DOI: 10.1590/1807-57622014.0194

Mental illness: perceptions regarding sufferers' identities

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The perceptions that women followed up at psychosocial care centers have about themselves, other people and society, in view of their mental illness, were addressed. The influence that this service had on their identities was examined. This was a qualitative, descriptive study using topical life histories. Data were gathered through interviews, direct observation and a field diary. Thematic analysis was interpreted using Goffman's framework. The results revealed that these women's perceptions of identity differed from before to after their mental illness. They perceived that their families were distant from them, with difficulty in dealing with the illness; that professionals were welcoming; and that psychosocial centers contributed towards reconstruction and expression of identities, thereby promoting self-knowledge, guidance and emotional support. However, they saw that the service lacked refinement of actions for ensuring rights and investment in new aid strategies with the capacity to defend possible identities that are flexible and adaptable.

Keywords: Personal identity. Mental health services. Mentally ill individuals. Psychological stress.

Introduction

Study seeks to understand how women with mental illness undergoing treatment in a mental health service facility (re)construct and reveal their identity through their perception of self, of others and society.

Identity is the set of features, images and feelings that a person recognises as being part of him or her self[1]. The discovery of identity depends on the person and the negotiations he or she undertakes with others occurring at any given moment and in any given context[2,3]. It is metamorphosis and is historically constituted, since the human being, full of possibilities, constantly (re)constructs him or herself throughout the course of his or her life and is both protagonist and author of his or her own history[4].

Thus, although the construction of identity in the contemporary world occurs within vast intertwining arenas of insecurity, in which life is bound to the dynamics of a globalized capitalist economy and interconnected with an institutionalised and permanent risk environment, living and surviving in this conjuncture enables it to be mutable, flexible and adaptable[5,6].

Goffman separates identity into three dimensions: social identity, personal identity, and ego identity. Social identity is defined by people who do not know the person in question. What they know about the individual is either what they have heard, what they have been socially permitted to know through the observation of the context which they frequent, or comes from their ancestors and information received from third parties. Personal identity, on the other hand, is constructed from a person's life stories. With respect to the ego identity, the individual is permitted to construct his or her own identity, which is more intimate, similar to the essence of the individual; how the person identifies him or herself[7].

This study concerns the perceptions of women with mental illness receiving treatment in a Centre for Pschycosocial Support (CAPS, acronym in Portuguese) in Brazil. By obtaining an insight into these women's perceptions of themselves, others and the society in which they live, we aim to illustrate how they (re)construct and reveal their identity in this health facility, in which health care is based on valuing singularities, social inclusion and overcoming stigmas.

We therefore established the following objectives: 1. Understand the perceptions that women receiving treatment in a Centre for Pschycosocial Support have of themselves, others, and society; 2. Analyse the influence the treatment offered in these facilities has on their identity.

This study seeks to encourage reflection about the influence of mental illness on identity and urge renewed discussion on the purpose of the new mental health services.

Method

Considering the nature and complexity of this issue, and to gain a deeper understanding of the object of this investigation, this study uses a qualitative descriptive approach based on social research methods. This method enables an understanding of the simultaneity of different cultures and times within the same social context, which considers the human being in society in terms of his/her relationships and symbolic production[8].

The research tool used to investigate the meaning of human experience was the oral history technique, with emphasis on the topical life history, which considers a specific stage, segment or sector of the personal life of the participant, who is seen as a protagonist in social life and the process of subjectification[8].

This study involved four women aged between 40 and 51 years receiving treatment in a type II CAPS, which treats people with severe mental illness, in a capital city of a state in the Northeast Region of Brazil.

The selection of the participants in this study was made during a prearranged visit to the centre where the study proposal was presented to the health professionals and service users. Interviews were then scheduled with those women who agreed to participate. Only women who did not show cognitive alterations in thinking, sensory perception, memory and communication during the initial visit and interviews were included in the study.

Information was gathered over a period of three months using detailed triangulation of individual filmed interviews, direct observation and annotations in a field journal. In-depth open-ended interviews were conducted using an invisible guide to steer the course of the discussion. A conducive atmosphere was created where interviewees could freely express themselves.

This study was carried out in accordance with strict ethical standards and was approved by the Committee on the Ethics of Research on Human Beings of the Federal University of Alagoas (number 006511/2011-47). All interviewees signed an informed consent form.

The interviews were examined using thematic analysis[8,9], complemented by the results of the direct observation and field journal annotations. The interview was watched several times in order create a comprehensive transcript which included details such as hesitations, laughing, crying, silent pauses and interviewer stimuli, leaving a space in the margin for notes. Fluctuating reading was then carried out whereby the material was codified by transforming the raw data of the text fragments which were aggregated and numbered into units of analysis to facilitate the understanding of the content. The units of analysis were organised in a table, maintaining the sequence of information guided by the objectives to facilitate categorisation[9]. The resulting categories were analysed using the theoretical framework proposed by Erving Goffman[7,10] and authors who address psychosocial rehabilitation.

Results

Delving into the history of these women facilitated the understanding of the different forms of construction of identity and ways of being and interacting with the world after the development of mental illness.

The life stories observed by this study revealed five thematic categories:

1. Perception of my identity: before the development of mental illness

Even at a tender age these women experienced significant suffering, and intense fear associated with traumatic experiences was part of life. The development of a future mental illness was a possibility, without their guardian being aware of it.

> "[...] It all started when I was 12 and I saw a woman throw herself under a train. That had an impact. At the time, I still had my parents, but no one bothered about me, they didn't seek treatment, and that fear of trains stayed with me." (E4)

Domestic violence, humiliation, fear, the loss of loved ones, jobs, financial independence, autonomy, dignity, privacy and respect, demanded adaptation to adversity.

> "[...] My son was arrested. Murdered... When he was in prison it was humiliation, sadness and anguish; first you gave the name, then they searched everything you took to see if you there was anything in it, then you had to take your clothes off. These things all hurt." (E3)

> "[...] My husband drank a lot, tied up the kids, hit me and the kids a lot, with a bicycle chain. He broke the broom handle hitting me, woke me up with freezing cold water, chased me with a knife. I put up with it all because I didn't have anywhere to go, I didn't have anyone to turn to." (E4)

Therefore, the construction of the identities of these women was delineated by the experience of mental suffering preceding the diagnosis of mental illness and search for services.

2. Perception of my identity: after the development of mental illness

The development of mental illness brings with it serious implications for a person's identity, such as low self-esteem and the loss of job skills and mobility, which lead to not feeling capable of working and self-censorship, which in turn confirm stigmas.

> "[...] I don't have the patience to work anymore. I worked hard in the past, but today I'm hardly capable of getting a bus. There are days when I'm fine and

> others when I’m not. When I was young I was employable, but who’s going to want me now with all my problems? They don’t want me.” (E1)

> “[...] It’s as if I was finished. I don’t feel like working, I don’t have the patience. I was selling fruit before I came here, but I started losing money, I didn’t know how to give the right change (begins to cry).” (E4)

One of the four interviewees worked, while the other three were dependent on government benefits. One of the women dependent on benefits reveals:

> “[...] I didn’t like having to retire (due to illness); I kneel down and give thanks for this money, but I don’t even know how to spend it, I didn’t have to sweat to earn it. The money comes from the government, but it’s not welcome, I spend it, but grudgingly, because I didn’t work to earn it.” (E2)

Being dependent on benefit generates conflict between the person’s work ethic and the merits of receiving a pension.

Experiencing mental illness can lead women to value the simple things of life and loved ones more, access inner strength, recognise their limits, and resignify life situations.

> “[...] I have learnt to value things more, people, my mother... Today I feel like I am more responsible. [...] I’ve discovered that I am neither as weak or strong as I thought [...].I have learnt that you should squeeze something positive out of negative things; life isn’t easy for anybody.” (E3)

The perception of self after the development of mental illness can lead the construction of identity down two pathways: loss of capacities, or resignification of life. In summary, the women’s perceptions of themselves are influenced by and influence the perception others have of their identity.

3. Perception of others about my identity: how do others see me after the development of mental illness?

For the interviewees, other people confuse mental suffering with the stigma of madness and associate the person's daily functioning with the permanent state of the illness. Medication is suggested to control behaviours that are considered undesirable.

> "[...] Whatever I did they said I was mad! And that annoyed me. Once they said "have you taken your medicine today? That hurts, but I learnt to deal with it." (E3)

Stigma permeates relationships when it is identified through information socially related to the service they use.

> "[...] The other day they said 'she comes from the CAPS, she's one of the nutters'. And I said: 'No, not nutters! They are my friends, not nutters. They are people just like you'. And they said 'Ah woman, you are mad aren't you!' [...] I can tell you, if I make a joke, they justify it straight way: 'she's mad!' " (E3)

The phrase "she's one of the nutters" reflects a socially constructed and concrete identity. However, the fact that people do not always realise that someone has a mental disorder, unless they are in crisis or bring forth information about their treatment, often protects them from internalising, accessing or feeling prejudice. Therefore, in various situations, the illness can often be socially invisible, which can help reduce the dissemination of the stigma and emergence of discrimination.

The following extract refers to when stigma is felt:

> "[...] My daughter has never asked me to go to a party with her and her husband and daughter. I feel that she is ashamed of me. She thinks that I don't behave myself, but I'm well behaved."(E1)

This example reveals the extent to which prejudice permeates the families of people with mental health disorders and how this contributes to the social detachment of these people.

On the other hand, how they are perceived depends on how they perceive others: giving affection also implies receiving.

> "[...] If I view someone with respect, I will be respected as well; if I love, I will be loved as well" (E2).

The understanding is that a person's relationship with others depends on how that person expresses his or her feelings and how he or she behaves towards others.

4. Perception of the identity of others: how do I view others?

The way one perceives others depends on the persons who are being observed: whether they suffer mentally or not, whether they are a member of the family of the person who suffers mentally, or one of the professionals that care for the person.

With respect to the identity of people who accompany people suffering from mental illness on visits to the CAPS, the perception is that they are an important source of emotional support. There is a belief that anyone is prone to becoming ill, and that people with similar problems can set an example of motivation and how to overcome difficulties, and that even the weakest have potential.

> "[...] When I saw people with the same problems I started to get better."(E2)

> "[...] I feel better when I'm with people with disorders because the understand me". (E1)

Although the women felt safe and understood in the CAPS, one mentioned a dependence on the service.

> “[...] I notice that they are super dependent on the CAPS. I think there are people that are afraid of leaving, because they feel more comfortable being able to talk to one another. They are well treated, are able to talk about things they can’t at home. They open up more here, joke, show who they are. Because if they try to get things off their chest at home and cry, the family is going to think that he or she is having a crisis and will admit them. Whatever they do it’s a crisis. If you cry it’s a crisis, if you laugh it’s a crisis.”(E3)

Therefore, although not part of the proposal behind the CAPS, relationships of dependence exist and require further analysis. However, the CAPS allows patients to express themselves more freely, as is the case of the following interviewee who mentioned feeling accepted, welcomed and understood by the professionals at the facility:

> “[...] I think the professionals here are very caring. They are very attentive with me and the others.” (E4)

With regard to family, the interviewees revealed certain gaps in their care needs. According to the women, their families do not understand the mental suffering they have to undergo, do not interact with the health care professionals, and do not go to meetings held to provide guidance on how to deal with a mentally ill family member.

> “[...] The CAPS makes an effort, but it’s family interaction that’s really lacking. When I started here I brought my brother as the person responsible for me, but he has never come to a family meeting. [...] Husbands, parents, children, brothers and sisters need to be more present. Once, I got the bus and the person said “let her sit down because she’s got a mental problem! Was that necessary? Did anyone ask?”(E3)

For the interviewees, this happens because people who do not have mental disorders are prejudiced, scared and prefer not to seek mental health care so that they do not have to face social stigma or self-stigma.

> "[...] I think they are prejudiced, scared. They are surrounded by problematic people who don't seek treatment! So I think they are scared of suffering discrimination, because they think if they seek treatment people are going to say they are 'mad'." (E3)

Therefore, the perception of others, be it family members, friends or professionals working in the CAPS, consists of the confirmation an identity permeated by stigmas.

5. The identity constructed in the CAPS: what influences me?

For the women, apart from the influences mentioned above, being in the CAPS is tantamount to feeling free to express their identity; it is a place of self-knowledge, learning and emotional support.

> "[...] Here [in the CAPS] I feel strong. Because, if I didn't have the psychological and physical support I get here, I wouldn't know how to control the situations that I have to go through out there."(E3)

However, considering the information about their diagnoses, the service has not provided the desired clarification, compromising the right to be clearly informed.

> "[...] With this story of the F20 code I receive this pension, but they've never said if it was depression, schizophrenia..." (E2)

With respect to group care, the interviewees mention that they are free to participate or not, but complain that it is exclusive.

“[...] They don’t make you participate, but at the same time they do, because if you leave, and that’s the only option, you won’t be alone”. (E2)

One of the questions raised was difficulty in creating bonds between service users due to the high turnover of group participants, leading to reticence among some participants which negatively affects the process of recovery.

> “[...] I talk less today, because I couldn’t talk about my life to people who I had never met. Every time they made up a group there were different people. Because someone who had already been discharged would ask me in the street: – So how’s that problem going? And I thought to myself that I was telling people too much about my life. So I learnt to talk less and not tell people everything that goes on at home.” (E2)

Another problem raised by an interviewee was the lack of a suitable environment for rest.

> “[...] One thing that I thought was strange was that there wasn’t a dormitory... when you wanted to sleep, you had to sleep on the bench.” (E2)

This situation is aggravated by a lack of medications, refreshments, delays in serving lunch, and allocation of resources.

> “[...] Yesterday I began to feel unwell because there was no medication.” (E1)

> “[...] They provide refreshments when they can. People complain that it’s not very much, that it could be better. Before, I used to have lunch, and the food was good, but I didn’t think much of the timing, sometimes lunch was delayed a lot.” (E2)

> “[...] The Public Prosecutor's Office gave a deadline but the managers didn’t do anything. I wish that the administration was more transparent, that they said what amount goes to the CAPS, how much is for food; because there is material in the Occupational Therapy sector in the Health Department, but it never reaches the CAPS [...]” (E3)

The analysis shows that the care provided under the CAPS has a positive influence on the construction and reconstruction of the identities of the women interviewed in this study. Patients are able to interact and exchange experiences, freely express themselves, and are treated with care and affection; however actions still need to be refined to effectively guarantee the rights of the mentally ill.

Discussion

This study gave an insight into the construction of identity among people with mental illness in the family sphere and in the CAPS, based on these women’s perceptions of self, others and society, before and after the development of mental illness.

The perceived identity before the development of mental illness resulted from life stories marked with suffering, particularly domestic violence, which was strongly evident in the participant’s biographies. Violence alters the construction of identity. Women often remain in abusive relationships due to fear, financial dependence and feelings of insecurity caused by threats made by their partners. This causes the victim to suppress her wants and desires, wounding her identity, violating her way of being and existing [11,12]. In such situations, “the mortification of the self” occurs, similar to the process described by Goffman[10].

Domestic violence produces emotional scars which are harmful to the development of the self. The abusive use of medications, insomnia, nightmares, anxiety, difficulty in taking decisions, depression, and suicidal tendencies are common in women in this situation. Furthermore, children exposed to this type of situation are more likely to be maltreated, making them more susceptible to illness[13] – “suffering some type of violence, be it an isolated event or ongoing and long-lasting, becomes part the life experience of the maltreated subjects [...] and this has implications that reverberate in the construction of identity”.[14]

These findings corroborate the fact that mental disorders are associated with life stories involving inhumane treatment, in which different losses, such as people and important values, contribute towards the construction of a perception of self among women who, according to Goffman, are stigmatised and feel incapable of working[7].

For Goffman, stigma is a collection of negative attitudes, beliefs, thoughts and behaviours that influence a person or the general public to fear, reject and discriminate[7]. It manifests itself in language, in disrespect, in interpersonal relationships, and in behaviours[15,16].

Also, with respect to stigmatised perception, the participants mentioned the loss of affective capacities, such as a low level of tolerance and motivation, which hinders the recognition of productive capacity. The findings also show that one of the participants was uneasy with the fact that she received a pension from the government due to her disorder. For this participant, receiving “money” without earning it obliges her to acquire the identity of someone whose only option is to assume the status of being mentally ill.

On the other hand, some women realise that reinterpreting high stress situations helps them to develop new forms of coping with the illness and makes them more resilient. This resilience helps them to face the risks of everyday demands and develop the capacity to deal with life’s adversities, transforming them and creating new vital alternatives [17,18]. From Goffman’s perspective, someone who is stigmatised is able to view the privation they endured as a blessing, based on the belief that suffering can teach a lot[10].

With respect to how these women are perceived by others, the group understood that society has an erroneous perception of mental disorders, that people judge them incapable of telling the truth, as being dangerous, strange or astute enough to ensure their rights in various situations. They believe they are undervalued by society because they take “controlled medication”.

“Medication” becomes a sign which transmits social information whose meaning or connotations vary from one group to another[7] depending on the situation in which it is used. People undergoing psychosocial care who take medication on a daily basis are treated in one way, while those that sporadically use medication are treated in another.

Goffman describes two forms of stigma: visible, where the individual is discredited; invisible, where the individual is discreditable[7]. In this sense, when the women do not hide their condition they become discredited. After, they start having less credibility, especially when they give information, claim something or express what they feel. Because they have characteristics that are different from the norm, they stifle their other characteristics[7,15]. Therefore, the word “mad” appears in their statements laden with discredit.

With respect to the women’s perception of others, they mention that they feel better with people who also have a disorder, which appears to be related to the fact that they feel more free to express themselves and be who they really are, which is one of the consequences of the choice of company of those who suffer from similar stigmas[7]. The intragroup alignments or the tendency to stratify themselves with their peers, appear to give them a feeling of security and being more understood.

However, the fact that they feel better with their peers and remain in the CAPS as a way of protecting themselves from life’s adversities reinforces the relationship of dependence. This protection is required in the initial stages of rehabilitation, but should be followed by reintegration into the social network and job market as a possible way of strengthening the capacity to cope with one’s self, with others and their choices[19,20].

It was observed that feeling secure was enhanced by the bonds created between the patients and care professionals, particularly when staff were caring and shared the understanding that someone who suffers mentally is human, thus establishing a relationship of trust and confidence which provides support and comfort[7,15].

With respect to family, there is a perception that family members are unprepared to provide the necessary support for social rehabilitation. Studies emphasise that the family of people suffering from mental illness should receive guidance and support to better understand their feelings and reorganise and reorder their roles to cope with the reality of mental illness[21].

The fact that a family member openly says he or she is accompanying a mentally ill person, without the intention of hurting her, but to protect her, promotes and reinforces the social stigmas that help to construct a virtual social identity that says this person is different and may be dangerous, and is also responsible for reviving feelings of fear, pity or revulsion towards the individual[20]. The stigma is not always visible, and on some occasions it is necessary to hide information so as not to be descredited[7].

Stigmas also affect people who not diagnosed with mental illness: two thirds of individuals with mental illness opt not to seek the benefits of mental health care services because they do not wish to be labelled as different and “mad”[22]. It is interesting to note that those who seek to avoid being labelled are generally aware of the stereotype and often even share the prejudice. However, they are strongly inclined to not apply these stigmas to themselves and try to avoid participating in groups that could give them this label.

Regarding the influence of the CAPS on identity, it was observed that this service allows users to express themselves without exposing themselves to judgement. However, certain decisions or changes in the CAPS still occur without adequate clarification and without involving patients and hearing their opinions and obtaining their agreement.

Alone, the care provided by the CAPS does not guarantee the fulfilment of the principles of the “anti-asylum" paradigm, which embraces social inclusion. For this to happen, a commitment to sound professional and ethical practices in mental health care is crucial[23].

It is necessary to understand the psychosocial model of health care which considers the rights of the subjects and forms of organisation of relationships within and outside the health service, and preserves horizontal power relations and an ethical commitment with users and the population[23].

Such a system, by considering the social, historical, psychological, biological and cultural context within which these processes occur, would contribute to promoting the social inclusion of the women interviewed in this study stereotyped as being different.

Based on the context within which this study was carried out, it is clear that the psychosocial model in Brazil is undergoing a transition and that a number of improvements to the CAPS are necessary. The limited funding of these facilities is evident in the lack of medications, a precarious environment which does not value comfort and privacy, lack of qualified professionals and effective care which meets the unique and subjective demands of the service users.

In summary, the identities of people with mental illness undergoing treatment in this health care setting suffer from the effects of stigmas which are socially reinforced by disinformation, from rejection by family members, incapacity, and the unfavourable environment of the service facility, reflecting Goffman’s findings. On the other hand, the facility promotes the construction of an identity in which relationships based on mutual support, freedom of expression, valuing individual differences and learning from pain are guaranteed.

Conclusion

This research revived life stories laden with suffering and revealed that the way of being and existing of the women interviewed by this study were violated even before seeking the mental health services. Today, after the development of mental illness, their perception of themselves is characterised by low tolerance to problems, low self-esteem, high levels of self-censorship, being “abnormal”, and being a burden to their family. At the same time, the illness has shown itself to be an opportunity for personal growth, developing responsibility, valuing the simple things in life and loved ones, resignifying experiences and pain.

According to the perceptions of the group, people in general do not identify people with mental illness unless social information is evident. However, when people realise that they are mentally ill, they assign identities such as “mad”, “strange”, “dangerous”, “unproductive”, “not deserving attention” and “astute” enough to simulate an illness to get benefit. People without mental illness were identified as being proud and prejudiced, in contrast to people with mental health treated under the CAPS, who are considered more sensitive, trustworthy, understanding, capable of sharing thoughts and experiences, as well as providing emotional support for others who are undergoing treatment.

In this sense, the CAPS allows people to be who they really are, and express their feelings and ideas without being judged, thus reinforcing the construction of an authentic and valued identity.

The many positive influences of the CAPS on the construction of the identity of people with mental illness range from changes in the conceptions of the study group, to the realisation that anyone can become ill and that crisis is transitory and when overcome the person will be able to take on adult responsibilities once again.

On the other hand, certain service norms and protective approaches violate the identity of the self by inducing the individual to adapt to rules or imposed situations, such as precarious facilities, lack of medication and other materials, and a high turnover rate among health professionals at the centre.

Finally, the social context of mental health care explored by this study is in the midst of change which is part of a paradigm shift towards deinstitutionalisation, in which it is necessary to invest wholeheartedly in people and their rights, whether they are service users, family members or health workers.

The effects shown by this study of mental illness on the identity of the women point to new challenges and require strategies which involve tolerance, cooperation, sensitive listening, help and consideration of potentialities which are capable of favouring possible, flexible, intentional and adaptable identities.

Collaborators

Nascimento YCML and Brêda MZ worked together in all stages of the production of this manuscript. Albuquerque MCS was responsible for critically revising this article for important intellectual content and the final approval of the version to be published.

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Translated by James R. A. Allen