (2001) compares performing everyday "normal" tasks to climbing a mountain. Normal, common tasks become overwhelmingly large.

Loss of functioning can affect every aspect of a person's life depending on the severity and persistence of symptoms (Lafond, 2002). Cognitive ability may change, causing the ill individual to lose the ability to process or follow directions, making it more difficult to cook meals or try new activities (Wittmann & Keshavan, 2007). Emotional instability may affect the person's ability to manage stress or engage in activities with friends which were once enjoyable (Wittmann & Keshavan, 2007). Another effect of symptoms can be a lack of interest in participating in activities that used to be enjoyable (Black & Andreasen, 2011). A struggle with daily activities with symptoms that affect social interaction can result in an increase in isolation (Mauritz & Van Meijel, 2009). A person's daily life can also be altered due to intrusive medication side effects as well. In a recent study that examined the distress caused by psychotropic medications, two-thirds of participants indicated they experienced a great deal of distress because of side effects, which included "weight gain, dry mouth, and sedation" (Covell et al., 2007, p. 435).

Self-Determination. A loss of independence along with a lack of support can be felt. With the decline in functioning as well as an increased struggle to perform daily tasks, the individual may rely on others for support and assistance more than they did in the past (Doka, 1989). Doka (1989) noted that many skills, like stress-reduction techniques, may need to be relearned with the help of mental health professionals. However, the individual may be reluctant to ask for assistance because of stigma, not wanting to give up independence, or because symptoms are keeping them from seeing that they need added support (Young, et al. 2004).

Aspects of life including housing can be impacted by changes in ability which can add to the loss of independence if the person is used to living on their own (Yarrow et al. 1963).

Individuals may find themselves in a position where they are required to receive treatment which can take away personal choice and freedom (Johansson & Lundman, 2002). Professionals may become involved to monitor the individual's symptoms or level of functioning. At times mental health professionals may make treatment decisions that do not involve the input of the patient (Johansson & Lundman, 2009). As more providers get involved in the ill individual's life, they may see more of their independence disappear. The cause of grief, mental health symptoms in this case, can create more challenges that intensify the individual's grief (Schwebach, 2002). Decisions like involuntarily hospitalizing a person do not only take away independence but adds to the trauma of loss the ill individual experiences (Mauritz & Van Meijel, 2009). The ill individual may also doubt that the diagnosed illness exists because symptoms are often invisible to the person who is having the symptoms (Overton & Medina, 2008). This blindness to the affects of symptoms can cause the ill individual to isolate and not engage in services or utilize supports. Many symptoms that a person with a mental illness experience decrease their functioning and affect their ability to see the changes in their life.

Relationships. Relationships change once a person develops mental health symptoms. Relationships with spouses, children, and parents change significantly as roles and expectations shift (Boss, 2010). Cognitive changes along with symptoms that affect a person's ability to socialize make it difficult for the ill individual to establish and maintain supportive relationships (Mauritz & Van Meijel, 2009). Family and friends may pull away after a while leaving the ill individual with fewer supports. Also, the support that may be there at the start of the illness may decrease as challenges continue. For example, cycling symptoms of bipolar disorder can exhaust

family and friend's support (Macias & Rodican, 1997). When a mental illness develops, the ill individual can become more dependent, creating more strain on supports (Mauritz & Van Meijel, 2009). Friends and family may be more involved with the person at first yet can burnout from the strain caused by their loved one's behavioral changes and intense symptoms (Doka, 1989).

Family burnout can lead to conflict, which affects resources like housing. Often ill family members end up living in structured community centers, like adult foster care, if their daily functioning has been so affected they cannot live on their own yet cannot live with family because of the family's exhaustion around the effects of mental health symptoms (Piat et al., 2011). Both family and friend supports can become sparse when someone develops a mental illness and the ill individual may be left to grieve on their own a life that existed before the development of the disorder (Young et al., 2004). When a lack of support is coupled with a decrease in engaging and meaningful activities, a person can feel more disenfranchised and isolated (Schwebach, 1992).

Role Change. The family member with the mental illness may grieve a loss of connection, past role, or intimacy with family members. Couples that include one partner who has a mental illness have a much higher level of marital strife than partner units who lack a mental health diagnosis (Butterworth & Rodgers, 2008). The strain of symptoms along with changes in personality and functioning abilities can result in the lack of support or even the loss of a spouse. Parental roles can shift as a result of mental health symptoms. A study done with fathers found that men were often worried about talking with medical providers about mental health symptoms because they worried it would affect their ability to continue parenting (Reupert & Maybery, 2009). In custody disputes, the presence of medical transcripts documenting mental health symptoms can lead to the parent's loss of custody (Hollingsworth,

2004). Ill individuals may also be aware of lost dreams that their own parents had for them, adding to their grief and possibly to their shame (Young et al., 2004).

Employment. Job security and potential job options can be affected when a severe mental illness develops. Symptoms create more barriers and challenges when working and when job searching (Haertl & Minato, 2012). In a qualitative study that examined the relationship between psychotic symptoms and grief, Wittmann and Keshavan (2007) found that the disappearance of stable, predictable employment was a major loss experienced by participants. An individual's decline in abilities may limit employment options or can cause them to be unable to return to pervious employment positions (Haertl & Minato, 2012). The ability to attend school or work that was taken for granted before the illness emerged becomes a daily challenge (Maurits & VanMeijel, 2009).

Symptoms like a lack of motivation or energy can impact a person's ability to attend to daily work or school needs. Haertle and Minato (2012) found that young adults who are involved in job training or educational pursuits when symptoms emerge may need to reevaluate their chosen career path. Individuals are often very fearful about disclosing mental health information to employers because of the fear that their work options will be more limited (Yarrow et al.,1963). Yarrow and colleagues (1963) found that common misconceptions held by employers included the belief that individuals with a mental illness were more unreliable and were more dangerous than candidates who do not have a mental illness. Employers can have negative assumptions towards people who have a mental health diagnosis which can affect their desire to work with people who are up front about their illness (Yarrow et al., 1963).The loss of steady employment also affects the person's ability to pay bills, live on their own, and engage in social activities.

Beliefs. Chronic illnesses, both physical and mental, affect an individual's perception and interaction with the world. Boss and Couden (2002) point out that the stress of a chronic illness affects the way an individual constructs their reality. This unexpected change of reality can challenge an individual's or a family's religious beliefs as they search for meaning in the pain they are experiencing (Bland, 1998). Some may have trouble seeing how God could let something so horrible happen to themselves or wonder why God would bring a lifetime of pain and struggles to them and not others. Some may even see their illness as a sign that God is punishing them. Because of this religious change their perceived place in the world may also be different. That person's assumptions about life along with their dreams are shaken and often times are forcefully shifted to a new reality (Boss & Couden, 2002).

Making meaning of mental health associated grief and loss can be more challenging and adds to the individual's grief. The intangibleness of the situation can make it difficult for the individual to name what has been lost (Young et al., 2004). In the struggle to find meaning in their situation, the person might also feel that there is no hope (Boss, 2010). Finding where the person fits in their new world is also a challenge, especially when they are faced with stigma and hostility (Wittmann & Keshavan, 2007). Accepting and embracing the uncertainty and senselessness of mental illness can be an aspect of grieving that can be a devastating obstacle for many. The process of gaining insight can be a long, gradual process (Lafond, 2002). Pervasive symptoms or life situations can keep individuals from gaining insight which keeps them from finding meaning in their struggles. The challenge becomes finding a way to endure despite the ambiguous or nonexistent meaning (Abrams, 2001).

After the individual has gained some insight and skills for coping with symptoms, the task of naming losses may become easier; however that is not always the outcome. The easiest

way of making sense of the illness is often to blame self or others instead of concluding that it could be random or even meaningless (Bland, 1998). An ill person may blame themselves, God, or others instead of confronting the intangible idea that no one is to blame. Society encourages this idea of placing blame (Bland, 1998). Often times the ill person or someone else in their life is seen as the cause of the illness by society. Not only can a person's faith in a deity shift, but their faith in others as well as themselves can disappear (Wittmann & Keshavan, 2007).

Dreams and Future Plans. There is also a great deal of ambiguity in everyday life. The ill individual not only is trying to cope with a loss of functioning but also struggles to accept a new norm of daily ambiguity. Often, knowing what will come next as well as what the final outcome will be is a luxury lost to someone dealing with a mental illness (Abrams, 2001). Many may feel that there is no clear beginning, middle, or end to the grief and instead it is more cyclical (Young et al., 2004). A person may start to gain skills and make progress for a period of time causing a plateau in grieving. However, symptoms can be exacerbated and cause a decline in functioning and with it an increase in grief. The struggling individual finds themselves at a previous level of functioning as well as a return of past feelings of grief. People can feel "frozen" or trapped in grief because there is no clear way of bringing closure to their experience (Abrams, 2001, p. 283). Keeping an attitude of hopefulness can be an incredible challenge when you experience an ambiguity of what every day will be like.

Not only does a person's daily life change with the onset of a mental illness, there is a shift to a new, ambiguous future. The ability to manage stress and change can alter what activities the person can engage in resulting in a change of future goals or a different expected life (Doka, 1989). In some cases, full time employment in the person's field of expertise may be too much of a challenge to return to right away and could potentially no longer fit their

functioning (Wittmann & Keshavan, 2007). The person may have to make difficult decisions

about their ability to work, how many hours they can work, and what type of employment would

fit their new situation. Many rights or future dreams can be taken away as the result of having a

mental illness. In the United States, certain states prohibit individuals with a mental health

diagnosis from participating in a jury, holding a government office, or having custody rights for

children (Johnstone, 2001). This type of "structural stigma" restricts people from pursuing

"normal" lifetime goals or dreams (Overton & Medina, 2008, p. 144). Structural restrictions also

keep individuals from having the life that they would dream of having.

     Personal Identity. The person's view of themselves changes as their life course and

daily patterns change. Symptoms, like psychosis, can greatly alter the person's sense of meaning

and identity (Wittmann & Keshavan, 2007). Self-esteem can plummet due to felt stigma or to the

shift in abilities (Feldman & Crandall, 2007). Activities and personal strengths that a person used

to excel at can become activities that the person finds extremely challenging. Being a patient or

"mental patient" can become a new identity (Macias & Rodican, 2008, p. 210). In Wittmann and

Keshavan's (2007) qualitative study on psychosis and grief, a respondent commented that the

most devastating loss she experienced was her loss of identity and confidence in herself. The

individual's own observations and functioning are no longer reliable and they must redefine who

they are as well as their expectations for themselves (Farone & Pickens, 2007; Mauritz & Van

Meijel, 2009).

     Self-stigma also has debilitating effects on individuals with mental illness. Overton and

Medina (2008) describe self-stigma as "an internal evaluation process whereby people judge

themselves" (p144). Not only do people with a mental illness have to combat societal stigma but

often they have to fight their own stigmatized views of themselves. Sometimes a person can

perceive society as having certain stigmatizing beliefs even though they themselves have not experienced these judgments but hear about them from others. Other people's experiences can influence how another person views others and interactions with others. Negative stereotypes can be adopted and used by individuals who struggle with mental illnesses. This self-stigma greatly impacts a person's self-esteem and beliefs about their ability to reach their goals (Overton & Medina, 2008). Even without experiencing a stigmatizing accusation from others, a person with a mental health diagnosis assign stigma or stigmatizing behavior to themselves.

Impact of Stigma

According to Link and Phelan (2001), stigma is present when "elements of labeling, stereotyping, separation, status loss, and discrimination" are all present and dependent on power within the societal structure (p. 367). Individuals with mental illnesses can have behaviors that are visible symptoms that make society uncomfortable or nervous. The individual with a mental illness is seen as inferior or dangerous and becomes marginalized by society (Johnstone, 2001). It is uncommon for those who do not have a mental illness to take the time to educate themselves about mental health symptoms; which contributes to the development of stereotypical views (Overton & Medina, 2008). The ill individual can also start to be seen as their illness which does not happen with other illnesses. For example, it would be odd to say someone is cancer however, it is quite common to hear that someone is schizophrenic (Link & Phelan, 2001). Many may not even realize that the way they talk about mental illness compared to other health issues is vastly different. Without education and awareness negative opinions and stereotyping continue.

Societal and individual stigma can create a sense of fear in people; creating a continual feeling of grief around a loss of identity. Stigma can make the individuals with a mental illness feel separated from the cultural norm, which breeds further loneliness for people struggling with

symptoms (Johnstone, 2001). In the United States, it is common, and often the norm, to hold

negative, stereotypical views of individuals with mental illnesses. A study on the dimensions of

stigma in regards to mental illness indicated that a person's belief about how dangerous an ill

individual is affects their rejection or acceptance response (Feldman & Crandall, 2007). Overton

and Medina (2008) found that media and television often portray persons struggling with mental

health issues as being dangerous, violent, unpredictable, untrustworthy, social outcasts, and

failures at life. It is also common for there to be a "spoiled collective identity" where the

mistakes of a few stigmatize and label the larger group (Overton & Medina, 2008, p.144). These

depictions can be more compelling than factual sources.

American culture values a strong work ethic, success, and independence. These values

can prevent society or family members from encouraging or allowing the ill individual to grieve

in the way they need to grieve (Simos, 1977). Adaption and struggle are also dreaded

experiences and society can expect ill individuals to triumph over their without burdening the

rest of society (Boss, 2010). Mental health symptoms sometimes attack cultural values which

causes people in society to see the other person as a menace to society instead of an individual

who is struggling with an illness (Boss, 2010). In many ways there is a culture of stigma and

distrust in the United States. Research indicates that individuals with mental illnesses have more

barriers and fewer opportunities because of societal stigma than other populations in the United

States.

Loss from Stigma. Grief around a lost social identity and a loss of relationships are often

unspoken and grieving occurs in private because the experience of having mental health

symptoms is misunderstood by society (Young, Bailey, Rycroft, 2004). Stereotypes add to

prejudice and create a reality where there is a normal and an abnormal way of acting or living

(Schwebach, 1992). When someone is labeled with a stereotype they are linked to a set of

"undesirable characteristics" which make up the base of the stereotype (Link & Phelan, 2001).

Society starts to develop an "us" and "them" mentality where "them" is seen as undesirable and

odd and "us" hold the desired normal characteristics. The ill individual is further separated from

others due to this linking which results in discrimination and a loss of status (Link & Phelan,

2001). Stereotypes and stigma keep individuals with mental illnesses from connecting with

others and leading a "normal" life in society. Stigma, fear, and stereotypes can cause others to

avoid or discontinue friendships with a person who has a mental illness once they learn the

person has a mental health disorder (Overton & Medina, 2008). Stigma and discrimination can

create more challenges for the person with a mental illness and can result in an increase in

symptoms as well as a slower recovery time because they are trying to hide their illness in fear of

other people's reactions (Johnstone, 2001). The unknown creates fear and further isolation for

individuals with a mental illness.

Fear and stigma also creates a lack of opportunity for individuals with a mental illness in

society. As previously mentioned, societal stigma can create barriers as well as continue an

attitude of fear in society while hampering opportunities for individuals with mental illnesses

(Overton & Medina, 2008). Fear of experiencing hurtful interactions with a prejudiced society

can keep people with mental illnesses from connecting with others around them. Friendships are

lost and new relationships may not come forth because of fear on both sides. This fear creates

avoidance and further isolation (Young et al., 2004). Resources and treatment options may also

be more sparse or difficult to get into making everyday life more challenging while creating a

feeling of alienation and desperation (Overton & Medina, 2008). The individual with a mental

illness may be given a lower societal status that could cause friends and acquaintances to avoid

him or her due to prejudice beliefs (Overton & Medina, 2008). A loss of status and standing in the community can be grieved. A lack of opportunities in society adds to the grief and confusion felt by people with mental illnesses. Some of these losses are associated with future dreams and life plans while other losses are seen in everyday living.

The combination of functional losses, identity losses, and loss from stigma create feelings of grief for people who develop a mental illness. The aim of this study was to examine the grief experience individuals encounter due to intrusive mental health symptoms.

Conceptual Framework

For the purpose of this study, the grief experienced by individuals diagnosed with a severe and persistent mental illness is viewed within the context of two theoretical frameworks: ambiguous loss and disenfranchised grief. Grief frameworks, including ambiguous loss and disenfranchised grief, are used to describe a difficult loss experience. Worden (2011) outlines two types of loss that cause disenfranchised grief. "Socially negated losses" are not seen as an actual loss by society and "socially unspeakable losses" involve losses that are not discussed in society (Worden, 2011, p.3). The loss of a pet or the loss of a child through miscarriage are examples of losses society categorizes as a non-loss. Deaths by AIDS or suicide are examples of socially unspeakable losses. Both types of disenfranchised grief are used to describe a death of a loved being and not to loss that is experienced during a person's life.

Ambiguous loss is also associated with complicated grief around the loss of a loved one (Boss, 2010). It is not uncommon for ambiguous loss to be associated with the loss of a person before they actually pass away. For example, Boss (2010) uses the term to describe the loss one might experienced when a loved one develops dementia while Boss and Couden (2002) use the term when discussing a families sense of loss when a member has a serious physical illness. More researchers are using these grief terms to describe losses that are not associated with the

death of a loved one. In past research these terms have not been specifically used when addressing the loss a person experiences when they develop a severe and persistent mental illness.

Research has been done on the struggle and loss that family members experience when a member develops a mental illness. Jones (2004) describes the complexity of the grief these family members experience. They struggle with feelings of guilt and shame as well as anger over the change in behavior and personality of their loved one (Jones, 2004). It is an exhausting experience that is often accompanied by few supports. Similarly, researchers like Young, Bailey, and Rycroft (2004) highlight the painful loss experience families face when a member has a mental illness while alluding to a few struggles the ill individual may face themselves. Families experience forms of disenfranchised loss as they struggle to adjust to having a family member with a mental illness. However, the individual who has the mental illness also experiences a great deal of grief and loss.

The losses an individual experiences when they develop a mental illness have been researched and documented. Losses ranging from cognitive functioning and emotional changes to loss of social support and daily activities have been reviewed in past research (Mauritx & Van Meijel, 2009). The effects of these losses on self-identity and self-esteem have also been explored by researchers like Farone and Pickens (2007). Attitudes like social stigma affect the individual's support and experience as they deal with the multiple losses (Feldman & Crandall, 2007). Stigma also adds to the ambiguity of the grief experience. Yet few have looked at the grief experienced by the individual who is enduring losses from the mental illness. There is a gap in understanding what the individual feels and how they process or attempt to process grief after having mental health symptoms.

Mauritz and Van Meijel (2009) looked at how individuals with schizophrenia experience loss and grief. They explored the internal losses associated with a change in daily living, decline in functioning, and the struggle adjusting to a "world of the illness" (, p.254). There are also external losses which includes a change in their place in society, decline in ability to connect with others, and loss of social support. The authors conclude that grief feelings, including blame, denial, anger, and guilt, are a result of both internal and external losses. However, the experience of loss and grief outlined in their study is not specific to schizophrenia.

Stigma affects many people from different backgrounds and past research has been completed to examine the presence of stigma in society for various groups of people. For example, Feldman and Crandall (2007) surveyed undergraduate students in California regarding the level of rejection for a number of severe and persistent mental illnesses. They found that "people are more willing to socially reject individuals with disorders" that are seen as being a person's own doing, are believed to be rare, and cause someone to be dangerous (Feldman & Crandall, 2007). Individuals who have a mental illness can be perceived as fitting into all three categories and are often severely stigmatized. Overton and Medina (2008) hypothesized that the strain of this stigma as well as the "negative expectations" portrayed by society affected the individual's view of themselves causing self-stigma (p. 147). Stigma hurts a person's ability to function at a societal and personal level. It creates a sense of doubt in the person due to the very negative opinions about the disorder in society. This is true for many people in society including individuals who have severe and persistent mental illnesses.

Individuals who are diagnosed with other mental illnesses, such as bipolar disorder or major depression, also encounter similar losses which lead to feelings of grief. Questions that examine how people experience the affects of loss due to mental illness, how society's views

affect their ability to talk with others about their loss, and how they view themselves as well as their place in society would provide a better picture about how individuals with mental illnesses experience grief. Gathering qualitative information from individuals who suffer from severe mental illnesses provides insight into common feelings, struggles, and challenges that are faced with a mental health diagnosis. This study will examine how individuals with a variety of severe and persistent mental illnesses experience the disenfranchised grief that accompanies the losses that follow mental health symptoms.

Methods

Design

This research project explored the grief individuals experienced after developing severe and persistent mental health symptoms. It was a qualitative, cross-sectional study that involved two sets of individual interviews. First individuals who had a mental health diagnosis were interviewed about their experiences. Questions for this participant population focused on exploring the participants' grief experience. Two facilitators of a Grieving Mental Illness group were also interviewed. Questions for the facilitators focused on why they started the process group and what experiences of grief and loss they see in their group members. The study was exploratory in nature. Gathering information through a qualitative method provided a better picture of the challenges, struggles, and stigma encountered as individuals with a mental illness adjust to a very different life. The study hypothesized that individuals who develop mental health symptoms are faced with daily losses that create a difficult and lengthy grief process. It was also hypothesized that individuals who are experiencing this grief have a lack of support and experience stigma by society as well as themselves.

Sampling

Participants for this research project were chosen with a judgmental sampling focus. To keep from opening up new and possibly painful feelings among individuals who lacked support, participants were recruited at a mental health drop-in center that facilitated Grieving Mental Illness groups. Participants were required to have completed at least six months of the group to ensure that they had spent time processing their grief. This criterion was also considered as a way to limit the negative impact of discussing their experience. Approximately 17 potential participants had participated in the grieving class. Three did not meet the parameters of the study due to the researcher's involvement in their current treatment or because of a short duration of attendance to the group. Of the remaining 14 potential participants, 10 still had contact information on file at the drop in center drop-in center. Five of the ten declined participation, never responded to the flier, or had relocated without informing the drop-in center of their change in address. The five participants included one male and four females who were all Caucasian and ranged in age from 43 to 65 years old. All had at least one Severe and Persistent Mental Illness (SPMI). Diagnosis' included Schizoaffective disorder, Major Depression, Generalized Anxiety Disorder, Obsessive Compulsive Disorder (OCD), Bipolar Disorder, and Post Traumatic Stress Disorder. The age of onset ranged from four to 28 years of age. All five were continuing to seek support at the drop in center either through use of drop-in services or case management.

After receiving approval from the organization's president, potential participant's were either approached by a drop-in staff with a flyer that outlined the focus of the study and how they could be involved or they were contacted directly by the researcher depending on the participant's connection to the center (see Appendix A). The researcher contacted individuals by

phone to gauge their interest and to answer questions. During these phone calls the researcher explained why they were being asked to participate as well as the parameters of the research project. If the potential participant agreed to participate in the study, an interview was scheduled to take place in their home or at the drop-in center. Interviews with the Grieving Mental Illness group leaders were added after the initial round of participant interviews to gain a broader perspective on the grief people experience and to explore why the group was started.

Human Subjects

Several parameters were instated to ensure that the group member participants in this study were treated appropriately and their personal information was kept confidential. A letter requesting approval was sent to the president of the nonprofit who runs the drop-in center to ensure that the company was willing to allow access to their database (letter was submitted to and is on file with the University of St. Thomas Institutional Review Board). After approval was granted from the nonprofit, an extensive research proposal was submitted to the University of St. Thomas Institutional Review Board (IRB). No aspect of the research, including recruitment or data collection, began until the IRB approved the study. A consent form was reviewed and signed by participants prior to the interview (see Appendix C and D). The participant was also given an opportunity to ask questions before signing the consent form. A copy of the consent form, along with a list of local resources, contact information for the researcher as well as the Committee Chair, and group facilitator phone numbers was given to participant in case they had follow-up questions or needed support. The original research proposal to the IRB was amended to include the facilitator interviews and a new consent form was drafted.

Facilitator interviews were not conducted until the amendment was approved by the review board. Both facilitators started the groups together roughly three years ago. They also are

both Licensed Individual Clinical Social Workers (LICSW). The facilitator who came up with

the idea of starting the group has worked in the mental health field for 23 years; 11 of those years

she has been a licensed social worker. The facilitator who joined her in creating the group has

been in the mental health field for four years. All of which were after she became a licensed

social worker.

Measurements

Group Member Participants engaged in one qualitative, in-person interview with the

researcher. The interviews were recorded and transcribed into Word Documents. Interview

questions included eleven open ended and five close-ended questions. Open-ended questions

encouraged more in-depth answers than yes or no and explored what the participant lost after

developing a mental illness, how they experienced grief, how grief has affected their daily lives,

if or how stigma played a part in their experience, and what was helpful as they have gone

through the grieving process. Questions were retrospective and focused on the person's past

experiences. Supplemental questions were added in each interview to expand the data and

encouraged the participant to share more of their personal story. Close-ended questions gathered

demographic information from participants including gender, race, current age, age of onset, and

mental health diagnosis (see Appendix B). Two of the five interviews occurred in participant

homes where as the other three took place at the drop-in center in a private meeting room.

Facilitator interviews were also qualitative, in-person interviews that took place in the

facilitator's homes. They too were recorded and transcribed into Word Documents. The

interview involved 10 open-ended questions which explored why the group was started, the

struggle and growth facilitators observed in group members, the loss and grief members

expressed in groups, and the effects of stigma on the grief experience. The interview also

included three close ended questions that asked for the facilitator's licensure, how long they had

been working as a social worker, and how long they had been working in the mental health field

(see Appendix C). Transcripts from all seven interviews have been kept on a password protected

laptop and on a thumb drive which is in a locked safe. All data will be destroyed five years after

the study was completed.

Analysis

Thematic analysis was used to analyze the data from transcribed interviews. In the

thematic analysis model, codes are placed in the data to assist with the creation of categories

which make up over-arching themes. Open coding was used in the analysis process to find

similarities or differences in the data. The researcher reviewed each line of the transcript and

coded themes or differences in the individual stories (Berg, 2009). The coding was comprised of

phrases or words that summarized ideas found throughout the transcript. Codes that were present

three or more times were put into categories and the categories were organized into major

themes. Similar themes emerged in each categroy.

<div align="center">Findings</div>

Each group member participant shared their story of how the development of an illness

slowly affected every area of their lives, causing numerous losses. The losses that accrued from

having a mental illness contributed to and caused the grief that participant's experienced. Losses

included symptoms interference by loss of daily functioning, loss of employment or financial

stability, loss of friends, disconnect between the individual and their family, loss of past

experiences or future dreams, and loss of identity. Stigma and self-medicating to cope with

symptoms contributed to the grief experience. Mental health symptoms such as skewed thinking,

where the person's perception of what is going on does not fit with reality, were also causes of grief.

Participants described how they experience grief and how it expresses itself in their lives. Several areas of growth were described by participants and indicated that the Grieving Mental Illness group contributed to their ability to grow. For example, the need for support, validation, and education were areas that group participants talked about needing and commented that the Grieving Mental Illness group provided a safe environment that offered all three things. Participants noticed a significant change in the way they viewed themselves and the world after accepting their grief and many commented that they wished they could have taken the class sooner. Facilitator observations and thoughts supported much of what group members noticed about themselves and the grieving process.

Major themes appeared in both group member and facilitator interviews (See Table 1). Themes for group member participants included being unaware of the presence of grief until joining the group, experiencing cycling feelings of grief, grief can be triggered, having a need to forgive and accept themselves, the need to forgive their families, having the feeling that they needed to hide, and learning how to live with grief. Facilitator interviews also presented themes, which included insight into grief and mental illness comes with time, healing comes through a safe place where experiences can be shared, and identifying potential barriers in society that keep people from recovering.

Table 1: Themes

Group Member Themes	Facilitator Themes
Being unaware of grief.	Cycling feelings of grief.
Experiencing cycling feelings of grief.	Gaining insight takes time.
Grief can be triggered.	Feeling connected with others.
Need to forgive and accept self.	Acknowledgement is needed.
Forgiving family.	
Feeling the need to hide.	
Learning how to live with grief.	

Group Member Themes

  Being Unaware of Grief. All five participants had never associated grief with mental illness until hearing about or joining the Grieving Mental Illness group. When asked when she first thought of grief accompanying mental illness, one participant responded,

> It was the class because before that I didn't understand any of my feelings…you don't really know what you're having until somebody says "Well, this is [grief]"…then it dawns on you that "Oh yeah, that is what I'm having. I don't know why I didn't think of that".

Group members talked about the surprise they felt upon realizing that the feelings they were experiencing were connected with grieving. One participant explained, "There's grief in all aspects… and that's where I had one of my 'Ah ha' moments about grief being fluid throughout life." A participant who spent a lot of time researching her diagnosis and treatment options had

also been surprised by the idea that grief could be a part of developing a mental illness. She

stated,

> For all the studying I do or the information hunting that I do I would have never, never
>
> associated grief with mental illness. So, I think most people associate grief just with
>
> death. I mean, that's all that I did but it doesn't have to be death. It could be grief for
>
> something that happened during the day that you didn't do.

Learning about grief in connection to the losses that accompany having a mental illness had been

new to all five group members upon entering the group.

Group member participants believed that they were not alone in their lack of awareness

around the connection between grief and mental illness. All five expressed concerns that mental

health providers were often unaware or too focused on symptoms to address areas of grief with

their clients. A participant explained this in more detail when stating,

> I don't feel like [providers] really know until you tell them what's going on. And of
>
> course if you've got grief and all these different things then you're hiding it….I don't
>
> think grief is one of the main things. It's the anxiety, it's the depression, it's the suicidal
>
> thoughts. I think it's those that [providers] focus on the most, um, because that's like the
>
> symptoms that are shown the most and the grief is hidden and a lot of times not even
>
> known by the person until they take a class like this and then all of a sudden you realize
>
> wow I have been really sad over these things that I didn't think mattered.

Participants described how identifying grief only happened when someone else helped point out

the signs that they were grieving. One participant went on to explain that not having someone

who is knowledgeable or even aware that grief exists makes it more challenging for the grieving

individual to see their grief.

I think people [don't] see any grief. They just think you're having a hell of a good time,

you know, but the people that have it are, I don't think are aware that they're grieving

over anything. They're just so caught up in the "I wish" and "I should" and "I want it to

be this way" but it's just never [going to] happen.

Identifying that they were not alone in their struggle to identify grief in mental illness helped

participants feel more empowered and set them on a course for taking steps towards better

understanding how that affected their everyday lives.

The realization that grief was a part of their experience was painful at first. One

participant talked about realizing that they had experienced a great deal of loss in life. They

stated,

I didn't even know that I was even grieving. I knew what I had lost but to grieve for it,

for what I had lost was different to me … And [the group] brought up a lot of things

[that] I was grieving about, with my mental illness, and….things that I could not do

anymore and, like getting a job and staying with a job, and um, losing friends

and…people that didn't understand about my mental illness and I didn't have a lot of

support from other people and I lost that.

Another participant had a similar experience of being saddened by the realization that loss and

grief were impacting her life. She stated,

It made me sad because I never really thought about it. I mean who stops to think about

grieving your health or loss of your health. Yeah, we grieve the loss of people, the loss of

things but I don't…I never stopped to think about grieving the loss of my life as it might

have been.

The pain of processing grief was expressed again when a participant stated "[The group] helps me because then I can think about what I actually am doing; if I am grieving…about something like sadness… it hurts too when you talk about it."All group participants identified the need to address the loss and grief in their lives yet also explained that it was a painful process.

Group members also commented that the realization that grief can come from SPMI symptoms can be a daily experience as loss continues to happen and symptoms continually interfere with their daily lives. A participant talked more about the many changes that had occurred since developing a mental illness. She stated,

> [The book] talked a lot about….you can have a depression and um,…you grieve it [and] that helped me because that's what it felt like… it changed my job, it changed my life, it changed my size, it changed my meds, it changed everything.

Another participant also talked about the extent of their loss. They stated,

> I didn't realize I was grieving so much…The grief was just everywhere…I was just so sad from everything, from all the things. From the friendships, the family, all the things that I lost, um the going out, the socializing, [and] having a job…I just didn't feel like I accomplished anything.

Group members recognized that identifying painful feelings of grief had been a crucial part of their recovery. This was expressed by a group member when she stated,

> I think once you can identify something it's much easier to work on it than if you're sitting there wondering "Why am I feeling this way?" and not know[ing] why. How do you work on something that you don't recognize? And that class helped me to recognize what it was and it was the grief.

A crucial step in the participant's lives was realizing that they were experiencing grief and that it was a normal response to the loss they had experienced.

Experiencing Cycling Feelings of Grief. The idea that grief was a cycle of emotions that continued throughout life was another prominent theme in the interviews. This cycling can happen within a matter of minutes or within several years. A participant expressed the uncertainty cycling emotions can bring.

> Living with mental illness, you're still going through the different stages of grief off and on all the time. You know, we're talking right now about anger and…a lot of us have anger, you know. And I've come through the acceptance part right now. Will I still feel that way in 5 years? I don't know. I'm just taking it as it is for right now.

She went on to describe a night earlier in the week when she had felt differently.

> The other night I had had a nightmare…and I woke up and I was just like "I can't stand this. I don't want it anymore." You know, the whole denial the whole anger, the why. "Why do I have to live like this? Why me?"…in that block of time I'm going through all the stages.

She continued to talk about the longevity of grief in her life. "Grief is fluid and it's going to be fluid throughout your life... every time you read about grief you read the stages …and then I'm like, ok,…once you've accepted it then you're done. Well no." Another participant reflected on the uncertainty she feels with grief. She stated that at the time of the interview she was feeling very positive about life yet that could change. "That's how I feel now, you know, not every day, but that's life. I always thought that at some point I'd have just like this eternal happiness and nothing would go wrong and um, that's not true." All five participants discussed the challenge of accepting this cycle of feelings of grief.

Group members also commented that the never ending flow of emotions can change unexpectedly or be present for unknown reasons. A participant shared an experience of being in group and suddenly having intense feelings of anger around a topic they were discussing. They stated "Sometimes, in your mind, things come up that you didn't even know that you were angry about". Later he talked about the helplessness that comes with not knowing how he would feel next. "I still don't feel like I'm in control of things. I feel like it's just controlling me and then when it decides to change it changes". Another participant explained the frustration she feels when she is unsure how long feelings of grief or symptoms will last. She talked about times when she could accept the grief and illness in her life yet other times she was unable to do so.

> When you do have depression, there are some moments that are good. Like you just can accept it and your life goes on and the days don't seem to drag on and on…Sometimes it takes me longer than an hour to get out of my anxiety state, you know, and then some days I don't get out of it like all day and I just keep taking my prns.

Sometimes participants could pinpoint where feelings of grief were coming from but admitted that other times they were unsure why they felt that way.

Grief can be Triggered. The cycling feelings of grief can also be unexpectedly triggered by events or symptoms. Reminders of what participants had lost brought up strong emotions and grief for participants. A participant that lived several states away from her immediate family talked about the pain of being unable to financially afford to visit them often.

> I don't have my grandkids to see, except for when I drive out there and that's getting awfully expensive. I have a special needs trust and I've took that down to such a low amount that I basically can't use it… I guess one thing [having a mental illness] did affect

was where my life would have gone had I not been sick. Educationally I might have gone

further but it interfered with it.

Another client expressed feeling grief around lost work experience. She often felt,

…left out when they talk about their jobs and stuff and it's just like making out some

papers or anything and they ask you what's your occupation and I can't really say that…

but um, I wish I could [be employed] again.

Not being able to work resulted in her having to rely on small monthly social security checks.

"That's another piece. That's one thing I grieve. I don't have much money." Other participants

shared the loss of dreams, which caused them grief. "I wanted to have kids, you know, so I didn't

have any kids because I didn't have any healthy relationships". Another shared their struggle

with separation that had formed in their family and the lack of trust family members had in her

ability to contribute to problem solving. She stated "…what gets me down…with the family

feuding and um, he won't let me help or anything…and I get nervous about it". Having

reminders of loss can cause grief to cycle and affect people's experiences again.

Symptoms of grief can be sparked by the effects or presence of symptoms. Many

participants talked about the lack of confidence or the loss of self that occurred after developing

a mental illness. There was a sense that they were grieving their old self at times. One participant

stated,

Part of me is missing….I really have to try to get my confidence back, which I am doing.

And it's better than it used to be but I miss the old me…the lady that laughed all the time

and didn't worry if she was going to have a nervous breakdown or didn't worry if she

was going to get depressed again or could go out and just work away and do certain jobs

and do them well.

Another participant had similar feelings about the change in her ability to complete daily tasks.

> When I wake up in the morning I don't feel confident like I used to. I feel more worried about what's going to happen. "Why am I like this? Am I gonna stay this way?"…Like right now I have so much laundry and my house is such a mess. You know, and that's not me … I think a lot of it for me is just the loss of motivation to do the things that I want to do. I need to keep a healthy environment around me so.

A participant talked about having symptoms of depression and stated "A lot of times it's a loss of energy [and] then I get really angry." The amount of energy that individuals invest in tracking and managing mental health symptoms can contribute to grief as well. A group member participant reflected on this and stated,

> I try to focus on not having skewed thinking and that's a lot of energy too, (laugh) that I lose. I'm like "ok, am… am I taking this too personal?" So, I don't trust my thinking…I'm constantly on guard and I know it's not just me because we talk about it in class…loss [of] energy wondering how we're going to feel [and] if we're…trying to stay in reality.

Having symptoms was another cause of grief that could easily change what stage of grief participants were in.

Need to Forgive and Accept Self. After realizing they were grieving, participants seemed to focus on forgiving themselves for past mistakes. Group member participants had held critical views towards themselves and struggled with finding their identity. Some of these negative views were based in mistakes participants had made. One participant talked about using alcohol as a way of not only coping with symptoms and grief but also to have respite from the self-hatred she felt.

A lot of self-loathing, self-hatred. Wanting to push it away…being mad at life, being

angry. A lot of anger and then of course to cover that all up I drank… …which then of

course brings financial repercussions, so. I spent lots of money on DUIs and lawyers

and…I've had to file bankruptcy…more loss than I thought!

Another participant discussed their substance abuse mistakes. They focused on lies they made to

keep a façade of being someone different.

It took a while to be truthful. Um, otherwise I'd lie to let them, whatever they wanted to

hear I'd say. You know, 'cause, you can, that's the stigma, you end up lying to people

then you lie to yourself. And then you start to believe that what they're thinking is the

truth and it's not.

One participant was very open about the mistake she made in marrying her ex-husband and the

verbal abuse she endured that was focused on her mental health. "I mean I let him do what he's

done to me, you know, but I was, um, weak, too weak to do anything about it. And that's another

grief that I have to let go." Participants described the process of forgiving themselves for life

decisions they made when they were trying to cope with their lives.

Participants also focused on forgiving themselves for mistakes or perceived mistakes that

were influenced by mental health symptoms. When symptomatic, participants made choices that

negatively impacted their lives yet in the moment they were unable to see these negative

outcomes. A participant that struggled with depression explained what the effects of symptoms,

like isolation, can have on relationships. She stated, "I isolated a lot and I lost a lot of

friends…my best friend, I lost her because of mental illness… I even lost friends who were

mentally ill who didn't understand me." Another participant who struggles with bipolar disorder

and experiences periods of mania talked about the struggle of living with decisions that are made

while symptomatic."I've had a lot of friendships that are, like, 20-30 years old…if I'm just

cutting you off after like 30 years that's new for me. So then of course I regret sometimes."

Several participants talked about the grief around losing friends because of the symptoms they

experienced. For some participants, symptoms made them assume that they had made or would

soon make a mistake which affected their ability to make decisions. A participant that struggled

with social anxiety described being unable to make new friends.

> I just can't do it. I just can't ask. There's people that have asked me and I've turned them
>
> down. To parties, to, you know, and I just, just couldn't, I still can't seem to break, but I
>
> know that once I break it, it'll be like no big deal, it's like "why was I thinking that?",
>
> you know. But it's just hard to overcome thoughts. Thoughts are really powerful.

Participants shared feelings of relief in being diagnosed with a mental illness because they had

explanations for some of their life experiences. One participant shared her experience of finally

being diagnosed.

> I think I was almost relieved when I was finally diagnosed with bipolar because then I
>
> knew it wasn't all in my head. You know, I wasn't crazy. I had an illness that could
>
> explain some of the things that I felt and did…I think that realizing that I needed to
>
> grieve the loss of my mental health and the limitations that it caused kind of…released
>
> me from feeling like it was all my fault. That the reason that I didn't go any further in life
>
> was because I was lazy when in fact it wasn't.

Knowing that symptoms contributed to mistakes they saw in their past helped participants

forgive and accept who they were outside of having a mental illness. However, accepting life

with a mental illness was and is challenging. A participant expressed the difficulty of accepting

her new normal and the challenge of letting go of things she had been holding on to.

> I just have to keep telling myself that this is my normal. It's hard and I've only more
>
> recently been able to just kind of … let go of stuff that I've been hanging onto
>
> forever…not even let go and maybe it's more just accepting.

Struggling with accepting and forgiving themselves was a major theme for group member
participants.

Forgiving Family. All participants talked about the pain and anger they felt towards
other people, especially family members, who had not supported them after they developed a
mental illness. Some felt very hurt by different things their family had said or done to them
because of their diagnosis. Speaking about their family's response to the development of mental
health symptoms, a participant stated,

> They sometimes think that shame is the way to [get rid of the mental illness]. I remember
>
> the shame that I had to go through and the feelings that it just, it hurt more and it brought
>
> me down even farther. It didn't pick me up or make me want to pull my boot straps up,
>
> you know, it just made me feel even worse, like, you know, I'm just a rotten person.

Another participant recounted a conversation they had had with their sister who thought that the
participant used their illness to gain advantages. "'Well, I think you use your Bipolar as
a…crutch or as…an excuse' that's what she said. And I'm just like, 'Yeah, I just love living with
these symptoms, like having suicidal thoughts all the time'."A different participant heard
similarly frustrating comments from her mother. She stated "What has been missing? My
family…my mom [said]…'I don't understand [your] depression. Your dad's depression wasn't
like this.'…That's hard to live with." Another participant talked about the pain she experiences
when family members made fun of people with mental illnesses at family gatherings. "My
family sometimes, they make fun of [mental illness]. You know, and I don't like that when

they're talking about [that]…I just felt uncomfortable when they were laughing about it…". At another family gathering, this participant learned that family members had been talking with her daughter about her mental health. After remembering this incident, she stated "[I] wish they would talk to me about it instead of talking to [my daughter]". Words can have painful effects and, in many of the participant's lives, what was said in the past drove a wedge between them and their family members.

Other participants described the pain and feelings of loneliness that came with a lack of family support. A participant was describing the struggle of not having family living close by when they stated,

> The holidays come and I don't have family around. I get sick and end up in the hospital, I don't have family around to come see me; nobody to come take care of me or help me out when I need help.

The same participant talked about the effect of her being open about abuse that had occurred in their family along with her having mental health symptoms.

> I didn't have much support from my sisters. Um, my mother and father quit talking to me and I quit talking to them. That was a big rift in the family. Um, and then my marriage did break up and I ended up at [the hospital] after many suicide attempts…

Another participant focused on the pain of having their kids misunderstand their experience of having a mental illness. She stated that she was "…grieving for my kids…that they would understand me and, um, support me and my family too." Many participants struggled with forgiving family members for not being available for support and for not trying to understand what their experience of living with a mental illness was like.

Participants also held anger towards family members for not confronting them about needing to get help for their mental health issues. A participant remarked that she had been angry at her parents, specifically, but had worked to change that feeling in herself. "Well my mom and dad didn't notice so I ended up being the way that I am. You know, and I used to have some anger towards them." She went on to explain the way she views their current support in her life.

> I guess it's kind of like the, what do they say, the 800 pound gorilla in the corner or whatever. It's, we don't really talk much about it. And they've never gone to like any classes or anything, so it's like support and not support.

Another participant discussed the confusion he struggles with around his family's lack of response to his illness.

> It should have been noticed by my family but they just let it go. Like oh, he's just being wild…I would almost cry in class because of thoughts …why nobody in my family sent me to a psychiatrist earlier. How they just enabled or just kind of thought everything was ok that I wasn't leaving the house, I wasn't going to the grocery store, and I wasn't doing anything or they just thought I'd grow out of it or they'd try to embarrass me to see if that would work…you think your family or somebody would say "Oh there's something wrong. This isn't normal", you know, "Maybe we should help him" and they didn't.

Accepting and processing grief had helped several participants forgive their families and accept what their relationships were like in the present moment. This participant went on to describe how processing his grief had helped him forgive his family for not helping him in the past.

> After the Grief and Loss my relationship with my mom changed because I kind of forgave her and I kind of brought up the things that… up was some of the things she'd done… I had a lot of hatred for her. You know, for doing stuff that was shameful, the

beatings and the, all the stuff that she did just really irked me but after the Grief and Loss

it was like 'Oh well, I can't change it'.

The loss of family was a major topic of discussion for participants and many remarks were made

that indicated they were trying to forgive family members.

Feeling the Need to Hide. Participants brought up times when they either felt like they

needed to hide that they had a mental illness or when other people expecting them to not talk

about their mental illness. In some cases this literally meant not going into the community. A

participant described the struggle they had going to the grocery store and feeling like he was

taking up other people's space. "I felt like I was inconveniencing people all the time, just by

putting my food on the conveyor belt. I just felt like, 'Oh, I should let them go first'." This

participant went on to talk about the challenge of joining the Grieving Mental Illness group.

I got really anxious and I don't like to cry in front of people. So when I'd start to get

misty I'd change the subject or I'd stop talking because then it would, then I'd be too

afraid to, um, expose myself, you know, too much in the class.

Even recognition for progress was difficult for this participant.

In my head I was thinking negative thoughts, that "Oh no, now I'm going to disappoint

them because something's going to happen and I'm going to disappoint them"…I was

just so scared and it caused me a lot of anxiety and when I got home it caused me a lot of

grief that I couldn't do something like that, you know, that it bothered me so much. That

someone could say something nice. Any kind of compliment was criticism.

The participant identified having fear of being rejected and judged, which caused him to want to

hide.

Worries about being judged were echoed by the other participants as well. One participant talked about her journey of sharing her experiences with other people and admitted that she still worried about being judged.

I finally kind of started talking about it, bit by bit and now…I still don't really want to, I have told some people at work that I know I can, where they won't, I think I feel judged maybe… then there are some people that I don't and I do have the fear that if I do tell people, and even with speaking out, could that damage my career?

A similar concern was expressed by a group participant who wanted to start volunteering with an organization that worked towards decreasing stigma around mental illness. She stated,

Sometimes I feel like starting seminars, you know, that could help people understand mental illness and like get up and tell my story and have a few people there who can get up and tell their story. …what happens if you go on T.V. or somebody sees you and you apply for a job and they say "Oh, that's that crazy lady that was on the news".

Developing trust in other people can take a long time. "I still haven't gained any friends outside of the [drop-in center]. Um, I still can't seem to trust people". All participants struggled with balancing protecting themselves by hiding the fact that they had a mental illness with wanting other people to know what having a mental illness is like.

There can be vulnerability when hiding is not an option. Participants talked about being hurt by people who knew they had an SPMI. For example, a participant talked about going to the Emergency Room for a medical emergency which was met with skepticism by doctors.

Even doctors don't know sometimes, …like going to a emergency room or something, you're there for something else besides your mental illness and then they treat you like,

um, that's your, that's who you are. You are mentally ill….they just think it's all in your

head.

Another group participant talked about the fear of letting other people know about telling people

in society that they have a mental illness.

I still don't tell people what my mental illness is, um, unless it's like you or somebody at

the [drop-in center], somebody who has mental illness I can open up to….They look at it

and if they don't see it then they open up about people who have mental illness like

they're, like lazy, and you know, they just do it on purpose. They make it seem like

you're doing it on purpose but you're not, it's it's something that just happens, you

know… helped make me realize that you can't really open up to a lot of people because

they really don't understand what's going on and they think that you're just living off the

government and living off your parents or, when, you know, you actually have a problem

working with people or being around people and that with a little help you can get your

life back.

Being vulnerable and honest with people about having a mental illness while trying to manage

symptoms and the grief that stems from having the SPMI is a difficult challenge. Participants

sometimes decided that it was not always worth the risk or energy.

After deciding that they wanted to be more open about their mental health symptoms,

many participants struggled with finding how to do so. One participant talked about the struggle

of making connections with people outside of the drop-in center.

I have a few friends outside of [the drop-in center] that I could talk to. But you know, I

don't talk to them, …what can I tell them. "Well I'm fifty-three. I worked for 28 years

and now I have a disease and I'm not working full time"...

 Another participant expressed similar frustration around explaining why he had been unable to work.

> That was very embarrassing because people always ask me "So where do you work?", and for me it was like "Oh, I'm um…". I was brought up that the guy works, you know, you always work. You work extra hours to take care of all your family. And the guy doesn't cry and the guy doesn't feel grief, and the guy doesn't… you're not supposed to feel sad around people. You're always supposed to be normal; not normal but whatever, it means.

Each participant reflected on how stigma was one reason they kept quiet about their experiences. A participant explained how the most painful stigma came from her closest friend and family. Sometimes she experienced stigma through her family's unwillingness to acknowledge or talk with her about the mental illness.

> I don't talk to my kids very much about it, my two sons, because it upsets them and I'm not sure if they don't like the idea of their mother being mentally ill or if it's because they're afraid that they may end up that way or if it's because they're afraid of it…or maybe there's a little stigma from them.

Group participants gave many accounts of their struggle to not hide the truth about having a mental illness and the fear they felt about the very real possibility that their openness could cause them more pain.

Learning How to Live with Grief. For individuals with a SPMI, life is a daily and unpredictable struggle. Four out of five participants talked about the interference symptoms had on their daily lives. Symptoms interfered with basic daily functioning and nominal tasks. For example, leaving the house can be a surmountable challenge. Every step of the day can be a

painful challenge yet participants saw growth in themselves around developing insight into how symptoms affected their lives and were developing ways of coping with symptoms. A participant reflected on the daily struggle she experiences and the constant awareness you have to have in order to try to cope with fluctuating symptoms. They stated,

> We become more self aware because we have to keep track of when we're in our, when we're going into our depression or with me, with bipolar, going into mania. Got to keep watching the signs… for me I sometimes have to give up even just day to day things because my symptoms are acting up. It's just continuing to do, bit by bit, the little things that you need to do. And all of a sudden I can look back, I'm like "Wow, I'm in a much better place now." So, and a lot of education, I mean for me. I wanted to learn a lot about my illness. and I think the reason I did that is because I wanted to, I hate, you know, the word normal, but I think normalize that how I'm feeling is…it's appropriate.

Another participant talked about the effects of having paranoia and explained "I was very paranoid. I just kept making up excuses not to leave which, you know, seemed… true at the time." They went on to describe how their life had changed since taking the Grieving Mental Illness class because they started to see the connection between feelings of grief and the losses they had endured due to having a mental illness.

> You don't grow out of mental illness…it just festers and becomes a worse wound and it got so bad that I was just a totally different person …and now I'm getting back to where I was before, you know, I let it fester too big…There was a lot of things that I had to overcome and the class helped me realize that to overcome it is to just accept it and once you accept it then you can just say "There's nothing I can change about it." So why not just, you know, let it go…just by going to the grief group and loss [you] learn things and

then you learn from each other too, what another person's life is like, you know, and how

they get around being anxious and how they, you know, work with their doctors.

Learning and developing awareness into how the SPMI affected their personal lives was an

important part of their growth.

Being aware of how mental health symptoms affected daily activities helped participants

start to see that overcoming challenges that symptoms presented was possible.

After grief and loss I did the cooking class. I started doing other classes because it was

like, [Illness Management and Recovery group] got me in to the [drop-in center], grief

and loss broke a lot of the stigma of feeling like people were judging me because they

really weren't, you know. And then the anger and then the frustration, the different

paranoid thoughts …by reading the book, it made me understand why I was having those,

you know, because of past, and what, the things I've lost from it.

Another participant had similar feelings about learning through the group.

It seems like I'm getting to understand more about what it is [that] I've been holding on

to and not grieving for… there's things that I've been angry about that I didn't even know

that I was angry about…I have to let it go once I go through it, so, that's what I do

usually and that helps with that class. Letting go and getting rid of junk.

Multiple participants expressed having more compassion with themselves after learning that they

were grieving. One participant stated "I used to put myself down and I didn't have much

confidence in myself or, or thought I was any good or, just this person just walking around doing

nothing." Another participant had a similar experience. "I'm not being as hard on myself for my

symptoms. I think that's my biggest accomplishment…one thing I don't do is I don't take my

mom's misunderstanding of depression so hard like I did." Being able to identify personal

growth helped participants as they learned how to cope with having an illness.

Group participants also saw growth in the way that they were managing symptoms. One

participant was able to develop coping techniques that allowed him to go back to work. He

stated,

> I know when I have work I'm mentally happy. It just makes me feel like, it just makes me
>
> feel productive and a good feeling to have someplace to go everyday and meet people
>
> and do a job, you know…I enjoy doing a job.

Another person talked about developing a better understanding around why she sometimes

struggles, which helped her cope with skewed thinking and helped her be less critical.

> I think then I really thought I was crazy because my thinking was so skewed. I remember
>
> thinking something and other people would say "No that's not how it is." and I would sit
>
> there and think "Why am I the only one who thinks that way?" and now I don't
>
> necessarily have that happen so often but when it does I have enough, what am I trying to
>
> say…enough, um, self realization to know that it's because sometimes the bipolar does
>
> cause me to see things differently or my experiences cause me to see things differently.
>
> So, I'm not always as hard on myself as I used to be.

One participant described how she was able to utilize skills more easily which helped her

manage symptoms.

> I have less panic attacks and…I deal with my emotions differently. I don't get hooked up
>
> on crying as much as I did. I mean I have my days, don't get me wrong but…, I learned
>
> how to cope by going to those. And sometimes I do distraction, which is in [Dialectical

Behavioral Therapy]. So I try to distract from myself so I don't go into my head as much.

But I think I've done a really good job to cope with what I've had to cope with.

Participants commented that identifying grief did not make the mental illness go away, daily challenges were still present, and yet knowing grief was a part of their experience affected how they saw the illness.

Facilitator Themes

The two group facilitators emphasized the pain, struggle, and growth that the group members expressed while also highlighting a few themes that they saw in individual grief experiences. Facilitator themes included cycling feelings of grief, gaining insight takes time, feeling connected and supported is a needed component when dealing with grief, and there is a need to acknowledge not only that mental illness is a disease but that huge amounts of grief and loss occur in people's lives when they develop a SPMI.

Cycling Feelings of Grief. Both group facilitators brought up issues that resulted in cycling feelings of grief. Life events or major losses were the main sources of grief which reappear throughout people's lives. One of the facilitators described some of these events.

Some of this keeps circling around, you know. Maybe your friends have a baby and you wanted one and it just hasn't worked out yet or you spent a lot of teenage years in the hospital so you lost a lot of your friends or didn't get to go to a reunion or, it all keeps circling back…[In] society, your worth is linked to your job and when they're not able to do that that's something that keeps coming back to slap them in the face…Not feeling like they're contributing or they are less than because they're not able to work.

The other facilitator also brought up areas that could cause grief. She stated,

> Their future earnings are much less so when people with mental illness, who have been
>
> hospitalized and lost their jobs, when it comes time for them to retire and collect social
>
> security they're going to have a lot less…loss of physical health because of either things
>
> that they do when they are symptomatic or because of the medications…and then just
>
> their capacity, you know, when people are psychotic or symptomatic in other ways their
>
> brains start developing lesions and they have less brain power down the road. You know,
>
> their baseline drops.

She also commented how addressing grief does not make the feelings of grief, like anger, go

away but can place it in the background of what the individual is experiencing.

> People sort of move down that path from a more black and white blame into much more
>
> tones of gray…so it gets defused. And because of that the energy around it gets reduced.
>
> So it doesn't go away, um, but I don't think it necessarily should go away, you know,
>
> because there [are] some things that people need to recognize that have been done wrong
>
> to them, um, but it doesn't become this sort of driving force to keep them angry.

One of the facilitators also brought up the struggle of self-image. She stated,

> How they look at themselves is…first [filtered through] mental illness and then
>
> everything else kind of gets washed away and so they lose the image of themselves as
>
> just an individual. You know, they're seen as having this disability…and that's been a
>
> hard thing to try to work through but I think that's the one thing that maybe comes over
>
> time… as people talk more and more.

How people look at themselves affects how they view their world and reality. Not only are

people losing aspects of their lives but the way they view the world shifts. Areas of loss can

cause grief to reappear over time.

Gaining Insight Takes Time. The facilitators pointed out that the process of gaining

insight and reaching a point where an individual can identify losses connected to having a mental

illness takes time. Both facilitators, like the group participants, noticed that individuals who enter

the Grieving Mental Illness group did not realizing that they are experiencing grief prior to

entering the group. One of the facilitators remarked,

> The biggest thing is that people didn't realize that they were grieving until they had a
>
> chance to think about it. Like "Oh, that's what it is! I'm not angry at people or myself,
>
> I'm angry at the fact that I got this".

The other facilitator also talked about the point where group members realize what they are

feeling is grief. She stated,

> [Group participants] still acknowledged not really realizing that what they were
>
> experiencing was a grieving issue…you can always tell when it happens, like there's this
>
> point where they connect that "Oh what I'm experiencing is grief"…people just sort of
>
> stop and you can see them stop and think. And you know that they've gotten it, at least at
>
> that point in time, they've gotten it and it results in some of the, the blame going away,
>
> you know, because it's a much more realistic view of what their lives are now, which is a
>
> combination of an illness interfering with their capacity but also their environment
>
> responding to their illness.

Facilitators have observed the relief comes with realizing a person is grieving yet it also takes

time and an opportunity to stop and consider what had been lost.

Group facilitators also noted that individuals needed to be at a certain point in their

recovery where they had some realization that losses had occurred because of the mental illness.

Processing grief can only happen when an individual is able to acknowledge the losses they have

experienced because of having a mental illness. Both facilitators discussed struggles that could hinder an individual's ability to accept loss from mental health symptoms.

> They can't be newly diagnosed. I think that's probably the hardest…Still reeling from the diagnosis and everything that goes with it, let alone figuring if they've lost anything yet . Most of our group members tend to be a little older…they're usually more middle age and up. Very few young and that probably is why, it's just too new…If they're too newly diagnosed…they're still kind of grappling with the fact that they have a diagnosis and aren't able to separate out enough. There's not enough, maybe, insight there or experience there…[It's] dealing with the immediate of what's going on versus what's been lost… people that, maybe, have been dealing with it for longer are a little more able to distance themselves and say "Yeah, I did lose this." And "My behavior 15 years ago was probably because, you know, I was angry at not being able to do something".

The other facilitator made similar remarks about the struggle of being newly diagnosed.

> People need to be at the point where they both get that they have a mental illness and have experienced some losses from it. Like, we had somebody in there once who had just recently been diagnosed and had no clue what was coming down the road…I can't imagine how overwhelmed they were. They weren't in there very long….I remember thinking, oh you need to have a little bit more comprehension of what you've lost.

She went on to explain that if an individual is not in a mental state where he or she can identify that they have a mental illness, whether that person is newly diagnosed or not, then making the connection that that person is grieving because of loss from a mental illness is a difficult step.

> … if you don't connect that you have a mental illness….if you don't even grasp that you have a mental illness it's pretty hard to figure out that you've had losses from it, you

know. You might connect that you have loses but to be in a group where it's being

continually being put back on the illness, it can be really frustrating.

Being at a place where a person could subjectively look at their life experiences and see how

symptoms or actions they made while being symptomatic caused losses was something the

facilitators identified as being important when trying to process grief.

Facilitators also indicated that having constant, intrusive symptoms could hinder a

person's ability to identify areas of grief in a group setting. One of the facilitators explained,

So it's sort of a niche group…not everyone has either been able to realize that they've

had losses or their illness has been contained to the point where they haven't lost a ton.

Or people are too symptomatic to really be able to do more of a processing group…I

think it can be damaging for people if they're experiencing too many symptoms to be

able to sit and develop the connection with others…. They can't, kind of, pull their brain

out of that enough to be able to attend to a group, a support group.

This facilitator also mentioned that Personality Disorder traits or symptoms could also disrupt a

person's ability to process grief.

At one point we had several people in that had more of a [Personality Disorder] diagnosis

and in more of an angry kind of phase. Not that people with [Personality Disorders] can't

really do well and get something out of it but the point where they were at was more of

like an angry, kind of entitled, and blaming mode not…blaming the environment versus

the illness… So you have to sort of get beyond that point to have some capacity to really

look at it…to look trying to fix it. You know, you can't be so angry that you aren't able

to figure out what to do about it.

The other facilitator brought up possible struggles someone with cognitive functioning could have when working through grief.

> Cognitive levels too. We had a member at one point [who] was just too low functioning, intellectually, to really grasp the group, you know, and maybe at some point down the line that could be something we could work on….but if you're hearing voices or real delusional, chronically, then it's probably not going to work very well just because the group setting may not work then.

Factors, such as mental health symptoms, personality disorder traits, and cognitive levels, were also seen as potential barriers for individuals in the Grieving Mental Illness group.

Feeling Connected with others. Recognizing and confronting grief and loss can be a difficult process. Facilitators identified that individuals need support as they go through this process and acknowledged that a group setting can have healing affects. One of the facilitators stated,

> It can get painful at times. You know, there are some fairly heavy discussions that can happen. But…the health of the group really pulls that through so that we don't, you know, leave people in this really icky spot…It's really amazing the power of the connection. You know, the human connection can really make such a difference. You don't really realize it until you're in a group like this. And suddenly the group dynamic just has so much great energy behind it. So, it's a very healing thing to be a part of.

She also mentioned that the structure of the group contributed to the connections and generated a supportive atmosphere.

> People are really given a lot of time to talk and to process they've really gotten to know each other and it's a source of support. They, they seem to really…connect well and

> strive to make each other feel comfortable and to give each other the okay to be who they are… so it's really a support group where they get to know each other and feel comfortable.

The other facilitator made similar statements when reflecting on the way support has developed in all of the Grieving Mental Illness groups. She stated,

> They seem to connect really well and give advice to each other and support and…everybody has bad days that comes into that group sometimes and everybody's real supportive about that too. They're having a day where they're more symptomatic or whatever and just can't stay focused and the group members have always been real supportive about that. They've become, I think, a good support system for each other.

She marveled at the group process and how the support they provided for each other sparked change in the individual group member's lives.

> Sometimes I think people are really judgmental of themselves. Yeah, and then as the group progressed you can see people getting kind of unstuck a little bit. Maybe, starting to branch out a little bit or able to see that things that maybe where they got set back in the past weren't setting them back anymore. They didn't get all stuck in their obsessions or the anxiety.

The group process and support it provided was a powerful force for helping people process and talk about areas of grief.

Facilitators identified a need for more services that address grief and emphasized the need for more supportive services. One of the facilitators responded to a question about gaps in grief services for people with SPMI diagnosis by stating,

Really any other providers providing [grief from mental illness] support. I don't know

that there's much else out there that's doing anything else like that, which is

unfortunate… we talk about recovery and I think and in order to recover you have to

acknowledge the losses first. Be able to feel the grief and then you can move through

recovery. Otherwise you just keep getting stuck.

They both identified the need of individuals to have support while processing grief and articulated the need for more opportunities that are grief specific.

Acknowledgement is Needed. Both facilitators indicated the need for more awareness around mental health related issues as well as awareness that grief from having a mental illness exists. They both talked about the need of more provider support and awareness around areas of grief. The facilitator who first started conceptualizing the group discussed what brought about her awareness about individual's experience with grief.

I really picked up on some clients going back to their past a lot and…feeling like they're

getting stuck with rehashing how their lives were before the mental illness hit

and…slowly I processed all of that and realized that it was a grieving issue and that there

wasn't really anything out there to help people, both acknowledge what they'd lost and

also figure out how to move beyond it.

Both facilitators commented on the lack of resources and research around the topic of grief from mental illness. One stated "…that it was definitely a needed thing and as we looked for a book to use as a guide we realized that there, that nobody was acknowledging it. So, that kind of brought out the need a little bit more." The other commented "I've never really seen anything else out there." They also talked about the need for others to help ill individual's acknowledge and name the loss or grief they have experienced in life.

One facilitator pointed out that it is difficult to see grief if the illness itself is not identified as a legitimate illness. She stated,

We don't, as a society, necessarily acknowledge that people who are sick with a mental illness are, one: are actually sick, half the time…If somebody were to get a diagnosis of having [Multiple Sclerosis] or something, it would be like "Oh, I'm so sorry. Is there anything I can do to help your family?" You come back with a diagnosis of Bipolar Disorder nobody says anything. So, just acknowledging it [and] that's where stigma comes in, is the fact that we don't acknowledge it…family members and friends are less likely to visit you in the psych ward than they are to visit you in a hospital bed in a medical ward… you go into the psych ward and you're there for a couple weeks and none of your friends visit you? That would suck…can you imagine two weeks in the hospital and none of your friends visiting you in the medical ward…you get flowers, cards, people visit, that's not necessarily, that's not the case for most people [who have a mental illness].

The other facilitator focused on how public ignorance and stigma could affect the ill individual's ability to accept having a mental illness. She stated,

I think stigma weaves a thread through everything and sometimes it's much more obvious than others but it's absolutely there. It, I think it's the reason why it takes a while for people to kind of get into the whole purpose of the group because there's such stigma out there who wants to admit that they have a mental illness to say nothing of looking at what they've lost because of it…. and if the stigma is out there interfering with your ability even to connect to that illness then, yeah it's going to be hard to drill down and to actually resolve some of the issues from it.

She went on to discuss the need for there to be more awareness around issues of grief.

> Probably a lot more awareness of the fact that grieving needs to happen. You know, just a
> comprehension that there is a loss. That people's lives don't just pick up and go back to
> what they were before. You know, too much time goes by, too much life happens, too
> many bridges get burned.

Awareness and acknowledgment that mental illness exists and that grief from losses occur when mental illnesses develop are needed so that ill individuals to gain the support that they need. One facilitator talked about the voice they try to give group members.

> I think [the group] shows them that [grief's] something legitimate. That they have lost
> something and that means something….Giving them voice to, maybe, to what they've
> lost. That it is an acknowledgement for something there that nobody else has
> acknowledged maybe for them.

Having other people acknowledge or legitimize individual's experiences of grief in having a mental illness is an important piece of recovery.

Strengths and Limitations

There are strengths and limitations associated with this study. Little research has been done with individuals who experience grief from mental health symptoms. Family members have speculated about possible grief experienced by their ill family members, however, hearing the individual member's experience with grief has been scarcely researched. Talking directly to the ill individuals was a unique strength of this study. This study considered the need for previous contemplation about the effects of grief on their lives before engaging in a research interview. Due to the struggle of functioning with symptoms, lack of support, stigma, and various other challenges, not everyone gets the opportunity to consider how they are grieving. This study

interviewed individuals who had started putting words to their grief story and were in the process of exploring what that meant for their lives. Participants had started the reflective process in a supportive, stable atmosphere and were able to utilize supports after participating in the study.

Limitations included a small participant base and a lack of diversity in participant demographics. There have only been three Grieving Mental Illness classes, each of which included a small number of clients. Not every person who went through the course had current information on file at the drop-in center due to their lack of involvement in recent drop-in activities. There were also individuals who declined to participate due to stressful life situations, which further limited the number of participants. This study interviewed middle-aged Caucasian individuals who were living within thirty minutes of a major city in Minnesota. All had access to services including medical insurance and financial assistance. All participants attended the same Grieving Mental Illness groups at a drop-in center in Minnesota. Further exploration with a broader cultural, regional and generation focuses would be highly beneficial to better understand the grief experience that accompanies the development of a severe and persistent mental illness.

Discussion

Interpretation of Findings

Grief from loss caused by SPMI is an unseen force in many people's lives, and adds to the daily struggle of living with a mental illness. A large portion of society, including individuals with a SPMI, do not see the connection between developing a mental illness and grief, making the journey to realization more challenging. Past research documents the grief and loss that family members experience yet very little research provides a voice to the individuals who have the mental health diagnosis. Past research describes the losses someone with a SPMI may experience. For example, loss can be seen in the lack of support, employment, functioning,

opportunities, and other more visible areas of decline in a person's life. However, it is important to recognize that grief is distinctly different than loss and plays a significant role in how the person with a SPMI views themselves, symptoms, others, and their reality. In past research we see a description of the more visible losses while this study describes the hidden experience grief.

Grief finds its way into how the person responds to life situations and can often get caught up in the cycle of confusing feelings. Research indicated that cycling symptoms of ambiguous loss can create a sense of hopelessness because there's no clear end point where the feelings of grief end (Young et al., 2004). Some of these feelings of grief can be attributed to being a part of the mental illness. For example, someone is sad and they have a diagnosis of depression then it would be easy to assume that the sadness is a symptom of depression. That is not always the case. This study indicated that grief can be hidden in symptoms; yet once grief has been named and identified, the feelings of grief, like sadness, can decrease or become more manageable.

Not only are people with a SPMI enduring daily struggles with intrusive symptoms but they are also struggling with cycling feelings of anger, sadness, and self-hatred. Even though experiencing these feelings is a normal part of grieving it can be confusing and difficult for the individual to see that they are associated with grief (Lafond, 2002). Even after identifying that certain feelings are connected to grief, individuals can experience situations or phases in life that rekindle feelings of loss. The future becomes ambiguous as the person's entire life begins to change. The change in life plans upsets the individual's dreams and plans while also breaking down the way the person managed daily stress. Both facilitators and group members identified difficult life transitions or situations where grief can cycle back through and provide more

challenges for the individual with a SPMI. Different events in life, like a friend having a baby, can be reminders of the loss that a person experiences because of having a mental illness. Someone's life course can be significantly altered causing them to lose opportunities or dreams. Even daily tasks, like waking up without unexplained anxiety can be a reminder of a life they do not have. The obstacle of "normal" everyday tasks can be a reminder of the loss a person has endured which can trigger another cycle of grieving (Johnstone, 2001). Group participants remarked on the ambiguity of everyday life that Abrams reflected on in his research (2011). Individuals with a SPMI wake up not knowing if or how the mental illness will affect their day lives. Having an understanding that grief is cyclical can help the individual develop ways of coping with feelings of grief when they resurface.

When an Individual with SPMI is unaware that they are grieving they can internalize feelings of grief and instead of seeing that feelings, like anger, are a normal part of the grieving process those feelings are aimed towards themselves. Group participants in this study expressed a great deal of relief after identifying that certain feelings were a normal part of grieving which resulted in them being less critical towards themselves. Normalizing feelings that are often not talked about can help the individual step back and examine where those feelings come from. This requires a safe atmosphere where the person can be vulnerable and receive support. Addressing grief and understanding where feelings of grief stem from can help the individual in their process of reclaiming areas that were lost because of the mental illness (Lafond, 2002). For example, one of the group participants talked about their process of recovery leading to being well enough to start working again. Once grief was no longer a barrier, participants could focus on other obstacles, like developing coping techniques for symptoms. Accepting the new reality can be a challenge yet facing the reality of having a mental illness and starting to rebuild ways of coping

with life can lead to a place where recovery and achieving goals is possible (Lafond, 2002). Finding acceptance in their lives as well as accepting who they are with the mental illness can develop more easily after addressing areas of grief.

Family member's lack of understanding, fear, and disappointment around their loved one developing a mental illness are felt by individuals with mental illnesses and can add to the person's grief. Different family member's experience of loss contributes to how they respond to their loved ones having a mental illness. Much research has been done that examines family member grief and loss when a loved one develops a mental illness yet very few have talked directly to the ill family member. The ill individual is greatly impacted by the way their family reacts to the development of a mental illness. Many participants described very painful memories where family members chose shame or criticism in an attempt to change their behavior, which caused participants to feel more disconnected from loved ones and added to the grief they experienced. Facilitators also commented on the effect family involvement or lack thereof can affect the way an individual views themselves or the illness. As research suggested, individuals with SPMI can be disenfranchised and left to grieve a lone with very little support (Young et al., 2004). Lack of understanding can cause people to be afraid or stigmatizing towards their loved one and support for families is an area where growth is needed.

Stigma about mental illness exists in society, causing individuals to feel alone and afraid, which affects their recovery. Research indicates that societal stigma depicts individuals with mental illnesses as not fitting societal norms. Participants expressed perceiving that others were stigmatizing them for being different. They felt that others were judging them without having concrete facts that showed they were being stigmatized. Perceived stigma decreased for most participants after acknowledging that grief was a presence in their lives, causing the individual to

feel more comfortable with who they were. Insecurities and self-hatred can be projected onto other people. For example, if an individual believes that it is their fault that they have a mental illness than other people must think that is the case as well. Fear can then keep the person from testing that negative belief about themselves and can keep them from discovering that their beliefs can be false. Perceived stigma also added to the self-stigma that individuals felt towards themselves. However, interactions with other people can strengthen or sometimes prove that the negative belief is actually being thought by other people. Group participants also gave examples where stigma was clearly playing a role in how another person interacted with them. Fear of how others would treat them was a reason that participants felt they needed to hide at times. Past research also indicated that stigma creates avoidance and isolation for the individual's on the receiving side of stigma. These negative interactions with society created fear in participants and made them reluctant to make connections outside of safe environments, like drop-in centers. Participants had many examples that pointed to societies "spoiled collective identity" and talked about feeling judged because of preconceptions people had about individuals with SPMIs (Overton & Medina, 2008, p,144). Stigma, whether it comes from within the person or society, stunts a person's ability to live the life they want to have and makes change seem impossible.

Grief and mental health symptoms can affect each other. Symptoms can cause loss which results in grief. Having symptoms of mania can disrupt relationships and create a loss of support. Grief can also add more tension and frustration, which can exacerbate symptoms. If someone sees their family members making fun of people who have a mental illness at a family gathering, the sadness they may feel could start a train of thought that result in more intense symptoms, like isolation. Issues like family or friend burn out complicate and add to the effects of symptoms on a person's life. Grief can also add extra barriers that can interfere with the ability to cope with

symptoms. Having feelings of anger because a person has lost their ability to contribute to their family can pull the person's attention away from important ways they need to keep themselves healthy, like eating, exercising, looking for work, or spending time with other people. Role shifts can greatly impact a family unit. Grief adds an extra layer of intense feelings and situational aspects to consider for a person who has a mental illness.

Overcoming obstacles from grief is possible with support. Group members held high positive regards for the Grieving Mental Illness group and gave many examples of how it helped them realize they were grieving while also learning tools to help them address and accept areas of grief and loss in their lives. For participants in this study, the group was a source of support as they learned about grief. Group facilitators provided encouragement while helping group members while verbalizing the grief group member's were experiencing. Group members were also huge supports for each other. Looking back through the difficult times in a person's life and examining the loss and grief that came out of those moments can be a very painful process. Having other people that understand not only the experiences you had but why the process is painful is needed for individuals so that they can work through grief. Participants identified a lack of support outside of the group. Grief associated with having a mental illness is not a common topic in the mental health field, let alone society as a whole. Very little research has been done around grief and mental illness. Some research papers have alluded to grief yet very few name individual's experiences as being a part of grieving. Individuals who are experiencing this kind of grief can come to a more solid place of understanding yet need to have people in their lives that can help them identify grief and provide them support as they look for it. Having adequate and reliable support is necessary when exploring grief and loss issues because it can be very painful.

Implications for Social Work Practice

Social workers need to be knowledgeable not only so they can help people address issues of grief but also so they can validate and put words to the grief people experience. Grief from mental illness is an area that very few providers consider when working with mental health clients yet it has a significant impact on individual's daily lives. Group members expressed a need for providers to understand what grief entails so that they could help point out areas of grief. Having someone normalize the confusing feelings and provide support as the person learns how to live with grief is necessary in the process of the person's recovery. Social workers, along with other providers, can get too focused on symptoms or accessing resources for their clients and do not address areas of grief. Identifying and spending time processing grief is a much needed step in recovery. Social workers need to find a balance where they are assisting their clients in getting basic needs met, helping the client learn how to manage symptoms, and identifying grief so that they can reach a point of acceptance.

Social workers can provide that voice and support in a way that is unique to other mental health professionals. Grief is one of those pieces that can affect many aspects of a person's life. Social workers are trained to look both at the whole picture of the individual's life as well as the smaller pieces. That skill can be useful when helping a client identify how grief is affecting their lives. Social workers can also bring awareness to other providers while helping the client learn how to communicate and describe issues of grief to others. Resources around identifying and addressing grief from mental illness are also scarce and need to be expanded. Social workers have the ability to create more groups and one-on-one individual opportunities for their clients that focus on grief.

Implications for Research

Further research on the effects and influence of grief on the lives of people who have a SPMI diagnosis is needed. Very little research addresses both grief and mental illness and very little exists from the ill individual's perspective. Learning more about their experience can be beneficial for society as well as social workers. Exploring different populations, such as a younger age range, would also be helpful in understanding the variety of experiences of grief individuals with mental illnesses can have. More information about other grief and loss programs would be worth exploring to find which approaches to helping people cope with grief are most affective. More research will also bring more awareness to the issues of grief found in having a mental illness. The more providers hear that grief occurs for individuals with a SPMI, the more techniques will be used in their practice to help individuals deal with grief.

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Appendices

Appendix A

Participant Flier

Grieving Mental Illness: Individual Experiences of Grief, Loss, and Growth

Whenever you lose something there is always grief attached to it. Share your story of grief, loss, and growth.

What is the study about?

This study would like to give you the opportunity to share your story and experiences of grief from developing a mental illness with others. Very little research exists around mental illness and grief that includes the perspective of individuals who have a mental illness. I want to include your experiences in my research so that others can benefit from your story.

What do I have to do?

You'll be asked to be a part of an individual 90 minute interview which will focus on your experience with grief, changes from mental health symptoms, supports, and personal growth or strengths from your experiences. The study takes place either in your home or at the [Drop in Center] on Mondays after 5pm.

For more information, please contact: Alissa Kaasa 612-578-5181

If you prefer to be called, please sign, provide your number, and give folded flier to receptionist at the front desk to put it in my mail box. This does not sign you up for the study. You are only agreeing to hear more about it.

_____   _____   _____

Interested Individual's Name (Print)   Signature   Home Phone

Appendix B

Group Member Consent Form

CONSENT FORM

UNIVERSITY OF ST. THOMAS

Grief Experienced Due to Severe and Persistent Mental Health Symptoms

Whenever you lose something there is grief attached to it. I am conducting a study about the grief experienced when symptoms of a severe and persistent mental illness affect and change a person's life. The study will look at the experiences individuals have who have lived through the development of a mental illness. Very little research exists that shares people's personal experiences of grief and loss around mental health symptoms. In participating in this study, you would have an opportunity to share your story so that some can see they're not alone and so others can better understand the struggle and grief of living with a mental illness. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Alissa Kaasa, St Thomas University/ St Catherine University joint Masters of Social Work Program. The researcher is _____. However, this study is not connected with _____ and will not affect your involvement or connections to _____.

Background Information:

The purpose of this study is to examine the grief experience individuals encounter as they develop a mental illness. The study will involve talking about with individuals who have a mental illness about their experience with the changes that occurred when symptoms developed. The information gathered from the interview will be used in a research paper and presentation to fulfill a requirement for the Masters of Social Work program at the University of St. Thomas/ St. Catherine University program. It is a Graduate Research requirement for Social Work students and will contribute to the student's knowledge about gathering research and preparing a research paper and presentation that will be given to the community. It is not a requirement of the program for the paper to be published yet it may be published in the future.

Procedures:

You were selected as a possible participant because you are an adult who participated in the Grieving Mental Illness class at the_____ for at least 6 months. _____ is not involved in this study; however, they have approved my contacting you as a potential participant. If you agree to be in this study, I will ask you to participate in a audio recorded interview that will last approximately 60-90 minutes long. The questions that will be asked in the interview will inquire about

observations and experiences you've had after developing a mental illness. No other records will be used in this study outside of the in-person interview.

Risks and Benefits of Being in the Study:

The study has some risk because the questions will ask you to reflect on potentially difficult and painful past experiences. Interview questions will explore your feelings and experiences of grief after developing a mental illness which could be an emotional topic. _____ and _____, the facilitators of the Grieving Mental Illness group have opened up the class to you if you with to rejoin for more support. You can also reach _____ or _____. I also have phone numbers for the county crisis teams, the Center of Grief and Loss, and the _____ in case you want their support.

There is no direct benefit yet very little research exists about the grief experienced when someone develops a mental illness. Providing your story may help others understand the experience and grief that can occur with mental health symptoms.

Confidentiality:

The records from this study will be kept confidential. The completed report will not include information that will make it possible to identify you in any way. The types of records that will be created for this report will include a recording of the interview as well as transcribed written copy of the interview that will be erased and/or shredded five years after the research is completed. The interviewer will be the only person who will have access to these documents which will be kept in a locked safe. _____ will not be named in the research paper. Also, _____ staff will not know you have participated in this study.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with _____ or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until April 1, 2013. Should you decide to withdraw data collected about you, the information will be withdrawn from the research paper. You are also free to skip any questions I may ask.

Contacts and Questions

You may ask any questions you have now and if you have questions later, you may contact me, Alissa Kaasa, at 612-578-5181. You may also contact the Ande Nesmith, Research Advisor for this study, at 651-962-5805 with any questions or concerns.

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

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study. I am at least 18 years of age. I understand that I will be audio taped. I understand that there is no compensation for any therapy services and I must pay them at my own expense if they are needed.

_____   _____

Signature of Study Participant   **Date**

_____

Print Name of Study Participant

_____   _____

Signature of Researcher   **Date**

Appendix C

Group Member Consent Form

CONSENT FORM
UNIVERSITY OF ST. THOMAS

Grief Experienced Due to Severe and Persistent Mental Health Symptoms

Whenever you lose something there is grief attached to it. I am conducting a study about the grief experienced when symptoms of a severe and persistent mental illness affect and change a person's life. The study will look at the experiences individuals have who have lived through the development of a mental illness. Very little research exists that shares people's personal experiences of grief and loss around mental health symptoms. In participating in this study, you would have an opportunity to share your story so that some can see they're not alone and so others can better understand the struggle and grief of living with a mental illness. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Alissa Kaasa, St Thomas University/ St Catherine University joint Masters of Social Work Program. The researcher is _____. However, this study is not connected with _____ and will not affect your involvement or connections to _____.

Background Information:

The purpose of this study is to examine the grief experience individuals encounter as they develop a mental illness. The study will involve talking about individuals who have a mental illness about their experience with the changes that occurred when symptoms developed. The information gathered from the interview will be used in a research paper and presentation to fulfill a requirement for the Masters of Social Work program at the University of St. Thomas/ St. Catherine University program. It is a Graduate Research requirement for Social Work students and will contribute to the student's knowledge about gathering research and preparing a research paper and presentation that will be given to the community. It is not a requirement of the program for the paper to be published yet it may be published in the future.

Procedures:

You were selected as a possible participant because you created a Grieving Mental Illness class at the _____. _____ is not involved in this study; however, they have approved my contacting you as a potential participant. If you agree to be in this study, I will ask you to participate in an audio recorded interview that will last approximately 60-90 minutes long. The questions that will be

asked in the interview will inquire about observations you have had while facilitating the Grieving Mental Illness group. No other records will be used in this study outside of the in-person interview.

Risks and Benefits of Being in the Study:

The study has some risk because the questions will ask you to reflect on the pain you've seen in other people. If you feel personal grief from your experience of a group facilitator, ou can contact the Center of Grief and Loss to gain further support.

There is no direct benefit yet very little research exists about the grief experienced when someone develops a mental illness. Sharing your observations may help others understand the experience and grief that can occur with mental health symptoms.

Confidentiality:

The records from this study will be kept confidential. The completed report will not include information that will make it possible to identify you in any way. The types of records that will be created for this report will include a recording of the interview as well as transcribed written copy of the interview that will be erased and/or shredded five years after the research is completed. The interviewer will be the only person who will have access to these documents which will be kept in a locked safe. _____ will not be named in the research paper. Also, Guild staff will not know you have participated in this study.

Voluntary Nature of the Study:

Your participation in this study is entirely voluntary. Your decision whether or not to participate will not affect your current or future relations with Guild Incorporated or the University of St. Thomas. If you decide to participate, you are free to withdraw at any time up to and until April 1, 2013. Should you decide to withdraw data collected about you; the information will be withdrawn from the research paper. You are also free to skip any questions I may ask.

Contacts and Questions

You may ask any questions you have now and if you have questions later, you may contact me, Alissa Kaasa, at 612-578-5181. You may also contact the Ande Nesmith, Research Advisor for this study, at 651-962-5805 with any questions or concerns.

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

Statement of Consent:

I have read the above information. My questions have been answered to my satisfaction. I consent to participate in the study.   I am at least 18 years of age. I understand that I will be audio taped. I understand that there is no compensation for any therapy services and I must pay them at my own expense if they are needed.

_____   _____

Signature of Study Participant   **Date**

_____

Print Name of Study Participant

_____   _____

Signature of Researcher   **Date**

Appendix D

Group Member Interview Questions

1. When did you participate in the Grieving Mental Illness group?

2. What drew you to the group?

3. Tell me about your experience of developing a Severe and Persistent Mental Illness?

4. What aspects of your life changed when symptoms developed?

5. What do you feel that you have lost because of mental health symptoms?

6. How did those changes make you feel?

7. Did other people treat you differently? If yes, how so?

8. Were you aware of these changes before you participated in the group?

9. What was missing that would be helpful as you dealt with changes and grief?

10. What has been helpful or encouraging as you have gone through the grieving process?

11. How have you grown from your experience?

12. Demographics:

    a. Gender:

    b. Age:

    c. Race:

    d. Diagnosis:

    e. Age of onset:

Appendix E

Group Facilitator Questions

1. How many Grieving Mental Illness Groups have you co-facilitated?

2. What made you want to start a group about grief and mental illness?

3. When did you first connect grief with developing a mental illness? How did you make the connection?

4. What areas of loss do you see in group member's lives?

5. How do group members experience grief?

6. What role does the group place in the individual group member's lives?

7. What supports are still missing for group members?

8. Do you see other professionals identifying and assisting people process the grief in mental illnesses? How?

9. Does stigma place a role in member's grief? How so?

10. How have you seen growth in your group members?

    Demographics:

    Degree/Licensure:

    Number of years worked as a Social Worker:

    Number of years in Mental Health field: