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‘Stealing me from myself’: identity and recovery in personal accounts of mental illness

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Abstract

Objectives—To understand and promote recovery from serious mental illnesses, it is important to study the perspectives of individuals who are coping with mental health problems. The aim of the present study was to examine identity-related themes in published self-narratives of family members and individuals with serious mental illness. It adds to the body of research addressing how identity affects the process of recovery and identifies potential opportunities for using published narratives to support individuals as they move toward positive identities that facilitate recovery.

Method—Forty-five personal accounts from individuals with severe mental illness, which were published in two prominent research journals between 1998 and 2003, were qualitatively analysed.

Results—Individuals with mental illness and their family members described a loss of self and identity that had to be overcome, or at least managed, for recovery to become possible. Writers described (i) a loss of self, (ii) the duality of (ill/well) selves, (iii) perceptions of normality, (iv) specific concerns about parenting and identity, and (v) hope and reconciliation.

Conclusions—Individuals’ stories of their experiences of severe mental illness describe severe challenges managing identity. Efforts to publish personal accounts that focus on strengths-based patient-centred stories, rather than on deficits, could be helpful to provide hope for patients. These published narratives highlight the importance of moving recovery and hope to the forefront among patient, family, and clinician groups. Increasing such information and role models can provide

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important resources to individuals working to redefine themselves and create a sense of self-worth and stable identity that will support productive, happy lives.

Keywords

identity; mental health; personal accounts; recovery

Researchers have recently acknowledged that to understand and promote recovery from serious mental illnesses, we must study the subjective experiences and personal perspectives of individuals who are recovering from and coping with mental health problems [1]. Self-narratives, when published as personal accounts, also provide important information and role models for patients and clinicians. The overarching aspect of recovery from serious mental illness is the redefinition of the sense of self, and the gaining of perspective that mental illness is simply one part of the self [2]. Published personal accounts can be powerful tools for supporting recovery among others as well as that of writers; the written word can be an instrument of ‘personal and collective liberation’ for those in recovery [3]. Reading others’ stories can offer a renewed sense of hope, provide guidance for identity reclamation or construction, and support individuals as they work to develop a new sense of purpose in their lives [4].

Personal accounts have provided an abundance of information on different facets of subjective experiences in recovery from mental illness [5]. Almost two decades ago it was suggested that the mental illness field did not pay sufficient attention to the sense of self and the subjective experience of patients [6]. Although we have made great strides in examining personal accounts since then, the inclusion of recovery is still in its beginning stages [4].

Identity and recovery

Psychosis is characterized by a lack of agreement between self and others about one’s self [7]. The dysregulation between the private self and public self during severe mental illness creates a great sense of crisis. The Green model of recovery processes proposes that key tasks of recovery revolve around the learning process that occurs when individuals with mental illness immerse themselves in their illness in order to become more knowledgeable about its management, effects, and the meaning it has in their lives [8]. Adopting an ‘illness identity’ may be a natural part of this immersion process [8–12]. At the same time, recent studies support the importance of a durable sense of self in the recovery of severe mental illnesses such as schizophrenia [13]; yet being diagnosed with a stigmatized disorder, and societal responses to that disorder, can have important negative effects on identity and self-definition [14]. Moreover, internalizations of negative self-definitions can change individuals’ self-concepts, and such internalizations may not be easily reversed, making the recovery process more challenging [14, 15]. Individuals’ self-perceptions and sense of optimism can also be affected by interactions and feedback from others, such as family [14, 16], and by available role models [17], including those available in published accounts. The lack of a clear model for how these processes of re-development of identity function in individuals with severe mental illness, leads researchers to continue to seek a conceptual theory that would be useful in facilitating the process of recovery.

These findings support the need to understand how identity is described in personal accounts of mental illness and underscore the need for a shift of emphasis from a focus solely on the symptoms of mental illnesses to a focus that includes the person in his or her environment [13]. Individuals’ stories present their efforts to describe their experiences, make sense of their suffering, and come to terms with an altered existence. The present study identifies and examines identity-related themes in published self-narratives of family member s and

individuals with serious mental illness. It adds to the body of research addressing how identity affects the process of recovery among individuals with mental illness, and identifies potential opportunities for using published narratives to support individuals as they move toward positive identities that facilitate recovery.

Methods

Data used in the present analyses include all first-person accounts from the journal *Schizophrenia Bulletin* published in 1998–2002 (n = 18) and all personal accounts from the journal *Psychiatric Services* published between February 1998 and June 2003 (n = 27). These two journals provide regular first-person accounts that focus on severe mental illness and have a broad audience of patients, clinicians, and researchers. In total, we identified 45 personal accounts, which included first-person accounts (n = 25, 56%), third-person accounts (n = 11, 24%) and some written from both the first- and third-person perspectives (n = 9, 20%). Most third-person perspectives were written by family members, and mixed first- and third-person accounts were written by individuals about themselves and another family member with mental illness (e.g. author and child), or about two family members with mental illness (e.g. author's two children or author's mother and child). Author gender distribution was 64% female (n = 29) and 36% male (n = 16). We identified psychiatric diagnoses that were referred to by the author of the accounts. These diagnoses included 25 individuals writing about schizophrenia spectrum disorders (schizophrenia, n = 22; schizoaffective disorder, n = 3); 11 individuals writing about mood disorders (bipolar disorder, n = 7; depression, n = 4), and 14 people writing about other disorders (borderline personality disorder, n = 2; dissociative identity disorder, n = 1; obsessive-compulsive disorder, n = 1; post-traumatic stress disorder, n = 1; pyromania, n = 1; and eight with unidentified forms of serious mental illness). These diagnoses (50) sum to more than the number of accounts (45) because several accounts addressed more than one diagnosis.

The qualitative methodology guiding this study was thematic analysis, a method for identifying, analysing, and reporting patterns, or themes, in data [18]. Thematic analysis involves collecting data (in this case, the first-person reports from selected journals); listing patterns of experiences; identifying data related to these patterns; and combining and cataloguing patterns into subthemes [19]. Thematic analysis is a flexible research tool that can provide a rich and detailed account of data [18].

We began our analyses by developing a preliminary coding scheme based on patterns of experiences hypothesized to be related to aspects of recovery. Three investigators met and reviewed a subset of articles, applying the preliminary coding scheme. The preliminary coding scheme was modified and new codes were added to adequately represent newly identified themes. The coding scheme included descriptive and interpretive codes as well as those identifying patterns in the data. Once the coding scheme was finalized, we used the qualitative analysis software package Atlas.ti [20] to code text from the 45 identified personal accounts. We check-coded 10% (n = 5) of 45 documents to assess inter-coder reliability. Of 177 passages reviewed and discussed, 80% were consistent across coders and accurate. Following coding, we used Atlas.ti to produce reports of coded text for individual codes as well as co-occurring codes (e.g. hope and mental health services), then further analysed these reports to identify prominent common themes related to identity.

This study was exempt from institutional human subjects protection requirements because it analysed only published material.

Results

Writers wrote starkly about the effects of mental illness on their conception of themselves and their family members. Writers described, in order of prominence, (i) a loss of self; (ii) the duality of (ill/well) selves; (iii) perceptions of normality; (iv) specific concerns about parenting and identity; and (v) hope and reconciliation.

Loss of self

The onset of mental illness was often described as taking away a person's sense of self. For many this resulted in the loss of their previously held identity.

[Bipolar disorder] is a disease that for me, literally steals me from myself—a disease that executes me and then forces me to stand and look down at my corpse. It is what the criminal lawyer in me calls a medical examiner's antithesis: life by strangulation [21].

In the most extreme version describing this kind of loss, writers expressed a sense that they, or their loved ones, were 'dead despite being alive'.

My son was already long gone, dying bit by bit over the 16 years of his battle with schizophrenia ... I had never had a real chance to say goodbye to David. He had disappeared into his illness so slowly, imperceptibly [22].

Less extreme were descriptions of serious mental illness taking away the good parts of who someone is, either the totality of their self, or a specific part of their identity, such as being a parent.

... For me [depression] has always been more than a disease: it has taken my self-esteem, confidence, and pride, heaved them into a swamp of worthlessness, confusion, and, frequently, utter hopelessness [21].

Other times, people described the person they knew, or the person they were, as having been replaced with an unknown self that was constructed from the ongoing experiences and symptoms of mental illness.

[The author's brother's] ideas, choices, and actions became increasingly incomprehensible to me. His discourse became vague. At the same time, his poorly articulated ideas became of increasing importance in his definition of himself [23].

Most of these passages describing lost selves were devoid of hope and were much more consistent with a focus on symptoms and illnesses rather than on possibilities for recovery or on available strengths and competencies. As such, these writers seem to have internalized longstanding traditions and negative expectations regarding prognoses for serious mental illnesses.

Duality of selves

Other writers frequently described themselves in terms of dichotomies that maintained conceptions of their real, authentic selves, separating those from the alternative selves that were present during a bad episode. These alternate selves were seen as part of who they were, but were separated as parts that they did not much like or were ashamed to show the world. At the same time, these individuals retained their sense of their authentic identities and with them a sense of hope for rebuilding.

Someone answering to my name was once a terrified, angry person who was showing up in emergency rooms nearly every night and throwing up into a basin, or was being looked for regularly by the police when threatening suicide. ... But that

wasn't the real me. That's not who I want to be. Nor are the other people who are seen through the pathology of borderline personality disorder showing their real selves [24].

It was a tragedy really, and I knew it. The nurses, doctors, and social workers who cared for her saw the illness, but could they appreciate the tragic dimensions of it? Katherine's old self and new self were so cut off from each other – family members not being allowed to see her now, and treaters not able to know what she had been [25].

For some, distinguishing between these two selves became impossible, a cerebral exercise they tired of and eventually gave up trying to resolve. These descriptions appeared resigned rather than hopeful about the future:

The depression I experience never feels like an illness. To me, it's a bad attitude, a deficiency of willpower, and something I brought upon myself. It is a weakness I'm ashamed of. ... Depression is who I am, not what I have, because that's a simpler explanation than trying to understand how both distinctions might be true [26].

Others maintained an ongoing struggle to reconcile the part of themselves that is struggling mentally with the rest of their roles and identities. These individuals worked to define their mentally ill self as only a 'fragment' of who they really are:

My sociologist friend reminded me that we are not only mental patients, we are also writers, doctors, fishermen, husbands, wives, and children. For so many of us, mental problems are really just a fragment of our being. But sometimes societal pressures make our condition a self-fulfilling prophecy [27].

Striving for normalcy

For many writers, being 'normal' and leading a 'normal life' were primary goals. It was a pervasive theme that conveyed an acknowledgement that having a mental illness made them feel 'abnormal', but also gave them a strong desire to become normal, and in some, a sense of hopelessness that although they may be able to 'act normal', they would never truly be normal. Individuals also defined being normal in different ways. Some defined themselves as not normal solely because they had a mental illness. This man recently diagnosed with bipolar affective disorder reported that everyone treated him differently because of his mental illness.

Whether it was stigma from my peers, stigma perpetuated by the professionals 'helping' me, or the self-stigma I experienced, any chance at having a semblance of a normal life seemed lost [28].

Other individuals defined being normal in terms of their ability to achieve major developmental or life milestones, such as having a career, or raising children. Yet other writers defined normal in terms of functioning; for example, describing normal functioning when they are on medication. Underneath any ability to act as normal, however, was a pervasive feeling that because of the mental illness they were not normal, and would never be normal in the truest sense: they would not be like others.

It is possible for mental patients to hide their illness from the world. No one need ever know, for we can 'pass' as normal. Many – not all – of us do this [27].

In a poignant story described by a mother reflecting on her son's ability to 'pull it together' for one last family event before committing suicide, she equates the self with being normal.

Was there a residue of olanzapine left in his system, or was the desire to return to the family so great that he managed to behave correctly anyway? If the latter is

true, then perhaps the self is not totally destroyed. Could there be a core of normalcy waiting to be retrieved? Serge wanted to belong to the family, and he was able to pull himself together long enough to be part of it [29].

This latter quote illustrates the identity dilemmas faced by individuals struggling with mental health problems. To behave in ways other than what are perceived to be correct, risks losing others' perceptions of one's valuable self, and interferes with one's ability to belong. What then, does a person with severe mental illness do when it is not possible to behave correctly at all times? These are some of the most difficult tasks associated with healing, recovering, and establishing an identity that encompasses these past experiences while supporting personal hope and growth.

Parenting and identity

Particularly painful for individuals' identity was the challenge associated with making decisions about whether or not to become parents. Feeling unable or unwilling to risk bringing children into the world left individuals with fewer role and identity options.

Feeling doubtful was my constant state of mind when I considered issues of pregnancy and parenthood. ... My mother tried to soothe my pain and told me I was still a loving person and that not giving birth to my own child didn't make me any less of a woman. She said I shouldn't need a baby to feel complete and that I was deserving and worthy of a loving husband. However well intentioned she might have been, I interpreted her words as meaning that I absolutely wouldn't ever be able to have a stable life with children and that the sooner I accepted that fact, the better off I would be. I was left feeling even more patronized and unworthy [30].

Those who made the difficult choice to remain child-free often felt regret or felt unfulfilled:

The disease has, because of unfortunate life circumstances created by incessant illness and because of doctors' recommendations (given the genetic passage of bipolar disorder from generation to generation), prevented me from having children I would dearly love. This, unquestionably, has been the cruelty hardest to bear: no children to love for a man who loves to love [21].

I have no kids. Thank God. I would not want to bring any in the world just to make them suffer too because of my sickness. But I don't want to die and leave nothing behind [31].

Others documented the experience of raising children with severe mental illness. One woman described her journey of raising eight children, three of whom had schizophrenia. While it had its challenges, she notes that families can be resilient.

Our voyage through turbulence was highly stressful. If stress caused schizophrenia, I and all of my family should be basket cases, and we are not! We may not be the Waltons, but we are a good strong family [32].

Hope and reconciliation

Despite these challenges related to their changing senses of self and identity, some writers maintained hope that individuals would continue to make progress in reclaiming their old selves or in developing new identities. Some indicated hope that the 'essence' of self would return.

I still grieve and hope optimal treatment can offer Susan a new freedom to be herself again, a new self different from what I knew, but hopefully still inhabited by this unique flame that is her essence. I hope to play music again with Susan one

day. I hope this day is not so far off. Most of all, I hope she and I will regain the joy of sharing simple things, simple thoughts, simple notes [31].

Others described a reconciliation of multiple selves.

I [now] have a much more realistic view of what parents who have any kind of mental illness may be challenged with. I have developed realistic expectations and goals, both for myself and for my family. Being mentally ill, in and of itself, does not deny a person motherhood [30].

This woman with schizophrenia struggles with reconciling the thought-voices that are part of herself.

I wonder sometimes, as I grow even healthier, if the voices will fade away completely. Will I miss them? Having lived with them for so many years, I wonder if it will feel empty or lonely without them. Thought-voices are part of who I am, and what makes me unique. With what will I replace them? I believe I will find other ways to be unique. Can I do it? I believe so. I am willing to try [33].

Finally, many writers conveyed a sense that, regardless of what aspects of selfhood the mental illness has taken, individuals must keep hope and continue trying to become the best person they can be, even when it is difficult.

Hope, sometimes even blind hope, must somehow be grasped. It is best grasped not by a lone sentry of the night, but within true community: a place to go, to feel worthy, to nourish a self-respect: a job, a friend, a neighbour, a lover. This is the true lifeblood, and it is this that incessant mental disease steals [21].

Discussion

The present analyses of identity in the context of mental illness confirm the central role of identity transformations – both positive and negative – in the recovery process. Challenges to individuals' sense of self and sense of self-worth were significant, and both individuals with mental illness and their family members described a loss of self and identity that had to be overcome, or at least managed, for hope to obtain and recovery to become possible. The present findings also show that much work needs to be done to include positive voices of recovery in published personal accounts of mental illness. Many of these accounts lacked hope, and few included stories of recovery that could provide hope and guidance to other patients and educate mental health professionals about recovery successes. Given the importance of hope in the literature on recovery, it should come as no surprise that hope can be a catalyst to the recovery process for patients with mental illnesses such as schizophrenia [17]. Therefore, it is even more important that the relative absence of hope in personal accounts of recovery from mental illness be recognized and remedied.

The present work supports that of Davidson *et al.* in placing the redefinition of one's individual self as a central task of recovery [2], but also further reveals this process as being a part of and affected by the larger community in the ways others have described [14]. Indirectly, the lack of hope in many of these accounts reflects ongoing community beliefs that include low expectations and limited chances for those with mental illnesses. Individuals suffering from mental illnesses are thus working to perform identity-reclamation tasks in a larger community in which the feedback received about possible and acceptable roles and identities may be negative or severely limited. Faced with inconsistent and sometimes disparaging messages, the struggle for a new sense of self can be profoundly undermined.

This analysis also points to the need to understand, among individuals with serious mental illness, the developmental processes that occur in all people. These processes include determining the direction of one's life, grieving for lost opportunities, and yearning for belonging and acceptance. Although their needs as patients are generally addressed, individuals with serious mental illness may find that their needs as persons may be ignored [34]. Current efforts are under way to develop therapies to assist individuals and families as they navigate these tasks, and such efforts would benefit from additional attention [35].

We also found that parenthood, as a typical and normal role, played a critical role in patients' conceptualizations of self and identity. Fear of passing disorders along to children, or of harming children as a result of symptoms, left many individuals without the opportunity to take on parenting – a role that could have provided a consistent and positive source of identity. Others also have found that individuals with serious mental illness are less likely to have children than other individuals [36]. It is also consistent with psychiatry's longstanding focus on pathology among parents with mental health problems and the detrimental effects on their children of such problems [37,38]. More recent research, however, suggests that parenting can provide value and meaning in life [39], and that that parenting may not cause the stress or demands that have often been feared would negatively affect parents' outcomes or psychiatric symptoms [40].

Conclusions

The present findings indicate that individuals' identity-related stories of their experiences with severe mental illness indicate severe challenges managing identity following the onset of illness. Efforts to publish personal accounts that focus on strengths-based patient-centred stories, rather than on deficits, could be helpful. In particular, stories that provide examples of individuals recovering from mental illness, of those who have moved through their illness identities to identify new competencies, and of constructing new, or reclaiming old, selves may provide important guidance and hope for both patients and clinicians. This is consistent with suggestions that messages of hope, strength, and encouragement are much needed, and that clinicians can assist in providing these; a positive life is possible for patients suffering from mental illness, and recovery narratives have the potential to convey this message [4]. Education about the value of competency, rather than dysfunction and illness-based approaches, could enhance opportunities for recovery [8]. Further, identifying normal developmental processes, including parenting and grieving, as separate but related recovery tasks, could support important personal development and thus contribute to recovery. Such strengths-based collaborative approaches allow clinicians and patients to co-create possibilities and to build hope rather than remaining mired in pathology, grief, and loss. Additionally, parenting may increasingly play a role in these processes as treatment improves and more individuals become willing and able to accept the risk of parenting [39].

In sum, these published narratives highlight the importance of moving recovery and hope to the forefront among patients, families, and clinicians. Increasing such information and role models can provide important resources to individuals working to redefine themselves and create a sense of self-worth and stable identity that will support productive, happy lives.

Limitations and directions for future research

We were limited to 45 published personal accounts for these analyses, and these were varied in their focus, scope, and authorship, presenting analytic challenges. Nevertheless, they represent genuine expressions of patient and family reflections, concerns, and ideas. Future research addressing the ways in which published accounts affect self-conceptions among readers would be very useful.

One disadvantage noted with using personal accounts is the bias of particular events that are recollected. Critical factors maybe omitted, and themes and terminology may be inconsistent across authors [5]. Furthermore, some have questioned whether the authors themselves are unrepresentative of patients with severe mental illness [4]. Despite these limitations, the individuals discussed in the present sample of accounts included individuals from a variety of circumstances, such as individuals who did not complete high school, professionals such as attorneys and professors, and relatives of writers, and includes all personal narratives published during the study period. The variety of voices that contributes to the discussion about the lived experiences of individuals with serious mental illness strengthens the discourse.

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