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„Mind Your Head!" – Experience of the Illness in Public Narrations of Psychiatric Patients

Abstract
The article explores the problem of reconstructing the experience of illness based on the narratives of people with mental disease. The research used the method of biographical interviews. The material consists of 16 biographical narratives of Dr J. Babiński Clinical Hospital patients. Their accounts form a coherent image of suffering caused by the illness included experiences preceding the disease, somatic symptoms, admission, and stay in the hospital. Thanks to the collected narratives, we have the opportunity to learn about the subjective experiences from the patient's perspective, which is not present in the literature on psychopathology.

Keywords: *mental illness, mental disorder, mental health, narration, experience of illness*

> *Nobody knows what one has to experience for the insanity to mature and to embrace the man completely. How many times people experience such nightmarish things that they should lose their mind immediately. However, they are not going insane.* […] *All it takes is ordinary life and bum. They are already frying in the hell of insanity!* […] *At the moment I see them circling green corridors, green linoleum and looking like algae or seaweed, wiggling and swaying.* (Krzysztoń, 1983, p. 6)

Introduction

Since always, a certain percentage of the population was called "abnormal". Abnormal, i.e., "different from what is usual or expected, especially in a way that worries somebody or is harmful or not wanted" (*Oxford Learner's Dictionaries*). Abnormal

means not only not normal, deviating from a standard, incorrect, unusual, and unnatural, but also deviant and strange. In psychology and psychopathology, four indicators of behaviour considered abnormal are distinguished:

- statistically unusual,
- maladaptive,
- described as abnormal by the society in which the individual lives in this way,
- reveals some perceptual or cognitive distortions.

As the history of research on abnormal human behaviour shows, dating back to ancient times, even the most sophisticated tools for measuring somatic indicators of mental health are accompanied by social indicators closely related to the level of knowledge of society about diseases and their etiopathogenesis. The history of psychiatry is also the history of changes in the attitude of societies towards the mentally ill and the relations between the notion of illness and mental norms in a given culture and historical epoch (Nolen-Hoeksema, 2017). It would seem that contemporary society no longer believes in the supernatural causes of mental illness.

Mind your head!

Given the low public awareness of the subject of mental health, a non-governmental organisation, the Anthropological Association „Archipelagi Kultury" (Archipelagos of Culture), in partnership with Dr J. Babiński Clinical Hospital in Cracov Kobierzyn, and Foundation Revita, implemented the project "Kobierzyn closer. Against the stigmatisation of the mentally ill", and as part of it an exhibition with a metaphorical title „Mind your head" (*Uważaj na głowę*). It is a permanent exhibition showing mental illness, treatment and recovery from the point of view of people who have experienced a mental crisis. It is placed in the basements of building XIV – a place where you have to be physically careful about your head because of the low ceiling. The exhibition symbolically refers to the crisis experience, compared to the descent to the "underground" of human existence. The exhibition consisted of souvenirs and objects related to illness and treatment. A special and unique feature of the exhibition are rooms arranged for places related to hospital stay and testimonies from hospital patients. Visitors learn about the world of a man who had to deal with a mental illness, ranging from symptoms through treatment to attempts to return to functioning outside the hospital. The exhibition tells about mental illness from a non-medical point of view. Patients,

hospital staff and educators formed a team that collected life stories of the ill and their loved ones and developed educational scenarios.

Method

The research aimed to reconstruct the experience of mental illness based on biographical narratives of psychiatric hospital patients. Several research questions were posed regarding the description of these experiences. In this article, I restrict myself to presenting some of the research material, which addresses three main research questions:

1) how do participants describe their first experiences of illness preceding the medical diagnosis?
2) what were their emotional experiences and physiological sensations during the development of the illness?
3) how do they describe their first experiences of hospital treatment?

The material consists of 24 narrative interviews focused on the experience of the illness, conducted with recovering women and men aged between 31 and 60. Therefore, the basis of the research was the oral narrative of the patients elicited during regular meetings in a narrow circle without the participation of people who had not experienced mental illness or had stayed in a psychiatric hospital. The participants in the study shared their experiences. This procedure ensured greater freedom of expression among people with similar experiences. The idea was to obtain broader stories about the study participants' lives related to mental illness (Chase, 2005). The narratives collected during meetings were recorded, transcribed and partly made available in writing or the form of recordings to the exhibition visitors. A narrative interview method was used, to give voice to the patients and create a narrative about mental illness in their language and from their perspective. The illness was a turning point in the patients' lives that forever determined their subsequent lives (McAdams et al., 2001). The research material used in the following analyses are the biographical narratives of 16 patients at the Dr J. Babiński Hospital.

Collecting interviews had two functions: a therapeutic and a documentary one. It is possible because narration is a method that allows a person to present their own story in an individual way and with their unique way of speaking (Atkinson, 1998). L. Colbourne and M. Sque (2005) and R. Reynolds (2012) indicate that thanks to the therapeutic dimension, a person becomes more aware of herself and understands herself, which helps merge personality and shape identity. Usually,

researchers have a problem with such a level of trust that the interlocutor speaks completely freely. In the implemented project, this part of the research strategy was not difficult because the research participants knew each other well and shared their common experiences of mental illness and medical treatment. The interviews were a story about an important aspect of life (Chase 2003a; 2003b).

We understand the narrative as a specifically human ability consisting of interpreting experience, storing it in the mind in the form of a holistic, integrated cognitive structure revealed in the story (Gaydos, 2005; Polkinghorne, 1988). The narrative is divided into small or personal and, after F. Lyotard (1979) into The Grand Narrative, understood as cultural texts that give sense to the world (Ryan, 2007). Narratives are treated as a separate form of discourse in which the narrator tries to retrospectively give meaning to experiences and organise and understand them (Bamberg & Georgakopoulou, 2008). The narratives collected from the project are small biographical narratives presenting individual life events.

The analysis of the material prompts one to look at it as stories, which, despite their diversity, form a common sequence of events telling the story of the illness process: from symptoms, through a hospital stay procedure, until independent living. Careful reading of separate, individual narratives allows for viewing them as records of work on identity, on constructing knowledge about oneself (Miller, 1997), which, in the context of this article, is associated with the necessary process of reconstruction of one's "own self", integrating parts of personality broken due to illness. Therefore, the work on identity becomes a constitutive process necessary for mental recovery.

Tracked and Surrounded[1]

The richest narrative themes are descriptions of experiences preceding the illness. It is the most dramatic thread and often hidden, because it shows this deviation from the norm. Few people dare to share these memories because they directly show the strangeness of behaviour, which becomes painful confronted with normal reality. They show the inability to enter a person's world when the symptoms intensify. This world is simultaneously experiential, tangible, and even sensual for the patient while feeling unable to influence him and the necessity of undergoing unusual sensations.

[1] The title was taken from Krzysztoń (1983).

Several times I had the impression that I was the result of an experiment, that some unknown social forces would use me for a task. (C1)

These are experiences that a healthy person has nothing to compare to, even with huge empathy, these experiences remain "foreign". However, the juxtaposition of unusual behaviours with descriptions of internal experiences can give a substitute for drama.

I couldn't sit still, I had to do something all the time. I met a lot of people, I actually accosted them. It was so weird. Everything seemed simple and clear to me. And that I am extremely special. And I felt strange things that had never happened to me before. But it was surprisingly pleasant. I felt so, really … Well, I had so much power. (D1)

In such circumstances, adequate behaviour is difficult to find, since the patient's experiences, even those disturbing, are accompanied by pleasant emotions, often of varying intensity. What gives pleasure drowns out and diverts attention away from what is disturbing.

It all seems logical and real, so it is very difficult to distinguish fiction from reality. […] This cannot be compared to anything I have experienced. (E1)

Changes in behaviour, moods and subjective experiences, are differentiated by the type of disorder. People suffering from affective disorders experience their first disturbing experiences differently from those in whom the mental crisis is caused by a traumatic experience or the use of psychoactive substances, and differently from people suffering from schizophrenia or another type of psychotic disorder. Descriptions of experiences caused by perception disturbances.

I started to hear the radio in my head. They spoke in a language I couldn't recognise. But it was not Latin, English or French, nor any Slavic. Some strange language. But there was music in my head. Very strange music. Maybe a bit similar to such an electronic rumbling; (F1)

I had visions of some strange books that rolled in front of my eyes on rollers. And I had a lot of visions with my eyes closed. The vision of buildings and people, animals and plants, and all this as if it penetrated one into another. I could not keep up with these visions, there were too many of them. (G1)

This strange world is real, determining the manner of conduct, arousing fear or joy. A world the otherness of which does not arouse the need to confront it with other people's experiences. Despite its peculiarities, it seems familiar.

I act according to the watch. The watch gives me a sense of security. When I was ill, it seemed to me that the watch was alive. Alive. It seemed to me that some objects were alive: that the train was alive, that the watch was alive. (H1)

There is some consequence in changes that the patient experiences. Since inanimate matter can come alive, change its identity, similar changes are also possible in the patient. He can be himself as well as someone else and a stranger.

When I was reading a man's autobiography, a conversation with a Nazi, I had the impression that it concerns me. And then, in turn, that I am a Jewish tailor surrounded by the Nazis. And I saw very strange people who walked outside the window, then sat, watching me. I don't know what was the hallucination of the day and what was overinterpretation. (I1)

Identification with other people, can be so strong that the patient loses his sense of self. Identity disorders can be so deep that the patient has a sense of change in their biography and ceases to know who he really is.

Soma

Unpleasant emotional and physiological experiences accompany disorders of self-sense. The mood most recalled by the narrators was a moving fear, manifested in, among others, the disappearance of motivation for any movement. Anxiety also accompanies the depressed mood characteristic of affective disorders, especially depression. The combination of sadness, gloom and lack of satisfaction with anything finds its expression in slow motion, which makes patients feel a sense of superhuman effort.

For us mentally ill, even small efforts cost a lot more. Stand up and do something small – for example, wash the dishes … Sometimes, in a state of deep depression, it's like getting Mount Everest. Stand up and eat something! I have no strength to get up and eat something. I am hungry, but I don't have enough strength to move. Sometimes a person is not washed for a week. This is so: a man stinks and will not go to wash, because he has no strength for it. If you take up a job, then you are so exhausted that you lie down after it. (B2)

The associated physical fatigue is not compensated by rest or sleep, which is usually disturbed and is associated with a disorganised circadian rhythm. Permanent physical fatigue is manifested in a decrease in the efficiency of cognitive processes

which slow-down are also the result of illness. Awareness of worse functioning in physical and mental spheres provokes fears about the future, coping with everyday life and becomes a source of overwhelming fear.

> *Panic fear of what will happen next. I cannot work, I cannot support myself, I cannot function. It is very difficult, it haunts me when I go to the office, I run errands. This is a huge obstacle. People talk to me and I don't answer it. The more I try to understand, the more I don't understand, the more I humiliate myself. I don't absorb it.* (C2)

Reduced level of functioning, awareness of the general inferior activity, feeling that this state is permanent and maybe final and unchanging, provoke further problems. The easiest way not to embarrass oneself is isolation and seclusion. Since going to the cinema or for a walk requires tremendous effort, and talking to friends may end with another litany of complaints, loneliness is the solution. Loneliness, which as a feeling is a symptom but also becomes a consequence of the illness and the cause of unpleasant experiences, related to a lack of faith in one's strength, sense of meaninglessness in life.

> *I lost all my passions and all interests along the way. I used to read a lot. At the moment reading the whole text with understanding … terrible. I don't have acquaintances, I don't have friends, I'm not going anywhere. I have nothing to offer. And I don't think anyone needs me for anything. I wonder so many times.* (E2)

A vicious circle of symptoms and causes winds up one another, leading to suicidal thoughts or attempts.

One of the critical physical symptoms, although uncommon, are the catatonic states occurring among others in schizophrenia. Description of such experience was also found in the narratives studied. It shows the patient's immobility and helplessness in performing any action impossible to overcome.

> *I just didn't move at all, just lay there. I didn't speak, I couldn't speak words physically. And it was a very strange condition. Then I found out that this is a catatonic state, that's what they wrote in the hospital treatment information card. It consisted in a total, 100%, all-out break with contact with reality. There was nothing! One thought that would bring me together.* (D2)

This experience of breaking contact with the environment can be compared to the metaphorical "death in life".

L'Hôtel Washington[2]

The severity of the symptoms makes it necessary to visit a psychiatrist. The decision to meet a doctor of this speciality is not easy. The first step is related to admitting to yourself that the experienced mental and somatic states are illness symptoms that cannot be dealt with alone.

> *It is not true that mentally ill people cannot recognise that something is an image of their mind. It is perfectly recognisable, you just have to accept that such things occur.* (A3)

However, the attitudes of the ill are usually the result of the process of psychotherapy and maturation to come to terms with the illness, acquiring the ability to respond to disturbing sensations and courage to talk about what is "abnormal" and ask for help. The ability and courage to self-report to the hospital during relapse is the greatest success in working with the mentally ill. Not everyone has the results of psychiatric rehabilitation as effective as the sample narrative:

> *It happened to me that I went to the hospital myself and more than once. I have always tried to delay it as much as possible. Going to the hospital, to the psychiatric ward, when I'm psychotic, is almost beyond my strength. This is a terrible decision, terribly difficult, impossible. Every step, with all the chaos in my head, was a hassle. Well, I went because what was I supposed to do? I was tired so much that I curled up.* (C3)

Many patients, especially during the first episode, do not respond quickly and efficiently enough. Some justifications are the circumstances of the "first time", because how they are to know that it is an illness, since many experiences are accompanied by quite nice sensations. In turn, unpleasant experiences can be so strong that they paralyse and block any activity. The worsening condition eventually brings a person to the hospital. In all narratives, it appears as an unpleasant, necessary place, to which man is condemned. A peculiar "purgatory", "memory reset", pain centre.

> *I do not remember the beginning of the first and second stay because I was terribly medicated. Because at the beginning you just give a lot of drugs to completely block the symptoms and try to reset a person so that he somehow … finds himself again.* (D3)

Pharmacotherapy is the basic treatment for patients. It is also a must. After all, mental illnesses and disorders have their biological, physiological background.

[2] The title refers to Styron (1990).

When I was in the psychiatric ward, a nurse came and unfortunately gave me an injection. Then I went to the toilet and there were such big windows. Opposite was the roof of the hospital and all the angels stood and said goodbye to me. I felt they were leaving. They had beautiful white robes and combat boots. (E3)

Stopping illness symptoms is only the first stage of a hospital stay. Treatment remains a long-term process, during which the patient struggles with unpleasant somatic sensations.

They walk and laugh at each other that they walk like that. They're just fucking walking. That's how everyone walks. When they get fat medicine, everyone walks. You walk, you can walk for two hours. And so pointless, meaningless. You must walk. It's not that it bothers you, you just can't stay in bed. (F3)

The effects of drugs vary depending on the psychopathological symptoms. They can have a stimulating effect or inhibit excessive stimulation. The arsenal of means is very large, from psychotropic drugs to auxiliaries. Some of them have, apart from curative, adverse effects on patients in the form of side effects, e.g., apathy, drowsiness, the risk of addiction. However, patients must deal with them.

Side effects are unpleasant, one could even say that this is physical torture. The neck is stiff, you have to swallow saliva all the time, because your mouth is dry, you tremble constantly. I don't know, I think all this is to free myself from intrusive thoughts. The treatment is painful. These drugs are painful, but they have done their job. Because during the week I somehow got myself together and somehow I started to move forward. (G3)

The primary form of treatment in hospital is pharmacotherapy – essential for all mental illnesses. However, using supportive therapy, e.g., art therapy and community-based therapy, provides an opportunity for a hospital to treat patients differently from how they are depicted in One Flew Over the Cuckoo's Nest.

Conclusion

Psychiatry and clinical psychology publications present the characteristics of disorders in an objective, dry and dispassionate manner. On the other side of the scientific descriptions, one can find literary works depicting madness, insanity, and the boundlessness of depression. Between one and the other work, there is a space in which only a few share the records of their illness experiences. Descriptions

provided by participants of the project help to tame the fear of an illness that can affect anyone, better understand it and contribute to reducing the stigmatisation.

The experience of mental illness should be included in terms of meaningful experience (Jarvis, 1987; Merriam & Clark, 1993) causing experiences so intense that they result in changes in the person's personality and life, lead to changes in the way people think, feel and act, perceive and value themselves and the world, the I – world relationship. As a result of significant events and life experiences, new senses and possibilities are discovered. The specificity of experiencing mental illness as significant lies in the fact that it is impossible to "get out of it" without specialist help and that the transition to the stage of building new relationships with the world, others and yourself, is preceded by destructive events. That is why it is important to understand the patient whose behaviour, although objectively leads to a breakup, does not have such a goal subjectively. As A. Kępiński (1979, p. 269) wrote: "An ill person cannot be treated only as an ill person, i.e., as a man who has left the ordinary human path. You need to look at his world with admiration and respect. This world may be strange, surprising, sometimes funny, and yet it has something great in it, it is a struggle of man with himself and with his environment, looking for his own way, it is a world in which the most manifests itself in human being".

The narratives presented can be expressed in terms of suffering. Specifically, covering this phenomenon's physical, moral, and social aspects. Acquaintance with narratives makes it possible to learn this suffering "from within", from the sufferer's perspective, "through the prism of his subjective experiences". Thanks to this perspective, getting to know another person as a member of the community we create together is possible.

The collected narratives not only provide insight into the experience of mental illness but can also serve a practical purpose. They can contribute to the development of a personalised approach in medicine. Some of them, available to viewers of the exhibition at the hospital in Kobierzyn, can be used for educational activities aimed at de-stigmatising people with illness, breaking stereotypes and changing social attitudes. The narratives can be used for educational activities aimed at a wide audience, including school and university teachers, those involved in non-formal education, those working with mentally ill people, and people with experience of illness.

In the future, it is worth noting the importance of qualitative research in developing knowledge about psychiatric patients. Conducted narrative interviews are an excellent complement to medical material and provide knowledge about patients and not just the illness. By examining the patient's perspective, it is possible to

better understand and help the patient, complementing pharmacotherapy with other interactions; it is possible to be closer to the person with the illness and get to know his or her inner world better.

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