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Manuscript title

Attempting to restore integrity of the self - A grounded theory study of recovery from major depressive disorder

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Abstract

Background: Major depressive disorder is a prevalent debilitating condition which may be alleviated spontaneously or through treatment. The processes of developing the disorder and achieving recovery from it are context-based. There is little information on the process of recovery from this disorder in Iran. This study was conducted to explore the process of recovery from major depressive disorder.

Method: A grounded theory approach (Corbin and Strauss 2008) was utilized to explore recovery from major depressive disorder. Twenty patients with major depressive disorder were recruited using purposive and theoretical sampling methods. Data saturation was reached after conducting 27 in-depth semi-structured interviews.

Results: Several themes emerged from the data, the primary of which was ‘Attempting to restore integrity of the self’, which included the two sub-themes of ‘attempting to restore health’, and ‘attempting to reacquire the lost abilities’. The process of attempting to restore integrity started concurrently with ‘losing integrity’ and in a context of poverty, inefficient healthcare systems, perceived support, feelings of failure, and social stigma. During the recovery process, participants adopted both ‘effective strategies’ and ‘ineffective strategies’. Following the attempt to restore integrity, participants experienced different levels of integrity, ranging from ‘complete recovery’ to ‘no recovery/relapse’.

Limitations: Given the limited transferability of qualitative findings, applying the results of this study to other cultures may be problematic.

Conclusions: The results from this study contribute to the body of knowledge regarding recovery from major depressive disorder in Iran. The data suggests that recovery from depressive disorder is a very personal experience that is affected by different and variable factors and conditions.

Keywords: major depressive disorder; recovery; grounded theory

Major depressive disorder (MDD) is a widespread mental health issue, with a prevalence of 5%–10% (Paykel et al., 2005a). Given the prevalence of MDD, the World Federation for Mental Health has spoken of depression as ‘a global crisis’ (World Federation for Mental Health, 2012). MDD is highly prevalent in Iran (Sadeghirad et al., 2010), being the eighth leading cause of disease burden. Hence, decreasing its burden and effects is a major priority of the Iranian healthcare system (Ministry of Health and Medical Education, 2010).

The concept of ‘recovery’ in MDD (defined as a persistent state of remission of symptoms; Dunlop & Rapaport, 2016) has gathered interest in recent years. Studies report that recovery from MDD is possible (e.g., Kessler et al., 2003; Simon et al., 2002) even without receiving professional help (Ridge and Ziebland, 2006), but is a complex phenomenon that requires further investigation (Kartalova-O’ Doherty and Tedstone, 2010; Skärsäter et al., 2009).

It is widely accepted that socio-cultural context plays a significant role in experiences and perceptions of recovery (Hatzidimitriadou, 2002; Humphrey and Townsend, 2005; Onken et al., 2007; White, 2007), and that culture differences impact the expression of depression (Karasz, 2005). Indeed, several studies have explored the process of recovery from MDD in different socio-cultural contexts using grounded theory (e.g., Ridge and Ziebland, 2006; Schreiber, 1996; Skärsäter and Willman, 2006). However, there is a dearth in the

availability of evidence regarding recovery in many cultures, with much research focusing on Western societies. Further studies are needed to develop a context-based understanding of recovery. One culture where differences in expression of depression may exist is Iran. Major depressive cases in Iran have been characterized by a high expression of somatic symptoms (Hakimshoostary, et al. 2007), potentially alluding to cultural differences in progression and recovery (Torkan, 2014). The aim of this study was to explore the process of recovery from MDD within an Iranian socio-cultural context.

2. Method

Corbin and Strauss's (2008) grounded theory approach (Corbin and Strauss, 2008) was utilized in this study to construct theory regarding recovery of Major depressive disorder in Iran.

2.1. Participants

The population of this study comprised all patients with MDD living in Zanjan province, Iran. Participants were recruited from The Dr. Beheshti Hospital in Zanjan. The inclusion criterion was having the ability to share experiences of recovery from MDD.

Primarily, purposive sampling was employed for recruiting patients with MDD who were experiencing recovery. Further, theoretical sampling was used to reach theoretical

saturation of emerging concepts. We reached theoretical saturation after collecting data from 20 participants. Participants' characteristics are shown in table 1.

2.2. Study setting

The study took place within the Neurotic Care Ward, and a private physician's office, both situated within Dr. Beheshti Psychiatric Hospital.

2.3. Data collection

Data were collected from April 2012 to October 2013 through semi-structured interviews. 23 interviews were conducted face-to-face, with telephone interviewing used for conducting four follow-up interviews. Interviews were conducted in a private clinic rooms. The first author conducted all interviews. Interview length ranged from 20 to 60 minutes, with a mean of 40 minutes.

A short introduction took place prior to interview to explain the aims of the study, and to obtain informed consent. The interview began by asking the open-ended question, 'Would you please explain about your current status?' Several questions based upon respondents' replies and previous interviews then followed. All interviews (save no 9, which was documented manually) were digitally recorded and transcribed verbatim. Filed notes were written in parenthesis at the end of each interview.

2.4. Data analysis

A variety of techniques - questioning, constant comparison, and paradigm model - were used to mine the data for concepts, context, and process. Theory was developed throughout this process through writing of memos. These were reviewed to discover interrelationships between concepts and categories (Corbin and Strauss, 2008). Storylines and diagrams for generating theory and identifying core categories were also generated. The Microsoft Word and MAXQDAv.10.0 were employed for data management.

2.5. Ethical considerations

Informed consent was obtained from all participants. Their right for voluntarily withdrawing from the study was protected. All data were anonymized and interviews transcribed verbatim. The Ethics Committee of Tehran University of Medical Sciences, Tehran, Iran, approved the study.

3. Results

3.1. Findings of analyzing data for context

The context of recovery from MDD fell into six main categories: loss of integrity, inefficiency of healthcare system, feelings of failure, perceived support, poverty, and social stigma. These categories (and sub-categories) are expounded below.

3.1.1. Loss of integrity

Participants' living with MDD experienced a loss of a sense of personal integrity, impacting upon many aspects of their lives. Several sub-categories of loss of integrity of self emerged, including emotional paralysis, thinking disturbance, cognitive decline, somatization, and inability in daily life. Through these sub-categories, MDD had impacted personal (physical, psychological, and spiritual) and social (interpersonal relationships and employment) aspects of participants' lives, further contributing to a loss of personal integrity.

Participant 17 referred to 'thinking disturbance' and 'cognitive decline' by saying, *"I do not trust anybody. I am a pessimistic person. When people are talking to each other, I think they are talking about me . . . No one accepts me because of my illness . . . My belief in God and the Prophet is reducing . . . I know that believing in God can help, but I have stopped saying prayers . . . I am willing to pray, but I am not able to."* This category and its sub-categories have been reported elsewhere (Amini et al., 2013).

3.1.2. Inefficiency of Healthcare System

Problematic aspects of healthcare delivery emerged from the data. Participants described practices of care that would not meet international guidelines. A lack of available beds within psychiatric care resulted in Psychiatrists focusing their efforts on quick hospital

discharge, to provide space for new admissions. Psychiatric treatments being prescribed by non-specialists (i.e., cardiologists or neurologists) was a recurrent problem, seemingly steaming from a lack of an existing referral system for MDD patients.

There was evidence that an overarching medicalisation of mental health resulted in MDD patients not being offered non-pharmacological treatments (i.e., cognitive and behavioral therapies).

“I felt compelled to visit Dr. X because I actually couldn’t find a good doctor in this city. ... Doctors only give patients medications and do nothing else. In most cases, they even make mistakes ... when I went to Dr. X, he discontinued my hypertension medications which had been prescribed by my cardiologist. Consequently, my blood pressure was drastically increased and I was hospitalized due to severe hypertension” (P. 16).

3.1.3. Feelings of Failure

According to participants, depression and recovery are complex and individualistic processes, affected by both cognitive and psychological factors. Various factors impacted upon participants’ perceptions of recovery, specifically: 1) feelings of failure, and 2) an inability to fulfill their goals, aspirations, and expectations. Most participants had developed depression subsequent to experiencing feelings of failure. Participants’ failure to meet aims,

and subsequent problems coping were often attributed to personal characteristics and traits (such as oversensitivity in interpersonal relationships, excessive commiseration, overdependence, novelty seeking, self-blaming, and aggression):

“I have become gradually oversensitive and shown sensitivity to others’ behaviors and conducts ... For instance, when I experienced a problem in my relationship with others or colleagues, I became too preoccupied with it. It even disturbed my eating and sleep—of course not as severely as when I was suffering from depression. When I returned back home [after experiencing problems in relationship with others or colleagues], I talked about my problems with my spouse and others and hence, it caused other kinds of troubles too” (P. 9).

3.1.4. Social stigma

Patients with depression experienced social stigma and discrimination, mainly within small socio-cultural and geographical contexts. Participants felt that others’ attitudes and conduct towards them had changed following the onset of depression and hence, they felt not as important, confident, and worthy as before in others’ views. The social stigma of depression also affected healthcare professionals’ attitudes and conduct towards Participants, and they described discrimination practiced by healthcare professionals.

“One of my problems is that my family members have no more confidence in me and give me no more responsibilities. I have good and healthy friends and would like to go shopping with them. However, my mother doesn’t allow me and takes me out by herself. She has no confidence in me. When my family members want to do an activity or buy something, they never ask my opinion. They only seek my sister’s opinion. It is like I have no real existence” (P .4).

3.1.5. Poverty

Poverty (lacking basic requirements for living such as a safe housing, financial pressure) hindered recovery from depression and aggravated it by preventing Participants from seeking treatments.

“Our financial status is not so good to do whatever we want...my doctor said, ‘Buy and use whatever I prescribe’. I answered, ‘I can’t afford them and need to become hospitalized’. We were under financial pressure. My husband is a simple blue-collar worker. There is no permanent job for him. He is on work for one day and is idle for two days. You will have no problem provided that you have a good financial state” (P. 6).

3.1.6. Perceived Social Support

According to Participants, one of the most important resources for coping was perceived social support. Participants received different levels and kinds of support from different

sources. The most important support sources were their family members (particularly spouses, children, and close relatives), religious and spiritual beliefs, other patients with depression, nursing staffs, and hospital visitors. Such resources helped Participants cope by providing them with financial support, paying attention to their needs, giving them a sense of responsibility, as well as valuing, loving, and listening to them.

Participant 7 referred to peers and nurses' support by saying, *"Other patients help me. During my conversations with them, they talk about their illness and I get familiar with their problems and the strategies which they use (for coping). Talking with other patients helped me understand that their condition was much more severe than mine. This fact helped me very much. Nurses also helped me very much and gave me hope. Not only their words, but also their behaviors helped me understand who I am, from where I have come, and to where I'm going."*

A lack of social support could have a detrimental impact upon participants. Participant 11 referred to receiving limited support from her husband,

My husband says, 'Would you like me to rent a house for you [in order to live alone in it]?'...I need somebody to talk with. However, my husband says, 'Don't speak please!' I cry and ask him to let me speak with him. But he says, 'We are here to sit and rest not to speak!'

3.2. Findings of analyzing data

Participants reacted to the loss of identity by employing both effective (those that facilitated recovery) and ineffective strategies (reactions, interactions, and emotions which did not aid recovery).

3.2.1. Effective strategies

Effective strategies were employed either in a logical and specific sequence or concurrently.

Effective strategies adopted by participants were:

- Consciously deciding to fight depression
- Reconnecting with God and spirituality
- Seeking help from others
- Psychiatric referral
- Attempting to adopt a realistic and positive attitudes
- Closely adhering to medical prescription and nursing advice
- Making use of nursing therapy and support
- Communicating with other patients
- Using complementary therapies
- Employing strategies for coping with multiple coincident stressors
- Attending educational and skills development programs

3.2.2. Ineffective Strategies

Ineffective strategies fell into the two sub-categories of passive ineffective strategies and active ineffective strategies. Both are explained below.

3.2.2.1. Passive ineffective strategies

One of the passive ineffective strategies adopted by participants was ‘doing nothing’. Participants adopted this strategy in different phases of recovery from MDD, particularly in the preliminary phases. The other passive ineffective strategies adopted in preliminary phases included showing patience and deliberate indifference towards problems. Deliberate indifference involved consciously attempting to pay no attention to symptoms, in the hope of achieving spontaneous recovery. This strategy differed from the defense mechanism of denial, in that denial denotes unconscious refusal to accept problems, while deliberate indifference denotes a more conscious process.

“In the first phases of the disorder, some conditions irritated me. I felt I had changed, and was not like before. However, I attempted to disregard these feelings and to suppose that nothing had happened to me” (P. 5).

Passive ineffective strategies were not helpful, and left participants feelings fatigue, frustration, and despair. The fatigue participants experienced was both physical and mental.

“I don’t know what to do. I’m really frustrated. I’m not satisfied with leaving my home and my spouse...I’m really suffering...I don’t know what life wants from me. I’m tired...I want to disappear so nobody can find me...I have no more hope now...What can I hope for? This is me and that is my husband [both of us are in trouble]” (P. 19).

Patients with such feelings paid little attention to recovery and treatments. For instance, participant 15 felt no hope for recovery:

“I didn’t think that visiting that doctor and taking his pills would be effective to me. I visited doctors many times...I think that complete recovery is impossible. I think that I can’t achieve recovery at all...but, I should attempt to independently fight this disorder and such feelings.”

Some participants had utilized strategies such as excessive sleeping and avoiding interpersonal relationships to detach from personal problems, or to evade personal responsibilities and religious duties. Some expressed resignation, and sought comfort and rationalization in Divine providence, stating ‘Whatever God wants will happen’. Many participants experienced anxiety over a variety of issues, including interpersonal relationships, fear of the future, and fear of sudden death.

3.2.2.2. Active ineffective strategies

Active ineffective strategies were the second sub-category of ineffective strategies. These encompassed actively employed behaviors, interactions, and emotional responses which have no positive effect on participants' recovery, potentially hindering recovery. These strategies included (but were not limited to) self-stigmatization, self-blaming, projection, aggression, excessive crying, referral to specialists in areas other than psychiatry, high-risk behaviors, attempts for forgetting unpleasant experiences, frequently changing the treating physician, and oversensitivity in interpersonal relationships. For instance, participant 5 showed projection and accused her father of paying little attention to her symptoms:

“My current problem is my father’s fault...he used to deny my disorder and say, ‘You aren’t sick. This is a transient problem’. He wanted to comfort me. For instance, he said, ‘Can you remember that we wanted to slaughter a hen when you were a child and you were sad about that? Your current sickness is the same. You will cope with it very soon’. [The result of my father’s attitude is that] I’m suffering from this disorder now.”

3.3. Integrity of Self

The core category of the study was ‘Attempting to Restore Integrity of the Self’. This centered around participants trying to reclaim aspects of themselves they had lost through

depression. Specifically, this included participants attempting to restore health and attempting to reacquire lost abilities.

3.3.1. Attempting to restore health

MDD had caused Participants physical, psychological, social, and spiritual problems. Symptoms of MDD were experienced in emotional, cognition, and physical domains. Nevertheless, many participants were on a journey of recovery to develop a sense of health and well-being. This was often referred to as ‘an attempt to get rid of the cage’. Participants most important aims in their attempts to restore health were; stopping feeling ill and starting feeling healthy, feeling peaceful (i.e. reducing anxiety), regaining appetite, reestablishing good sleeping patterns, reducing feelings of guilt, becoming free from despair, developing optimism, avoiding aggression, and eliminating negative self-image, physical pain, depressive feelings, fatigue, or lassitude:

“When I was ill, I used to cry all days. I was very tired both physically and psychologically. I was disappointed at everything. I contemplated suicide and wanted to leave this world. I was in a predicament. I felt that I did not have anything in the world and hence, I told myself ‘Why should I stay in the world?’ I liked nothing at all. Gradually, I got better. Now, I have none of those problems. Thank God” (P. 19).

3.3.2. Attempting to reacquire lost abilities

MDD impacted upon various attributes, including cognitive (memory, concentration, decision-making), affective (optimism, enjoyment), and social (effective management of personal and social affairs). Participants' attempts to restore integrity of self had helped them reacquire some of these lost abilities and skills. Two participants (numbers 7 and 9) noted that after attempting to restore integrity, their symptoms were alleviated, abilities and skills were reacquired, and they attained higher levels of health and functionality than before.

"I experienced some unpleasant conditions before falling into depression which have been alleviated now. For example, I can refer to oversensitivity, competing with others, having a sense of inferiority when being with others, being afraid of starting new activities, and inability to complete activities" (P. 9).

In spite of attempting to restore integrity of self, only a handful of the participants had achieved desirable outcomes and experienced what they considered to be complete recovery. The majority of participants felt they had achieved partial recovery, but wished to experience further improvement. Accordingly, we use the term 'partial recovery' for referring to this state. For others, the process of attempting to restore integrity was not fruitful, and they had experienced neither symptom alleviation nor reacquired abilities and skills.

A sub-section of Participants had experienced relapse after partial recovery. According to these Participants, relapse could be attributed to incomplete treatment, inattention to underlying causes, and physicians' inattention to residual signs and symptoms. Participant 13, who had experienced relapse noted,

"My doctor discontinued my medications. I had achieved partial, not complete, recovery. I was still worried and sad. I didn't like to go to parties and do things like that. Ten to twelve days after discontinuing medication, it recurred and I became like before...Now, I'm blue and gloomy and have headaches. We owe debt and can't pay it back. All these problems are preoccupying me and I'm angry, agitated, and nervous about them. I can't tolerate them...I cry...I'm going mad...I'm not in a good mood, can't tolerate children's noise, and get angry about that."

3.4. Theory Development

Recovery from MDD can be aided by the restoring of the integrity of the sense of self, through employing internal strategies. This process can be hampered by external aspects of the social world, including poverty, inefficient healthcare system, and social stigma. The aim of this process is to restore health and reacquire lost abilities and skills. The outcome can be either complete recovery, partial recovery, no recovery, or relapse.

4. Discussion

This study explored the process of recovery from MDD. Findings showed that the process of recovery from MDD involved ‘attempting to restore integrity of the self’. This process was unique to each Participant. Ridge and Ziebland (2006) reported similar findings, underlining the individual nature of the experience of MDD. Some of their participants equated recovery with symptom alleviation and regaining functional capacity, while others saw recovery as equating to moving away from depression and disability toward ‘normal’ functioning. The latter group believed that recovery is the ability to have a fruitful life in spite of experiencing symptoms of depression. Skärsäter and Willman (2006) found that recovery from depression was a process of transition, with participants fluidly moving through stages of change. Moreover, Higgins (2008) found that patients’ experiences of recovery differed from each other due to their different personal expectations and capacities.

Our findings revealed that participant’s journey to restore integrity involved striving to restore health, and to reacquire lost abilities and skills. Participants explained their experiences of MDD by focusing on symptoms and difficulties caused by MDD. Consequently, they equated recovery with getting rid of the symptoms, reacquiring lost skills and abilities. These findings imply a biomedical understanding of depression management. Previous studies also proposed the same biomedical-oriented focus for

recovery from depression (e.g., Kirsh et al., 2008; Spijker et al., 2001) and other psychiatric disorders (e.g., Anthony, 1993; Bracken and Thomas, 2005; Fitzpatrick, 2002; Hasson-Ohayon et al., 2009; Hoff, 2008; Kingdon and Young, 2007; Walsh and Daly, 2004). Despite many critiques of the biomedical approach, this model's use is widespread (e.g., Anderson and Hope, 2008; Anthony, 1993; Bracken and Thomas, 2005; Fitzpatrick, 2002; Hasson-Ohayon et al., 2009; Hoff, 2008; Kingdon and Young, 2007; Kirsh et al., 2008; Walsh and Daly, 2004). According to this model, the underlying causes of mental disorders are genetic and neurological factors. Consequently, this model considers drug therapy as the primary treatment modality (Aidoo and Harpham, 2001; Dejman et al., 2008; Kingdon and Young, 2007; Okello and Ekblad, 2006).

An important finding of this study was that while attempting to restore integrity, some participants attained higher levels of health and functionality compared with their pre-depression status. This finding challenges the biomedical model. Participants also highlighted the role of social and environmental factors in developing MDD, and they adopted different strategies for achieving recovery. This is in line with the empowerment approach advocated by Crossley and Crossley, (2001) and Crossley, (2004). Moreover, participants also equated recovery with developing a sense of health and well-being. This is congruent with the psychological model of recovery (Anderson and Hope, 2008). Accordingly, the biomedical model cannot be the sole prism through which to view recovery.

Findings also revealed that three potential outcomes of attempting to restore integrity were ‘complete recovery’ (for a minority of participants), ‘recurrence’, and ‘partial recovery’ (for the majority). This is in line with the findings of the previous studies (e.g., Cole et al., 2006; Mechakra-Tahiri et al., 2013; Spijker et al., 2002). However, the proportions of these three outcomes in previous studies differ from each other due to differences in the definitions of recovery from MDD, and study populations (Cole et al., 2006; Mechakra-Tahiri et al., 2013; Spijker et al., 2002).

Two important points regarding the recurrence of MDD were relapse rapidity and frequency. Scott and Dickey (2003) also reported a high recurrence rates. Indeed, some authorities refer to MDD as a ‘recurrent disorder’ (e.g., Maj and Sartorius, 2002). Our findings revealed that the most important reasons behind recurrence were incomplete treatment of MDD, physicians’ inattention to residual signs and symptoms after partial treatment, and healthcare professionals’ inattention to the underlying causes of MDD. Previous studies also have confirmed the role of these factors in MDD relapse (e.g., Boulenger, 2004; Judd et al., 2000; Nasser and Overholser, 2005). Accordingly, combination therapy has been proposed for MDD management (e.g., Ma and Teasdale, 2004; Paykel et al., 2005b; Trivedi, 2006), and the absence of combination therapy is deeply felt in our sample.

This study offers fresh insight into the perceptions of recovery from MDD in an Iranian population. Participants' readiness to draw attention to health professionals' failings suggests a cultural shift from affirming the knowledge of hierarchical structural authorities to one where authority can be challenge in appropriate circumstances. The study also has implications for mental health nursing worldwide. The results provide evidence of the ideas and core concepts surrounding recovery beginning to be absorbed by patients within mental health populations, and thus challenging the prevailing and long standing hierarchies and theories regarding the management of MDD. The absorption of this message consequently demands a more recovery-focused approach from mental health nursing in both policy and practice, in order to meet the changing demands and expectations of patients.

5. Conclusion

Recovery from MDD is an individualized process that can be facilitated by the afflicted individual and external forces. Given the uniqueness of the recovery journey, biomedical models alone cannot independently explicate it. Consequently, healthcare professionals need to avoid adopting a one-size-fit-all approach for managing MDD. Interventions for MDD management are recommended to be recovery-oriented, and should be focused on enhancing their personal capacities and abilities according to their circumstances. However, given the limited transferability of qualitative findings, the results of this study may not be

applicable to populations with other cultural norms. Further research would generate a wider range of experiences.

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