

## **Hell on earth: Textual reflections on the experience of mental illness**

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### **Abstract**

*Background:* Some people who by themselves or by others are understood as having mental health problems have written autobiographies about their experiences.

*Aims:* The aim of this study is to explore how people write about their experiences of being mentally ill.

*Method:* Twelve Scandinavian autobiographies were studied using content analysis based on phenomenology and hermeneutics.

*Results:* Three themes were identified: feeling like a stranger in life and places, the transformation of life experiences into questions of disease and feeling ashamed.

*Conclusions:* People's experiences of being mentally ill might be understood as the result of medical constructions unsuitable for the persons themselves. We could instead say that mental problems are not diseases, but severe and painful phenomena in people's lives.

**Keywords:** *mental health, autobiography, user knowledge, medical model*

### **Introduction**

Throughout history, many people have experienced mental health problems. Some of them have written autobiographies on this topic. The experience of being mentally ill and the role of mental health care services have thus become texts. Personal experience has in this way been presented directly by service users themselves, both to the public and to the professionals. In fact, in the last 50 years, the autobiographical tradition in the mental health field has grown rapidly. Some of the texts have gained attention and recognition worldwide (e.g. Green, 1964). One might argue that these texts represent important predecessors for the work on antistigma highly emphasized today (Mitchell, 2010; Shooter, 2010). Hence, these texts could be an important guide for the professionals. By analysing 12 Scandinavian autobiographies, this study aims to explore the following research question:

How do Scandinavian service users describe their experiences of being mentally ill?

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## Method

### Sample

To find literature suitable for the project, we browsed Swedish, Danish and Norwegian library websites. This search, however, offered no relevant books published before 1950. Accordingly, we found older autobiographies on a database for Scandinavian antiquarians. The authors' admission to the hospitals might influence their experiences, depending on when and where they were admitted. Thus, their stories will show variations. The asylum era might result in descriptions of being mentally ill that are different from those of the period when neuroleptics became a dominant part of the treatment or when the de-institutionalization of the mental health services took place. Hence, we selected books from the following three periods: 1850–1950; 1950–1980 and 1980–2008. We chose one Swedish, one Danish and two Norwegian autobiographies from each period because the second period only offered this option (Figure 1).

Dahlin's (1919) book is not an autobiography, but contains autobiographical elements from diaries and letters, all written by patients who contacted the author. The books range from 89 to 199 pages. In summary, the 12 autobiographies represent 1819 text pages.

### Content analysis

Our purpose was to make visible the thoughts, meanings and experiences of the authors. Thus, principles from text analysis inspired from phenomenology were suitable since the primary objective was the direct investigation and description of mental problems as a phenomenon (Kvale & Brinkman, 2009). First, we read each book carefully in order to identify every author's experiences of having mental problems. Second, we compared our notes and identified the various themes. Thus, the texts were brought together into meaningful units reflecting the authors' lived experiences. The process of condensation made it possible to identify three major themes. Third, we compared the themes within the different books (Graneheim & Landman, 2003; Kvale & Brinkman, 2009).

### Methodological and ethical considerations

We studied the texts written by people who were capable of expressing themselves through writing. This might mean that those who do not write might tell different stories. Furthermore, we recognize the possibility that the need for sharing their experiences might be stronger among those with critical views than among those with good experiences of mental health care.

Period Country	The asylum era (1850-1950)	Neuroleptics gives hope (1950-1980)	Deinstitutionalisation (1980-to date)
Danish author	Minna Holck (1918)	Robert Henningsen Jensen (1979)	Lars Jensen (2003)
Norwegian author	Haaken Bergh (1925)	Stella Danner (pseudonym for Merethe Wiger) (1955)	Espen B. Jaer (1995)
	Johan Sedevard Jacobsen (1932)	Erna Storfjord (1977)	Arnild Lauveng (2005)
Swedish author	C.S. Dahlin (1919)	Helene Reeder (1975)	Ann Heberlein (2008)

Figure 1. The sample of 12 Scandinavian autobiographies.

By highlighting their own stories, we illustrate understandings of being mentally ill from their point of view. Thus, the results are valid as experienced phenomena. At the same time, as researchers, we are responsible for the selection of quotations; others could have made different choices. The strengths of the study are that both the authors have read all the books, made reflections about the contents and together have selected the themes focused on in this article. Furthermore, the quotations presented to underline the findings are all translated into English by the authors. Hence, there is a risk of an unintended translator bias (Wiener, 2000).

The original authors' purpose was not to write for the sake of our research. Consequently, we run the risk of degrading strong, emotional stories about troubled lives. We may also have brought to surface difficult feelings among those who are alive today. This was, of course, not our purpose and we have tried to present the authors with respect and interpret their texts in a favourable light.

## Results

By analysing the texts, we identified three themes: (a) feeling like a stranger in life and places, (b) the transformation of life experiences into disease and (c) feeling ashamed. Astonishingly enough, themes (a) and (c) were to be found in all the books. Theme (b) was, of course, not present in the books written by those who themselves thought that they were not ill (Bergh, 1925; Dahlin, 1919; Jacobsen, 1932).

### *Feeling like a stranger in life and places*

The analysis shows that life and places are strongly connected. When referring to mental problems, most of the authors describe how this affects their experiences of the external environment and vice versa.

Bergh (1925), Jacobsen (1932) and the contributors to Dahlin's (1919) book did not consider themselves as being mentally ill. Being hospitalized against their will, made them feel like strangers in a foreign world. These authors described their fellow patients as *the others* and named them the lunatics, mad men, wild, infuriated and uncontrolled (Bergh, 1925; Dahlin, 1919; Jacobsen, 1932). *They* did not feel mentally ill, but someone else meant that they were: "[...] Dr. Dedichen [...], without any reason, wrote I was insane. [...]. Moreover, I had no opportunity at all to tell my version of the story about this totally fabricated claim" (Bergh, 1925, p. LII).

As a stranger, Bergh (1925) calls the asylum "the front door to hell" (p. XXXIII). The doctor becomes "The Grim Reaper" (p. 21). The title of Dahlin's (1919) book "The Swedish Hell" also signals the treatment system as somewhere one does not want to be.

The experience of being in hell and meeting the devil is repeated all through the texts, also by them who agreed with their diagnosis. "The Master Devil" is Holck's (1918, p. 64) description of a doctor. Danner (1955) refers to "the devils that put me behind bars" (p. 24), while Jaer (1995) meets patients who are "wearing the Mark of the Beast", "having the Devil's Horn" (p. 32). "Sometimes I see demons and witches", "The Angel of Death is an interesting person, by the way he is former medical doctor", Jaer (1995, p. 43) claims while being in the locked ward.

These nine authors accepted their diagnosis. Nevertheless, when the illness occurred, the feeling of losing control and becoming strangers in their own lives was dominating. Holck (1918) has an inner feeling of losing both her self-control and spirit when becoming psychotic:

The free – or in some way the free will – a will that *Correlates to our true personality*, the personality which we both deny but also keep like an indispensable property, the one I gradually lost in that very moment I began being a stranger to myself. (p. 13)

Storfjord (1977) also illustrates her anxiety attacks as something out of her control, something that took her away from herself and made the surroundings scaring:

All of a sudden, everything was a black, aching pain. [...]. Things passed by, pictures, objects and interior; everything in total chaos. The evil spirit has followed me. The ego is gone [...]. I run like a hurricane through the shop, like the devil, the lunatic. (pp. 113–153)

Something from outside struck Jensen (2003) as well. A gloomy alien described as a demon came into his life. He asks “why this devilish and disastrous attack had affected [his] soul” (p. 11).

Lauveng (2005) emphasizes the feeling of being a stranger: “somewhere inside me someone wondered if ‘she’ still was ‘me’, but recognised that it must be wrong, because ‘she’ was sad, and yes, I, I was nothing. Just grey” (p. 19). Heberlein (2008) also asks questions about “What’s happening to me?” (p. 26). As a helpless part in a big, inner conflict, she is, like the previous subject, fighting with ghosts from other worlds:

What’s wrong with me? Why is a constant war going on inside my brain? [...] Why are all the arguments, thoughts and ideas fighting inside *my* head? Why are they colonizing my brain? Are they I? Or is it a devil or an alien taken place inside my head? (Heberlein, 2008, p. 50)

Horror animals and birds also exist in this new, foreign world. Holck (1918) meets people in animal disguise. Jaer (1995) was for more than 20 years among dogs from hell and was regularly followed by a bird commanding him to behave badly. Lauveng (2005) meets a wolf, gnawing her foot. This pain of being in another world is genuine: “This bird inside my chest is scratching me. I am bleeding. This is not a fucking construction. It is very much real. Has God abandoned me? Where did You go?” is how Heberlein (2008, p. 96) expresses her situation.

These findings show that having mental health problems, or being told by others that one is insane, strongly affects his or her understanding of who and where he or she is. The feeling of losing oneself alienates one from the outside world. On the other hand, the descriptions of encounters with devils and the absence of God illustrate how the feeling of being in a strange and scaring place – Hell on earth – affects one’s inner life.

#### *The transformation of life experiences into questions of disease*

The majority of the authors translated the scaring phenomena into some kind of diagnostic terms. Holck (1918) understood later on that the feeling of being in hell had to do with her illness. Danner (1955) puts it this way:

All the time inside the asylum, I was convinced of being in the hands of the Nazis. Then – and first *then* – the clouds disappeared from my eyes. I understood that I was insane and why I had to be inside a locked ward. (p. 12)

In spite of the fact that Reeder (1975) understands the commanding voices as a kind of higher consciousness and not as a symptom of illness, she still prefers using the term *disease* about

the contact she has with both God and the devil. She writes that “The common opinion is that I have been ill” (p. 55). Storfjord (1977) underlines the connections between her experiences and the medical system. For her, the feeling of being under the surveillance of the devil is definitely a disease:

[...], we all need a doctor whose main task is to help somebody like us who needs to talk to somebody about the disease. This must not be overruled. They cannot just label us as self-centred and talkative. It is true. We are ill. (p. 48)

Lauveng’s (2005) opening sentences are about her disease and the recovery:

The reason for writing this book is that previously I was a schizophrenic. This seems well-nigh impossible, like being a “former AIDS-patient” or “former diabetic”. A “former schizophrenic” is something that practically does not exist. You are never offered this position. You are allowed to be “wrongly diagnosed” as schizophrenic. You are allowed to be “schizophrenic without symptoms,” the one keeping the disease under control with medication, or you are just now in a good period. [...] I have been schizophrenic. I know what it was like. [...] Now I have recovered. That must be allowed. (p. 14)

By making the experiences into texts, the authors seem to convince themselves that they have (had) a mental disease. The title of Danner’s (1955) book, *I Was Insane*, illustrates several of the confessional elements in the autobiographies. Jaer (1995) highlights his “lifelong” disease. He is no longer longing for recovery, but wishes for as many good periods as possible. Jensen (2003) writes that “YES I AM mentally ill; every fucking rumour about me is true. I HAVE been in the locked ward; I HAVE had electroconvulsive therapy. YES, they HAVE, fuck you, sedated me and sent electricity through my bizarre brain [...]” (p. 92). Jensen (1986) confirms that “After all, one thing is clear. I am, due to my disease, much more self-centred than most other people are. Because of my illness, I, Robert, have to be sickly self-centred all my life” (p. 52).

While analysing the autobiographies, mental problems as phenomena seem to have a lot in common, even when the diagnoses are different.<sup>1</sup> We might look at the texts merely as reports by mental patients on their day-to-day interactions with staff and their environment. However, it might also genuinely constitute a manifestation of their inner experiences. Based on our analyses, we are of the opinion that the autobiographies offer evidence for the latter (except Bergh, 1925; Dahlin, 1919; Jacobsen, 1932). The spiritual dimension of their experiences is not new. Even before mental problems became illnesses, people blamed both God and the devil when life was difficult. In our society today, the medical understanding is the dominating perspective and this seems to be the fact for nine of the authors as well. They place their personal knowledge into a medical psychiatric perspective, even when their experience of meeting the diagnostic world is negative.

### *Feeling ashamed*

The authors felt shameful on having or being told by others that they had mental health problems. The patients from the first period are all struggling for justice because they found it hard to be labelled and perceived as insane (Bergh, 1925; Dahlin, 1919; Jacobsen, 1932). Bergh (1925) claims that “the medical records from the different madhouses consist of slander and lies” (p. XXXII). Jacobsen (1932) has a similar experience: “The authorities are like a common tell-tale able to accuse anyone for whatever they find suitable” (p. 74).

Thus, applying for financial compensation, which these people did, is understandable. They wanted to renegotiate the definition of their experiences.

However, their battle was also driven by the shame they experienced while being admitted to the hospital. Danner (1955) underlines that her mental problems made her feel ashamed. When being told by the doctor that she was not a schizophrenic, but has had a nervous breakdown, she felt a kind of comfort. For her, the seriousness of the illness was comparable to the burden of shame. This interpretation is denied by Storfjord (1977). She fights to hide her anxiety from her family, friends and colleagues. She felt embarrassed and lied to avoid others from getting to know of illness. Similarly, Heberlein (2008), while thinking and planning suicide, felt ashamed for the pain and uncertainty she inflicted on her family. Lauveng (2005) was afraid and ashamed to tell people about her problems, and in the beginning, she avoided asking for help (p. 19). Reeder (1975) writes of the prejudice in society and how she felt stigmatized because of her mental illness. Jensen (1986) says that “I was certainly ill, definitely, but I hid my problems very carefully” (p. 21). At the same time, he claims that “Every attempt to understand human beings is a play with shadows. We do not really know what a mind is. Homo Sapiens will now and forever remain unknown” (p. 41).

Jensen’s (2003) aim is to de-mystify mental health problems. This is because he believes that enlightenment will take away the feeling of shame among those who are suffering from mental illnesses.

## Discussion

The analysis does not show any geographical differences related to the authors’ experiences. Independent of nationality, their representations of being mentally ill had a lot in common: their pain is like being in hell. In hell, they lose control and become strangers in their own lives. Hell is illness. To become mentally ill is shameful. Submission to a psychiatric regime is the result for most of them. Consequently, these experiences might be regarded as a common phenomenon independent of where in Scandinavia the authors live. With respect to the periods, their experiences are also remarkably similar. However, this study shows variations in the authors’ understandings of their experiences over nearly a century. Except for Holck (1918), the others from the first period claim that they were not mentally ill and thus hospitalization was absurd. Others, like family, friends and authorities, found their behaviour to be abnormal and problematic and sent them to asylums. Their own experiences of not being ill made them, after all, suffer because of the great injustice of being labelled insane. Somehow, Reeder (1975) in the second period differs from the others. She denies having a disease, but understands that the health service has this opinion. In the last two periods, none of the other authors question whether they are mentally ill or not. It is, however, possible to find signs of differences regarding the authors’ views of recovery for people with mental health problems in general.

We have illustrated these variations in Figure 2.

Question \ Period	The asylum era (1850-1950)	Neuroleptics gives hope (1950-1980)	Decentralisation (1980-to date)
Do the authors’ consider themselves mentally ill?	No	Yes	Yes
Is it possible to recover from mental illness?	No	No	Yes

Figure 2. The conceptualization of mental health in 12 Scandinavian autobiographies.

This figure simplifies the message from the authors, but it shows tendencies in the trend over the past 100 years. If we look at the connection between the two questions in the figure, it is possible to interpret the trend in different ways.

- (1) On the one hand, if one cannot recover from mental illness, the fight to avoid the diagnosis will be hard. People will struggle in order to maintain their hopes and plans for the future. From this point of view, the trend described might be understood as some sort of human progression, allowing people to both become mentally ill and recover from this psychiatric disease. Thus, we may be moving towards the final acceptance of the medical model in the mental health field.
- (2) However, the possibilities of recovery, especially from severe mental illnesses, are highly questioned in the medical scientific discourse when they are understood as biological, chronic diseases (Deegan, 1993; Topor, 2011). Consequently, the authors' emphasis on recovery might imply a criticism towards the basic assumptions of the medical model on mental illness. As Lauveng (2005) puts it: "Now I have recovered. That must be allowed" (p. 14). Accordingly, it is possible to argue that the trend points in a direction towards a demedicalization of mental illnesses and asks for other explanatory models of the phenomena that we today describe as mental illnesses.

Insight into one's disease is still regarded as a sign of recovery in most of the mental health services in Scandinavia and captures the ambiguity of these confessions of illness. These confessions may be the key to the services they need, but imply at the same time a subjection to an identity as a person at risk of being mentally ill. "Once people believe they suffer from an illness, there is no one left inside to take a stand toward the illness; they give up control and others take responsibility for them" (Deegan, 1993, p. 7). This quotation of Deegan shows the paradox that is also visible in this study. The autobiographies show that people both value and criticize the dominant medical model. Somehow, it must be possible to feel mentally ill without being subjected to the medical model and definition of illness. One way to contribute to this change might be to take the service users' own experiences as sources for understanding and guidance for the professionals.

## Conclusions

This study shows both variation and similarity when experiences of mental illness are transformed into text. "Hell on earth" serves as a unifying description of the selected authors' experiences of mental illness. Furthermore, it is possible to argue that their encounters with the mental health services made this hell even worse. The autobiographies differ in their understandings of their experiences and their views on recovery. On the one hand, the path from denial to confession might be understood as the accomplishment of the medical model of mental illness: mental problems are diseases. On the other hand, this confession might be understood as a construction built up by a more and more powerful medical system. When the medical understanding differs from people's own perceptions and experiences, we can say that mental problems are not diseases, but severe and painful phenomena in people's lives. The last view requires alternative descriptions, understandings and treatment approaches than what purely medical care systems offer.

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## Note

1. Holck (1918) was diagnosed with psychosis; the patients presented by Dahlin (1919) were considered as having serious mental problems; Bergh (1925) and Jacobsen (1932) were also considered as having serious mental diseases; Danner (1955) was diagnosed with psychosis, Reeder (1975) with schizophrenia, Storfjord (1977) with anxiety and Henningsen Jensen (1986) with psychosis. Jaer (1995), Jensen (2003) and Lauveng (2005) were considered as schizophrenic; Heberlein (2008) was considered as having a bipolar disorder.

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