Dimensions of Loss from Mental Illness

Amy E. Z. Baker
University of South Australia

Nicholas Procter
University of South Australia

Tony Gibbons
University of South Australia

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Amy E. Z. Baker

Nicholas Procter

Tony Gibbons

University of South Australia
School of Nursing and Midwifery

This review explores the nature, scope and consequences of loss resulting from mental illness. Losses are described within four key themes: self and identity, work and employment opportunities, relationships, and future-oriented losses. In reflecting upon review findings, several assumptions about loss are illuminated. Findings are situated within the cornerstones of recent mental health reform, specifically a recovery-oriented approach and social inclusion. Particular attention is directed towards notions of risk and responsibility and tensions in realizing the impact of loss within an individualized recovery framework. Implications and recommendations for policy and practice are highlighted.

Key words: *loss, mental illness, recovery, risk*

Loss is central to many areas of healthcare, ranging from perinatal loss (Callister, 2006; Franche & Mikail, 1999) to weight loss (Chaston, Dixon, & O'Brien, 2007), to that affecting people with HIV/AIDS (Yang & Kleinman, 2008). In much of the healthcare literature, loss is intimately connected with the concepts of grief, mourning and bereavement, with grief often portrayed as the characteristic response to a loss (Appelo, Slooff, Woonings, Carson & Louwerens, 1993; Engel, 1961; Morrison, 1997). What constitutes appropriate responses to loss and grieving has been widely debated. At one end of the spectrum, authors suggest that loss and grief are

perceived and experienced in personal ways (Lendrum & Syme, 1992; Morrison, 1997; Rothaupt & Becker, 2007) and according to factors such as culture (Weston, Martin, & Anderson, 1998), level of development, support systems and the success or failure of past experiences and present attitudes (Morrison, 1997). In contrast, there have been many attempts to categorize grief into specific stages or phases, with several authors contending grief to be the necessary reaction and prerequisite for healing and recovering from a loss (Appelo et al., 1993; Lafond, 1994). Such recipes for grieving may be unhelpful as they tell us how people ought to experience loss (Weston et al., 1998), when grief may not necessarily be experienced (Repper & Perkins, 2003; Stein, Dworsky, Phillips, & Hunt, 2005). Inherent to these discussions about loss and grief is an intense preoccupation with the individual, a manifestation of individualism in modern Western society. At this point, it is important to note that this review reflects a modern, Western perspective, as this holds important implications in respect to concepts such as self (MacIntyre, 1990) and approaches to healthcare (Conrad, 2005; Giddens, 2009).

Authors agree that people who have a mental illness experience a profound degree of loss (Baxter & Diehl, 1997; Johansson & Lundman, 2002; Lafond, 1994; Macias & Rodican, 1997; Perese & Perese, 2003; Repper & Perkins, 2003) and in many instances, these losses extend to families, communities and societies. For example, globally, across both genders and the socio-economic spectrum, depression is the leading cause of years lost to disability (World Health Organization, 2008). Yet this statistic fails to reflect the many losses people with mental illness experience due to widespread stigma and social exclusion. These social problems often result in shame, despair and ostracism, affect areas of daily living such as housing, employment and social opportunities (Carr & Haplin, 2002) and are cited by mental health consumers as a reason for not seeking help (Groom, Hickie, & Davenport, 2003; Hayward & Bright, 1997). Yet to date, no comprehensive review of loss resulting from mental illness exists. In addition, the types and consequences of losses have not been clearly articulated within the literature. This review addresses several key questions: What is the nature, scope and consequences of losses experienced

due to mental illness? And why is the concept of loss relevant to recovery and the flourishing of human beings affected by mental illness? By the term recovery, the authors refer to the approach underpinning current mental health policy and practice. Perhaps the most well-known definition of recovery is provided by Anthony (1993, p. 15): "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by the illness." Following a review of relevant literature, arising themes, sub-themes and their practical application will be considered. Analysis will be guided by theoretical work of Anthony Giddens (1991, 1999, 2002, 2009), highlighting social theory that emphasizes phenomena which in our everyday lives we acknowledge as primary features of human action. This will involve looking beyond assumptions surrounding the phenomenon of loss which are taken for granted.

The following search strategy informed this review. Nine databases were searched including: MEDLINE, Allied and Complementary Medicine (AMED), Academic Search Premier, CINAHL, PsycARTICLES, PsycINFO, Psychology and Behavioral Sciences Collection, Scopus and Health Source: Nursing/Academic Edition. Search terms included 'mental disorder' OR 'mental illness' OR 'psych$' OR 'schizophrenia' AND 'loss' OR 'lost' OR 'lose' OR 'grief'. Abstracts were assessed for applicability as were reference lists of selected articles to obtain further literature. Limitations imposed included peer-reviewed papers written in English in the past 15 years, with the exception of core informative pieces. The review was limited to adults/adolescents and excluded children. Papers were excluded if: (a) factors other than mental illness or related factors, such as treatment or stigma, resulted in loss, for example, the death of a significant other; and (b) mental illness was not the primary diagnosis of participants.

Variation between and within the quantitative and qualitative paradigms of the studies included in this review cannot be captured in a single set of quality criteria. As selected quantitative studies used statistics as a form of descriptive narrative, papers were not rejected based on quality appraisal scoring; rather, quality was gauged by the level of rich description and

insight into the phenomenon under study. This same approach was taken when appraising other non-research publications and reports that held particular relevance and contributed further understanding to the topic of interest. There is controversy surrounding the viability of combining findings of research studies that use different methods (Barbour, 1998). We take the view that while there may be multiple explanations of phenomena, they ultimately relate to a common underlying reality (Mays, Pope, & Popay, 2005) and therefore can promote a broader understanding of a research topic. Quantitative studies were included for their capacity to reveal dimensions of loss, while the researchers sought to augment these findings using richer, descriptive accounts from a number of qualitative studies and analytical papers. Thus, thematic analysis was chosen for its ability to identify and bring together the main, recurrent or most important issues or themes to emerge from the combined research literature (Mays et al., 2005). Synthesis was carried out in several stages. First, each study was independently reviewed and findings were summarized in point form, classifying key themes and categories. These were discussed with two fellow researchers with the view to explore similarities and differences within the topic area, as well as divergent viewpoints. Studies were not grouped by inclusion criteria (i.e. studies that provided insight into the experience of loss versus those that described or evaluated the extent of loss) as a considerable amount of overlap was identified across the selected studies and conceptual papers. Findings were then grouped according to similar themes and sub-themes.

This review begins by exploring the term "loss" within the field of mental health and everyday language used to depict mental illness. The nature, scope and consequences of losses that occur due to the presence of mental illness will then be presented. Finally, review findings will be situated within the contexts of recovery and social inclusion, with particular attention to the concepts of risk and trust, highlighting implications for both mental health practice and the wider society.

Loss Arising from Mental Illness

The notion of loss is central to many everyday expressions, though typically disrespectful terms, used to portray mental health problems within Western society: for example, 'He's losing it,' 'She's lost the plot,' 'He's lost his marbles,' 'She's losing her mind,' and 'He's losing control.' In a study of how mental illness was portrayed in children's television in which the 59 of 128 episodes viewed contained one or more references to mental illness, 'losing your mind' was the third most common term depicting mental illness and all references to mental illness had a central implication that the character was losing control (Wilson, Nairn, Coverdale, & Panapa, 2000). The concept of loss manifests within other derogatory phrases used to describe people with mental health issues, including 'a screw loose,' 'gone in the head,' 'a can short of a six-pack,' and 'gone insane.' An Australian poet and mental health consumer, Sandy Jeffs, explored sayings which denote madness in her poem entitled *A Thesaurus of Madness* (Jeffs, 1998). Many of these sayings encompass loss, such as "suffers from loss of reason," "a camel short of a caravan," "a brick short of a load," and "a sandwich short of a picnic." Other terms which have been used to depict people with a mental illness include "lost souls" (Fitzpatrick, 2007) and being treated as a "lost cause" (Lewiston, 2007).

Loss is also central to many official criteria for mental disorders; for example, several features that characterize major depressive disorder include the loss of interest or pleasure, loss of appetite and loss of libido (American Psychiatric Association [APA], 2000). Negative symptoms of schizophrenia, including affective flattening, alogia and avolition reflect a loss of normal functions (APA, 2000) and positive symptoms produce a loss of usual cognitive functioning and a capacity to orient oneself to both external and internal reality (Wittmann & Keshavan, 2007). As with depression, anhedonia is also common in schizophrenia (APA, 2000). Other examples of losses that characterize mental disorders include the loss of sleep during manic episodes in bipolar disorder, fear of abandonment—a potential loss—in borderline personality disorder (APA, 2000) and weight loss and amenorrhea in anorexia nervosa (Lee, 1995).

Loss of role performance, including prospects for the future, is also an important diagnostic feature of many disorders (Appelo et al., 1993). In addition, it has been argued that in the case of schizophrenia, much behavior indicative of this disorder is incorrectly interpreted as psychopathological or as a lack of motivation, instead of being an ordinary reaction to the many losses arising from schizophrenia (Appelo et al., 1993). There is also a large body of work examining significant loss as a possible aetiological factor in mental illness, however, this topic is outside the boundaries of the current review.

Loss from mental illness has been conceptualized broadly as a pervasive sense of "something missing" (Vellenga & Christenson, 1994) and as more nebulous and stigmatized than loss arising from physical disorders (Baxter & Diehl, 1998). The losses arising due to mental illness will now be considered in four key areas: self and identity, work and employment opportunities, relationships, and future-oriented losses. However, it should be noted that in many instances, losses encompass several categories and therefore, the following categories are not mutually exclusive.

Loss of Self and Identity

Loss of self or identity as a result of mental illness has been articulated in a range of ways including being stripped of one's identity (Jeffs & Pepper, 2005; Joseph-Kinzelman, Taynor, Rubin, Ossa, & Risner, 1994), shattering the core sense of self (Young & Ensing, 1999), the dispossession of selfhood (Letendre, 1997) and no longer knowing who one is (Macias & Rodican, 1997). Sandy Jeffs describes the intense nature and consequences of this type of loss:

> With the onset of mental illness, one is often stripped of one's identity and left with a sense of failure and distress. One feels like a shell; a being of no substance; one who walks in the shadows of others and casts none of one's own; a victim of the spooks and phantoms that pervade one's mind. (Jeffs & Pepper, 2005, p. 92)

Various metaphors have been used to illustrate this loss experience. In a study exploring the impact of bipolar

disorder on the development of self and identity, one partici-
pant's experience of losing the things that help to define their
sense of self was symbolized as a reed floating in the wind
(Inder et al., 2008). In a different study which explored every-
day occupations before and after diagnosis in focus groups
with four young men who had schizophrenia, loss of self was
portrayed in the analogy of a computer crashing that needed
to be rebooted (Gould, DeSouza, & Rebeiro-Gruhl, 2005).
Another participant described that his psychological map had
been taken away, stating, "If you don't have a map, you don't
know where you are or where you're going...You could be
lost." (Gould et al., 2005, p. 470). Gould and colleagues' study
was titled "And then I Lost that Life" to highlight the losses
experienced due to schizophrenia.

Loss of former self was one of four categories generated
within the Personal Loss from Mental Illness (PLMI) scale, a
brief measure assessing loss from mental illness (Stein et al.,
2005). This category included three items that reflected changes
in self perceptions due to mental illness (Stein et al., 2005). Loss
of identity also emerged as the central theme of the mental
illness experience for participants in an ethnographic study
which used photovoice as a methodology (Fleming, Mahoney,
Carlson, & Engelbretson, 2009). In this study, identity loss was
described as the culmination of the effects of suffering and
stigma, however, findings are limited by the fact that data
were generated from an artistic interpretation of participants'
experiences, rather than from participants themselves, and it is
unclear whether measures such as member checking occurred
(Fleming et al., 2009). Loss of a previous life or self was also de-
scribed elsewhere in the literature (Browne, Hemsley, & St. John,
2008; Davies, 2001; Lim, Nathan, O'Brien-Malone, & Williams,
2004) and the loss of a 'normal life' for people with schizophre-
nia has been described by family members as one of the most
devastating aspects of this disorder (Stein & Wemmerus, 2001).
Loss of time was discussed in relation to losing youth (Bassett,
Lloyd & Bassett, 2001), periods whilst unwell (Browne et al.,
2008; Lim et al., 2004; Robertson & Lyons, 2003) and due to a
lengthy diagnosis (Joseph-Kinzelman et al., 1994).

A recent study examining all first-person accounts (n=45)
over several years from two well-known psychiatric journals

yielded five themes, the most prominent of which was a loss of self (Wisdom, Bruce, Saedi, Weis, & Green, 2008). For many, this resulted in the loss of a previously held identity, yet for others it involved removing the good parts of the person or specific identity roles, such as being a parent (Wisdom et al., 2008). The authors also noted that the majority of passages describing a loss of self were devoid of hope and associated with a focus on symptoms and illness rather than recovery or strengths. In other studies, identity loss was connected to the experience of insubstantiality (Inder et al., 2008) and one person's experience of identity loss was connected to self-loathing and feeling that others detested him (Macias & Rodican, 1997).

Other losses related to self and identity included dignity, respect and self-esteem. Loss of control over one's life experienced whilst hospitalized was perceived to lead to a loss of dignity (Joseph-Kinzelman et al., 1994; Letendre, 1997; Nilsson, Nåden, & Lindström, 2008). Findings from a study exploring patients' experience of involuntary psychiatric care suggest that the feeling of decreased human dignity arose from a perceived loss or lack of respect from others, described broadly as a violation of integrity (Johansson & Lundman, 2002). Elsewhere in the literature (Yang & Kleinman, 2008), loss of moral status was discussed as having major implications for people with stigmatized conditions such as schizophrenia, including a 'social death.' Loss of self-esteem was described by a group of young men who experienced employment issues following psychosis (Bassett et al., 2001) and lost self-esteem was also reported as a consequence of losing control over one's life due to hospitalization (Letendre, 1997). Similarly, a loss of self-confidence was identified by a group of men with serious mental illness (Noh, 2004) and in reference to feelings of help-nessness, hopelessness and a view of being defective (Lim et al., 2004). Lost confidence was also perceived to result from the combined stigma of having a mental illness and receiving a pension (Browne et al., 2008). Further, people who had experienced psychosis described losing confidence in others due to impaired judgement (Koivisto, Jahonen, & Vaisanen, 2003).

Other concepts related to the loss of self included freedom, choice, control and independence. Loss of freedom was discussed mainly in reference to being hospitalized (Davies, 2001;

Dipple, Smith, Andrews, & Evans, 2002; Pereira, Furegato, & Pereira, 2005) and due to limited autonomy experienced whilst in involuntary care (Davies, 2001; Johansson & Lundman, 2002). One participant perceived that an absence of freedom in this environment perpetuated a range of losses, including justice, speech and attention (Pereira et al., 2005). More broadly, Anthony (1993) speaks of the loss of rights and equal opportunities that may occur following the label of mental illness. In a study with women who had puerperal psychosis, loss was one of three themes, comprising a loss of control in the areas of self, decision-making and treatment (Robertson & Lyons, 2003). For participants who had experienced psychosis, loss of control over one's self was reported to result in feelings such as causing harm to others or oneself and being controlled by outside powers, which in turn culminated in reactions such as insecurity, exhaustion, guilt and sleeplessness (Koivisto et al., 2003). Participants in another study expressed loss of control in bodily terms, related to medication side-effects such as foaming at the mouth, slurred speech or contortion of facial muscles, and loss re-emerged in stories of forced abortions, body-searches and restraint whilst in hospital (Davies, 2001). The loss of control associated with hospitalization or treatment procedures led to strong feelings of being trapped and anguish (Letendre, 1997) and further contributed to a loss of self or identity (Joseph-Kinzelman et al., 1994; Letendre, 1997). Another loss related to freedom was the loss of belongings such as clothes and money during admission to hospital (Joseph-Kinzelman et al., 1994) as well as other possessions outside of hospital (Lewiston, 2007). Furthermore, for some people who had spent long periods of time in hospital, a loss of community, asylum and safe place were experienced at the point of leaving hospital (Davies, 2001). In a study exploring consumers' insights into the recovery process, loss of control and independence were specifically connected to the initial stages of acknowledging the illness and seeking help (Young & Ensing, 1999).

Loss of health and abilities. Loss of health-related quality of life was studied in a large population survey in Finland, using two instruments which enabled comparisons of severity across different conditions (Saarni et al., 2007). Results showed that

people with typically chronic disorders, including dysthymia, generalized anxiety disorder, agoraphobia and social phobia, experienced the largest losses in health-related quality of life, however some conditions, including bipolar disorder and schizophrenia, were not included in this study (Saarni et al., 2007). Of note, results for people with dysthymia and generalized anxiety disorder were comparable to those reported by people 20 years older with conditions that considerably decreased health-related quality of life, such as Parkinson's disease and heart failure (Saarni et al., 2007). Loss of health has also been reported due to treatment and medication effects. For some consumers, treatments have resulted in losses in the areas of motivation (Bassett et al., 2001), energy (Bassett et al., 2001; Nilsson et al., 2008), weight (Nilsson et al., 2008), bone density (Perese & Perese, 2003), normal sexual and reproductive functioning (Chernomas, Clarke & Chisholm, 2000; Perese & Perese, 2003) as well as a sense of health generally (Dipple et al., 2002). Several participants who experienced a loss of energy connected this with their medications' effect on thought processes, describing a fear of "chemical lobotomy" (Nilsson et al., 2008). In a study exploring the everyday experience of being a patient in a psychiatric hospital, participants reported medications caused a loss of "ability to do things," memory and concentration (Letendre, 1997). Loss of concentration was also noted as a consequence of bipolar disorder (Inder et al., 2008). Participants in another study described the difficulties associated with losing memory, ability to learn new things and access previously obtained knowledge and these created a sense of insecurity and impediments to an active life (Erdner, Magnusson, Nyström, & Lützén, 2005).

Also identified within the literature were the loss of abilities (Bassett et al., 2001; Fisher & Mitchell, 1998), including the ability to focus (Gould et al., 2005) and cognitive and emotional abilities (Wittmann & Keshavan, 2007). Participants in one study felt they had lost the 'privilege' of experiencing normal emotions as a result of puerperal psychosis (Robertson & Lyons, 2003). Other people with a mental illness spoke of lost abilities to undertake multiple roles and tasks simultaneously following the onset of their illness (Lim et al., 2004). The loss of roles (Browne & Courtney, 2007; Corring &

Cook, 2007) and routines were described as being a part of the burden of having a mental illness. Roles and routines also comprised one of four categories of loss in the PLMI scale (Stein et al., 2005).

Loss of work and employment opportunities. Losses in the area of work encompassed a number of factors, including the loss of previous work (Inder et al., 2008; Nilsson et al., 2008; Stang, Frank, Yood, Wells, & Burch, 2007), employment opportunities (Bassett et al., 2001; Vellenga & Christenson, 1994) and earnings (Kessler et al., 2008; Marcotte & Wilcox-Gök, 2003; O'Neill & Bertollo, 1998). It is likely that this area has received greater research attention than other kinds of loss however, due to the massive economic implications for society. For example, a recent study estimated serious mental illness to be associated with a loss of $193.2 billion in personal earnings across the total U.S. population during 2002 (Kessler et al., 2008). There is a vast body of knowledge reporting on productivity loss due to mental disorders and predominantly data are collected using self-report methods. Productivity loss resulting from mental illness covers a range of circumstances including absenteeism (Acarturk et al., 2009; Hoffman, Dukes, & Wittchen, 2008; Stang et al., 2007), presenteeism and work-cutback (Stang et al., 2007) as well as lost productivity from low rates of workforce participation (O'Neill & Bertollo, 1998; Lindström, Eberhard, Neovius, & Levander, 2007) and premature mortality (Insel, 2008). Due to the extensive range of measurement tools used, mental disorders studied, and factors such as geographical variability and inflation, it is difficult to make comparisons across studies. However, core issues pertaining to loss in this area have been summarized below.

Losses experienced due to the costs of treating mental disorders are experienced on both a societal and an individual level. Unlike many other medical disorders, losses to society in the form of healthcare costs are derived from indirect rather than direct costs, such as public income support payments and the effect of reduced educational attainment (Insel, 2008). Productivity losses for participants with social phobia accounted for approximately 95% of total costs of this disorder, which equated to more than four times the total cost for a person without a mental disorder (Acarturk et al., 2009).

Furthermore, this study was based on self-report and did not include the impact of presenteeism, both factors likely to result in underestimation (Acarturk et al., 2009). In a study examining the direct and indirect costs for patients with schizophrenia (n = 225), productivity losses accounted for approximately 43% of the total costs which included medical costs, care and living costs (Lindström et al., 2007). Of a cohort of 59 patients with bipolar disorder, approximately half reported missing at least one week of work during the past month and 41% reported fearing the loss of their current job due to their emotional state (Stang et al., 2007). Additionally, almost half (47%) felt their performance was 'sometimes to all of the time' lower than that of their peers and 17% cited their disability as the reason for unemployment (Stang et al., 2007). However, as this study was conducted with patients from a psychiatric clinic that was part of a large managed care organization, findings are not generalizable, as they do not represent those who do not have access to such care (Stang et al., 2007). In another study which included 1502 participants, people with mental health problems (n=358) reported the second highest number of job losses, behind musculoskeletal disorders (n=468), yet again, it is necessary to question the generalizability of these results, as this study was conducted with men from rural areas only (Solomon, Poole, Palmer, & Coggon, 2007).

Consumer accounts of losses in the area of work revealed some of the possible reasons for losing employment and the meaning and consequences of such loss (Bassett et al., 2001; Davies, 2001; Inder et al., 2008; Lewiston, 2007; Lim et al., 2004; Macias & Rodican, 1997; Nilsson et al., 2008). The inability to create consistency due to bipolar disorder was perceived to lead to disruption and discontinuation in education, employment and career development (Inder et al., 2008). In another study exploring psychosocial issues with people with bipolar disorder, participants connected a loss of work with lost status, both educational and financial (Lim et al., 2004). Another person described how he had lost responsibility after losing a job (Macias & Rodican, 1997). Other losses stem from the loss of work, creating a fierce cycle that may involve a loss of income, decreased self-esteem and motivation in job-seeking (Bassett et al., 2001). Loss of vocational opportunities was one of several themes in

two studies about men who had psychiatric disorders (Bassett et al., 2001; Vellenga & Christenson, 1994). Studies with women who had a severe mental illness revealed similar findings with regard to loss of employment opportunities, vocational potential or related factors (Chernomas et al., 2000; Hochman, Fritz, & Lewine, 2005; Pereira et al., 2005). The desire to work is evident in many participants' narratives (Pereira et al., 2005), but the risk of potential loss, of losing either a job or financial benefits, were also of considerable concern, as illustrated by one participant who stated, "I want to try and find a job, but I'm scared...that I'm going to get sick and I'm going to lose my job, and I'm going to have no money and how am I going to get back on welfare?" (Chernomas et al., 2000, p. 1518).

Loss of Relationships

It is widely reported that people with mental illness experience severe disruptions and losses in relationships (Fisher & Mitchell, 1998; Kulkarni, 1997; Lim et al., 2004; Pereira et al., 2005; Stein et al., 2005), ranging from relationships with family (Chernomas et al., 2000; Lim et al., 2004) to social contact with colleagues (Nilsson et al., 2008). Compared with people without a mental illness, people with mental illnesses experience a higher rate of divorce (Kessler, Walters, & Forthofer, 1998; Overbeek, Vollebergh, Engels, & Meeus, 2003; Butterworth & Rodgers, 2008). Findings from a study conducted over a decade ago (Kessler et al., 1998) estimated that in the U.S., approximately 23 million years of marriage among men and 48 million years of marriage among women were lost due to divorce associated with prior psychiatric disorder. In addition, there is a large body of work emerging about loneliness and social isolation for people who have a mental illness (Browne et al., 2008; Elisha, Castle, & Hocking, 2006; McCrea & Spravka, 2008; Nilsson et al., 2008). Loss has been described in terms of a lack of fellowship and relief (Nilsson et al., 2008), lost trust in others (Koivisto et al., 2003) and the loss of place in a social milieu (Wittmann & Keshavan, 2007). One factor perceived to lead to a loss of support from others was frequent changes in living arrangements, which created barriers to adequate support for some participants (Chernomas, Clarke, & Marchinko, 2008). However, Corrigan (2003) points to a range

of factors leading to lost social opportunities for people with a mental illness, ranging from biological effects to societal stigma.

Loss of friendships and intimate relationships. Lost friendships were also commonly encountered by people with a mental illness in the studies reviewed (Chernomas et al., 2000; Chernomas, et al., 2008; Lewis, 2004; Nilsson et al., 2008; Parker, 2001). The loss of friends was connected to lost employment or education opportunities (Chernomas et al., 2008; Macias & Rodican, 1997) as well as lost energy and lack of mutuality (Nilsson et al., 2008). Some consumers perceived that lost friends did not understand their illness, which in turn created difficulties in relating with and connecting to the world around them (Chernomas et al., 2000). One person described the risk of disclosing illness and her choice not to, in the hope of preserving friendships (Parker, 2001). Lost friendships were experienced as particularly difficult for people who already had limited supports (Chernomas et al., 2008). Lost relationships with partners or spouses was also evident in several narratives (Dipple et al., 2002; Inder et al., 2008; Lim et al., 2004; Nilsson et al., 2008) and the loss of a sexual self was considered particularly challenging for people who had spent considerable time in hospital (Davies, 2001).

Loss of family. Lost relationships with family members due to the impact of mental illness was highlighted in several studies (Chernomas et al., 2000; Fox, 1999; Lim et al., 2004) and this was sometimes expressed in terms of abandonment (Young & Ensing, 1999; Pereira et al., 2005). Overwhelmingly however, the literature describing lost relationships with family focused upon children. Loss of relationships with children for women who have a mental illness is estimated to be high (Miller, 1997). For example, in one study, the percentage of mothers with serious mental illness who experienced custody loss was more than four times that of mothers without such disorders (Park, Solomon, & Mandell, 2006). The importance of custody issues for people with a mental illness, and women in particular, is reflected in many consumer accounts within the literature in the area of motherhood (Bassett, Lampe, & Lloyd, 1999; Dipple et al., 2002; Fox, 1999; Savvidou, Bozikas, Hatzigeleki, & Karavatos, 2003) but notably also within studies that did not

specifically aim to explore parenting issues (Chernomas et al., 2000; Joseph-Kinzelman et al., 1994; Lewiston, 2007; Lyon & Parker, 2003; Pereira et al., 2005). Custody loss or losing contact with children was the greatest fear of mothers in one study which sought to understand the parenting experiences of 42 women with a mental illness (Nicholson, Sweeney, & Geller, 1998). In a study examining reasons for custody loss with 82 women who had a persistent, severe mental illness, approximately one third of the women (35%) cited their psychiatric condition as the central factor leading to the loss of custody of their children (Hollingsworth, 2004). Yet in another study, none of the mothers with a chronic mental illness who had lost custody of their children attributed this loss to psychiatric problems, however, the sample size was much smaller (n=10) (Sands, 1995).

The loss of relationships with children due to mental illness is not confined to custody loss. As Nicholson and colleagues (1998) point out, losing a child may occur through voluntary placements whilst a parent or carer is in hospital, through involuntary removal because of assumed, suspected or documented abuse or neglect or as a consequence of divorce. Furthermore, the loss of relationships with children and loss of motherhood may be experienced temporarily, such as during the postnatal period if a mother experiences puerperal psychosis (Robertson & Lyons, 2003). Yet although many postnatal mental illnesses are short-lived, consequences of a sense of lost motherhood and not being able to fulfil mothering duties may lead to intense feelings of guilt and inadequacy (Robertson & Lyons, 2003). Separation from children may also be prolonged during periods when mothers with a mental illness are unwell, resulting in the fear of custody loss (Schen, 2005). There are also reports from parents with a mental illness of 'diagnoses being used against them' by spouses and child welfare workers, leading to custody loss (Ackerson, 2003). Worry of this potential loss may contribute to a mother's decompensation, non-compliance with treatment (Nicholson et al., 1998) or result in reluctance to seek healthcare (Ackerson, 2003; Miller, 1997), assistance with parenting skills (Bassett et al., 1999; Sands, 1995) or childcare (Kulkarni, 1997).

Even when children are returned to the care of parents

following temporary removal, mothers may worry of recurring loss and be aware that their behavior will be constantly monitored (Nicholson et al., 1998). Findings from a study exploring whether parents treated in public mental health services perceived they might lose child custody or visitation if they were not adherent to treatment showed almost 20% (n=36, 19%) perceived this to be the case, with the most prevalent sources of pressure being family (42%), followed by social services (28%) [Busch & Redlich, 2007]. Fear of losing custody was one of eight themes in a study exploring parenting roles for mothers with a mental illness, and this issue permeated all focus group discussions (Bassett et al., 1999).

Future-oriented Losses
    Several future-oriented losses have already been considered, including the loss of future employment opportunities and the fear of potential custody loss. Loss of future was the final of four categories of loss included in the PLMI scale (Stein et al., 2005) which included items such as hope and plans for the future. It has been suggested that cumulative losses from mental illness may result in a loss of hope for the future (Lewis, 2004) or loss of a viable future (Wittmann & Keshavan, 2007). Fear of potential losses, including the loss of supports and resources, were evident in personal narratives about the experience of schizophrenia (Hochman et al., 2005; Parker, 2001) and because of the early onset of schizophrenia, this illness may take the form of lost potential, the loss of whom the person would have been were it not for the illness (Hochman et al., 2005). Lost opportunities (Noh, 2004), possibilities (Davies, 2001), goals (Deegan, 1996) and dreams (Corring & Cook, 2007; Davies, 2001; Deegan, 1996; Gould et al., 2005) appeared within many narratives about living with a mental illness. A lost sense of future is also noted to be closely connected to, and impact upon, flourishing in the present time (Deegan, 1996).

Discussion

    This review reveals the enormous range and consequences of losses that occur due to mental illness. One striking finding was the number of qualitative studies in which loss was

reported as a theme but where the research did not specifically set out to explore this issue. These included studies exploring the mental illness experience generally (Davies, 2001; Fleming et al., 2009; Gould et al., 2005; Vellenga & Christenson, 1994; Wisdom et al., 2008), barriers to employment for men with a mental illness (Bassett et al., 2001), gender-related concerns (Lyon & Parker, 2003) and parenting experiences for women with a mental illness (Bassett et al., 1999; Robertson & Lyons, 2003). As we delve deeper into the nature and scope of loss associated with mental illness, the binding element of these circumstances is the way in which they relate to the self-identity of an individual, the logic of which has been examined by Giddens (1991). All human beings continuously monitor the circumstances of their activities as a feature of what they do, and such monitoring has discursive features, albeit limited in some situations. This has been explored by Giddens as a feature of social reflexivity whereby individual action is bound to social processes and circumstances.

Loss is often described as 'personal loss' (D'Andrea & Daniels, 1992; Harvey & Miller, 1998; Stein et al., 2005) yet so often, this epithet fails to accurately portray the nature of the loss experienced. Repeatedly within the literature, what is described as a 'personal loss' affects or is influenced by others, where 'others' may refer to an individual, group or society. This is easily apparent when a relationship is lost, as it is likely that this loss will impact on another person. However, a loss of employment will affect others, whether it is family members or more broadly the societal impact of unemployment. Similarly, many of the losses in the 'self or identity' section in this review are also influenced by others. For example, dignity or respect only exist, and are subsequently described, in reference to others, as are rights and freedom. Hence, many of the losses reviewed here are essentially social in nature and need to be considered in this light. It is recommended that clinicians and future researchers in this area avoid using expressions such as 'personal loss' and instead, adopt phrases that more accurately reflect the social nature of loss, such as 'interpersonal loss.'

It could be argued that our use of the category 'loss of self and identity' does not suitably capture the social nature of these losses. However, we remain mindful that though we are influenced by social contexts, we still possess and create our own

individuality (Giddens, 2009). Furthermore, losses were predominantly described in terms of being a loss to an individual, also captured in terms such as 'personal loss' and the assumed relationship between loss and grief, as previously noted. This emphasis upon the individual is a reflection of the individual model of disability and overarching individualism that dominates within Western societies (Giddens, 2009). More broadly, these observations can be understood within the structural phenomenon of individualization (Beck, 2007; Beck & Beck-Gernsheim, 2002), in which people are increasingly forced to construct their own life situations and biographies, in contrast to development through traditional cultural and social institutions. This process, imposed upon the individual by modern institutions, also shifts the opportunities and risks associated with making decisions onto individuals (Beck, 2007), which has important implications for people who have a mental illness as well as mental health reform in Western societies. These issues shall be considered in more detail shortly.

Although a range of losses have been highlighted to result from mental illness, effort to assess loss (Piper, Ogrodniczuk, Azim, & Weideman, 2001) and support people in this context is often lacking (Lafond, 1994). Several reasons for overlooking this topic have been offered. First, the impact of mental illness is not readily recognized as a loss or as a subject for grieving and thus generates an additional problem for people affected by mental illness, of grieving a loss when it is not recognized as a loss by society (Lafond, 1994). In addition, people who have sustained extensive loss may be threatening, 'as they reflect our own fears, and remind us of our own vulnerability,' which may result in a need to create distance from the person (Myhrvold, 2006, p. 125). Both potential explanations are largely concerned with micro considerations and it has been argued that social work may be better served by conceptualizing interventions in ways that more explicitly incorporate both micro and macro concerns (Wheeler-Brooks, 2009).

Turning to possible macro concerns, we live in a risk society (Beck, 1992; Giddens, 2002) that emphasizes managing risks and generates a diversity of possible futures (Giddens, 1999). Risk is closely connected with the concepts of security,

safety, responsibility and the aspiration to control, particularly with respect to controlling the future (Giddens, 1999). Giddens (1999) also notes that risk has several sides, one referring to the chance of avoiding an unwanted outcome and the other being an energizing quality, such as in financial markets. Risk plays a major role in policies and approaches within mental health care, although largely with the aim of assessing and managing risk (Kemshall, 2002; Pilgrim, 2008). In light of this and the intensity of emotions often experienced from loss, individuals and systems which support people with a mental illness, including families, health professionals and mental health policy, may avoid the topic of loss to avert possible risks. Yet by ignoring the subject of loss, people with a mental illness are denied the opportunity to disclose and share experiences of loss and engage in potentially cathartic responses. In turn, this may perpetuate stigma and social exclusion, by further marginalizing and disenfranchising people with a mental illness.

Risk is also closely bound to the concept of trust (Eriksson & Hummelvoll, 2008), a relationship which is of special interest within the field of mental health. In this review, issues of risk and trust governed decisions as to whether people with a mental illness disclosed their illness (Parker, 2001) or sought work (Chernomas et al., 2000). Mental health consumers also need to have trust in systems of care. Individual responsibility, empowerment and hope are cornerstones of a recovery orientation. For people with a mental illness, a great deal of self-trust and self-confidence will be crucial if the recovery approach is to be realized in its entirety. Exploring loss and its consequences may be considered a risky approach, yet this is crucial to rehabilitation (Lunt, 2001) and recovery in mental health (Davidson, O'Connell, Tondora, Styron, & Kangas, 2006; Deegan, 1996). On this point, Davidson and colleagues make an important distinction that it is peoples' access to opportunities for taking risks that needs to be increased, not risks to providers or communities.

Stigma, social exclusion and social isolation and how these social problems impact upon the lives of people with a mental illness permeated throughout this review, including the meaning and consequences attributed to lost relationships,

the loss of dignity, respect, confidence and employment op-
portunities. Related to this, it is notable that the majority of
losses reported were intangible, such as relationships, sense
of freedom and opportunities. Exceptions to this observation
were items such as personal belongings and physical elements,
such as weight and bone density. At a therapeutic level, it is
important that health professionals working with people who
have a mental illness are mindful of the many losses that may
impact upon clients in their journey of recovery (Chernomas
et al., 2000; Gould et al., 2005) and the role that such loss and
grief may play in perpetuating mental illness (Dipple et al.,
2002). People who have a mental illness may need assistance
in addressing losses (Bassett et al., 2001) and grieving lost op-
portunities (Wisdom et al., 2008) and this may take the form
of acknowledging clients' experiences of loss and fears about
potential losses (McCrea & Spravka, 2008), grief counselling
and stress management (Chernomas et al., 2008). However,
it is important to note that within the literature, the concept
of loss appears to have been taken for granted, for example,
that grief must take place following a loss in order for recovery
(Lafond, 1994) or reintegration within society to occur (Appelo
et al., 1993). In challenging this assumption, it is recommended
that this topic not be approached so prescriptively, but rather
according to the needs of people affected by loss.

Many of the losses encompass several of the categories
developed for this review; for example, the loss of employ-
ment opportunities may be categorized as a future-oriented
loss. Loss has multiple dimensions and is therefore difficult
to categorize. Furthermore, in many instances, losses precipi-
tate from one another, resulting in a messy tangle of losses that
is complex to discuss. The four core categories summarizing
losses in this review reflect the volume of literature apparent
in each of these areas, and should be approached with caution.
For example, the areas of work and relationships for people
with mental illness may have received greater research atten-
tion than others. Another example is the literature about loss
of custody for parents with a mental illness, which was over-
whelmingly focused on mothers' experience of custody loss,
with loss of custody amongst fathers with a mental illness

rarely encountered in this search. This review is limited by the search terms used to obtain papers. Words such as 'reduction', 'diminished' and 'decreased' and consequences of losses, for example 'loneliness,' 'divorce,' and 'suicide,' which imply losses in areas such as relationships and future, were not used as search terms for this review. The review was also restricted to works written in English, most of which were delivered from a modern, Western perspective. These observations and overall review findings underline the need for further research in the area of loss from mental illness, with particular consideration to how other cultures perceive this topic and the impact of loss on recovery.

The vast array of losses that result from mental illness and the impact of such loss described in this review are important contributions to inform future mental health policy and practice. Pertinent to this task, particularly in light of the individualized recovery approach, will be to consider the largely social nature of loss and how this influences matters such as risk and responsibility. These observations point to the urgency in increasing opportunities for social inclusion and social capital for people with a mental illness. Further, it is important to ensure that people with a mental illness are included in the planning and evaluation of future mental health services and policy. Finally, crucial to realising a recovery vision that supports self-determination and empowerment, opportunities need to be made available within a supportive environment to assist people to explore loss, take risks and grow beyond the presence of mental illness.

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