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Exploring the Perception of Personal Loss Resulting from Mental Illness

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Acknowledgements

Of the many wonderful individuals who have been so supportive and influential throughout this

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Abstract

This paper looks at the experience and meaning given to loss as a direct result of living with a severe and persistent mentally illness. This is addressed through an examination of the research literature along with a quantitative survey and a qualitative interview involving individuals who carry this mental health label with an adult onset of their mental illness who were a part of an urban continuing day treatment program. Recommendations are given as to possible interventions that could be made in the form of group or individual therapy in the continuing day treatment program which might directly address some of these issues.

Exploring the Perception of Personal Loss Resulting from Mental Illness

Individuals with severe and persistent adult onset mental illness experience loss across many areas of their lives. While there has been a significant amount of study and work done with loss in general, there appears to be little aimed at discovering the resultant specific types of loss and meanings given to it by the population of mentally ill individuals directly experiencing it – how they "themselves view their illness or cope with its realities" (Vellenga & Christenson, 1994, p. 361).

It is important to understand the loss experienced by these individuals because the ability to cope with loss is associated with mental health (Murray, 2001). A vital part of dealing with and recovering from mental illness includes the necessary grieving and the ability to adapt to these losses and one's differing status and role (Baxter & Diehl, 1998). In order for mental health practitioners to assist individuals with mental illness in dealing with their grief issues there needs to be an understanding of loss in general. But this understanding also needs to be applied specifically to the mentally ill population and the individual in particular.

Loss, as a part of life, is experienced universally by individuals with or without mental health issues. However there are also unique losses experienced as a result of a mental illness and the changes that can occur as a consequence of this. It is these resultant losses and their personal implication to the severely and persistently mentally ill population that will be explored within the context of this paper and study. Areas concerning how research has viewed loss in general will be explored initially. From there, a more in depth examination of the literature will be presented looking at loss involving the population with diagnoses of serious mental illness both in generalities and specifics. Finally, there will be a review of options put forward for assisting individuals in dealing with the losses experienced as a result of their mental health

challenges.

General Experience of Loss

According to Voirst (2001), the journey of human development is one where loss is not only present but a necessary aspect. It is not the experience of loss but the being able to let go of what was lost; the giving up of "cherished parts of ourselves" (p. 16) and our dreams and relationships. Voirst stated that "central to understanding our lives is understanding how we deal with loss" (p. 17) as this determines the loss experience and therefore the lives that we lead. In the sections below, the general experience of loss will be explored in order to lay a ground work for approaching the more specific research on loss that is to follow.

Research Emphasis on Loss

Loss and grieving have received considerable attention in many forms from research, books, support groups, and the media. As noted earlier, the emphasis of this paper is on losses specifically experienced as a result of mental illness. However it can be helpful to take a broad overview of how loss is emphasized in past and current research literature.

Traditionally most research on loss and grieving had focused on the death of a significant individual – generally a spouse, parent, or child (Worden, 2005; Harvey, 2002). The focus of research has more recently expanded to include life partners or other close relationships including death due to suicide, trauma, sudden infant death, abortion, and the grief in the loss of a pet (Worden; Harvey & Miller, 2000). Moving from a focus on loss strictly due to death, some research has dealt with the loss of relationship through non-death situations such a divorce, infertility, custody disputes, infidelity, and long-term illness such as Alzheimer disease (Schlossberg, Waters, & Goodman, 1995; Bridges, 2004; Harvey; Harvey & Miller).

In addition to considering loss dealing primarily with relationships with others, in more

current research there has also been a focus on those losses involving the self such as losing

one's employment with its affiliated financial and identity losses (Schlossberg et al., 1995;

Bridges, 2004; Harvey, 2002; Harvey & Miller 2000). There are losses experienced by caretakers

of those with physical or mental illness in the quality of their own lives (Harvey; Harvey &

Miller). Furthermore, a number of studies have looked at the losses experienced by those with

serious physical illness which have resulted in impairment of function or identity.

The ongoing expanse of the research literature on loss has moved into a greater variety of

specific issues and broader categories over the past few decades. This growth in available

understanding of loss demonstrates the wide impact of not only loss, but its universal sway on

the human condition.

Universality

In addition to the very specific losses which will be discussed later that can result from

having a mental illness, these individuals also deal with the types of losses that are present

simply as a part of the human condition. Loss as a natural part of life is a universal experience.

According to Kübler-Ross and Kessler (2005), "everyone experiences many losses throughout

life" (p.29). This encompasses more than loss through death but loss involved with change, with

letting go of expectation and attachments, and loss resulting from personal growth (Viorst,

2002).

Worden (2005) discussed that evidence shows all people grieve a loss to some extent or

other and that this has been demonstrated across cultures and societies. "Welcome or not, change

is unavoidable…..when we face our personal tragedies, we may feel helpless, or at least limited

as to what we can do" (Prochaska, Norcross, & Diclemente, 1994, p. 13). Just the aspect of

transition as a part of life involves change and therefore loss of what was before. Bridges (2004)

stated that "every transition begins with an ending" (p.11).

When experiences do not fit with beliefs, such as the conviction that the world is a fair and just place, part of the experience of loss may be the destruction of valued belief patterns (Harvey, 2002). A component of the way identity is formed is through the circumstances in our life and whether we value them or not. Bridges (2004) indicated that "our whole way of being…is developed within and adjusted to fit a given life pattern" (p. 12). Losses can change one's identity when the loss is associated with something used to define oneself. Loss may not be easy to identify in words but rather may be felt as something missing. The thing that is missing may be something once possessed by the person such as a particular marital status, or it could be an anticipatory circumstance such as having children. The loss may be experienced as a disappointment or sense that something is not whole. Harvey specified that losses can be accumulative when a recent loss interacts with previous ones which are not fully resolved.

While loss is present as a part of life, the argument has been made that it can be of value and is, in fact, important to personal growth. Voirst (2002) argued that losses are not only natural, they are a necessary part of growth as individuals learn to let go and move on. Harvey (2002) contended that many believe this growth comes only when one has learned to do the hard work of making meaning out of loss. While loss is unavoidable, specific responses to it are not. Some losses lead to grief reactions, others do not; it all depends on the perception of what was lost and the personal meaning given to the situation or experience.

Manifestations of Grief

Loss that is experienced as causing grief can be manifest and addressed with in a variety of ways. There are a number of models, including the well known work of Elizabeth Kübler-Ross (1997), which deals with five distinct stages and ways of conceptualizing grieving and loss

including denial/isolation, anger, bargaining, depression, and acceptance. Kübler-Ross' book *On Death and Dying,* first published in the 1960s, dealt primarily with loss due to death although it has also be applied more broadly.

While Kübler-Ross' stages and concepts continue to predominate in the field of loss study, there is a wide range of subsequent theories and models addressing the stages and manifestations of loss more specific to mental illness and/or trauma. Baxter and Diehl (1998) mention a number of these including:

Judith Herman (1992) suggests three tasks in progressing from initial trauma to recovery. These tasks include the establishment of safety, remembrance and mourning, then reconnection with ordinary life….Patricia Deegan (1998) [who had experienced mental illness herself]….grouped the stages of recovery from mental illness into denial, despair, and anguish, and finally the cornerstones of recovery: hope, willingness, and responsible action….John Strauss (1992)….suggests three phases of recovery [from mental illness]: stabilization, reassessment, and integration. (p. 350)

Maddison and Raphael (1972) indicated that grief "is a syndrome with suffering and impairment of functioning….[it] is not always followed, as it should be, by a return to health" (p. 786). According to Worden (2005) normal grief can be manifest in a number of ways including sadness, anger, guilt and self-reproach, anxiety, loneliness, fatigue, helplessness, shock, yearning, emancipation, relief, and numbness. Worden also pointed out that there can be a variety of physical sensations for which medical attention may be sought without identification of the symptom as being related to grief. Both an individual's thinking processes and behaviors can be markedly affected in the early grief stages.

Although the general perception is that these symptoms are only associated with loss due

to death of a significant person in one's life, Murray (2001) indicated that these various

symptoms can also be associated with loss of a personal nature. This could be something prized

by the individual, such as an attachment to youthfulness or a hope for a life experience different

than what one has. It is the individual's perception of their loss which results in the specific

manifestations experienced and also gives meaning to their experience (Cournos, 1986; Rumpf,

Lontz & Uesseler, 2004).

Meaning

While loss may be a universal experience, the experience of grief concerning a specific

loss is a private one. According to Kübler-Ross and Baxter (2005), "losses are *very personal* and

comparisons never apply" (p. 30). What might have minor impact on one individual could be felt

in a much different manner by another. The impact on an individual is determined by the

meaning given to it by that person, the value given to that which was lost (Murray, 2001). Not all

loss leads to a grief response. The meaning given to the loss will determine the reaction be it one

of grief or of any of a wide range of emotions from indifference to acceptance to even joy if what

one lost was something considered a burden.

In looking at when loss becomes grief, Stein, Sworsky, Dryw, Phillips III, and Hunt

(2005) differentiated these by specifying grief as an individual's response to a loss experienced

personally on an affective and cognitive level. Kübler-Ross & Baxter (2005) define grief as "the

intense emotional response to the pain of a loss" (p. 227). Murray (2001) stated that grief is a

complex emotional reaction to the perceived loss of something of value to the individual. Harvey

(2002) took this further in noting a loss to be major when "the loss [is] of something in a

person's life in which the person was emotionally invested" (p. 4).

The perception of the loss by the individual gives it meaning and determines its value to

each person. It is this unique, lived viewpoint that determines whether a loss is felt as something good or bad. Maddison and Raphael (1972) pointed out that many believe that the process of mourning a loss can positively contribute to the development of personality. They went on to emphasize that "grief is an essential reparative process of the human individual in dealing with the unavoidable trauma of object loss" (p. 789).

 Importance to what was lost may be given a greater or lesser value in various cultures. The social context of the loss also can define or influence the stress level experienced around a particular loss situation (Murray, 2001). Any meaning experienced by an individual comes from personal interpretation. Even if noticeably apparent to someone looking at a person from outside, a loss' impact may not be perceived or even obvious to the person affected by it. Murray noted that "individual differences in reactions to similar situations of loss can be quite marked" (p. 227).

Loss can be taxing on several levels. It can "threaten an individual's sense of security because it can challenge, or even totally discredit, important assumptions about the world" (Murray, 2001, p. 231). The person can have a perception of loss of control as predictive abilities seem shaken by the untrustworthiness of previous assumptions. "Loss makes the world a less predictable, more fearful place" (Murray, p. 231).

Another area where loss can have impact is on mental health. There is an intricate association between the perception of suffering related to illness and psychological well-being (Rumpf et al., 2004). Understanding the meaning given to specific losses holds importance in the field of mental health. For simplicity, unless otherwise noted, losses referred to in the context of this paper will be those which are perceived of as potentially or actually resulting in a grief reaction from the severely and persistently mentally ill population.

Having looked at issues regarding loss in general, it is apparent how intricately involved loss is in the human experience. It is not only universal in its occurrence but has great impact on lives of the individuals experiencing it. Grief resulting from loss can be manifest in a variety of forms and intensities which comes from the meaning individually given to the loss (Maddison & Raphael, 1972; Rumpf et al., 2004). Having looked at the general experience of loss, it is important to consider what is known about loss for those with mental illness.

<div align="center">General Loss in Mental Illness</div>

As this paper attempts to address the unique losses experienced by individuals designated as having severe and persistent mental illness and the areas where these losses are experienced as suffering or causing grief, it is important to look at the research literature in more detail in regard to this specific population.

<div align="center">*The Severe and Persistently Mentally Ill Population*</div>

The severe and persistent mental illness (SPMI) population is described by Vellenga and Christenson (1994) as "persons who have a frequent need for stabilization in crisis, a frequent need for hospitalization, and an ongoing need for outpatient care (Lefley, 1990)" (p. 360). Vellenga and Christenson also assert that severe and persistent mental illness is not defined by a particular diagnosis but by the extent of interference in an individual's life including "self-care, employment, education, and the ability to interact and socialize meaningfully with others (Goldman, Gatozzi, & Taube, 1981)" (p. 360). Experiences of the severely and persistently mentally ill can include a variety of "distortions of reality, such as hallucinations and delusions, affective instability, dependency, and severe restriction of activities. Feelings of worthlessness, self reproach, and inappropriate guilt may haunt the individual" (Vellenga & Christenson, p. 361).

Vellenga and Christenson (1994) discussed the overwhelming nature of this type of chronic mental illness and how all of the definitions and symptom descriptions do not give more than a glimpse into the lived experience of individuals with severe and persistent mental illness diagnoses. Often these individuals have little if any involvement in the design of their plans of care nor do they believe that mental health professionals truly grasp their situations (Vellenga & Christenson).

The significance of the impact of the severe and persistently mentally ill populations' symptoms on their lives is pronounced. It influences not only their lived experience but that of those connected to them (Baxter & Diehl, 1998; MacGregor, 1994; Miller, 1996). It is important to consider the influence there can be on the families of those with serious mental illness (Harvey & Miller, 2000; Jones, 2004; Riebschleger, 1991).

Families

There has been little focus in the literature on the losses experienced due to mental illness. What research there has been often looks at the family or support system of those with severe mental health diagnoses and their perceived or experienced loss (Marsh, 1999; Stein et al., 2005). A considerable portion of the findings examine the complexity of their experiences of having a family member with a serious mental illness, their reactions, the stages of grief they go through, and suggestions for assisting them with this process. Some of these findings are included in the following examples.

The families of those with mental illnesses' experience of loss is generally referred to as a complicated grief due to the variety of issues with which they are dealing such as changes in the family system, loss of expectations, and ongoing losses. Jones (2004) argued that families experience a complex loss due to three complicating factors: "(i) the continuing presence of the

person who is felt to have been lost; (ii) feelings of anger (and subsequent guilt); and (iii)

feelings of shame" (p. 961). Families move through many phases, a few of which can be

numbness/shock, disorientation, anger, anxiety, fear, longing, guilt, depression, helplessness,

empathetic pain, and shame (MacGregor, 1994; Marsh, 1999).

Agnes Hatfield (1987) indicated that rather than the recovery process related to the

individual dealing with mental illness, the family of the individual goes through different phases

dealing with stress, coping, and adaptation. Many relatives of individuals with mental illness

experience a protracted grief due in part to their inability to share their experience due to fear of

social stigma (Miller, 1996). Because families go through a complex loss when they have a

family member who suffers from a serious mental illness, it is suggested that the partnership

between families and caregivers needs to be enhanced in order to provide more direct support

(Jones, 2004; Riebschleger, 1991). Both individual and grief therapy is recommended for family

members of those with relatives with mental illness in order to find the specific meaning they

give to their losses (Miller).

From the research looking at the families of those with serious mental illness, it can be

seen that this is a complicated and ongoing grieving process. While there is less research found

for those individuals actually dealing personally with the severe and persistent mental illness, it

is important to examine what is known.

Individuals with Mental Illness

While there are studies that look at mental illness as a result of loss (such as depression

experienced after the death of a loved one or the loss of one's health), there is very little

information on loss as a direct result of a mental illness (Stein et al., 2005; Vellenga &

Christenson, 1994). Having a mental illness is often associated with losses in areas including

marital and family prospects, relationships with family and friends, employment and financial securities, and social status. In this section it is the research into the general losses due to mental illness that will be examined along with how these losses occur.

Baxter and Diehl (1998) indicated that "mental illness is traumatic and involves losses from which people need to recover" (p. 2). The self once known to the individual can be gradually or rapidly eroded without the opportunity for the individual to construct a new positive one to replace it. Murray (2001) referred to how mental illnesses can be complicated and compounding, with one loss leading to further ones. Beliefs about the losses can magnify the reaction to the actual losses, such as the belief that being discriminated against for employment due to one's mental illness means the inability to ever be employed again.

MacGregor (1994) indicated that at the inception of mental illness, losses begin occurring over the individual's life span. The symptoms of mental illness can threaten and even "rob the individual of feelings of agency, power, and meaning" (Rogers, Poey, Reger, Tepper, & Coleman, 2002, p. 172). These symptoms can take from the person the individual schemas which assisted them in feeling there is purpose and choice in their lives. Vellenga and Christenson (1994) stated that "a pervasive feeling of *distress* was acknowledged by subjects living with a major mental illness" (p. 368). Furthermore, Harvey (2002) discussed how mental illness combined with increased homelessness can result in compounded losses and suffering as pertaining to social roles, hopelessness, despair, personal identity, and self-esteem.

For those with limited support resources and ongoing losses, the stress may overcome their ability to successfully cope (Murray, 2001). Adjusting to a loss can be a short-term, one time situation in which an individual's assumptions about the world are revised in a lasting way. But in many situations involving mental illness with its ongoing losses, the process is a

continuing, life-long process ((MacGregor, 1994; Murray).

The significance of personal and ongoing loss in the lives of individuals with serious mental illness can be of life-long impact as the situation imposing the loss is continuing (Harvey, 2002; Murray, 2001). Each loss or accumulative losses introduce the opportunity for a variety of responses depending upon the value of that which was lost or the narrative believed by the person experiencing it (Harvey; MacGregor, 1994). Examination of loss as a direct result of mental illness calls for understanding the perceptions of the losses experienced.

Meaning Given to Experienced Losses

There is a need to speak directly with those who have experienced losses as a result of their mental health symptoms, treatment, or diagnosis in order to assess the meaning or significance they give to these losses. As discussed earlier, the individual's perception gives the loss its meaning. Research examining the meaning given to losses shows how perception influences this meaning for the individual (Harvey, 2002; Murray, 2001).

Link, Struening, Neese-Todd, Asmussen, and Phelan (2001) stated "If a person [who develops a mental illness] believes that others will devalue and reject people who have mental illnesses, that person must now fear that this possibility of rejection applies to them personally" (p. 1622). Dinos, Stevens, Serfaty, Weich, and King (2004) found in their study of the experiences of 46 individuals with mental illness, that the meaning given to their losses and encounters dealing with their mental illness diagnoses varied widely. These meanings often depended upon their perception of what their diagnosis meant according to what they believed from media or their culture depictions.

Dinos et al. (2004) indicated that some of their study participants related their diagnosis to what they had heard on TV, such as believing that a diagnosis of schizophrenia meant they

had the worst diagnosis because it was always depicted as dangerous and out of control. Others believed that if others knew, they would be stigmatized at work and in social situations. Some resisted treatment because of beliefs they had about it, stigmatizing them further. Some believed that they might suffer physical violence if others knew of their mental illness.

Cournos (1986) pointed out that not all losses are experienced as bringing suffering and sorrow; some even are experienced as positive. Dinos et al. (2004) found that other participants noted that the experience of mental illness was not necessarily negative with some participants speaking of it as "positively life-enhancing" (p. 178). There were also those in their study who were relieved at having a diagnosis and realizing they were not alone. Murray (2001) identified a growth in competence, emotional strength, maturity, and coping abilities from the integration of loss into one's life.

Vellenga and Christenson's 1994 study on the persistent and severely mentally ill clients' perception of their mental illness resulted in what they referred to as four themes. These were identified as "stigmatization and the resulting alienation, loss, a pervasive feeling of distress, and acceptance on two dimensions (a personal acceptance of having a mental illness and a need for acceptance by others)" (p. 359). While these themes can be identified and linked to the perception of loss discussed in this section, they are also discussed in more detail in later sections specific to each concept.

This section has examined the research literature on the wide-ranging issues of loss in mental illness. It has reviewed the specific population and their general experience and meaning of loss in addition to that experienced by their families and caretakers. Moving from the broad view in this section, the focus of the next one becomes increasingly defined.

Specific Loss in Mental Illness

Research identifies several areas of an individual's life which may be impacted by loss due to severe and persistent mental illness. Each of these categories will be examined individually in order to understand the areas where grief might have impact on the life experience of those experiencing these types of losses. There are a variety of types of losses which can occur for people dealing with significant mental illness, one of the most important of which is the impact of their symptoms or labels on their interpersonal relationships.

Relationships

The research literature repeatedly notes the importance of personal relationships to an individual with severe and persistent mental illness. The ability of an individual experiencing loss to receive positive support from society and from family can influence positive adjustment to loss (Murray, 2001). Yet because of the nature of their illness and personal and social factors, these essential connections can be hard to maintain and even more difficult to form. This can come in part from social withdrawal or isolation, attributable to actual or perceived stigmatization, which adversely impacts individuals with severe mental illness (Ritsher & Phelan, 2004). Holmes and River (1998) note that "as a result of psychiatric stigma, persons with severe mental illnesses are denied access to social opportunities that most people take for granted" (p. 232). This can be as simple as the casual associations formed in a work place to the lack of financial means to go to movies or out to eat with others.

Holmes and River (1998) emphasized that "Individuals with severe mental illness question their ability to cope effectively with the daily challenges they face. As a result, persons struggling with self-stigma are reluctant to actively participate in social activities" (p. 232). These individuals may limit their risk in other areas of mental or physical challenges in order to

keep their stress levels down for fear of exacerbating their mental health symptoms thus reducing their ability to strengthen their capabilities or self-efficacy.

Ritsher and Phelan (2004) in referencing their study on internalized stigma noted "the most consistently harmful outcomes were associated with alienation" (p. 265). One client in a study by Vellenga and Christenson (1994) stated, "Having a mental illness is a very lonely life because you are really ostracized …you give up a lot of things other people have in their life, like a close relationship" (p. 368).

Loneliness and social isolation can come from lack of access to social situations, ineffective social skills, social stigma, fear of consequences, limiting risk, or any number of reasons. One of the principle factors of loss in the seriously mentally ill population is stereotyping and stigma which not only influences relationships but also impacts externally and internally felt stigma, perceptions, and shame (Murray, 2001; Ritsher, Otingam, & Grajales, 2003).

Stigma

One of the most influential factors upon those with mental illness is that of stigma through the effects it has on self-esteem and the actual and perceived regard of others. Camp, Finlay, and Lyons (2002) discussed the prevalence of negative images and stereotypes of mentally ill individuals in our society including advertising, the media, and everyday jokes and insults with the portrayal of those with mental illnesses as being violent and basically different and inferior to others.

Nairn and Coverdale (2004) described how those individuals with mental illnesses in their study found the media portrayals as "stigmatizing" along with being "unjustified and personally disabling" (p. 286). Stigma is an area with considerable emphasis in the area of

mental health. This appears to be experienced in most cultures with it being acutely associated with shamefulness in places such as Hong Kong (Tsang, Tam, Chan, & Cheung, 2003).

These stereotypes have lead to a generalized stigma of those with mental illness. Hayward and Bright (1997) defined the term stigma as "the negative effects of a label placed on any group" (p. 199). The effects of this stigmatization of the mentally ill can have varying sources of impact on the individual depending upon whether it comes from an external or an internal source.

External Stigma

When the source of stigma is external, it comes from sources outside of the self. This can be from a person close to the individual with a mental illness diagnosis or from a more generalized source such as societal attitudes and depictions (Blankertz, 2001; Ritsher et al., 2003).

Dr. David Sacher (1999), in the U.S. Surgeon General's report on mental illness recognized stigma as a barrier to wide-ranging opportunities for those with mental illness including receiving adequate treatment. Stigma obstructs mental health recovery on many fronts. It can eat away at an individual's personal and social network and status leading to lower resulting employment situations, social isolation, and a delayed or prolonged course of mental health intervention (Ritsher et al., 2003; Link et al., 2001). Several of these areas which deal directly with loss are discussed later in this research section.

An area of considerable concern to those dealing with serious mental illness is their worry over what others think of them. Because of a reluctance to acknowledge mental illness for fear of negatively influencing others' perception of them, individuals may not be able to openly acknowledge their losses. This can lead to disenfranchised grief, a non-validated or unsupported

loss (Harvey, 2002; MacGregor 1994). Additionally, the concern over stigmatization can be a factor in an individual with mental illness in not asking for help or in refusing hospitalization or treatment (Dinos et al., 2004). Dinos et al. went to state, "attempts to avoid disclosure resulted in stress, isolation and a sense of shame" (p. 178). So in addition to not reaching out for support, fear of what others might think can add additional burdens onto the individual dealing with mental illness.

Corrigan, Thompson, Lambert, Sangster, Noel, and Campbell, (2003) specify that one area where the perception of others can impact an individual with mental illnesses' life is when dealing with autho,☐ ☐   figures. This frustration can occur once it becomes known that someone has a mental illness and thereafter experiences being dealt with either as a person of lesser value or reliability. These individuals can experience distress over not being taken seriously when they are trying to make an important point or be understood (Sellers, Sullivan, Veysey, & Shane, 2005; Watson, Corrigan, & Ottati, 2004).

One area where there can be difficulty for those with a mental illness in dealing with authority figures is with law enforcement. According to Watson et al. (2004) there can be a "tendency [by police officers] to question the credibility of persons with mental illness." Also noted was the possibility that there can be "exaggerated perceptions of dangerousness [which] could lead to behaviors that escalate the situation" (p. 50). This can lead to inappropriate arrests and judicial involvement of the mentally ill which as Sellers et al. (2005) noted may require strategies targeted to educating or assisting law enforcement dealing with the mentally ill.

As noted, external sources of stigma can overtly exert negative consequences on the life of an individual with a mental illness label. It might also impact them by making persons unwilling to risk feared consequences of seeking assistance or in other ways making their

diagnosis known. Another consequence of external stigmatization is the impact it can have when individuals believe that the external beliefs are accurate and accepts these portrayals as accurate for themselves, thus adding to their internal stigmatization (Corrigan, 1998; Ritsher & Phelan, 2004; Ritsher et al., 2003).

Internal Stigma

Ritsher et al. (2003) summarized Corrigan's (1998) description of internalized stigma as "the deviation, shame, secrecy and withdrawal triggered by applying negative stereotypes to oneself" (p. 33). As a result of their study of the effects of stigma on those with serious mental illness, Link et al. (2001) stated, "Contrary to the claim that stigma is relatively inconsequential, our results suggest that stigma strongly influences the self-esteem of people who have mental illness" (p. 1623). The stronger the individual's belief in stigma, the more likely they as a person with a metal illness diagnosis, are to have low self-esteem and more severe symptoms (Lloyd, Sullivan, & Williams, 2005; Link et al.). What individuals experience as another's or society's view of them will affect their self-esteem (Blankertz, 2001).

Blankertz (2001) spoke to how there has been little attention given to looking at self-esteem in the community mental health setting. Even though this is an important aspect for individuals with severe mental illness, little is known about how they understand or conceptualized their self-esteem. Blankertz went on to state "self-esteem is a relatively unexplored area for individuals with [severe mental illness]" (p. 462). Camp et al. (2002) spoke to how individuals can apply the stigmatizing standards to themselves even if they are not an accurate description of that individual's attributes and characteristics, thus allowing outside perceptions to influence their view of themselves. Link et al. (2001) emphasized that:

One of the most tragic consequences of the stigma of mental illness is the possibility that it engenders a significant loss of self-esteem—specifically, that the stigma of mental illness leads a substantial proportion of people who develop such illnesses to conclude that they are failures or that they have little to be proud of. (p. 1622)

Internalizing stigmas can have harmful effects beyond those of the direct discrimination from others as internal perceptions can additionally impact individuals with strong negatives beliefs about their mental illness label (Ritsher & Phelan, 2004). Ritsher and Phelan stated "they may suffer a number of negative outcomes, such as demoralization, lowered self-esteem, impaired social adaptation, unemployment, income loss and reduced medication adherence" (p. 259).

It is important to note that there are also some individuals with mental illness who do not apply the stigma to themselves but may accept it as accurate when applied to others with a mental illness, thereby resisting accepting or being affiliated with the diagnosis or label of a mental illness for themselves. Camp et al. (2002) found that if an individual rejects the societal stigmatization of those with mental illness as being wrong or based on ignorance and specifically does not identify personally with them, there are not the negative effects on self-esteem and self-valuation that might otherwise occur.

The influence of stigma, both external and internal can strongly impact the quality of life for a person with mental illness in a daily or life-long manner. The extent to which this occurs depends on its influence on their self-esteem and beliefs about the accuracy of the stigmas (Corrigan, 1998; Ritsher et al., 2003). One area which can be impacted by this can be the perception individuals have about the possibilities available to them in their future, whether they are willing to risk believing that things can improve or if they become resigned to hopelessness (Anthony, 1993).

Future/Hope

Although there appears to be little in the literature or research regarding the impact of a severe and persistent mental illness' impact on one's hope for the future or plans for leading a typical life, there can be significant losses in this area (Harvey & Miller, 2000). In these situations, it is not necessarily a loss of something tangible of which a person is already in possession, but rather a loss of an anticipated and valued concept held in high regard (Barone, 2005; MacGregor, 1994).

According to Freud, loss can be not only of concrete persons or things, but also of abstractions which were of value (Barone, 2005). This can be seen when there is the loss of the belief that one will marry and have children. It could be the realization that plans to travel widely are not realistic. Any number of anticipated expectations or dreams may eventually be relinquished as the impact of a severe mental illness becomes increasingly apparent. Although situations such as these may not be tangible objects that an individual had actually attained and no longer possessed, they could never-the-less be experienced as objects of attachment. As such, giving them up could be perceived as a loss of something of value to the individual.

The losses encountered in regard to the future or the hope that an individual feels which occur as a result of having a severe and persistent mental illness are experienced as very real (Anthony, 1993; Barone, 2005; MacGregor, 1994). Additionally, in their present everyday lives, there are current and very tangible losses with which they must deal.

Standard of Living/Quality of Life

With the increased difficulty in obtaining employment experienced by many individuals with mental illness, many are unable to gain the independence and financial benefits necessary to acquire the resources that contribute to a high quality standard of living (Corbiere, Mercier, &

Lesage, 2004; Harvey & Miller, 2000; Holmes & River, 1998; Mojtabai, 2005). They may also lack the training or developmentally acquired skills necessary for functioning or even meeting minimal standards in their roles in society including roles such as parenting, employment, or self-care (Anthony, 1993; Hollingsworth, 2004).

Employment

Work is a primary determiner of one's identity and status in our society and can assist one in developing a perception of incentive and purpose (Harvey & Miller, 2000; Greig & Bell, 2000). It gives an opportunity for the individual with a mental illness to interact with members of the community with some degree of parity. However, finding employment is often a challenge for those with a mental illness (Harvey & Miller).

Corbiere et al. (2004), using results from 2000 World Health Organization put forth that "the unemployment rate for people with mental illness greatly exceeds that of people with physical disabilities, with between 70% and 90% of individuals with severe mental illness…being unemployed worldwide" (p. 460). Gaebel and Baumann (2003) noted that the most common area of discrimination faced by people with mental illness was in the workplace or when seeking employment.

Harvey and Miller (2000) discuss the general difficulty for individuals with mental illness in not only gaining but in maintaining favorable employment. In Dinos et al. (2004), an example was given of a woman who was fired from her employment after having discussed her mental illness diagnosis with a supervisor. Many individuals with mental illness diagnoses are careful to say nothing about their diagnosis or treatment to co-workers or employers (or potential employers). If they find some disclosure necessary, they may downplay things considerably by indicating that it is just a touch of depression, etc. (Dinos et al.).

Lack of gainful employment can lead to loss or non-attainment of items requiring financial means to obtain (Holmes & River, 1998; Mojtabai, 2005). This can impact the quality of life and standard of living of those individuals with mental illness unable to find adequate financial resources through work, personal assets, or public/private assistance programs (Corrigan, 1998; Hiday, Swartz, Swanson, Borum, & Wagner, 1999; Link et al., 2001).

Housing and Transportation

Procuring adequate housing or transportation can be a challenging if not impossible task for some individuals with mental illness due to their difficulties discrimination and in acquiring adequate financial and other resources (Anthony, 1993; Corrigan, 1998; Corrigan et al., 2003; Harvey, 2002; Harvey & Miller, 2000; Holmes & River, 1998; Link et al., 2001). Additionally, societal stereotyping can impact their ability to procure these basic necessities.

Harvey and Miller (2000) spoke of the "special obstacles" (p. 191) such as residential housing laws designed specifically to exclude those with mental illness or landlord discrimination which are encountered by ex-psychiatric patients in their search for housing. Even if housing is obtained, there is significant risk with this population concerning an inability to maintain stability of housing thus risking returning to a homeless situation (Mojtabai, 2005).

Depending on community resources, financial or personal means, or assistive programs, even arranging for transportation to other than medical appointments (which is available in some metropolitan areas) can be daunting if not impossible for many individuals. Corrigan et al. (2003) stated that "people with mental illness are part of a disenfranchised class" (p. 1106). With lack of resources and the means to make changes, the problem of poor living situations can compound resulting in circumstances well below acceptable standards of living.

The lack of the basic physical resources to meet an adequate standard of living impacts

not only the person living with a severe mental illness, but it can have strong bearing on those

dependent upon them as well (Corrigan, 1998). Additionally this can lead to a loss of the access

to development of those skills and abilities required to handle responsibility for others (Anthony,

1993; Corrigan; Dinos et al., 2004; Hollingsworth, 2004; Lloyd et al., 2005).

Parenting

One specific area of challenge to those with severe mental illness is the ability to parent

one's own children. This is a right which cannot be presumed secure by many of these

individuals (Hollingsworth, 2004; Mowbray, Oyserman, Bybee, Callahan, & MacFarlane, 2004).

Often children are placed in alternate care when a parent has had repeated hospitalizations for

mental health issues, was single, had a poor employment history, lacked respite care for the

children, or lacked parenting skills (Hollingsworth).

Not only can there be the threat of loss of parenting rights, there can also be delay of

treatment for mental health symptoms because of this threat as some individuals with mental

illness put off seeking assistance for fear of losing their children. Hollingsworth (2004) cited that

statistics show "increased likelihood of child custody loss for most women with persistent mental

illness" (p. 345). Hollingsworth indicated that certain types of mental illness are accompanied by

attributes such as affective difficulties that interfere with the ability to care for and provide the

safety and nurturing required of parenting. Although often in need of parenting assistance, many

mothers with severe mental illnesses may not reach out for training or help, in part, because of

fear of losing their children. For the same reasons, many mothers with mental illnesses, including

affective disorders, do not seek out mental health assistance even though they are at the highest

risk for having parenting problems (Mowbray et al., 2004).

Being secure in one's ability to be an effective parent along with the security of having

the support necessary to prevent the loss of parenting rights can contribute to a sense of well-being and lowered anxiety for those whose parenting is impacted by their mental illness (Anthony, 1993; Hollingsworth, 2004). This is just one facet of what can contribute to comfort and welfare for these individuals and one facet of what can be lacking for them as well.

Well-being

In looking at well-being, consideration is given to aspects of the individual with a mental illness' experience of safety and ability to trust others (Anthony, 1993). Additionally, their capability to look out for their best interest, being able to get past problems without getting stuck on them, and their general mental states such as anxiety all are impacted by having a severe and persistent mental illness (Barone, 2005).

Hiday et al. (1999) "found a substantial rate of violent criminal victimization among persons with severe and persistent mental illness" (p. 62). They showed that this was more apt to occur when combined with substance use and homelessness. Visibility of many of those with mental illness makes them easier targets for violence.

Kirk, Haaga, Solomon, and Brody (2000) discussed limits that are often placed on individuals dealing with severe mental illness from external sources of which they may have little or not control. Additionally, Kirk et al. suggested that many who have experienced severe mental illness will purposefully limit the challenges of their life in employment, social, and other areas in order to not experience the stress or demands which they worry they may not be up to handling and which if occurred could aggravate their previous problem. By doing this, they are also lowering the quality of their life and well-being by removing many of the supports and involvements which could assist them in maintaining their mental health (Kirk et al.).

Many factors influence the well-being of persons with severe mental illness. Standard of

living, relationships, and hopes for the future can present strong areas of loss along with the

impact of internal and external stigmas on the life experience of these individuals. While the

research is limited in looking specifically at this population, it is substantial enough to recognize

that there are ongoing actual and potential losses occurring with these individuals (Anthony,

1993; Blankertz, 2001; Dinos et al., 2004; Ritsher et al., 2003). Having looked at these areas, it is

important to go beyond and consider what the literature presents in the way of dealing with these

losses.

<div align="center">Dealing with Loss Due to Mental Illness</div>

There are many areas to consider in dealing with loss due to mental illness. Kübler-Ross

and Kessler (2005) stress the importance of working through grief, not leaving unfinished

business as they assert "many problems in our lives stem from grief unresolved and unhealed"

(p.227). Knowing the impact of suffering can assist in an understanding of the meaning and an

ability to target salient aspects of the suffering for treatment interventions. Additionally, Rumpf

et al. (2004) spoke to the importance of being able to measure the impact of suffering on an

individual in order to "judge the necessity and success of treatment" (p.53).

Also there are frequently common themes which require attention when dealing with the

individual who has experienced a meaningful loss, especially when it is due to a mental illness.

Considerations of acceptance, spirituality, and recovery verses cure are all necessary. Baxter and

Diehl (1998) indicated that there is importance in addressing reactions such as, "Why did this

happened to me? What did I do to deserve this? What do I do now?" (p. 349). Kübler-Ross and

Kessler (2005) stated "Your task…is to fully recognize your own loss, to see it as only you can.

In paying the respect and taking the time it deserves, you bring integrity to the deep loss that is

yours" (p. 30). There can be occasions which might arise for individuals to look at their identity

and value to society after a significant loss (Harvey, 2002). All of these address aspects of

dealing with loss as individuals with mental illness strive to put their losses within a framework

which makes sense in their worldview. The first of these themes to be examined is the concept of

recovery verses cure.

<div align="center">Recovery/Cure</div>

Anthony (1993) emphasized the concept that in dealing with loss due to a mental illness,

focus should be on recovery rather than cure. Whitwell (1999) spoke of recovery as "being

restored to your former state" (p. 23). Prior (1999) directly challenged him by defining recovery

as "recovery of a meaningful life" (p. 30). Prior saw Whitwell's definition as being one of cure

rather than of recovery.

Concentrating on recovery rather than cure can be a primary method for coping with the

mental illness and its symptoms. In Vellenga and Christenson (1994), in reference to his mental

illness, one client stated "not that it will go away, but that I can live with it" (p. 369). Baxter and

Diehl (1998) noted that part of an individual's ability to deal with the repercussions of mental

illness focuses around re-establishing an improved identity of oneself to use as a solid basis upon

which to work toward recovery. For example, many individuals in the Nairn and Coverdale

(2004) study sought to depict themselves as everyday people – as ordinary, working toward this

by being productive, dealing with diversity, and possessing high self-esteem.

If treatment is aimed at recovery rather than cure, it is necessary to examine how

recovery might be viewed. One aim for the outcome of treatment of loss and grieving issues for

those with severe and persistent mental illness is aptly stated by Barone (2005):

A 'good-enough' work of mourning may be described as the achievement of a

psychological change, which enables the patient to overcome loss, to restore the quality

of life, to reinstate a hopeful and creative attitude towards reality, and to recreate a sense

of psychic aliveness without denying the experience of loss itself. (p. 22)

With this as a guiding vision toward which treatment efforts might aim, it is worth taking a look

at a variety of suggestions that have come from the body of research in dealing with individuals

with severe and persistent mental illness and their losses.

In order to offer appropriately designed programs and treatments dealing with recovery

rather than cure in addressing loss and grieving issues of this population, it is imperative that not

only do they need to have the issues of loss addressed that are universal, but that there be an

understanding of those losses specific to this group that have occurred as a result of their unique

experiences with their mental illness. Lloyd et al. (2005) elucidate three specific themes to be

addressed in treatment: "(i) loss of control; (ii) stigma; and (iii) change in self-perception" (p.

246). To meet these needs, there are various avenues and approaches that are recommended.

First, we will consider loss of control.

Loss of Control

When individuals do not believe what they do will have any impact, there can be an

experience of loss of control over their lives and situations (Corrigan, 1998; Harvey, 2002; Lloyd

et al., 2005; Murray, 2001). This can contribute to hopelessness, lack of follow-through with

medical advice, increase in mood related difficulties, and decreased motivation to assist in one's

recovery or to participate in one's life (Camp et al., 2002).

Educating individuals about their mental health diagnosis and their treatments can assist

them in not only understanding what is happening to them, but it can help them to more actively

participate in managing their symptoms. Lloyd et al. (2005) suggested having individuals attend

a "medication group which emphasises [*sic*] the biology of mental illness and the necessity of

taking medication despite uncomfortable side-effects" (p. 248).

For specific issues such as parenting concerns, education may also provide some sense of control over the fear of losing child custody. Hollingsworth (2004) suggested education and skills training for parents with mental illness in addition to support systems for respite care when required in order to prevent some of the loss of custody and inappropriate parenting for people with persistent mental illness.

In order to assist those who feel a loss of control in relationships, social skills training which is designed around an individual's specific goals is recommended by Lloyd et al. (2005) as an effective treatment for those who experience limitations and social dysfunction related to mental illness.

According to Murray (2001), "internal factors such as locus of control, attributional style and a tendency to self-blame" (p. 228) are important factors related to loss. As such these can be considered for specific attention in a treatment plan for dealing with loss (Murray). In assessing specific areas where individuals with a serious mental illness may be experiencing a loss of influence or power, it is important to look at their areas of priority. According to Vellenga and Christenson (1994), "therapists often perceive the client's problems from the perspective of long-term implications and prognosis, but clients view the situation in the context of their present pain and need for relief" (p. 361).

As this research project plans to use the information obtained to develop treatment protocols, treatment priorities for dealing with loss due to mental illness will be examined as a part of this literature review. An important part of recovery comes in assisting clients to regain their sense of control in areas of concern to them in their lives. Additionally, as recommended by Lloyd et al. (2005), both stigma and self-perception are areas of strong import if recovery is to

impact the life of an individual with a prolonged mental illness.

Change in Self-perception and Impact of Stigma

The concept of stigma reduction and self-esteem enhancement are prevalent themes in the research. Part of assisting people to cope with their mental illness "involves addressing both societal and self-stigma" (Holmes & River, 1998, p. 232).

Many individuals with severe and persistent mental illness are unable to achieve the positive self-attributions which are valued by society due to either their impairments from mental illness or societal devaluation. Therefore they may be unable to affect their self-esteem positively from these resources (Blankertz, 2001). But according to Blankertz, studies have shown that self-esteem can be amenable to modification. She went on to suggest a need for targeting the most significant cognitive components of self-esteem for individuals with serious mental illness which, according to her study on this, are stigma, mastery, and overall functioning.

Ritsher et al. (2003) note that "internalized stigma is one aspect of stigma that mental health professionals can address with individual clients directly" (p. 33) and as such "serves as a worthy target of insight-oriented psychotherapy" (p. 33). As more is learned about how individuals with severe and persistent mental illness think about and perceive their losses, then more accurate targeting of their cognitions and processes can be attempted. Ritsher et al. proposed that in addition to working with clients to reduce illness symptoms, interventions should also include the reduction of internalized stigma. Ritsher and Phelan (2004) stressed that internalized stigma works against the positive results of treatment and thus these treatments could benefit from a focus on overcoming internalized stereotypes and stigma.

As has been noted, work to address the impact of stigma and self-perception of individuals in the population with long-term mental illness is not only important, it is the

foundation for much of recovery (Holmes & River, 1998; Link et al., 2001; Ritsher et al., 2003; Ritsher & Phelan, 2004). Additionally assisting individuals to regain some sense of control over their mental health and lives contributes to this as well (Lloyd et al., 2005; Murray, 2001). Another concept in dealing with loss due to mental illness is acceptance of the reality of one's mental illness, life situation, and self along with feeling accepted by others (Harvey & Miller, 2000; Hayward & Bright 1997; Ritsher & Phelan).

Acceptance and Inclusion

Self-acceptance, specifically as it comes to acknowledging and allowing oneself to be okay as one is, mental illness and all, while being a difficult concept to grasp, has great ability to assist many individuals in working with their life as they currently experience it (Hayward & Bright, 1997; Vellenga & Christenson, 1994). Acceptance from others is important as well. There is considerable value in feeling a part of one's community and a sense of belonging within it (Harvey & Miller, 2000; Kirk et al., 2000; Ritsher & Phelan, 2004; Vellenga & Christenson).

When dealing with pain, Viane, Crombez, Eccleston, Poppe, Devulder, Van Houdenhove, and De Corte (2003) stressed the importance of acceptance, adaptation, and focusing on the positive aspects that can be found in relation to the experience of the individual. These values can be an important aspect of dealing with the loss and pain of grieving when an individual is able to access them. A client quoted in Vellenga and Christenson (1994) proffered, "if I don't fight it, but accept it, I seem to be able to deal with my illness" (p. 369). As a caveat to this, according to Hayward and Bright (1997), while acceptance of a mental health diagnosis is a positive aspect of treatment, it is important that the effects of this mental illness label on self image also be addressed.

Community with others of like diagnosis is one area which applies very strongly to the

population with severe and persistent mental illness on several fronts. It can assist individuals in acceptance of their situation, in recognition that they are not alone in their symptoms, by offering support of others who truly can understand, providing much needed socialization from a group with whom there is less chance of social ostracization, and providing role-models of others who have succeeded in moving on in their lives. Ritsher and Phelan (2004) strongly put forward:

> What is needed is the antidote for alienation: interpersonal engagement, such as that provided by the fellowship of self-help groups, the role recovery inherent in supported employment or the healing power of the psychotherapeutic alliance. People with SMI [severe mental illness] must get the message that they are not alone and that others like them have succeeded in building rewarding lives in the community. (p. 267)

Having a safe place to share one's losses can be used as a means to assist acceptance and healing. Barone (2005) looks at the mourning process as one where an individual can look at and attempt to adapt to the painful changes and reality of the loss while maintaining a slowly increasing hope rather than resigning to a depressive state.   Harvey (2002) speaks to the importance of an individual being able to tell loss stories and be open about feelings of loss in order to begin the healing process. This is a method of coping and beginning to adapt to the situation. Individuals with mental illness may experience disenfranchised grief when unable to find a safe audience to work through this process. Within the therapeutic process whether individually or in a group of others with similar issues, this process of healing disclosure can be fostered and acceptance begun.

Being able to find self-acceptance of oneself and the realities of one's mental illness, allows a place to apply energy to changing what can be changed rather than fighting or rebelling against what is at the moment (Hayward & Bright, 1997; Vellenga & Christenson, 1994; Viane

et al., 2003). Additionally, having a place with safe individuals to openly share in a supported environment of acceptance allows movement toward healing and recovery of many of the losses experienced by individuals with profound and ongoing loss. One last area of import to how individuals deal with loss and struggles experienced due to mental illness is personal spirituality.

Spirituality

Spirituality is an area which assists many individuals with mental illness in giving meaning to their experience and losses. In addition to meaning, it can offer hope and a change of perspective around the lived experience of mental illness (Harvey & Miller, 2000; Murray, 2001; Rogers et al., 2002).

Rogers et al. (2002) noted that as much as half of coping time of individuals with severe mental illness is devoted to religious beliefs or behaviors by those who perceived this to be effective for them. This was seen to be increasingly true with more severe symptom manifestations. According to Rogers et al., a possible explanation was that, "it may be at the periphery of one's own power and the limits of one's own resources that people are more likely to look beyond themselves for control and meaning" (p. 163). Further, Rogers et al. found that two thirds of the participants found moderate assistance from their religious practice with a full third indicating that it was their most important coping mechanism.

It is apparent that there are many aspects and facets to dealing with loss due to mental illness. This section has examined the use of spirituality, self-acceptance, acceptance from others, and working toward recovery through increasing a sense of control, dealing with the impact of stigma, and improving self-esteem when dealing with the impact of loss with this population.

Kübler-Ross and Kessler (2005) presented their idea that "those who grieve well, live

well….grief is the healing process of the heart, soul, and mind" (p. 229). Kübler-Ross and Kessler also submit the concept of grief being "an emotional, spiritual and psychological journey to healing" (p. 227). As has been discussed in the review of the research literature, loss is a universal experience, but in addition to the general loss encountered as a part of the human experience, those with persistent and profound mental illness deal with loss specific to themselves. It is their perception of their loss occurring because of their mental illness that this study proposes to examine.

Summary of Literature

The literature shows that there are indeed losses incurred by the population of individuals with diagnoses of mental illness which are attributed to their having those very diagnoses. What has had very limited attention in the research is the experience of those losses by those incurring and living with them. Nor has the impact or meaning which is given by these individuals to their losses been awarded much consideration in the studies of the losses experienced by those with significant and persistent mental illness.

This study hopes to fill some of the gap in understanding the experience of loss in individuals with loss due to mental illness. The main emphasis of this study is on the qualitative aspects, the actual experience of loss. It seeks to understand the perception, from individuals with significant and persistent mental illness, of this type of loss.

Study Design

Purpose

One objective of this study is to ascertain the personal losses incurred as a result of prolonged mental illness from the perspective of those with lived experience. A second objective is to determine which of those losses, if any, are experienced as having a negative impact on the

current lives of those individuals.

 This study will also attempt to find which of these losses are experienced as most stressful or difficult for these individuals as not all loss is perceived as negative or even meaningful. It is hoped that the information gathered from this study will assist therapists in the treatment and planning of ongoing and future group and individual therapy to assist those individuals experiencing loss as a result of mental illness.

Method

 This study was originally designed around the Quantitative Perception of Loss Survey (Appendix A). It quickly became evident that although this would provide valuable information, it in no way would give satisfactory indication of the effects these losses might have upon the lives of those facing them. With a desire to gain a greater appreciation of the lived experience of loss by those participating in the study, the methodology turned toward taking a qualitative look at this issue.

 According to Creswell (1998) "qualitative research is an inquiry process of understanding …that explore[s] a social or human problem. The researcher builds a complex, holistic picture" (p. 15) creating an intricate accounting of this multifaceted problem or subject matter. This type of research provides a vehicle to accomplish the desired purpose of the study in greater depth than the survey alone would allow. Because, according to McLeod (2003), "most qualitative researchers adopt a philosophical stance that human knowledge is contextualized and local," (p. 71) finding a way to gain access to that knowledge requires some method of entry into the lived experience of those researchers wish to better understand.

 There are numerous types of qualitative research. McLeod (2003) offered a succinct summarization of the courses of action in common for these various approaches when he stated

"the process of carrying out qualitative research can be divided into two broad types of activity: gathering data and analyzing data" (p. 73). How these two are accomplished depends upon the specific method.

The qualitative method selected for this study is Phenomenology which was simply expressed by Creswell (1998) as a study which "describes the meaning of the **lived experiences** for several individuals about a concept or **phenomenon**" (p. 51). Creswell depicted the phenomenological approach as including the following traits:

- The researcher must set aside personal preconceived ideas about the meaning of the problem being studied.

- Research questions are formulated to assist individuals to explore and describe their experiences from their daily lives surrounding the problem being studied.

- Data is collected from individual participants through in depth interviews. The number of participants in one study can range from five to twenty-five.

- Data is analyzed through a series of steps allowing for the codings of statements and clustering of these codings according to meaning. These clusterings are then tied together to provide a description of what was experienced and how it was experienced.

- The report endeavors to present this material in a manner which will allow the reader to have a greater understanding of the lived experience of the study participants surrounding the issue being studied.

The above traits were used as methodology for the phenomenological approach to this study. The questions guiding the study participants in the interview/discussion process are listed in Appendix B with the data collected through digital tapings. The sorting and categorization of data from the transcribed tapings was facilitated by use of The Ethnograph v5.0, a computer

coding program for use with phenomenological research.

<div align="center">*Sample*</div>

This research study was conducted at a continuing day treatment (CDT) program situated in an urban clinic which is a branch of a larger health system incorporating two hospitals and numerous urban and suburban clinics. This clinic is located in Rochester, New York. The clinic provides mental health care to an urban, multiracial, low-income population offering a variety of treatment programs in addition to the CDT program including an outpatient mental health clinic, a chemical dependency unit, a sexual behaviors unit, and an intensive psychiatric and rehabilitative training program. The CDT program offers mental health services to the seriously and persistently mentally ill population and currently serves 157 individuals who are scheduled to attend the program between three to five days per week.

Of importance to this research project was the combination of the continuing day treatment program staff and clientele with that of another CDT program within the health system which was closed a few weeks prior to the beginning of this study. In addition to changes including new settings, staff, clients, procedures, and schedules, this resulted in considerable loss of staff for both settings, increased crowding, and loss of many short and long-term client affiliations for the merging participants. This created significant stress, change, and loss for some of the clientele which may have impacted this study.

<div align="center">*Population*</div>

The continuing day treatment program serves a variety of clients with mental illness. As mentioned previously, the population is primarily urban, low-income, and multiracial including African American, Caucasian, and Hispanic clienteles primarily. These individuals are classified as having severe and persistent mental illness both with and without a co-occurrence of chemical

addiction (MICA). Clients' length of treatment varies from weeks to months to years depending upon individual situations. Clients' mental competencies also differ due to specific mental illness factors and medication status among other variables. In order to have a more accurate contrast between pre-symptom and post-mental illness quality of life, it was decided to limit the study to those who had an adult onset of their mental health symptoms. Due to all of these factors, it was therefore important that potential participants be screened carefully.

Criteria for Selection

There were no anticipated risks or benefits to participants because of participation in this research study. This study was designed to gain information that may provide information which could assist in developing group and individual interventions which may more specifically and effectively address concerns about loss. It is probable that the continuing day treatment program will consider this information in formulating ongoing and future group interventions and thereby participants may experience some benefit if involved in these sessions.

Voluntary participation in the project was sought from the clients in the continuing day treatment program who met the following criteria as determined by their primary therapist.

1. Clients with adult onset of mental illness defined as onset at age 18 or later who were currently being treated at the continuing day treatment program for their mental illness.

2. Clients who were currently classified as having serious and persistent mental illness with or without a chemical addiction co-occurring diagnosis.

3. Clients designated as being mentally competent to understand the consent and authorization for release of information forms, able to reflect upon their life changes, and able to understand the concept of the survey regarding life quality and loss.

4. Clients with willingness and availability to participate.

5. Clients who did not have as their primary therapist the principle investigator.

The number of participants was determined by the number interviewed prior to reaching a point of saturation of information for the qualitative aspect of this research survey. As indicated in Table I, there were 13 clients who participated in the study including seven women and six men. Ages ranged from 23 to 62 with ethnicity including Caucasian, African American, Latino, and Native American. All 13 had severe and persistent mental health issues, most of whom had more than one DSM IV-TR diagnosis. These included disorders of Schizophrenia, Psychotic, Eating, Schizoaffective, Bi-polar, Paranoid, Post Traumatic Stress, Major Depressive, Borderline Personality, Panic, and Agoraphobia. Additionally seven of the participants had co-occurring disorders involving chemical dependency/substance abuse.

Table 1

Demographics

N = 13

Age Group

<22	0
23-27	2
28-32	1
33-37	0
38-42	3
43-47	2
48-52	3
53-57	1
58-62	1
>63	0
	13

Gender

Female	7
Male	6
	13

Mental Health Diagnosis

Yes	13

No	0
	13

Chemical Addiction

Yes	7
No	6
	13

Ethnicity

African American	2	
Asian	0	
Caucasian	10	*
Latino	1	
Native American	1	*
Other	0	
	14	*

* One Participant indicated both Native American and Caucasian

Instruments and Measures

There were both a quantitative and qualitative feature to this research project with the emphasis being on the qualitative aspect.

As there was no instrument currently available to specifically measure the contrast of experience before the onset of mental illness with the current experience, the principal investigator generated the survey and interview protocols which will be used in the information gathering process. The written survey (see Appendix A) and the qualitative interview topics (see Appendix B) were designed by the principal investigator from client interactions, information from research literature (Stein et al., 2005; Ritsher & Phelan, 2004), input from individuals with persistent mental health issues who are not affiliated with this study, Brockport Counselor Education faculty, and with input from the continuing day treatment program mental health professional staff. The written survey was designed to cover a variety of life experience areas including 32 statements with 4 statements in each of the following quality of life areas: (a) relationships, (b) self-esteem, (c) productivity, (d) future/hope, (e) perceived esteem from others,

(f) mental/physical capacity, (g) standard of living, and (h) well-being.

Appendix C offers a summarization with each of the questions listed according to the specific quality of life category – this list was not given to participants. The statements are not grouped by category on the participant survey form but are dispersed at intervals throughout the instrument with half of the questions being reverse scored items. The written survey was worded at a 6th grade reading level (6.1).

The survey makes a statement and asks the participant to indicate how closely it describes his/her experience both before the onset of mental illness symptoms and after the onset by marking a Yes or a No response. A Likert scale was rejected upon the recommendation of CDT program staff/administration as previously, clients had shown a tendency for central tendency responses rather than fully appraising the questions when using this type of scale. This survey was used to assess changes in quality of life by contrasting the perceptions indicated prior to the individual experiencing mental illness as compared to the quality of life as the participants currently experience it with their ongoing mental illness. This was a one time self-report survey and was completed in an individual session with the principal investigator to eliminate any coaching or influence from other participants.

Immediately upon completing the written survey, the client was asked to participate in a discussion with the principal investigator. The discussion focused on the following areas.

1. Areas of loss due to mental illness currently experienced as most troublesome

2. Areas of loss due to mental illness not covered in the written survey

3. Meaning or positive outcomes from areas of loss

4. Participant suggestions for treatment program options to assist them with the above

   losses

There was an option of debriefing at the conclusion of the survey and interview for the participant if they desired it.

Procedures

The principle investigator approached continuing day treatment (CDT) program primary therapists with a written list of criteria for selection of participants (noted previously) and were given an oral description of the study parameters. They were asked to provide the principle investigator with a list of their clients from the CDT program whom they believed fully met criteria for the study.

Participants were approached individually by the principle investigator. The study and issues surrounding consent were explained to them. They were informed that participation or non-participation in the project would have no effect on their treatment. If they agreed to participate in the study they were asked to sign consent and authorization for release of information forms (see Appendices D and E) which were stored separately from the research responses.

Participants were instructed not to put their names or any of their background information on any of the research forms other than to answer four non-identifying demographic questions (see Appendix F). The interview portion of the survey recorded common themes of loss with no identifying information included in order to assure confidentiality. Any information that was shared in the interview portion of the information gathering remained confidential in that identities of the participants making particular comments were known only to the principal investigator. The completed surveys and the responses from the interviews were stored with the completed surveys and interview responses of the other participants in a locked filing cabinet away from other client information. The interviews were also digitally recorded and later

transferred to a secure computer with the initial recording erased from the portable recording device. There was no way to trace a particular survey, recording, or coding to a particular person. Following completion of this study and no later than December 31, 2006 (Xyz Health System's Institutional Review Board extended this date to March 1, 2008), all forms will be destroyed and records erased.

Continuing day treatment program participants who met the study criteria, who agreed to participate, and who signed consent and authorization for release of information forms were asked to complete a survey about their quality of life before experiencing mental illness and also about their quality of life as they currently experienced it (see Appendix A). Following taking the surveys, participants were asked to discuss with the principal investigator specific thoughts or feelings they might have about loss due to their mental illness prompted by the questions mentioned in the previous section (see Appendix B). This included a debriefing opportunity at the conclusion of the discussion/interview.

<center>Results</center>

<center>*Survey Results*</center>

All 13 participants completed the full perception of loss survey of 32 questions making a total of 416 responses. Of these, there were 136 responses that showed a change which was identified as a loss with 31 responses indicating a gain and the remaining 249 statements being unchanged. This resulted in an average of 10.5 loss responses and 2.4 gain responses per participant with a range of 1 to 27 losses and 0 to 9 gains among individual participants.

Taking the average results by gender into consideration there were losses of 10.7 and gains of 3.1 for the seven individual female participants and 10.2 losses and 1.5 for the six individual male participants. When comparing those with co-occurring chemical addictions and

mental health diagnoses with those without the chemical addiction co-occurrence the following

was found. There were average losses of 10.4 and gains of 2.9 among those individual

participants with co-occurring disorders and losses of 10.5 and gains of 2.5 among those without

the co-occurring designation.

Please refer to Table II for specific data on the categorized results.

Table II

Categorized Perception of Loss Survey Results

N = 13	**Total Loss (TL) = 136**	**Total Gain (TG) = 31**
Mean	**Total Loss = 10.5**	**Total Gain = 2.4**
Relationships	Total Loss = 18	Total Gain = 0
Self-Esteem	Total Loss = 15	Total Gain = 1
Productivity	Total Loss = 20	Total Gain = 9
Future/Hope	Total Loss = 25	Total Gain = 4
Perception of Esteem from Others	Total Loss = 12	Total Gain = 4
Mental/Physical Capability	Total Loss = 20	Total Gain = 5
Standard of Living	Total Loss = 16	Total Gain = 4
Well-being	Total Loss = 10	Total Gain = 4

Gender	**Female (7): TL = 75**	**TG = 22**	**Male (6): TL = 61**	**TG = 09**
Mean	**TL = 10.7**	**TG = 3.1**	**TL = 10.2**	**TG = 1.5**
Relationships	TL = 11	TG = 00	TL = 07	TG = 00
Self-Esteem	TL = 09	TG = 01	TL = 06	TG = 00
Productivity	TL = 08	TG = 07	TL = 12	TG = 02
Future/Hope	TL = 16	TG = 02	TL = 09	TG = 02
Perception of Esteem from Others	TL = 06	TG = 03	TL = 06	TG = 01
Mental/Physical Capability	TL = 09	TG = 04	TL = 11	TG = 01
Standard of Living	TL = 10	TG = 02	TL = 06	TG = 02
Well-being	TL = 06	TG = 03	TL = 04	TG = 01

Chemical Addiction	**Yes (7): TL = 73**	**TG = 16**	**No (6): TL = 63**	**TG = 15**
Mean	**TL = 10.4**	**TG = 2.9**	**TL = 10.5**	**TG = 2.5**
Relationships	TL = 09	TG = 00	TL = 09	TG = 00
Self-Esteem	TL = 07	TG = 00	TL = 08	TG = 01
Productivity	TL = 11	TG = 06	TL = 09	TG = 03
Future/Hope	TL = 11	TG = 01	TL = 14	TG = 03

Perception of Esteem from Others	TL = 07	TG = 02	TL = 05	TG = 02
Mental/Physical Capability	TL = 14	TG = 03	TL = 06	TG = 02
Standard of Living	TL = 10	TG = 01	TL = 06	TG = 03
Well-being	TL = 04	TG = 03	TL = 06	TG = 01

Relationships

This category had total losses of 18, total gains of 0, with 34 statements marked as unchanged. With category losses ranging from 10 to 25, losses of relationship fall in the upper middle of the range. With category gains ranging from 0 to 9, gains in the area of relationship are at the bottom with none indicated by any participant.

The statement which was indicated as the highest area of loss by the participants taking the survey was that of loss of value as a member of their family circle with a total of 7 of the 13 participants noting a loss in this area. Loss of number of good friends, enjoyment in meeting new people, and comfort with close relationships were in the 3 to 4 range. As noted above, no participants indicated any gains on any of the statements in this category.

Self-esteem

This category had total losses of 15, total gains of 1, with 36 statements marked as unchanged. With category losses ranging from 10 to 25, losses of self-esteem fall in the lower part of the range. With category gains ranging from 0 to 9, gains in the area of self-esteem are near the bottom with only 1 indicated by any participant.

Losses were noted by 5 and 4 participants for the statements looking at having a healthy respect for oneself, feeling stigmatized or labeled, and a decreased pride taken in appearance. There were only 2 participants who indicated a loss in comfort in new or challenging situations. The only gain in this category was one participant noting an improvement in taking pride in his/her appearance.

Productivity

This category had total losses of 20, total gains of 9, with 23 statements marked as unchanged. With category losses ranging from 10 to 25, losses of productivity fall near the top part of the range. With category gains ranging from 0 to 9, gains in the area of productivity are near the highest seen in any category.

With 8 participants indicating a loss in being usefully employed, this statement showed the single highest area of loss. There were 5, 4, and 3 losses respectively in amount of energy, interest, and excelling. With 9 participants indicting gains, this category had the highest amount of gain of all of the categories in the survey. There were 4 gains to 3 losses noted in for the statement referring to the number of things at which participant excelled which was only 1 of 2 statements in the survey which showed more gains than losses.

Future/Hope

This category had total losses of 25, total gains of 4, with 23 statements marked as unchanged. With category losses ranging from 10 to 25, losses of future/hope fall at the top of the range with the most losses noted by participants in this area than in any other category. With category gains ranging from 0 to 9, gains in the area of future/hope are near the middle of the category ranges.

With 6 or 7 participants indicating a loss in each of the four statement areas of this category, future/hope showed the greatest number of losses with only an average number of gains noted. The statements indicated loss in areas of expectation of a fairly typical life, looking forward to activities of the day, hope for the future and making plans for the future. This latter statement of making plans for the future was the only statement with more than 1 gain with 2 gains noted.

Perception of Esteem from Others

This category had total losses of 12, total gains of 4, with 36 statements marked as unchanged. With category losses ranging from 10 to 25, losses of perception of esteem from others fall near the bottom of the range. With category gains ranging from 0 to 9, gains in the area of perception of esteem from others are near the middle of the category ranges.

The main area of loss in this category was in loss of respect from others with 5 participants indicating this. Being talked about and being treated poorly by authority figures were noted as losses for 3 and 2 participants respectively. There were 3 gains to 2 losses noted in for the statement referring to people not taking the individual seriously which was only 1 of 2 statements in the survey which showed more gains than losses.

Mental/Physical Capacity

This category had total losses of 20, total gains of 5, with 27 statements marked as unchanged. With category losses ranging from 10 to 25, losses of mental/physical capacity fall near the top of the range. With category gains ranging from 0 to 9, gains in the area of mental/physical capacity are near the upper middle of the category ranges.

Loss of concentration was the primary loss noted by 7 of the participants. Uncertainty about being a good caregiver/parent and along with lack of self support financially were indicated by 5 individuals. Living independently showed 3 losses and 2 gains along with 2 gains for supporting oneself financially.

Standard of Living

This category had total losses of 16, total gains of 4, with 32 statements marked as unchanged. With category losses ranging from 10 to 25, losses of standard of living fall in the lower middle of the range. With category gains ranging from 0 to 9, gains in the area of standard

of living are near the middle of the category ranges.

Not being in charge of one's finances was noted as the biggest loss in this category with 7 participants selecting this as a loss and no one showing a gain. Difficulty in finding a nice place to live was indicated as a loss by 5 individuals with no one showing a gain. There was a split of 2 losses and 2 gains for the statements about having enough money for basic needs and having the transportation to get where they needed to be.

Well-being

This category had total losses of 10, total gains of 4, with 38 statements marked as unchanged. With category losses ranging from 10 to 25, losses of well-being fall at the bottom of the range with fewer losses indicated by participants in this area than in any other category. With category gains ranging from 0 to 9, gains in the area of well-being are near the middle of the category ranges.

Losses were indicated by 3 individuals in the areas of being able to get past problems without getting stuck on them and with feeling safe or secure. A loss was shown by 2 participants in the area of being more anxious than others and in being able to trust others to look out for their best interest. A gain was shown by 1 participant in each of the 4 statements in this category.

Please refer to Table III for specific data on the individual statements and categories.

Table III

Categorized Perception of Loss Survey Results

All Categories	Total Loss = 136	Unchanged = 249	Total Gain = 31

Relationships		Total Loss = 18	Unchanged = 34	Total Gain = 0
• I was a valuable member of my family circle.				L = 7 G = 0

	L = 4 G = 0
• I had very few good friends.	L = 4 G = 0
• I enjoyed meeting new people.	L = 4 G = 0
• I was uncomfortable with close relationships.	L = 3 G = 0

Self-Esteem   Total Loss = 15   Unchanged = 36   Total Gain = 1

• I felt stigmatized or labeled.	L = 4 G = 0
• I took pride in my appearance.	L = 4 G = 1
• I was very uncomfortable in new or challenging situations.	L = 2 G = 0
• I had a healthy respect for myself.	L = 5 G = 0

Productivity   Total Loss = 20   Unchanged = 23   Total Gain = 9

• I was usefully employed.	L = 8 G = 1
• There were very few things at which I excelled.	L = 3 G = 4
• I had just the right amount of energy to get through the day.	L = 5 G = 2
• There was nothing much that interested me.	L = 4 G = 2

Future/Hope   Total Loss = 25   Unchanged = 23   Total Gain = 4

• I expected to have a fairly typical life.	L = 7 G = 0
• I did not make plans for the future.	L = 6 G = 2
• I didn't have much hope for the future.	L = 6 G = 1
• I looked forward to what I was going to do most days.	L = 6 G = 1

Perception of Esteem from Others   Total Loss = 12   Unchanged = 36   Total Gain = 4

• Authority figures treated me well.	L = 2 G = 0
• People didn't seem to take me seriously.	L = 2 G = 3
• I was generally respected by those who knew/know me.	L = 5 G = 1
• People talked about me behind my back.	L = 3 G = 0

Mental/Physical Capability   Total Loss = 20   Unchanged = 27   Total Gain = 5

• I was uncertain of my abilities as a parent or caregiver.	L = 5 G = 0
• I could support myself financially.	L = 5 G = 2
• I was not capable of living independently.	L = 3 G = 2
• My concentration was good.	L = 7 G = 1

Standard of Living   Total Loss = 16   Unchanged = 32   Total Gain = 4

• I was not in charge of my own finances.	L = 7 G = 0
• Finding a nice place to live was difficult.	L = 5 G = 0
• I had enough money to pay for my basic needs.	L = 2 G = 2
• It was difficult getting to places I wanted to go.	L = 2 G = 2

Well-being   Total Loss = 10   Unchanged = 38   Total Gain = 4

• I was often more anxious than others.	L = 2 G = 1
• I was able to get past my problems without getting stuck on them.	L = 3 G = 1
• I usually felt unsafe or insecure.	L = 3 G = 1

- I could trust those responsible to help me to look out for my best interest.   L = 2   G = 1

Interview Results

As put forth in the Methodology section of this paper, the thirteen participants with severe and persistent mental illness whose interviews results are presented in this results section are the same individuals as those who completed the loss survey addressed above.

Losses as Background

It was noted by the interviewer/writer that many of the losses which the participants eventually discussed in their interviews were not readily identifiable, acknowledged, or initially remembered by them. Some individuals had indicated no changes in those areas on the survey where they later identified losses. Early in the interview, there appeared to be a lack of awareness of these situations as losses or if noted, the possible relationship to their mental illness. It was observed that many of these losses may have been absorbed into the everydayness of many participants' lives thus becoming inaccessible to them without a different perceptual window through which to view these situations.

One young man in his mid-twenties indicated that he had experienced no losses surrounding employment or any of his aspirations in that area. As the interview was wrapping up, he casually mentioned "Sometimes I dream about things, like what would happen if I wasn't this [mentally ill]…. I was going to be a Marine. When they found out I was in the hospital [mental health related], he gave me all of my stuff back." Further exploration established that this situation was a big disappointment and loss for him. This same man denied any concerns surrounding being stigmatized or labeled. However in the interview he indicated hesitancy about initially discussing his diagnosis with others he was meeting saying, "[Admitting a mental health

diagnosis] could be a problem. Like if you're just meeting new people….it would be hard."

Another young man, also in his mid-twenties had strongly denied any repercussions or losses from his mental illness other than frequent college transfers making his education more difficult and his needing to live in a group home. When discussing where he hoped his college education would get him as far as his career, he mentioned "I tried to get into the Navy, but I was on [psychiatric] medication so they wouldn't let me." Following this, he readily acknowledged that this had been an impactful area of loss, not one he had forgotten but just one that hadn't come to mind as a loss.

A woman in her mid-forties stated "Before I did [have a mental illness], I had a way lot of friends….[now] I don't really have anyone." She reasoned that it is natural for friends to drift apart. She did not note a possible connection between her lack of maintaining relationships or of making new friends and some of her mental health symptoms such as anxiety, fear, dependence, and her preference to isolate reflected in the before mentioned and the following statements. "I don't want to take chances anymore….I'm afraid to try things new, and I just like being in the old mold and just doing what I always usually do….I don't know what would happen. Just something bad might happen, I think….[now] when I have friends, my mom always seems to get mad and doesn't like want me to have friends."

Unlike those who were unable to initially recognize particular losses until the interview progressed or a particular topic was discussed in greater detail, other participants had losses that were readily identifiable although the ability to recognize and comprehend the source and impact of these losses varied. With some of their losses remaining on a more superficial level and others emerging more fully, a wide range of reactions to those losses was seen.

Losses Attributed to Non-primary Causes

Some individuals recognized areas of loss they had experienced but did not readily attribute those components of their lives which had been altered as due to their mental illness in full or in part. Many of these individuals seemed to ascribe these losses or disappointments as just-the-way-it-is. There did not seem to be an examination of the possibilities that these things might alter should there be changes in their mental health or treatment. There appeared to be more a resignation to their circumstances and a general implied feeling that those particular aspects of their lives needn't be examined too closely. Many participants, when describing their lives, seemed to overlook losses attributable to mental illness as fate or as an intrinsic part of their life situation.

An oft mentioned situation was a lack of the ability to concentrate which was noted as the reason for stopping educational and other opportunities. When looked at further, the participants indicated that the concentration problems usually stemmed from psychiatric medication side-effects or from symptoms of their mental illness such as being distracted by auditory hallucinations. So although mental illness may have been the root of the need to stop attending educational training, many participants generally experienced the more immediately identifiable lack of concentration as the sole problem. A man around fifty said "My concentration and everything was so mixed up…. if I wanted to go to school, I don't think I could make a serious attempt at it." A woman around thirty indicated a similar sentiment stating "Well, I'm trying to go back to school. I took a test, and I flunked it. I couldn't pass it….because of the concentration. I couldn't concentrate at all, and I had to keep on reading what I was, you know, doing."

While losses were experienced as a background or a given part of one's life by some,

others more readily identified them but lacked clarity of cause. In some of these cases, this failure of understanding lead to even greater loss as it contributed to a devaluing of self.

Losses Blamed on Personal Failure.

For those participants who were aware of losses and attributed problems in their lives as being primarily due to their personal shortcomings, there tended to be self-blame and often a loss of self esteem. A mention of a difficulty or challenge being due to a mental health symptom or the result of a side-effect of treatment may be acknowledged, however with these individuals there was most always a "Yes, but" type of statement or belief attached to the acknowledgement. This would serve to effectively disallow the previous information enabling them to hold intact their previously held beliefs of personal responsibility and failure.

Even though this mid-forty year old man indicated an intellectual understanding of his mental illness's contribution to many of his adult life's difficulties, he blamed himself and believed it was a weakness to need help to handle his symptoms. He stated "Slowly I lost myself in it to where I'm seeing a psychiatrist. You know, you don't do that. You work through it. You be a man about it." He acknowledged that when talking about his struggles and losses, he could understand the concept that they were due to his mental illness, but had the feeling that it was him; that it was a character flaw; "the mental illness is me." He went on to state "The doubts and the fears and the weakness….it's like I failed as a father, I failed as a husband, I failed as an employee, I failed as a brother, and I failed as a friend." He explained "I'm on DSS. I'm not working for a living; I'm not supporting myself….It's troubling feeling less than a man. It's very troubling." What self-blame he doled out onto himself was added to by some of his symptoms, as he explained, "hearing the voices don't help either. Because what I don't beat myself up with, with my own mind, that other part of me helps."

Ascribing loss solely to personal deficits and flaws which at least partially was due to a mental illness appeared to put additional weight onto the burden felt by those with significant mental illness. The value of understanding, in part, the contribution mental illness has had was expressed by a man in his mid-forties. "It answers – having the diagnosis answers a lot of questions of why, of how….Yeah, there was an answer. I'm one of the guys; I need an answer." Along with this examination of identification of loss, the categorization of these losses is worth perusal.

The Substance of Losses

The discussion of the participants' losses generally followed two lines, the first line being losses associated with the actual or concrete. These included things and situations which the participant already had in their life prior to the intervention of their mental illness. An example of this would be seen with the statement of a man around fifty who said "I lost my family through it [mental illness]….I lost the respect of my mother and father." Often this actual loss was not one limited to the past but an ongoing one as noted by one woman also around fifty. She stated that her children had lost respect for her and currently "use it [mental illness] as a reason they don't have to pay attention to Mom because she doesn't know what she is talking about."

The second line which the discussions followed was losses associated with the anticipated or non-concrete. These include things and situations for which the participant had expectations or desires of having or experiencing but which they had not attained or do not foresee happening as a result of their mental illness. An example of this from the same male participant quoted above would be "I was hoping that me and her could settle down and get a family, children, one boy, and one girl. You know, how you plan that."

There were situations where something actual or anticipated was lost from a participant's

life but where the meaning given to this was either neutral or positive. A woman around sixty very firmly replied "No" to any question of whether not being able to work was a problem or represented any kind of a negative in her life; in fact she preferred not working. Additionally a man in his mid-twenties had noted the loss of friends and the lack of ability to make new ones was not bothersome to him. He stated "I never really thought about it because I don't care."

There were situations mentioned where the reason for the loss of the actual also affected the loss of the anticipated. The above participant noted that he had lost a job assisting with circuit board repair due to his mental health symptoms including "I couldn't control my hands. I couldn't control the solder iron and stuff." That had so far led, in part, to the loss of his stated desire to "get into technical school so I can get into circuit boards." Many of the examples of losses presented in the following section have this overlap.

Losses from Living with a Mental Illness

The participant's articulated perception of their loss covered a wide array of topics. Many of these can be grouped to reflect areas of commonality with those expressed by others in the study. Often a loss will fall into two or more topic areas such as would be the case with loss of self esteem, financial independence, and dreams of a career due to loss of the ability to be employed. Common themes of loss which emerged from the participant interviews are delineated below

Self-esteem. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting self-esteem.

- "I don't feel like a whole person….I guess I lost my confidence."
- "I feel like I should be doing a lot better for myself…The voices are saying to me all of the time, 'You're not doing this. You're not doing this.'"

- "When people talk to me, I just feel like I'm lower than they are or something like that, you know."

- "I think I used to be really good-natured, had a sense of humor, and easy going. Now I'm not that way. Now I'm kind of anxious and I get depressed. I'm not that way."

- "I felt like scum."

- "I'm not worthwhile to be with. Like I can't offer anything. I got a mental illness."

- "The pride I had…I miss it….It's so hard."

- "The – I want to say fear [affecting self esteem]. It feels like there's more fear in my life, of anything….The fear of the unknown, and the fear of trying, that I'd fail. The fear of meeting people and letting them into my life."

Family. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting family relations.

- "My kids sometimes I don't think they trust me, so that kind of bothers me…. when I want to do things with them or if I want to talk to them, you know, sometimes they act like I'm not quite there or something."

- "My children went away to my family….I needed some help with them, because I was raising them by myself….I got severely mentally ill."

- "I had lost a lot of friends and family, which I trusted like friends….I cannot trust nobody. I can talk to a person, but I cannot trust them like 100%. I can't….[mental illness affected] my family, because I cannot communicate with them. It's really hard for me. I try to talk to them, but I don't know if they understand me."

- "I don't get along with my family. My family treated me like a little girl all the time."

- "For the longest time my children didn't call me…. My mother was still very angry with me….A year before my dad died, I didn't see him at all. I was told that he wanted nothing to do with me. When he died, I felt a really big gap. I felt bad, because I wasn't able to see him before he died.

- "I'm on DSS….and I'm the reason why the taxes are going up, which was pointed out to me Thanksgiving. You know, one of my brothers said that. If I don't keep in touch with them, then they can't hurt my feelings….Now I'm special….I've got a couple screws loose.

- "I don't think my mom blames it on me, but it seems like it's hard for them to believe that I actually hear voices or seem like I converse with them. Little things, too, where I'm on medicine and drool on the pillow at home. She gets a little ticked off about things like that….They place judgments…. it seems like they figure sometimes that I should know that this stuff isn't real

Socialization. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting social relations and activities.

- "They are the only one that is talking and I'm not talking, they never hear me talk. They never hear me speak or say anything….It's like they don't know me. They know me, but don't know me, know me. Like they don't know my favorite color or anything, you know, things that are bothering me, things I like to do. I never tell anybody anything about that."

- "A lot of people understood me….[After mental illness] a lot of them kind of disappeared."

- "I lost a lot of friends because of my problems with mental illness and addictions."

- "I lost my girlfriend because she didn't want to be hanging around with a person who was mentally incapable…. Mental illness, she was biased against it."

- "So, I, you know, don't really have a lot of activities I do at night, but just watching a little TV sometimes, because I couldn't awhile ago. My concentration and everything was so mixed up. I couldn't really concentrate on shows on TV."

- "I have been hearing threats like in my head. "If you do this, you're going to get jumped," you know, if you should go for a walk and that. Threats in my head like that it makes me un-at ease or can't relax…. I have been nervous, and I have a hard time relaxing."

- "I didn't stay in contact with my friends. I haven't talked to them…. I like having friends, but they are friends I don't need to be hanging out with….if I want to stay sober, then probably not friends I should."

- "It's sort of hard to date. To explain to a woman why my hands are shaking."

- "Fear of meeting people and letting them into my life. The ones I did let into my life years ago, you know, I pushed away. Then the hurt and the pain came, and I don't want that no more. So, I don't let people into my life….I don't want them to hurt me, but then I'm alone and that hurts."

Stigma/judgment. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting stigma, respect, judgment, and a feeling of not being understood.

- "Some people they could tell that my continence, you know, the way I look, maybe I was crazy or something. I didn't quite dress like everyone else….They treated me

different, like substandard and stuff like that. Actually, I was doing my very best, you know."

- "I want to work with handicapped children and retarded children….When I work with them, I don't have to worry that I am going to be judged or will they like me. They'll give me unconditional love, you know, and I don't have to worry."

- "They don't understand. They think that I should be able to handle more than what I'm handling."

- "If they find out that I have an illness, they'll make fun of me. You can't do this. You can't handle this and all of that. They'll start laughing at me, and I was made fun of a lot."

- "Maybe it is that they don't understand, because they don't have mental illness. They always think, 'Oh, you know, it's this or that.' It's always attributing to your mental illness, but whether it is or not."

- "I get angry about it….it's like they're intrusive. I'm not doing anything to hurt them, so why I'm shaking is really none of their business.

- "I got to a point where it was–it felt like they were hitting me. I know it wasn't true, but I felt it. You know, snickering behind my back. I know they weren't happening. I hope not, but it felt that way, and, you know, mocking me. So, I just stopped hanging around them."

- "My therapists kind of patronize me, I think. I don't think they, you know, really believe what I say. Sometimes they don't believe it….they're not taking me seriously."

Dreams/goals. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting dreams, goals, and aspirations.

- "I wanted to be married, have children."

- "I wanted to be a medical secretary, but it didn't work out because of my mental illness."

- "It bothers me a lot, because I never got a chance to raise [my children]."

- "I thought I would get in a relationship or everything would work out, but it doesn't seem that way.

- "To go to college and have a family and work."

- "I don't have a family. I don't have children…I feel like I'm sort of left out because I don't have any children. My brothers and sisters all have children. Of course it would have been irresponsible for me to have a child I couldn't take care of and that's why I don't."

- "I think that's part of the reason for my depression, because, you know, feeling that things would work out like everyone else."

- "I worked as a home health aide, and once, if ever, my anxiety gets under control, I want to study as an LPN."

- "Oh the house with the white picket fence and stuff…with the wraparound porch. Complete, I had the complete picture."

Self-sufficiency. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting self-sufficiency, autonomy, finances, and self-confidence.

- "I could live on my own and take care of myself, but not right now."

- "I guess I lost my confidence."

- "I wasn't deciding, my parents were….everybody had to make my own decision."

- "I lost my independence….They seem to have pretty much the control of what I do, who I see, and that makes it a little difficult."

- "It's like I feel as though I'm just being controlled and I can't do…what I would really like to do."

- I can't do what I've done in the past…which is being able to get up in the morning, get dressed, shower…go downstairs and make a nice breakfast for my family."

- "I've been wanting to go back [to college]…but they are like, 'No…you're done with school.'"

- "My parents get me confused, the way they see things….Sometimes I look at it the way they do and then other times I don't, which, that scares me because I want to be able to see things as they are."

- "[I've lost] the ability to make a proper judgment. It scares me….Before I had no problem having a judgment call….Making my own calls scares me."

- "The relying on somebody, and I feel that I'm incapable of doing things for myself. I feel like I don't have the power to do it."

- "A loss of independence. Relying on the government for monetary [means]…[My sister's] got the credit card that goes to the trust fund. So, there's another example of loss of independence.

- "I have to more or less prove what I spend my money on. I always have to bring receipts back, that kind of thing."

- "It does impact me financially because I'm on a budget. You only get so much money on SSI….Things I did in the past that I can't do now. I can't buy sneakers or other stuff like this, new clothes, or a new TV….it just minimizes my financial stuff."

Education/employment. Listed in this section are a sampling of comments made during participant interviews dealing with their experience of losses in the area denoting education, employment, career, and mental or physical capacity.

- "I can't work for a long time without, you know, the medicine having a good effect on me…I mean that the medicine sometimes, you know, makes me drowsy and other stuff, and I can't, you know, concentrate real good….it makes me lazy."

- "It was hard to remember….Memory losses, yeah."

- I want to work, but I cannot go – I start working. I stay for a month or less than a month, then I break out…I cannot control myself in doing the work, or I just start crying and my body starts getting too tired."

- "[My boss] couldn't take it. He got kind of mad at me. He says, 'You're making me lose customers.'…I wasn't talking to [the customers] right. So he fired me.

- "I try to work a regular job, but then my illness gets in the way. I either end up having to take time off to go in the hospital because I'm all stressed out.

- "I think maybe [what's most difficult is] just getting through school and finishing school because of the mental illness."

- "At work, to concentrate on the work and do it. I don't know; it just seems like sometimes something won't let me, you know, do the things."

- "In general, my employment history is non-existent, except for that one job. So, the ability to hold a job without anxiety, depression, and losing my temper, that's been difficult."

- "Employment wise, towards the end of my employment, my fuse got real short. My acceptance of other people's opinion was zero. Everything had to be my way."

- "Education, my concentration just dwindled to where I would read a paragraph, and I got to go back and read it again, then again, and then again. Three or four times, and I'll get frustrated. So, I'll close the book, and I won't pick it up for months."

- "The tremors and lack of concentration to where I wanted to go back and get a degree in engineering. I can't even hold a screwdriver to a screw."

There are many and varied losses expressed by the study participants which, although frequently similar to what others had articulated, were unique in experience to them. From this individualistic experience, each participant had a platform from which to ascertain their view of a change which has occurred in their lives because of their mental illness or its treatment. These changes were sometimes expressed as losses, sometimes as neutral, and not infrequently as positive.

Gains from Living with a Mental Illness

A frequent and strong theme that emerged in the interviews both spontaneously and in answer to inquiry was that of the benefits experienced by the study participants which they attributed to either living with a mental illness or as a result of treatments received for mental illness symptoms. Only one participant, a woman in her mid-forties, said there had been nothing positive that had come from her experience with mental illness. Many spoke unreservedly about improvements they had made and things they had learned. Some seemed eager for the

interviewer to understand and perhaps even be impressed by the progress which they believed had been made. One man around the age of fifty made reference to important relationships he felt he had acquired through single or brief encounters stating things such as "I gained all new friends. Judges and stuff" and described in detail the value of a few of these to him. Others appeared to aim their discussion of these areas of gain or progress toward themselves in a manner suggestive of self-persuasion. One woman around forty pondered how treatment might have helped her stating "Well, medication, you know, kind of relaxes you and kind of unscrambles some of your thoughts….Maybe you think slowly. Maybe you think more rationally."

Generally talking about what was positive seemed to come easily to mind. However, these discussions did not build upon themselves in the manner of those dealing with losses which often elicited additional layers or discoveries as the interview progressed. The gains discussed ranged from significant personal changes which impacted daily life on an ongoing basis to meeting a romantic interest. Below are examples of those positive things which the participants attribute to their experience with severe and persistent mental illness and its treatment.

Self-esteem. Improvements in confidence and self-esteem were mentioned by interviewees of both genders and various ages. A woman around forty stated "It's just giving me like more self-worth, more worth for other people." A man in his mid twenties noted "My self-esteem is better now. I got more confidence in myself than before. I was just not growing….I feel that I really progressed as a young adult and really doing things step-by-step and learning how to cope with things I need to do." A woman around thirty expressed pride in herself as she described "I found out that I am a good mother and very responsible when it comes to my children." A mid-forty year old man indicated satisfaction in having been taught in group how to

use "your wise mind."

Self-sufficiency. Improvement in self-sufficiency was mentioned by others. A man around forty said "I've become more independent….I'm not so much dependent on people." A woman in her mid-fifties stated that she is learning to be an adult through "some of the groups, my therapist." Another woman around sixty noted "I always wanted to be taken care of. Now I'm at the point where I feel that I can take care of myself and be responsible."

Social. Appreciation and satisfaction was expressed by some in the areas of socialization and social skills development. A mid-twenties male described his changes as "Back then I was real quiet. I'm more talkative now. My social life, you know, really gone up. I really learned to meet lots of people….I just meet a lot of new people. Really talkative, really open up to people, too." One woman around forty expressed pleasure for the community afforded her from living in a group home "It's positive. For me it's like having peers and like sharing a room with other females I think has been a good experience, because I don't have any sisters. We can talk and kind of bond and everything else." A man also around forty spoke a similar sentiment about the opportunities afforded him socially as he said "I have lots of friends who are in the mental health system." A woman around fifty described how she had learned improved communications skills when relating to others. She said "When I'm talking to somebody, you know, I try to be honest….sometimes because I'm not sure if I get my point across, then I really watch myself to make sure I do, because of the mental illness."

Personal growth. There were a wide range of gains noted in areas of personal growth. One man in his mid-twenties noted "it helped me stay balanced." A woman around fifty indicated "when I'm dealing with people…because of my mental illness….that makes me a little bit more understanding." This thought was echoed by a man around forty indicating that having a

mental illness had given him "compassion for other people who are suffering." A woman around forty asserted "I'm learning, still learning, because I get tested." She went on to later state that she had learned "to appreciate things more...little children…animals…creation." A man around fifty had begun to care about getting his GED where he hadn't valued his education before. A woman around sixty stated "I feel now like there's hope and acceptance." She went on to describe growth where she had learned "I don't have to sit there and buy their love. In the past that's something I always did." A man around fifty explained how he had learned to control his temper "I don't fly off the handle so much anymore." "My character," was where one man in his mid twenties indicated he had seen most of his growth. He believed his mental illness "just makes me stronger….going through this will make me…maybe appreciate things more."

Sobriety. Sobriety was a source of significant pride and satisfaction as expressed by many of those with chemical dependency. There was a sense of personal accomplishment that went along with this. And although gaining sobriety was not a result of having a mental illness, it was linked by the participants to the combination of treatments they received through the MICA (mental illness, chemical addiction) programs. A man in his mid-twenties spoke with pleasure of "my clean time" and a man around fifty said "I've been straight for three and a half years." A woman around sixty described having "seven months clean as far as abuse goes…I've just celebrated a year clean from alcohol." A man around fifty with twenty-one years of sobriety simply said "Having the sobriety is positive."

Along with looking at the results of the discussions about the losses and gains from the experience of these thirteen individuals with diagnosis of severe and persistent mental illness, this study queried these participants about their suggestions for the continuing day treatment program in which they were involved for mental health treatment. Interviewees were asked

"What do you think would be most helpful to you in dealing with these losses? What types of things could your mental health treatment program offer to you that might be helpful?" Below is a listing of all of the ideas given by the participants, sorted by category, for ways in which the program might assist in addressing their losses along with general suggestions as volunteered in the interviews.

Client Suggestions

   Educational literature.

- "Maybe give me some literature on mental illness, depression, and schizophrenia. You know, if I get some literature, so I can read about it."

- "I think another thing that the therapist could do is give me some material on depression. You know, exactly what it is and what it does to you. I think I would like some help on that, too."

   Family education.

- "Maybe workshops, your families, getting families to get more involved….To learn more about your illness and stuff like that."

- "The only thing they can do is talk to the individual [family member or other who doesn't understand participant's mental symptoms]. Maybe talk to the individual on my behalf and explain a little bit about my illness, and how they should accept it. Maybe I'd have my therapist do that with my kids or something or my sister."

- "For me I think it would have to be like an independent one-on-one. [More time with your therapist?] Yes….that and, you know, maybe having a family session where my family can come in and sort of like put our heads together and see what we come up with….Probably a combination of educational, but also, too, maybe they would be

more comfortable talking about maybe their worries with me, that maybe they don't say to me."

Groups/classes/skills training.

- "Education. Maybe a little education.....On losses, on feelings, on the isolation."

- "Almost being assertive. [An assertiveness class?] Yeah."

- "I've been going to meetings called The Voices meeting. [Having a group that dealt specifically with that one symptom of voices?] Yeah, it would be interesting hearing what they have to share, whether it's in common. We all have our own unique stories, dealing with it, you know, what they found helpful."

- "There's some aspects a lot of us don't talk about, you know, teenage things, or younger than that. [A group that encouraged you to go back and talk about things that happened earlier?] I suppose it could help."

- "Learning to cope and dealing with things that I have lost in the past. So, I'm saying basically things that could help–groups that can help me get through what I've lost, and something I can just find. Something that was new [to replace what was lost]."

- "Concentration, social skills. I don't know that's probably about it, social skills....Help me get things out more though. If I keep it in, I don't know, I guess it affects me. It will break me down again though if I keep it all bottled up and just explode like I did before....it would help me cope better with society though and make new friends, learn how to make new friends."

- "I'm still having a hard time with financial burden, because like I said there's temptations that I can't say no. [A budgeting class?] Yeah, because like I said I never

was taught. They never taught me how to budget money.…and taking care of my needs, personal and physical needs."

- "I think some memory techniques. I think I can use like some memory techniques."

- "I think working on… self-esteem or being more positive…building better character."

Employment.

- "You know, taken those tests and applying for jobs and that. Never having anything pan out.…[A work readiness preparation?] Yeah, probably."

- "I would want them to help me find a job. Maybe we can work on finding a job might be good."

Program/staff.

- "Reduce the number of clients. It's overcrowded.…It's pretty intense to have a lot of people."

- "Allowing clients to spend more than half a day in program."

- "Don't be so–I don't want the [MICA] staff being judgmental. I feel that sometimes they are."

- "Just a little bit more closeness with the doctor…. just frequently."

- "Just my symptoms and whether I'm under the right kind of medicine or not."

- "Don't look at me and tell me to come back in three months. It seems like it's I walk in, "How are you doing?" Check my weight, check my tremors, what's been going on. "Okay, have a nice day." Then there's another person standing at the door waiting for his appointment. The closeness or caring that I expected from a psychiatrist so I can open up I feel like I'm just another number.…Take five minutes before I come in and read my chart on your last notes to refresh your memory."

- "Being able to talk it out with my therapist [more time one-on-one time with therapist]. Right."

- "Be here for me….I'll talk to my therapist if I have a really serious problem, Instead of blowing up, getting upset and everything, knock on the door and see if I can talk to the therapist. If she's not there, one of the therapists or the nurse or something where they can sit down and listen. That's all I want I want somebody that can be there, who will listen to me."

- "I think sharing with you and the other therapists."

Exercise.

- "Maybe like exercising, more exercising, floor exercising. A little bit of aerobics. We get that like on Mondays. It would be good to have it more often. Maybe twice a week."

- "Exercise."

Along with looking at the results of the participants' discussions about the losses and gains from their experience with having a severe and persistent mental illness, this study also briefly probed their perceptions of the survey and interview experience itself.

Survey/Interview Impact

Because of the possibility of distress in various forms being elicited due to the discussion of what could be painful topics surrounding loss, there was a debriefing opportunity given at the end of each interview. None of the interviewees expressed any distress at the end of the session. One woman around fifty said it had been "a little upsetting" when looking at her losses but stated about the experience "It has been good. I'm glad I talked about it. It's good." The only other individual commenting about a problem with talking about her losses was a woman around the

age of thirty. She spoke of being upset when "talking about my mother especially. Talking about my illness, because honestly, I don't want to be like this. I want to be better for myself, for my children, you know….I feel – when I was talking, I was feeling upset. But now that I've got it out of my body, I feel better, a release."

This same woman had been nervous about participating as she rarely opened up to anyone other than a program counselor with whom she had a long-standing relationship. At the last minute, with the program counselor's encouragement, she decided she wanted to try doing the study and was very surprised with what a positive experience it was for her. She explained afterwards "I feel like my heart hurts. I got too much on my mind. I feel a release that I could talk. I wasn't sure I was able to take it out and talk to you….but with you, I feel very relaxed. I don't know why, but I feel good."

Most every participant expressed some degree of appreciation or benefit from having been a part of the interview portion of the study although the survey aspect of the study was not mentioned as having any impact either way. Responses about the experience ranged from a fairly neutral comment about feeling good or fine about things to expressions of how unexpectedly helpful or self-esteem boosting the experience had been. A man in his mid-twenties said that it was nice "something to get off my chest because I'd be thinking about stuff like that all the time." A woman in her mid-fifties was very pleased to do the study stating "I'm glad that I talked with you….I hope it helps – like I said, I hope it helps somebody that could really use it." Other comments were simple with a woman around sixty saying "Good. Very good" in response to how she felt at the end of the survey, and a man around fifty commenting "I feel like it was a positive experience." One man who was around forty stated "This is actually a nice experience to be able to talk about things like that."

For some there seemed to be a feeling of having really been heard and understood. A woman in her mid-forties expressed it this way. "Well, thank you for spending the time with me, because you have been very, very helpful. I'm glad that I can get this off my chest and, you know, and talk with somebody that you really know. You're very perceptive and you really know. I just want to thank you." A male participant, also in his mid-forties, hung around the door after the session was over and expressed surprise at how much he had revealed in the interview and how good that experience was. At the end of the interview he had said "Good, to talk about it.... I covered some stuff that I haven't told anybody. It felt good to let it out….It actually amazed me that it didn't hurt as much as it used to hurt….to think of it. To think of it to me is to feel it, and it really wasn't that bad….To let it out (brief laugh), that check valve. Open up and let some steam go."

All of the participants had been in treatment for their mental illnesses for lengthy periods and for some, in numerous settings. With this, they had frequent therapy sessions, both individually and in groups where there were opportunities to discuss their losses. However, many indicated that this had been a unique and helpful experience, an occurrence which was not a formal goal of the study plan. One way this situation may have differed from previous sessions which participants had experienced with therapists was that the sole purpose of the session was for the interviewer to focus on listening to and understanding the individual's experiences without attempting to offer assistance, consolation, suggestion, or other intervention. The participants understood this to be a one time encounter, that there was no right or wrong way to do it, and that they would not be required to act upon anything that was discussed. So in addition to obtaining the information sought from the participants surrounding their experience of loss due to having a mental illness, there appeared to be an unintended benefit where participation in

the study produced a positive experience for those involved.

Study Results

This study covered the perception of loss experienced by individuals with persistent and severe mental illness diagnoses using both a quantitative based survey and a qualitative based interview of thirteen voluntary participants attending treatment in an urban continuing day treatment program. With the results of the survey and the interview components having been presented separately, it is important to now take a look at the combined results of the information provided.

The general area on the survey where there was the greatest loss indicated was that of losses in the category of loss of hope especially for their previous expectations being met in the future. All four questions in this category received very high marks. This was also borne out in the interviews. While many responses were made directly to loss of dreams, this sense of loss of hope was seen across all of the categories where the losses experienced in those areas were often expressed as ones in which change for their future was not expected.

The category of productivity in addition to the category of mental and physical capacity showed the second highest indication of loss on the survey results. The primary focus of productivity loss was the loss of being usefully employed which received the highest mark of any individual statement in the survey. The interviews strongly collaborated this finding with the expressions showing high significance for many of the participants. There were some whose identities and sense of worth were strongly tied to their ability to work and feel productive. The fact that these two categories received similar scores was linked in the interviews by the comments about how much the mental and physical capacity losses affected the ability to be productive in employment, educational pursuits, parenting, and the ability to be financially

independent. Although these categories came in second on the survey result to loss of hope, if the scores from these two categories were combined as they were in the experience of the participants from their interview results, they would far outdistance all other categories as a source of meaningful loss to these thirteen participants.

The survey category of productivity was the only one to show significant gains. These were primarily in areas not involving employment. The main area which was identified as showing a gain was that of an improvement in excelling in things in their life and slight gains in energy and interest. While there were numerous gains described in the interviews by many participants, the expression of excelling in areas of their lives was not one corroborated in the interviews.

Relationships came in next in the survey results for losses. It was the only category where there were no gains noted on the survey. In the interviews, dearth of positive changes was not corroborated as some of the participants indicated improved ability to make social connections although some noted this only in the acquisition of friends within treatment programs. The single statement which stood out in the area of relationship loss was that of being a valuable member of the family circle. In the interviews discussing social losses including friendships, family concerns carried the highest emotion and importance in participant's expressions. There was frequent mention of not being understood by one's family, especially having the effects of their particular mental illness symptoms misunderstood. Additionally, there were struggles with respect and tolerance observed. While losses in other social concerns, such as friendships, were mentioned, those affecting family were noted to be of primary importance.

Standard of living was the category which came next in number of losses seen on the survey results. Not having control of their finances was the strongest area of loss in this area.

This was also seen in the interview results with mention of its effects on their lives and also on their self-esteem. Second to this on the survey was finding a nice place to live. Unlike those mentioned in the literature who dealt with homelessness, only a couple of the participants mentioned this as having been a problem for them. Most instead, mentioned finding it difficult, if not impossible, to live in a situation of their choosing. Although having enough money to meet basic living expenses did not score high on the survey, there was more emphasis given to it in the interviews. Often the desire to be employed was described as being driven by financial motives.

Self-esteem came in right behind standard of living in the survey and had the distinction of having only one gain noted in this entire category, the second least area of gain of any in the survey. The one gain was of one participant indicating an improvement in taking pride in her appearance. Feeling stigmatized or labeled and having a healthy respect for self were both areas where a moderate degree of loss was noted on the survey. This was also found in similar degree in the surveys with more emphasis on loss of self-respect than of feeling labeled or stigmatized. Considering the lack of gains in any other statement area in this category, the importance of self-esteem as far as impact of loss may move it up in significance.

Perception of loss of esteem from others showed the second least level of loss in the survey with the specific area emphasized being a decrease in being respected. In the interviews, this primarily was referred to as most problematic when it involved family members. The lower numbers in this area of the survey were borne out in the interviews. However, the impact of the participant's concern about not being taken seriously or being discussed behind their backs took on greater significance when the distress was described more fully in the interviews by those who noted these losses.

The category with the lowest losses indicated in the survey results was well-being. In

generally this was found to be a similar representation in the interview results. While there

certainly were troublesome losses involving difficulty getting over past problems or in regard to

trust, for the most part, these issues did not seem to play a role in the forefront of most

participants' lives. For those who did have struggles in this area, it seemed to be around

experiencing anxiety and how to deal with it.

The window into the world of those with severe and persistent mental illness has been

expanded by the vantage point afforded through the examination of both the quantitative and

qualitative aspects of this study. The data from the surveys along with the subjective information

from the interviews together provide a rich view of loss due to mental illness as shared by the

thirteen participants.

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

As is well depicted in the combined results of the study, there are losses due to mental

illness for all participants. For some there were numerous areas where they felt loss in their lives,

for others the losses were more limited to specific areas, but all felt the effects. There were very

similar results between genders when identifying loss on the survey. With those having a

chemical addiction in addition to other mental health diagnoses, the only difference seemed to be

a slight increase in positive changes in their lives. This increase, as they primarily alluded to in

the interview section, came as a result of things they had learned during treatment for their co-

occurring disorders. As had been illustrated in the interview discussion, the meaning of these

losses varied with the outlook of the individual experiencing them. While a loss for one would be

noted to be of minor effect, another with a similar loss would experience their loss as life

changing. Additionally, how readily available the awareness of a particular loss was varied from

one which had faded into the fabric of life to one which was highly charged, an everyday-

thought-of situation. The degree of understanding of the source of losses and the impact on personal self-esteem was raised as an issue in the study. And of marked interest is the positive life factors depicted by nearly all participants that had come as a result of having, dealing with, or receiving treatment for mental illness. The unintended benefits mentioned as having come from participation in the survey are also worth noting.

In general, the areas identified by study participants as most affected by loss either due to intensity of impact or frequency of occurrence are: (a) family relationships, (b) concentration, (c) employment, (d) education, (e) autonomy/control, (f) self-respect, (g) feeling understood, (h) financial control, (i) communication, (j) being of value, (k) goals/dreams, (l) hope for future, and (m) pleasure in the moment/day. While there were obviously many other areas of loss and specific instances where the effect of that loss on an individual was intense, those listed above represent the losses which generally seemed to lead to the strongest grief reactions from the individuals taking part in the study.

There are many areas found in the literature on loss involving those with mental illness, which are supported by the findings of this study. One is the observation that these losses are ongoing in the lives of these individuals and as such have an impact which may be felt throughout their lives (Harvey, 2002; Murray, 2001). Many of the areas of loss cannot be ameliorated, others, with training such as communication skills or assertiveness training can be lessened or even eliminated. But the majority of the losses delineated by these study participants will have an enduring effect in their lives.

Another situation found in this study which supports the literature is that of self-limiting behaviors which are driven by fear leading to the diminishment of personal resources supportive of the development of a higher quality life. As mentioned previously, Kirk et al. (2000) spoke of

the purposeful self-restricting of challenges in the lives of those with the experience of severe

mental illness. This is may be done in order to limit the stress or demands which they believe

could be too much for them to deal with and which they worry might aggravate their well-being

or mental health symptoms. While protecting themselves in this fashion, they are also

diminishing the quality of their life and well-being by removing access to some of the very

situations which could assist them in maintaining their quality of life, self-esteem, and their

mental health (Kirk et al.). This was expressed quite poignantly by both a male and a female

participant and was illustrated in statements which were quoted earlier.

The literature had a very strong emphasis on external stigmatization. While there was

mention of this by a few participants, it did not seem to have the degree of impact on them as

alluded to in the many studies in this area. Those who did describe concerns about this referred

to family members or mental health staff/officials, but usually not toward society or friends.

Perhaps, as noted previously, Camp et al. (2002) found that the negative effects of societal

stigmatization might be avoided if the individual believes the depictions are inaccurate or

uninformed and is able to avoid identification with them. Many participants indicated a sense of

comfort and affiliation with the other clients within their treatment program. One possibility is

that this provided them with access to a society within which they could fit without concerns of

being judged or labeled. Internal stigmatization, when present, seemed to lead to strong blame

and de-valuing of self. Often, this was in reference to the expectations coming from the

individual's family rather than general societal stigmatizations. These participants had deeply

internalized family values and when unable to live up to them due to their mental illness

symptoms, attributed this inability to personal defects. They seemed unable to allow for the part

their mental health diagnosis may have played or for a re-evaluation of the standards against

which they measured themselves. In general, unlike those studied in much of the literature, stigmatization was not noted to be an area which produced much cause for grief reactions for those participants in this study.

This study covered a wide range of possible loss areas. Future studies might find it valuable to focus on a particular facet of loss, such as the ability to be gainfully employed, and the effects this has on individuals with severe and persistent mental health diagnoses. Greater depth and understanding of a specific loss issue could be obtained from this. Also, there could be exploration of the issues of loss due to mild or moderate mental illness rather than just with the population diagnosed with severe and persistent mental illness employed with this study in order to look at the experience of a wider range of individuals.

Another area of future study might be one considering the many areas found in this study where participants felt they had grown or had positive changes in their lives from having a mental illness. Some of this growth was attributed to things they had learned from treatment (skills, etc.), but many found acceptance of their situation in at least part and were able to have a perception which served them rather than diminished them surrounding those particular losses. It might be valuable to look at the ways participants made meaning from their losses, such as how some arrived at the place where they viewed these as a way to build character or to gain understanding for others. Related to this, might be a study designed to discover how individuals with mental illness grieve their losses and what aspects of the grieving remains to be addressed for them.

Future studies might be indicated to look at the unintended positive benefits which clients described immediately after participating in the survey and interview. There could be speculation that these benefits came from an opportunity to "be heard and understood" with no expectations

from the listener or possibly from an open ended time period to say what they wanted to say or some combination of factors. Looking for concrete causes rather than supposition could prove to be of value. Additionally, an examination of the lasting effects of this positive experience could be constructed. One could examine how long participants continued to experience feeling good, increased self-esteem, or as they described, the release of some of the burden of their loss. Also, noting any changes which may have resulted from this one time experience might give important information.

A limitation of this study was the one-time only interview with participants. It might have provided greater depth of information to have the ability to go back to see if further thoughts in this area had come up for participants following the initial discussion. To do this, the number of individuals in the study may need to be significantly reduced due to time and data constraints.

An area of the study which would be altered by the writer/interviewer would be a change of wording for some of the statements on the survey which reflected a reverse phrasing. This would be done in order to make them simpler and more accessible to the study population who expressed difficulty with concentration. While only one participant asked about a statement on the survey, it is believed that the accuracy of the survey may have been greater had this been done.

This study clearly shows that in addition to living with severe mental illness and coping with its symptoms, individuals with a long history of this are also dealing with collateral issues. The losses experienced by these individuals can be demoralizing. They can add stress and other pressures to an often unsettled situation which could impact efforts of treatment or exacerbation of symptoms. The ability to move from grief reactions to acceptance and even meaning making varies individually depending on personal resources and perceptions. In addition to the treatment

of mental illness and its symptoms, efforts should be made to assist these individuals in dealing with their losses. This would most likely bring an improved quality of life and ability to function to those in considerable need of relief.

<div align="center">*Recommendations*</div>

Below are ideas for ways to address, from a mental health standpoint (as opposed to case management or social service one), some of the loss issues which the participants in this study have experienced in their lives. Although most of these are for group interventions, it is certainly feasible and even recommended that individual therapy sessions also incorporate relevant aspects where appropriate. Not all suggestions would be suitable for each individual due to a wide variance of their capability to participate fully or even in part. This is not a linear or process although some milestones must be reached before others can be of value. The below suggestions are grouped according to themes discussed earlier in this paper.

Control

The loss of control has great impact on many aspects of the lives of those with mental illness thus providing for a broad array of loss. Giving individuals back means to regain whatever measure of control possible is of high value. This can be approached through education and skills training to assist the person's belief in their ability to have an impact on their own life.

- Literature designed for clarity and readability about their mental illness
- Individual and family educational sessions with primary therapist focusing on their diagnosis and specific symptoms as applicable to the individual
- Mental health psycho-educational groups using discussion and media tools
- Psycho-educational medication groups

- Psycho-educational training for specific areas such as parenting, handling finances, job readiness, memory/concentration skills, social skills, communication skills, making changes, decision making, etc.

- Groups working on methods of dealing with loss or other difficulties resulting from mental illness such as stress management, spirituality, reframing

- Identification of client priorities both immediate and long-term

- Exploration of new possibilities which can replace those things which were lost especially in the areas involving goals and dreams

- Encouragement for individuals to take greater control over their treatment program, choices, medications, appointments, etc.

Self-perception

With an individual's acknowledgement of their mental illness and its ongoing impact on their life, it is vital that they not define themselves by their diagnosis. They most likely will require assistance in framing their losses and life in a way which allows them to safely examine what might be a shaken identity and a need to redefine their personal and social value.

- Process groups where those with a healthy acknowledgement of their mental illness can assist those who are just beginning to address this.

- Individual and group exploration of the meaning individuals give to having a mental health diagnosis

- Exploration of the impact of stigma and labeling from society, family, friends, and particularly from self on the belief systems and self-esteem of individuals

- Skills training groups addressing areas affecting self-esteem such as personal care or new ways of feeling productive and of value

- Cognitive group work on self-esteem and self-blame

- Insight oriented therapy for dealing with internalized stigma

- Facilitated support groups with other individuals who are dealing with losses from similar symptoms such as a group for individuals with concentration difficulties or one for those dealing with hallucinations

Acceptance

Acceptance of their losses/changes, of self as is – mental illness and all, and from others can be key in an individual's ability to have increased contentment and a "recovery of a meaningful life" (Whitwell, 1999, p. 30). Acceptance allows applying energy to changing what is amenable to change rather than toward the struggle or rebellion against the existing moment.

- Concentrating on recovery rather than cure along with an exploration of what this would mean to the individual

- Provide or encourage opportunities for engagement in the society of others both in program and in the community where there can be development of a sense of belonging

- Interpersonal engagement with others having like losses and struggles where they can "get the message that they are not alone and that others like them have succeeded in building rewarding lives" (Ritsher and Phelan, 2004, p.267).

- Provide opportunities for individuals to feel heard and understood as they work through the grief of their loss due to their mental health diagnosis – a safe place to be open – encouraging the questions like "Why me?" Perhaps a group on the telling of personal stories with care taken to avoid perseveration from week to week. Once the

stories had been fully told, the group would move on to dealing with these questions and losses.

- Group work exploring alternate ways of looking at specific losses – giving new meaning to them

- Group work to discuss the growth and positive outcomes individuals have found in having a mental illness or from its treatment

- Providing opportunities for individuals to experience success

- Using creative involvement to move toward a reinstatement of hopefulness toward reality

Summary

While the experience of loss can be categorized as has been done in this study, it is necessary to endeavor to understand the individual worldviews and responses driving the findings. This study has attempted to do so through the addition of the interviews to the original plan for the survey alone. Efforts were made to gain a greater awareness of the participants' unique perspective by adding their voices to their survey responses. It is hoped that the discussion of this topic has brought a greater understanding of the lived experience of loss for these participants with severe and prolonged mental health difficulties. Although leaving many questions and areas yet unanswered or insufficiently explored, it is believed by the writer that the study has been successful in this undertaking

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Appendix A

Circle <u>YES</u> or <u>NO</u> for how closely the statements describe your experience.

<u>**Before onset of mental illness**</u>   <u>**After the onset of mental illness**</u>

1. I was a valuable member of my family circle.

   Before: Yes   No   **After**:   Yes   No

2. I felt stigmatized or labeled.

   Before: Yes   No   **After**:   Yes   No

3. I was usefully employed.

   Before: Yes   No   **After**:   Yes   No

4. I expected to have a fairly typical life.

   Before: Yes   No   **After**:   Yes   No

5. Public authority figures treated me well.

   Before: Yes   No   **After**:   Yes   No

6. I was uncertain of my abilities as a parent or caregiver.

   Before: Yes   No   **After**:   Yes   No

7. I was not in charge of my own finances.

   Before: Yes   No   **After**:   Yes   No

8. I was often more anxious than other people.

   Before: Yes   No   **After**:   Yes   No

Circle <u>YES</u> or <u>NO</u> for how closely the statements describe your experience.

<u>Before onset of mental illness</u>   **<u>After the onset of mental illness</u>**

9. I had very few good friends.

    Before: Yes   No   **After**:   Yes   No

10. I took pride in my appearance.

    Before: Yes   No   **After**:   Yes   No

11. There were very few things at which I excelled.

    Before: Yes   No   **After**:   Yes   No

12. I did not make plans for the future

    Before: Yes   No   **After**:   Yes   No

13. People didn't seem to take me seriously.

    Before: Yes   No   **After**:   Yes   No

14. I could support myself financially.

    Before: Yes   No   **After**:   Yes   No

15. Finding a nice place to live was difficult.

    Before: Yes   No   **After**:   Yes   No

16. I was able to get past my problems without getting stuck on them.

    Before: Yes   No   **After**:   Yes   No

Circle <u>YES</u> or <u>NO</u> for how closely the statements describe your experience.

<u>Before onset of mental illness</u>   **<u>After the onset of mental illness</u>**

17. I enjoyed meeting new people.

   Before: Yes   No   **After**:   Yes   No

18. I was very uncomfortable in new or challenging situations.

   Before: Yes   No   **After**:   Yes   No

19. I had just the right amount of energy to get through the day.

   Before: Yes   No   **After**:   Yes   No

20. I didn't have much hope for the future.

   Before: Yes   No   **After**:   Yes   No

21. I was generally respected by those who knew me.

   Before: Yes   No   **After**:   Yes   No

22. I was not capable of living independently.

   Before: Yes   No   **After**:   Yes   No

23. I had enough money to pay for my basic needs.

   Before: Yes   No   **After**:   Yes   No

24. I usually felt unsafe or insecure.

   Before: Yes   No   **After**:   Yes   No

Circle <u>YES</u> or <u>NO</u> for how closely the statements describe your experience.

<u>Before onset of mental illness</u>   **<u>After the onset of mental illness</u>**

25. I was uncomfortable with close relationships.

    Before: Yes   No   **After**:   Yes   No

26. I had a healthy respect for myself.

    Before: Yes   No   **After**:   Yes   No

27. There was nothing much that interested me.

    Before: Yes   No   **After**:   Yes   No

28. I looked forward to what I was going to do most days.

    Before: Yes   No   **After**:   Yes   No

29. People talked about me behind my back.

    Before: Yes   No   **After**:   Yes   No

30. My concentration was good.

    Before: Yes   No   **After**:   Yes   No

31. It was/is difficult getting to places I wanted/want to go.

    Before: Yes   No   **After**:   Yes   No

32. I could trust those responsible to help me to look out for my best interest.

    Before: Yes   No   **After**:   Yes   No

Appendix B

Qualitative Survey of Loss - Script

Now that you have finished the survey on changes or losses you might have experienced since the onset of your mental illness symptoms, I would like to discuss with you some of the thoughts or feelings that may have come up for you.

1. Are there particular areas where you have losses because of your mental illness which are troublesome to you in your life right now? (Things about which you feel sad, angry, hurt, frustrated, or annoyed, etc.)

2. Are there losses you have experienced because of your mental illness which were not on this survey?

3. Have you found growth or meaning in any of these losses; anything positive that has come out of them for you?

4. What do you think would be most helpful to you in dealing with these losses? What types of things could your mental health treatment program offer to you that might be helpful?

5. Debriefing – I am wondering how you are feeling right now…

Appendix C

Categorized Perception of Loss Survey – Informational Only

Relationships   1 – 9 – 17 – 25

- I was a valuable member of my family circle.

- I had very few good friends.

- I enjoyed meeting new people.

- I was uncomfortable with close relationships.

Self-Esteem   2 – 10 – 18 – 26

- I felt stigmatized or labeled.

- I took pride in my appearance.

- I was very uncomfortable in new or challenging situations.

- I had a healthy respect for myself.

Productivity   3 – 11 – 19 – 27

- I was usefully employed.

- There were very few things at which I excelled.

- I had just the right amount of energy to get through the day.

- There was nothing much that interested me.

Future/Hope   4 – 12 – 20 – 28

- I expected to have a fairly typical life.

- I did not make plans for the future

- I didn't have much hope for the future.

- I looked forward to what I was going to do most days.

Perception of Esteem from Others   5 – 13 – 21 – 29

- Authority figures treated me well.

- People didn't seem to take me seriously.

- I was generally respected by those who knew/know me.

- People talked about me behind my back.

Mental/Physical Capability   6 – 14 – 22 – 30

- I was uncertain of my abilities as a parent or caregiver.

- I could support myself financially.

- I was not capable of living independently.

- My concentration was good.

Standard of Living   7 – 15 – 23 – 31

- I was not in charge of my own finances.

- Finding a nice place to live was difficult.

- I had enough money to pay for my basic needs.

- It was difficult getting to places I wanted to go.

Well-being   8 – 16 – 24 - 32

- I was often more anxious than others.

- I was able to get past my problems without getting stuck on them.

- I usually felt unsafe or insecure.

- I could trust those responsible to help me to look out for my best interest.

Appendix D

Xyz Health System

Consent Form

Exploring the Perception of Personal Loss Resulting from Severe and Persistent Mental Illness as Experienced by Individuals with Adult Onset of Mental Illness

Introduction:

As a member of the Xyz Continuing Day Treatment Program (CDTP) you are being asked to participate in a research study. It is being conducted as a portion of Janelle Atwood's (Principal Investigator) master's thesis for the Department of Counselor Education at SUNY College at Brockport. The research study was approved by Xyz Health System's Institutional Review Board and is being conducted through Xyz's Department of Psychiatry and Behavioral Health. You should read this form carefully and ask the Principal Investigator/Student Researcher any questions you may have before deciding whether or not to participate.

Purpose of Research Study:

The research study is being conducted to gather information on what losses are experienced by individuals resulting from long-term mental health illness and which of these losses are meaningful to them. The participants' opinions in these areas may assist the CDTP staff to plan future treatment groups addressing these concerns.

Confidentiality and Voluntary Participation:

Participation in this study is voluntary. Your choice to participate or not to participate will have no effect on your present or future treatment. If you do choose to participate in this study, you are free to change your mind and withdraw at any time, for whatever reason. If you do so, the information you have already provided will be kept in a confidential manner.

You will be asked <u>NOT</u> to put your name or any of your background information on any of the research forms other than to answer four non-identifying demographic questions. In the interview portion of the survey the Principal Investigator will digitally record the interview with no identifying information included in order to assure confidentiality. Any information that you share in the interview portion of the information gathering will remain confidential and will be known only to the Principal Investigator. Your completed survey and your responses from the interview will be stored with the completed surveys and interviews of the other participants. There will be no way to connect your responses to you.

All research forms will be kept in a separate locked cabinet to be viewed only by the Principal Investigator and will be kept separately from all treatment clinic files. Digital audio recordings will be transferred to a secured computer to which only the Principal Investigator has access. The digital recording will then be deleted from the recording device. Consent Forms and research forms will be destroyed by shredding along with deletion of the recordings from the secured computer at the end of December 2006.

Description of Study Procedures:

You will be asked to complete a survey about your quality of life before you experienced mental illness and also about your quality of life right now. Following this, you will be asked to discuss with the Principal Investigator specific thoughts or feelings you might have about loss due to your mental illness.

Risks or Benefits of Participation:

There are no anticipated risks or benefits to you because of your participation in this research study. This study is designed to gain information that may provide suggestions which could assist in developing group interventions which may more specifically and effectively address concerns about loss. It is probable that CTDP will consider these suggestions in formulating their ongoing and future group interventions and thereby you may experience some benefit if participating in these sessions.

Payment:

There will be no payment for participation in this research study.

Contact Persons:

Student Researcher/ Principal Investigator:	Janelle Atwood Xyz CDTP (585) 555-5555
Faculty Advisors:	Susan Seem Tom Hernandez Department of Counselor Education SUNY Brockport College at Brockport (585) 395-2258
Xyz Health System, Department of Psychiatry and Behavior Health	M. H. Team Leader CDTP Xyz Health Center (585) 555-5555

If you believe you may have suffered a research related injury, contact Janelle Atwood at (585) 555-5555 who will give you further instructions.

If you have any questions about your rights as a research subject, you may contact the Office of the Institutional Review Board at Xyz Health System at (585) 555-5555, Monday through Friday, 8:15 to 5:00 p.m.

<u>Signature and Date:</u>

I have read (or had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this study. I have received (or will receive) a copy of this form for my records and future reference.

Study subject: _____ PRINT NAME

Study subject: _____ SIGNATURE

_____ DATE

Appendix E

Xyz Health System

Exploring the Perception of Personal Loss Resulting from Severe and Persistent Mental Illness as Experienced by Individuals with Adult Onset of Mental Illness

Authorization for Release of Information

The federal Health Insurance Portability and Accountability Act (HIPAA) requires study investigators to get your permission to use information about your health that is either created or used as part of the research. If you have never received a copy of the Xyz Health HIPAA Notice, please ask the investigator for one.

The Principal Investigator will make every effort to keep information learned about you private. It is possible, however, that the protected health information disclosed with this authorization may be re-disclosed by others without your authorization and may no longer be protected by the HIPAA regulation.

Information that will be used includes your answers on the written survey and common themes of loss from the interview which you will complete in a one time session with the Principal Investigator. You will be asked <u>NOT</u> to put your name or any of your background information on the survey other than to answer four non-identifying demographic questions. Any information that you share in the interview portion of the information gathering will remain confidential and will be known only to the Principal Investigator. Your completed survey and interview responses will be stored together with the completed surveys and interviews of the other participants. There will be no way to connect your responses to you.

The Principal Investigator will use your answers on the survey and from the brief interview to conduct the study. The study is designed to gain information which will assist in the formulation of suggestions for group programs which might address loss as a result of mental illness.

The information collected during your participation will be kept in a separate locked cabinet, to be viewed only by the Principal Investigator and it will be kept separate from all treatment clinic files. Consent Forms and research forms will be destroyed by shredding at the end of December, 2006.

Your authorization for this study will not expire unless you cancel it. You can always cancel this Authorization by contacting the Principal Investigator. If you cancel your Authorization, you will also be removed from the study. However, standard medical care and any other benefits to which you are otherwise entitled will not be affected. Canceling your Authorization only affects uses and sharing of information after the Principal Investigator gets your written request. Information gathered before then may need to be used and given to others.

As stated in the Consent Form in the section on Confidentiality and Voluntary Participation, you can refuse to sign this Authorization and not be a part of the study. You can also tell us you want to leave the study at any time without canceling the Authorization.

By signing this Authorization form, you give us permission to use and/or share your health information.

Study Subject:

_____ Signature

_____ Date

Person Obtaining Authorization:

I have read this form to the subject and/or the subject has read this form. An explanation of the research was given and questions from the subject were solicited and answered to the subject's satisfaction. In my judgment, the subject has demonstrated comprehension of the information

_____ Print Name and Title

_____ Signature

_____ Date

Appendix F

DEMOGRAPHICS

Please indicate the categories below which best describe you.

Age Group:

18 to 22 _____   23 to 27 _____   28 to 32 _____   33 to 37 _____

38 to 42 _____   43 to 47 _____   48 to 52 _____   53 to 57 _____

58 to 62 _____   63 to 67 _____   68 to 72 _____   73 to 77 _____

78 to 82 _____   83 to 87 _____   88+ _____

Gender: Female _____   Male _____

Do you have a Chemical Addiction?   Yes _____   No _____

Ethnicity – mark as many as apply:

African American _____

Asian _____

Caucasian _____

Latino _____

Native American _____

Other (specify) _____