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EXISTENTIAL LOSS IN THE FACE OF MENTAL ILLNESS: FURTHER DEVELOPING PERSPECTIVES ON PERSONAL RECOVERY IN MENTAL HEALTH CARE

abstract

Personal recovery entails the idea of learning to live a good life in the face of mental illness. It takes place in a continuous dynamic between change and acceptance and involves the existential dimension in the broadest sense. With cognitive self-regulation and empowerment as central elements, however, current models of recovery mostly have an individual focus instead of a relational one. Furthermore, there seems to be an emphasis on the component of change. Little attention is paid to the role and integration of dealing with loss in personal recovery. In this paper, the role of loss in mental illness will be elaborated from an existential perspective. This will be done by relating existential changes to possibly disruptive experiences of loss in wider experience. With the help of several perspectives on dealing with loss it will be argued this can be integrated in processes of recovery. Then, it will be elaborated how reexperiencing a state of being surrounded, or being included, being held is a necessary part of recovery. The result consists of a refinement of the view on personal recovery. The aim of this paper is therefore twofold: (1) to arrive at a better understanding of what existential loss and loss in wider experience in the context of psychopathology entails, and (2) to further develop perspectives on recovery in mental health care.

keywords

mental illness, personal recovery, existential dimension, loss, meaningfulness

*To the question about the meaning of life
everybody answers with the story of his own life.
(Konrád, A Feast in the Garden, 1992)*

1. Introduction Recovery denotes a personal process of living with mental illness. Thirty years ago, the concept of recovery was introduced in mental health care by Patricia Deegan. She understood recovery as an attitude, a stance, and a way of approaching the day's challenges. Moreover, she emphasized the unpredictability of the process: "It is not a perfectly linear journey. There are times of rapid gains and disappointing relapses. There are times of just living, just staying quiet, resting and regrouping. Each person's journey of recovery is unique" (Deegan, 1988, pp. 96-97). Since its introduction, the concept has become increasingly important in mental health care worldwide. The implementation of recovery-oriented care and the development of the concept has continued to provoke discussions. Various definitions of recovery have been suggested, some of which echo the idea of a personal journey put forward by Deegan. Such definitions are formulated by Anthony (1993), Slade (2012), and Davidson (2012). A recent study by Van Weeghel *et al.* has put forward that personal recovery is an evolving and dynamic concept. Most elements have remained constant over time: the idea is that the concept of recovery represents processes rather than outcomes, including elements of connectedness, hope and optimism, identity, meaning in life, empowerment, responsible risk taking, and coping with challenges (Van Weeghel *et al.*, 2019; see also Andresen, Oades, and Caputi, 2003). Furthermore, the notion of personal recovery can be distinguished from that of clinical recovery. The words *journey*, *process*, and *nonlinearity* are often mentioned in the context of personal-subjective definitions, and words such as *functions*, *abilities*, and *symptoms* are usually employed with regard to clinical-functional definitions of recovery (Van Weeghel *et al.*, 2019).

However, an overarching theoretical framework of recovery to support empirical research on the topic is still lacking. This may have to do with the fact that personal recovery is subjective by definition. Agreement on its meaning therefore remains challenging. Moreover, although recovery takes place in a continuous dynamic between *change* and *acceptance*, there seems to be an emphasis on the component of change. In light of the dynamic of recovery this is a one-sided view. However, in the literature, a shift in attention can be noticed from "What is recovery?" to "How does recovery come about?" (Van Weeghel *et al.*, 2019). In this respect, according to Leonhardt *et al.* (2017), an important element is the recognition of the need for

patients to make decisions about the *meaning* of the challenges they face in their recovery. In other words, a better understanding of the challenges that patients face is necessary in order to understand how coping with these challenges plays a role in recovery.

The goal of this paper is to offer a more nuanced understanding of the dynamic of recovery as a starting point to further develop its conceptual framework. To accomplish this, I return to the first definition of recovery by Patricia Deegan and focus on the losses and challenges that often accompany mental illness. First, the broader context of the existential dimension in psychopathology and in recovery will be elaborated. Then, I consider how experiences of existential loss and challenges can be understood in the context of mental illness and from an existential point of view. Various perspectives will be offered on how dealing with challenging experiences can be integrated in a process of recovery. It will be argued that recovery can be regarded as a process of restoring right relationships. This idea will be presented as a way to further develop perspectives on personal recovery in mental health care.

In human perception, sensorimotor interaction with the environment (or embodiment) and social interaction (or intersubjectivity) are inseparably linked (Fuchs and Schlimme, 2009). The lived body corresponds to the bedrock of unquestioned certainties, which attunes us to the world and to others. Our body, which incarnates us in the world, literally provides us with *sens* through moving around. The French word *sens* cannot only be understood as meaning, but also as directedness and orientation (Edgar, 2016). We do not only experience our being-in-the-world itself, but we can also take stance on these experiences, on ourselves, and on our situation. This reflexive situation has been a central theme in phenomenology and philosophical anthropology. Heidegger, for instance, characterized our condition as “the being who is concerned about its being” and “who relates to its being” (Heidegger, 1927/1962). Kierkegaard defined the self as relating to itself (Kierkegaard, 1849/2008). The evaluative relation with ourselves and with the environment is what constitutes the existential dimension (De Haan, 2017). It functions on a daily, basic, and practical level, but also on the complex level of values, life goals, and worldview (Mooren, 2011/2012).

It has been stated that the existential stance forms the very precondition for the emergence of mental disorders (Fuchs 2011). The idea here is that because we do not align with ourselves and with our present situation, we can suffer from alienation (De Haan, 2017). According to De Haan, the existential stance may be involved in mental disorders in several ways. First, it may play a *constitutive* role in the disorder. This is, for example, the case in anxiety disorders where the fear of getting a panic attack is an inherent element of the disorder itself. Second, mental disorders can *include* patients’ stance-taking. Depression for instance also affects one’s reflective stance on things: it is part of being depressed to have no hope for future change and to have a distorted perception of the past. Third, the existential relation of patients to their experiences and situation can have important *modulatory* effects on the course of the disorder and on patients’ well-being (De Haan, 2017, pp. 529-530).

The existential dimension, understood from our bodily engagement with the world, thus has a central role in how a disorder comes to expression, as well as in how patients relate to their experiences and situation. The ways in which these aspects intervene with each other determines how exactly the existential dimension is involved in the course of a person’s disorder and in processes of recovery. In general, usually questions are involved concerning one’s own existence, the relationship to one’s own body, to other people, and to the world (Boertien and Kusters, 2018). Dealing with these questions in a successful way often results in new meanings (see e.g. Boertien and Kusters, 2018; Dröes and Witsenburg, 2012). In the next section, the emergence of these types of questions will be considered from the perspective of changes in the sense of reality and belonging to the world.

2. The existential dimension in psychopathology and recovery

3. Existential loss in the context of psychopathology

There are many threats to making sense of experiences that accompany mental illness (Van Weeghel *et al.*, 2019). One of the reasons for this is that abnormalities of atmospheric qualities of subjective life are central to phenomenological accounts of mental illness (Sass and Ratcliffe, 2017). This involves what Jaspers calls a “transformation in our total awareness of reality,” a “transformation of basic experience which we have such great difficulty in grasping” (Jaspers, 1963, p. 95). The most common psychiatric term used to describe such experiential alterations is *derealization*. Derealization can be defined as “loss of sensation of the reality of one’s surroundings” or as altered “feelings and sensations of ... reality as perceived by the individual”, and is often paired with *depersonalization*, which usually refers to altered reality of oneself (Sass and Ratcliffe, 2017, p. 91).

The phenomenon of a changed sense of reality and belonging to the world has been described by Ratcliffe in terms of existential feeling.¹ The concept concerns an existential orientation or an ‘opening’ onto the world (Merleau-Ponty, 1964, pp. 163-164), and denotes how the overall experience of being-in-the-world is inseparable from how one’s body feels in its surroundings. That is to say, an existential feeling “is the way in which one finds oneself in the world” (Ratcliffe, 2008, p. 129), while a shift in the feeling is felt accordingly as “a changed relationship to the world as a whole” (2008, p. 124). At times, the world may feel close or distant, threatening or overwhelming, and our relationship with the world may involve a general sense of belonging or estrangement. It is precisely when they are subject to change that existential feelings become particularly salient. For instance, in the context of religious experience one can experience there being a higher order to which one harmoniously belongs, a higher power from which one is inextricable (James, 1902). In the context of psychopathology, however, existential feelings often seem to be related to impoverished experience, thought, or activity (Ratcliffe, 2008). This impoverishment can go as far as existential feelings becoming pathological.

Ratcliffe understands the criteria for existential pathology on the basis of the view that in existential feeling the world is disclosed pre-intentionally as a *possibility space*. Existential feelings have a dynamic versus a static nature, which concerns the ability to change perspectives, and they have to do with relation versus isolation, which concerns the ability to relate to other people (Ratcliffe, 2017). Existential changes that involve a particular kind of loss – that is, a loss of contact with oneself, with other people, and with the world – are thought to be pathological when they condemn a person to a diminished existential realm. Existential pathology is thus an inability to change perspectives, which results in an isolation from others or, in other words, a retreat from a shared world (Brett, 2002). Although this loss of relatedness may vary depending on the kind of disorder, in general diagnostic categories encompass a wide range of “existential changes”, i.e., changes in the ontological dimension that can be distinguished from each other in terms of a person’s access to the possible (Sass and Ratcliffe, 2017, p. 93). These experiences on the level of a sense of reality and belonging are common in the schizophrenia spectrum, but they can also be found in other conditions, such as dissociative, anxiety, and mood disorders.

4. Perspectives on dealing with loss in wider experience

Existential changes do not only operate on the deepest existential level, but they also influence wider experience. How exactly this is the case is for the most part still left unexplored. However, several issues have been noted that may be involved when a person experiences existential changes. Besides a diminished sense of reality, this concerns issues

¹ In his attempt to relate existential feeling to wider experience and thought, Ratcliffe calls the sense of reality and belonging the “global anticipatory structure of experience”. See: Ratcliffe, M. (2017). *Real Hallucinations. Psychiatric Illness, Intentionality, and the Interpersonal World*. Cambridge, Massachusetts / London, England: The MIT Press.

such as altered meaning, altered familiarity, and diminished vitality and relevance (Sass and Ratcliffe, 2017). In other words, existential loss can also result in loss in wider experience. This has also been stressed by Muthert, who identifies six types of loss that can be distinguished in the clinical care of people with a psychotic vulnerability: loss with regard to health; activities or practical matters; dreams, desires, and expectations; relationships; stigmatization, and experiences of fellow patients (Muthert, 2012). The range of domains in life which can be affected by psychopathology shows the potentially disruptive nature of it. Moreover, it is important to notice that it is bidirectional. On the one hand, existential changes may influence a crisis or a disruption in wider experience. On the other hand, loss in wider experience does not only imply *what* is lost; the loss also has an effect on *how* someone experiences the world as a whole (Ratcliffe, 2017). The extent to which this is the case depends on whether the specific experience is regarded as a disruption. A bigger disruption threatens the existing sense continuity to a greater extent. In other words, challenges that people with mental illness face can affect the emotional, social, and existential bonds with the surrounding world. Whereas sense-making has to be understood in the life of the moving body, existential loss can literally result in a standstill.

In a figurative and sometimes also in a literal sense, recovery then often concerns starting to move again, thereby searching for directedness, and orientation. This is often accompanied by the emergence of new meanings (see e.g. Boertien and Kusters, 2018; Dröes and Witsenburg, 2012). Dealing with difficulties is part of this process, and when successful, can contribute to processes of recovery. In terms of existential changes, the ability to change perspectives and to (re-)establish relationships is of crucial importance here. Being able to change perspectives influences decisions that patients make about the meaning of the challenges they face in their recovery. Moreover, relating to other people is an openness to alternative possibilities and to the realisation that what is given to one now is not all there is. At the same time, acceptance of what happened also plays a crucial role. Several perspectives on dealing with loss in wider experience can be distinguished from a theoretical point of view. These theories have in common that health is never a perfect state of being. Rather, it is precisely the ability to adapt and the ability of self-control in light of the physical, emotional, and social challenges of life (Huber, 2014).

Hermeneutical theories give attention to dealing with loss and existential challenges in terms of a reorientation of existence. A common view is that of Attig. He emphasises that the entire person is at stake during processes of actively dealing with loss: emotional, psychological, behavioral, physical, social, intellectual as well as spiritual aspects. Various environments of the person also play a significant role: the physical world, the social world, the world of the self, and the world of the lost (Attig 2011). Three subprocesses can be distinguished. A first process is to realise to a greater or lesser extent that the loss is there. This concerns the *recognition* of the loss. A second process involves looking for respect for the *uniqueness* of the experience(s). A third process concerns searching for an '*understanding*' of what has happened (Attig 2011). The development of new meanings is particularly important in the third process. Various factors may play a role in this regard. First, the movement of positive psychology emphasizes the role of embodying a positive attitude, which consists of elements such as hope, optimism, resilience, and trust. The concept of flourishing denotes "a state where people experience positive emotions, positive psychological functioning and positive social functioning, most of the time," living "within an optimal range of human functioning" (Frederickson and Losada, 2005; on trust, see e.g. Mújdricza, 2019). Second, religion can also function as an existential resource. The relationship between religion and health has been studied particularly in the context of the 'religious coping paradigm'. Religious coping will often occur where non-religious coping

fails, especially in situations involving loss of life, health, and relational embeddedness (Van Uden and Zondag, 2016).

Furthermore, narrative theory can also play an important role in a process of recovery. Sharing the experiences helps to structure thoughts and feelings. This in turn creates “free spaces” for new experiences and restores the ability to regulate behavior and feeling (Bohlmeijer, 2007; see also Lewis, 2012). This allows ‘answers’ to be adjusted over time and to take up the experiences of loss and challenges in the larger context of one’s life story. This enables to establish a meaningful connection between what is lost and what is (still) possible (Muthert 2012). Relating loss with all aspects of existence therefore seems to be an indispensable step in a successful process of personal recovery. However, importantly, regaining control and understanding sometimes does not soothe the pain. What is needed might then not be a search for understanding, but an attempt to face the loss and accept it as a reality.

In any of the perspectives described above, a phenomenological approach seems to relate best to approaching processes of recovery. Phenomenology puts emphasis on the person being a *Dasein* – “Being-in-the-world” – and considers the constructed, interpretive aspects of experience (Corrie and Milton, 2000, p. 9). It predominantly seeks to explore, describe, and clarify with an open attitude. In this context, particularly existential phenomenology may be valuable. Existential phenomenology is potentially concerned with most of the aspects of personal recovery in its psychological dimensions, as it considers issues such as death anxiety, isolation, responsibility, and meaning (Huguelet, 2006).

5. Recovery as restoring right relationships

In the previous sections, recovery has been addressed as a process which is characterised by the dynamic of change and acceptance. Dealing with loss has been put forward as a necessary part of this dynamic. It has been argued that the existential dimension has a crucial role in these processes. However, despite of the fact that the existential dimension is at the core of recovery, it is questionable to what extent it is actually being addressed as a crucial element in mental health care. The most holistic model available for psychiatry is the well-known biopsychosocial (BPS) model, which was brought to medicine by George L. Engel (1977, 1978). This model, however, does not explicitly acknowledge the existential dimension. Currently, many researchers think that biopsychosocial is not enough, and that the model should be expanded to include the existential or spiritual dimension as well (see e.g. Katerndahl, 2008; Sulmasy, 2002). In her forthcoming book on enactive psychiatry, De Haan argues for a biopsychosocial-existential model from an enactive perspective (De Haan, 2020).

The perspective on recovery that has been developed in this paper further supports this view. In the previous sections, loss in the context of psychopathology has been understood from the perspective of existential changes, i.e., changes in the sense of reality and belonging to the world have been taken into account. The idea has been put forward that existential loss in the context of psychopathology may involve a loss of relatedness with a shared world, resulting in impoverished experience. This loss may influence the relationship with oneself, with other people, and with the world as a whole. Experiences of crises may have a profound impact on this, as it disturbs the existing sense continuity. Sense continuity is based on a complex set of relationships that involves coherence, commitment, and connection in time and space (Antonovsky, 1987).

Based on the philosophical-anthropological notion that a human person is a being in relationship (Sulmasy, 2002, p. 25), it can therefore be argued that existential changes and experiences of loss that a person with mental illness may face has to do with a disruption of “right” relationships. It is this idea that I wish to put forward with regard to our understanding of recovery. Understanding the human person as a being in relationship involves viewing

the human person as intrinsically spiritual (Sulmasy, 2002; Lonergan, 1958). From the above follows that a successful process of recovery can be understood as a process of restoring “right” relationships. This involves developing new relationships to what is lost or being challenged in order to be able to focus on what is still possible. In a broader sense, this can be understood as restoring intrapersonal physical relationships, interpersonal relationships, and extrapersonal relationships, involving those with the interpersonal environment, and with the transcendent. In other words, recovery is aimed at coherence, commitment, and connection in time and space (Antonovsky, 1987). The restoration of right relationships thus implies a restoration of our engagement with the world, with other people, and with ourselves, in other words: it concerns the existential dimension of *sens*.

At the same time, as Deegan (1988) stated, “essential aspects of the recovery process are a matter of grace and, therefore, cannot be willed. However, we can create environments in which the recovery process can be nurtured like a tender and precious seedling” (p. 18). A restoration of relationships implies that a necessary part of recovery should also include reexperiencing a state of being surrounded, being included, being held: a sense of trust. One way to enable this, if not the most important way, is with interpersonal encounters and with the help of “free spaces” (Van Weeghel *et al.*, 2019). This direction would provide the conceptual framework of recovery with a foundation in philosophical anthropology, which has direct implications for recovery-oriented practice. It adds an existential or spiritual dimension in the broadest sense to what is otherwise often thought of as just “providing enough social support” for patients.

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