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# Loss and Grief in the Context of Mental Illness

*Bernice Brijan & Derek Strijbos*

## **Abstract**

In this article, we take a first step towards a phenomenological study of loss and grief in the context of mental illness. We argue for a distinction between various aspects of the experience of loss in the context of psychopathology, as well as between the experience of loss and the presence of grief over loss from a self-relational, existential stance. A first aspect of the experience of loss is the loss that is intrinsic to psychopathology. This concerns the alteration of a certain way of being-in-the-world, which can be understood as involving a particular kind of loss, namely that of being part of a shared world. A second aspect is the experience of loss that occurs as a result of and/or following on experiences of mental illness. Both aspects stand in a complex diachronic relationship with each other. In order to understand the relationship between the experience of loss in the context of mental illness and the presence of grief, the role of the existential, self-relational stance is crucial. Taking an existential stance enables a person to relate to their own experiences and situation, thereby enabling to feel the experiences of loss as something to grief about. In this way, grief can play a central role in a person's journey toward recovery.

## **Introduction**

The confrontation with illness is generally understood to be a disrupting experience or a crisis of some sort. Illness breaks or interrupts the habitual patterns in a person's life. In the face of illness, what had previously been taken for granted changes and becomes itself an object of consciousness. For instance, a person may become consciously aware of their own body, of those body parts that are not functioning well, or of the disease or disorder. In a very general sense, then, illness can be experienced as a loss of health. At the same time, however, two people diagnosed with the same disease or disorder can undergo two very different experiences of illness, based on how they feel and live through the experience. *How* a person experiences illness is, among other things, determined by the discursive resources available to interpret their condition, and by the meaning and value that they ultimately give to it (Aho, 2011). This distinction is important, as it implies that the experience of illness does not only involve what is intrinsic to the condition, but also a person's stance towards these experiences. In other words, because human beings have

the capacity to relate to themselves, to others, and to the situation, there is also always an existential aspect to illness. That is, illness is related to our existence, to the experience of being alive, to being bodily situated in time and space and in a world. As such, it differs from a strictly psychological perspective. In the existential relationship towards experiences of illness it becomes possible to relate to the consequences of the disease or disorder for a person's life, to feel grief over the loss that comes with illness, and to give meaning to those experiences.

The difference between the experiential aspect of the illness itself and the existential stance towards it has been generally acknowledged in the context of somatic illness (Carel, 2016). For instance, in the situation of revalidation after an accident, there is much attention for how life has changed because of a loss of abilities, and there may be care involved regarding the insecurities for the future that the situation brings about. When it comes to mental illness, however, the distinction between the illness itself and a person's existential stance towards it is more difficult to make. Unlike the experience of, for instance, breaking an arm, which involves a somatic and local problem towards which an existential stance can be taken, mental illness is concerned with the psyche itself: it involves symptomatic changes in experience and behaviour, including self-directed attitudes. In other words, a self-relational component is involved in mental illness (Glas, 2019). The implication of this is that the attitude towards the experience of illness is not "neutral" but it is influenced or colored by the mental illness itself. This can, for instance, be seen in the context of depression: a person who experiences depression relates to the depression in a depressive manner (e.g., demoralization in treatment because one is convinced that they are beyond or don't deserve help). This characteristic of mental illness complicates the distinction between the experience of illness and the existential stance a person may take towards these experiences. Furthermore, a diminished ability to engage in activities, to take care of oneself, and to perceive one's surroundings may also bring about a variety of losses in terms of identity and relationships.

In this article, we argue that it is important to carefully distinguish between various aspects of loss in the context of mental illness. After a brief survey of existing research on the topic, a first step will be taken by mapping the various aspects involved concerning loss and grief in mental illness. We argue that the loss of health that comes with mental illness can be specified more accurately: it involves the loss of a specific way of being-in-the-world. This must be distinguished from a sense of loss that is directed at but not intrinsic to the experience and consequences of illness. Finally, we will briefly consider the existential stance towards loss and grief in mental illness and sketch some ways in which the different aspects identified so far interrelate diachronically in the development of and recovery from mental illness. Thus, this article

provides an initial step in the study of grief in the context of mental illness from the perspective of phenomenology.

### **Loss and Grief in the Context of Mental illness: State-of-the-Art**

While a sense of loss, which may be experienced as grief, is well recognized in many life-changing events, the losses caused by mental illness appear to be more ambiguous. The available studies mention several reasons for this ambiguity. First, it has been suggested that the sense of loss around developing a mental illness is conceptualized as typically less visible (Young et al., 2004). This may be because the person who experiences a sense of loss may not be aware that what they are feeling is grief related to the development of a mental illness (Young et al., 2004). As a result, losses are often not clear or obvious to the individual themselves (Worden, 2009). This may find expression in accounts that do not explicitly mention grief, although it seems to be present below the surface. A second reason mentioned for the ambiguity of loss around mental illness is that there may be a lack of socially accepted opportunities to grieve, a phenomenon which has been named “disenfranchised grief” (Doka, 1989)<sup>1</sup> or “ambiguous loss” (Boss, 2000, 2010)<sup>2</sup>. Because losses are frequently neglected by the public eyes (Baxter & Diehl, 1998), they are therefore often unspoken. This may cause an unseen sense of loss for the ill individual or even a private experience of loss, possibly experienced as self-blame, personal inadequacy, or powerlessness (Young et al., 2004).

The ambiguity around loss in the context of mental illness also finds expression in the fact that the first-person experience of loss by the patients themselves has rarely been investigated. Most available research in the context of mental illness is on the loss experienced by family members of people who are confronted with mental illness (Davies & Schultz, 2004; Miller et al., 1990; Ozgul, 2004). Various accounts describe the painful processes that family members go through in watching their family member suffer from mental illness. For instance, the following first-person description speaks of the difficulty of mourning for a loved one:

Although grieving for someone who has died is painful, some sense of peace and acceptance is ultimately possible. However, mourning for a loved one who is alive – in your very presence and yet in vital ways inaccessible to

- 1 The term “disenfranchised grief” is used to describe grief that is real but invisible. This concerns loss that ‘cannot be openly acknowledged, socially validated, or publicly mourned’ and therefore cannot be put into context and given meaning.
- 2 The term “ambiguous loss” describes losses that suffer an “absence of public validation, documentation or ritualization”.

you – has a lonely, unreal quality that is extraordinarily painful. (Brohoff, 1988, p. 116)

Despite the scarcity of studies that address the sense of loss of people with mental illness themselves, however, there is evidence that loss is a central aspect of the experience of mental illness (Buchman-Wildbaum et al., 2020). More specifically, in some qualitative studies among people who were diagnosed with schizophrenia it has been reported that loss is a profound, central, and “overwhelmingly painful” experience (Mauritz & Van Meijel, 2009). In this context, most of the available studies focus on concrete losses. For instance, grief over (the loss of) relationships is reported to be one of the most dominant themes among people with mental illness (Baker & Procter, 2015; see also Muthert, 2007, 2012). Depending on the exact situation, this theme may play a role in various ways. For instance, although grief is not explicitly mentioned, the following account describes how there is envy over (the capability of having) relationships. This envy seems to be intertwined with experience of loss of possibilities due to the mental illness. A complex interaction thus becomes visible between, on the one hand, experiencing a mental illness and taking a stance towards it and, on the other hand, experiencing grief over something in the outside world that relates to having and being confronted with a mental disorder.

I want to love. I envy those who can relate to each other... When my heart burns away, will they pick up the ashes and say, “He loved too much but he never knew how to show it so his heart burned away and there are the ashes”? ... My desire burns to sorrow and freezes to ice. My cries hide in my heart. (Bouricius, 1989, pp. 204-205)<sup>3</sup>

Various other aspects of loss in the context of mental illness have also been investigated, such as the effects of loss on self-identity and self-esteem (Farone & Pickens, 2007) as well as how attitudes like social stigma affect the individual’s support and experience as they deal with multiple losses (Feldman & Crandall, 2007). On the one hand, it becomes clear from the available studies that the sense of loss resulting from mental illness is enduring and complex in nature (Appelo et al., 1993; Wittmann & Keshavan, 2007; Young et al.,

3 J. K. Bouricius is an example of family members who have noticed that their ill relatives often report experiencing strong and complex emotions. In her work, she presents samples of her son’s diary writings, who had suffered from schizophrenia. See also, Kring, A., & Germans, M. (2003). Subjective Experience of Emotion in Schizophrenia. In J. Jenkins & R. Barrett (Eds.), *Schizophrenia, Culture, and Subjectivity: The Edge of Experience* (pp. 329-348). Cambridge University Press.

2004). On the other hand, the lack of studies on first-person accounts of grief in the context of mental illness suggests that more work needs to be done on the topic. This is accompanied by an ambiguity surrounding various aspects of loss in the context of mental illness. A distinction is often made between the loss that occurs itself and having a sense of loss, akin to grief, as a reaction to the experience of loss. It is unclear, however, how the experience of loss that is intrinsic to the mental disorder relates to the experiences of loss that occur as a result of and/or following on the onset of the disorder. Moreover, in understanding grief in the context of mental illness, it must be taken into account that the reaction to the experience of loss in terms of grief is influenced by the self-relational component of the mental disorder itself. In what follows, then, various aspects of loss in the context of mental illness will be distinguished from each other and further clarified. This will be carried out from the perspective of phenomenology, which provides valuable tools for distinguishing between and understanding different aspects of lived experience.

### **The Experience of Loss Intrinsic to Psychopathology: Existential Changes**

Although the experience of being ill in general has received relatively little attention within the philosophy of medicine and health (Carel, 2016), in the previous decades the interface between the fields of philosophy and psychiatry has been developing rapidly. Particularly in the discipline of phenomenological psychopathology extensive accounts have been developed of how diagnostic categories such as schizophrenia, major depression, and mania encompass a wide range of existential changes. Phenomenology, the philosophical discipline that focuses on lived experience, departs from the view that we always already find ourselves pre-reflectively in a world, situated in a realm where it is possible to direct ourselves towards entities, events, and situations in these and other ways (Ratcliffe, 2020). This implies that, from a phenomenological perspective, the first principle is not a Cartesian “I am”, but “I am open to a world”. The pre-reflective situatedness in a world is understood to constitute a background sense of reality and belonging. That is, when we have an emotional experience of something, or when we perceive or think about something, we are immersed in this background sense of reality and belonging to the world, which allows the things that we deal with to show up and matter to us in the ways they do. While this background sense of reality and belonging to the world is presupposed by other (e.g., psychological) types of understanding, for the phenomenologist it is itself an object of enquiry.

From the perspective of phenomenology, it is acknowledged that questions which involve the background sense of reality and belonging to the world cannot be satisfactorily answered from a standpoint that takes the pre-reflective

situatedness in a world for granted (Ratcliffe, 2009).<sup>4</sup> This is the case when existential changes occur that impact the overall structure of experience. It has been suggested that the profound and enduring existential alterations in how one experiences and relates to the world and to other people in the context of mental illness concern the overall structure of experience. In first-person accounts of mental illness, the existential changes that occur are often described in terms of inhabiting a world that is different from one that was previously taken for granted.<sup>5</sup>

For instance, persons with diagnoses of major or severe depression often describe their experience in terms of being in a different world, an isolated, alien realm that is adrift from a consensual reality that others continue to inhabit. To them, everything looks somehow different, unfamiliar, lacking in significance, and the person feels unable to practically engage with the world or “connect” with other people. As first-person accounts of depression further suggest, disturbances of world are closely associated with changes in bodily experience: one’s entire body may feel heavy, uncomfortable, painful, and oddly conspicuous (Sass & Ratcliffe, 2017). Furthermore, the world of severe depression is often experienced as unchanging and inescapable (Sass & Ratcliffe, 2017). The following account of depression by Meijer (2019) describes how existential changes involved with depression concern profound and all-enveloping changes in how one experiences the world.

Everything worthwhile is slowly being scraped away and what remains is bare rock. Fear or sadness often cause an overkill of feelings. A depression, on the other hand, weeds out the good feelings, making everything more barren and emptier, and giving free way to the bad feelings. While fear or sadness often have to do with what is valuable, depression shows that nothing is valuable. Depression is not black either, let alone jet-black. It may be dark, in the way in which a night is dark, when the light is withdrawing from the world, making the environment seem more dangerous

4 On the role of belonging in the context of recovery, see the other chapter by Brijan, also part of this volume.

5 As Karl Jaspers (1963) writes: “Everything gets a new meaning [and] there is some change which envelops everything with a subtle, pervasive, and strangely uncertain light.” See Jaspers, K. (1963). *General Psychopathology*. University of Chicago Press, p. 98. This may be accompanied by experiences of derealization and depersonalization. Derealization is the subtle but pervasive alteration in the general sense of reality and meaningfulness, while depersonalization refers to an altered reality of oneself. Derealization and depersonalization experiences are common in the schizophrenia spectrum, but they can be found as well in other conditions, including cases of dissociative, anxiety, and mood disorders.

and making it more difficult to navigate – it is already quieter than during the day and what is still there is less visible. (p. 34)<sup>6</sup>

The account shows that the alterations involved concern both lived world and lived body, as well as agency, space, and sense of time. Later on, Meijer (2019) describes alterations in the sense of time in terms of being stuck in a “continuous, soggy now, apart from the rest of the world,” an experience that she understands in terms of becoming uprooted (p. 42).<sup>7</sup>

There is an extensive wealth of literature on phenomenological inquiry in the context of mental illness especially regarding the phenomena of schizophrenia and depression (e.g., Fuchs, 2013; Fuchs & Röhrich 2017; Sass & Parnas, 2007). In the case of schizophrenia or a psychotic break, alterations often find expression in the so-called delusional mood, which is the subtle but pervasive alteration in the general sense of reality and meaningfulness. This may involve feelings of unfamiliarity, perhaps alternating or even combined with a disconcerting familiarity akin to *déjà vu*. The person may speak of things seeming somehow unreal or yet paradoxically hyperreal (Cutting & Dunne, 1989; Sass & Ratcliffe, 2017). In later or more chronic stages of schizophrenia, the sense of reality seems flatter and more detached, involving a sense of meaninglessness, devitalization, personal irrelevance, and unreality (Sass & Ratcliffe, 2017). This may be accompanied by certain forms of bodily alienation where one’s body seems somehow machine-like or imaginary.

In a general sense, then, the alterations in the context of mental illness may find expression in a radically altered world, a sense of isolation from other people (who may also look somehow different), an experience of one’s body as conspicuous or perhaps alien, a pervasive feeling of unfamiliarity, and/or an experience of unreality (Sass & Ratcliffe, 2017). As a result, the person no longer experiences or believes in quite the same way anymore: the overall structure of experience has changed. In the context of mental illness, a certain way of being-in-the-world is altered. For this reason, it has been suggested that the existential changes that occur in the context of mental illness involve a particular kind of loss. This loss differs from the loss of health that characterizes each experience of illness, regardless of the nature of the condition. Instead, the loss under consideration here seems to precisely concern the loss of a certain way of being-in-the-world or, in other words, of being part of a shared world. This loss may find expression in a loss of the sense of other people and a loss of possibilities involving access to other people. This is closely related to other losses that find their source in the same existential changes,

6 Own translation from Dutch into English.

7 Own translation from Dutch into English.



such as a loss of self (for example, an experience of one's body as alien) or a loss of (aspects of) the material world (for example, a feeling of alienation or estrangement from the world as a whole) (Ratcliffe, 2008).

The perspective of a more general phenomenology of loss in the context of mental illness perhaps clarifies how the famous quote by psychiatrist Van den Berg (1972) in his work, *A different existence*, can be understood. In this work, Van den Berg states that, despite all the possible variations of mental illness, there always seems to be one common thing: namely, that a person with mental illness stands apart from a shared world. He describes:

The variations are endless, but the essence is always the same: the psychiatric patient stands apart from the rest of the world. This is why he has a world of his own: in his world, houses can sway forward, and flowers can look dull and colorless. (Van den Berg, 1972, p. 105)

For Van den Berg, standing apart from a shared world essentially relates to an existential loneliness. He states that:

The psychiatric patient is alone. (...) Loneliness is the central core of his illness, no matter what his illness may be. Thus, loneliness is the nucleus of psychiatry. If loneliness did not exist, we could reasonably assume that mental illness could not occur either. (Van den Berg, 1972, p. 105)

From the perspective of phenomenological psychopathology, it is this incapability to be part of a shared world that is understood to condemn a person to a diminished existential realm (Ratcliffe, 2008).

### **The Experience of Loss as a Result of Psychopathology: More Specific Losses**

Besides a more general form of loss that concerns the loss of a certain way of being-in-the-world, suffering from a mental illness can also cause worldviews to shift, relationships to change, abilities or functioning to decrease, and support to disappear (Macias & Rodican, 1997). This brings in the theme of loss from a different perspective. That is to say, the confrontation with mental illness does not only imply a phenomenological change of being-in-the-world that can be characterized as an experience of loss, but it may also result in other kinds of losses, which are not strictly speaking intrinsic to those phenomenological changes themselves, but rather more concrete and objectifiable *within* one's (altered) lived experience of the world (see also Lafond, 2002). More specifically, the available studies suggest that the role of loss in the context of mental illness stretches beyond the loss of health itself to loss that is

related to the broader social world (Baker & Procter, 2015; see also Muthert, 2007, 2012). Furthermore, mental illness is understood to be accompanied by both actual losses and symbolic losses. This distinction is usually made to clarify that some kinds of loss involve aspects of life that are intangible, but, nonetheless, vital and necessary, while other kinds of loss involve aspects that are concrete and tangible. Symbolic loss is, for instance, the loss of identity or the loss of life events that are not yet and never will be, such as school graduations, weddings, and births.

In the context of mental illness, losses ranging from cognitive functioning and emotional changes to the loss of social support and daily activities have been reviewed (Mauritz & Van Meijel, 2009). Particularly in the context of schizophrenia, several of such losses have been further specified. Some of those losses relate to a person's inner life while others relate primarily to the outside world. For instance, regarding the latter, the loss of connectedness with activities or practical matters has been specified as well as the loss of relationships, the loss because of stigmatisation, and experiences of loss by fellow sufferers (Muthert, 2007). For instance, the following first-person accounts give an insight into the way in which mental illness may affect relationships. More specifically, it shows how existing relationships may involve feelings of distrust after things that have happened, resulting in damaged relationships.

I lost my trust in the people. They did horrible things to me. Yes, I was psychotic then, I know this. I am probably making it up in my mind... But my trust is gone.

It is written to honor your father and mother. Oh, how often did I read this. But how am I supposed to honor them after everything they have done to me? (Muthert, 2007, p. 45)<sup>8</sup>

When it comes to loss that relates to a person's inner life, the loss of dreams, longings, and expectations has been mentioned. For instance, the following account addresses the longing for children and the choice of not having children because of the danger of passing on psychopathology.

I have always wanted to have children. And I would probably be a good father. But the illness I have, they say, is hereditary. I don't even want to think about it. This is not something you can do to your child. So, no, no child. (Muthert, 2007, p. 41)<sup>9</sup>

8 Own translation from Dutch into English.

9 Own translation from Dutch into English.

It becomes clear from the previous accounts that there is a second central aspect of loss in the context of mental illness, which is the experience of loss as a result of and/or following on experiences of psychopathology. As has been illustrated, this aspect often has to do with things or situations in the outside world (as experienced) that cannot be realized or that appear or have become impossible because of the confrontation with a mental disorder. Importantly, this second aspect of loss must be distinguished from the first aspect of loss, which has been elaborated in the previous paragraph: the phenomenological alterations in being-in-the-world that come with mental illness, which can also be characterized as an experience of loss and to which a person may relate. This is not to say that we regard these different kinds of loss occurring in mental illness as clearly separated and independent phenomena. Rather, we see them as intertwined and often interdependent, highlighting different aspects of the dynamic and diachronic complexity of loss and grief in mental illness.

### **The Importance of an Existential Stance and the Relationship with Grief**

Despite much attention in phenomenological enquiry for the loss that is intrinsic to experiences of psychopathology, the aspect of loss that occurs as a result of and/or following on the confrontation with a mental illness has to date been neglected in phenomenological psychopathology. The presence of those various aspects of the experience of loss in the context of mental illness calls for an investigation of the relationship between them. A phenomenological perspective, which differs from other types of understanding in that it takes into account the background sense of reality and belonging to the world, may serve to cast light on this complex relationship. This background structure, which is of a pre-reflective – and therefore not cognitive – character, with dynamic, interpersonal, and bodily qualities, is understood to provide the background for more specific experiences. The distinction between the two aspects of the experience of loss in the context of mental illness indicates that there is a complex relationship between a more general phenomenology of loss that is intrinsic to psychopathology and a more specific phenomenology of loss that concerns the experience of loss as a result of and/or following on experiences of psychopathology. In those aspects, the background sense of reality and belonging is involved as well as more specific experiences.

It falls outside of the scope of this article to explore the exact relationship between the two aspects of the experience of loss in detail. However, a few remarks can be made with regard to central elements that are helpful in further clarifying this relationship. The first concerns the distinction between the experience of loss and the role of grief. At the start of this article, grief has been identified as a (self-relational) reaction to loss. In the context of mental illness, the various aspects of the experience of loss (intrinsic to experiences

of psychopathology and/or caused by or following on experiences of psychopathology) may thus prompt a reaction of grief. It is at this point where the role of the existential stance seems to come in and which, in the context of care, plays a central role in personal recovery. That is, the human capacity to relate to themselves, to others, and to the situation is crucial in the ability to relate to experiences of loss and, thereby, to feel grief about them. In understanding the relationship between the experience of loss and the role of grief, the existential stance is thus of particular importance: it serves as a phenomenological articulation for the presence of grief.

Because of the distinction made between the experience of loss that is intrinsic to mental illness and the experience of loss that is a result of and/or following on experiences of psychopathology, it is important to note that the existential stance can be directed towards the former as well as to the latter, resulting in a complex dynamical relationship between the two aspects. Furthermore, because of the self-relational component that is involved in mental illness, a grief-reaction may itself also be colored by the process of mental suffering and recovery from it. As the experience of loss is concerned with the background sense of reality and belonging as well as with more specific experiences within an experienced reality, grief-reactions can be characterized as well by a certain two-sidedness: they may be about something specific but at the same time they have an all-enveloping character.<sup>10</sup> There is also a complex diachronic aspect to the relationship between the various aspects of loss in the context of mental illness. For instance, it may be the case that a reduction of symptoms is necessary for someone to regain the experience of being part of a shared world. Only then may it become possible to realize what has happened and what has been lost within this shared world. Furthermore, through time, those elements may also influence each other, depending on the course of the disorder and developments in recovery.

## Conclusion

In this article, we have taken a first step towards a phenomenological study of loss and grief in the context of mental illness. We argued for a distinction between various aspects of the experience of loss in the context of mental illness, as well as between the experience of loss and the presence of grief from a self-relational, existential stance. A first aspect of the experience of loss is

10 The background sense of reality and belonging to the world has also been described in terms of a possibility space. The complex relationship between a general phenomenology of loss in the context of mental illness and a more specific sense of loss can therefore be approached and further understood in terms of the experience of possibilities. See Ratcliffe, M. (2008). *Feelings of Being: Phenomenology, Psychiatry, and the Sense of Reality*. Oxford University Press.

the loss that is intrinsic to psychopathology. This concerns the alteration of a certain way of being-in-the-world, which can be understood as involving a particular kind of loss, namely that of being part of a shared world. A second aspect is the experience of loss that occurs as a result of and/or following on experiences of mental illness. Both aspects stand in a complex diachronic relationship with each other. In order to understand the relationship between the experience of loss in the context of mental illness and the presence of grief, the role of the existential, self-relational stance is crucial. Taking an existential stance enables a person to relate to their own experiences and situation, thereby enabling to feel the experiences of loss as something to grief about. In this way, grief can play a central role in a person's journey toward recovery.

Much remains for further research. In order to better understand the processes of loss and grief in (recovery from) mental illness, we see it as particularly important to get a clearer picture of the interplay between the various dimensions identified in this article. This requires both philosophical and phenomenological analysis, as well as further empirical investigation. Importantly, the first-person accounts of people suffering and recovering from mental illness are vital in coming to understand the complexities of loss and grief they experience.

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