

# Same diagnoses, different lives: A qualitative study of adults with severe mental illness in treatment and in education

Arnhild Lauveng, Sidsel Tveiten, Tor-Johan Ekeland & Torleif Ruud

**AB:** This study focuses on how adults diagnosed with severe and persistent mental illnesses experience their lives and relations and their own engagement in these relations in two different environmental conditions.

*Participants* include 14 patients in psychiatric treatment in Norway and 15 students at schools for adults with mental illnesses in Denmark. All participants have been diagnosed with severe mental diseases persisting for a minimum of two years and with pronounced impact on daily living.

*Data* were collected through qualitative interviews on two occasions 6 to 8 months apart for most participants.

*Findings and interpretations* showed that the two groups of informants described their lives quite differently. Patients described a focus on receiving treatment for their disease, few stable and mutual relations, and a generally low quality of life, whereas students described a focus on social relations, interests, and personal growth. Students also described a higher quality of life, little loneliness, and greater satisfaction with life. This suggests that the main problem for many patients struggling with persistent and severe mental illness might not be the illness itself but a lack of environmental conditions supporting personal development.

## Introduction

Standard treatments for mental diseases are often based upon a medical model of disease. However, mental illness differs from somatic illness in numerous ways, including causes, diagnostic methods, treatments, and prognoses. This might have implications for treatment and understanding of the core problem of the condition and could lead to questions about whether the medical model is the most effective frame for intervention. Self-disorders have been described in many classical theories for schizophrenia (Benedetti, 1964; Winnicott, 1965, 1984). In recent years, anomalies in the basic “sense of self” have been rediscovered as potentially crucial for understanding psychosis (Henriksen & Parnas, 2012; Raballo et al., 2011). There has also been some research on “sense of self” in severe personality disorders (Nelson et al., 2013).

If anomalies in sense of self are a core problem in severe mental diseases, a core treatment should be to strengthen this sense of self. Humans are social beings (Mitchell, 2000), and our identity develops through interrelations with others (Bronfenbrenner, 2001; Mitchell, 2000; Mead, 1936; Winnicott, 1965). Disturbances in relationships, such as relational trauma in childhood, may cause disturbances in adults; this indicates that relationships can be an important factor in treating such anomalies. These theories fit well with reports emphasising relationships between therapists and patients as crucial for therapeutic outcomes (McCabe & Priebe, 2004) and align with statements from service users emphasising the importance of personal growth.

However, recovery can be defined in different ways. Slade (2009) specifies a difference between clinical recovery and personal recovery. His key features of a clinical recovery

include having an outcome that is observable, able to be rated by a clinician, and representing a stable definition across individuals (Slade, 2009). He defines personal recovery as a consumer-based understanding, individually defined and having an experiential nature that involves a personal experience of living a satisfying, hopeful, and contributing life.

This perspective of the importance of quality of life and personal recovery also aligns well with a meta-synthesis of 97 qualitative peer-reviewed articles regarding psychosis (McCarthy-Jones et al., 2013). They identified four themes that are important for these patients; two included basic human needs such as sleep, economy, relationships, security, and hope.

Despite this, standard psychiatry is often more focused on the treatment of symptoms than on personal growth and well-being. A focus on the connection between sense of self and the importance of personal growth, personal recovery, and severe mental illness will make it natural to focus on the importance of relational and environmental conditions. This shift in focus might also actualize the question of whether a medical system is the best option for nurturing human development. For children and teenagers, families and schools are natural environments for personal development, and schooling might also be an option for adults with mental health problems. In Denmark, there are schools for adults in various life situations, organized differently according to students' problems and needs (Jørgensen, 2004). An example is schools for adults with persistent mental illness, where students attend for several hours three to five days a week. The purpose of such schools is not treatment but

development. They offer small classes, highly individualized instruction, no exams, and a large number of practical and theoretical topics. All attendance is voluntary<sup>1</sup>.

### Aim and research questions

The aim of this study is to explore the experiences of persons with similar diagnoses and backgrounds both in psychiatric treatment and in schools for adults with mental disorders.

### Research questions:

- What kinds of environmental conditions, including relationships, are the patients and students describing?
- How do patients and students describe themselves and their participation in these environments?

### Design and informants

**Design:** A qualitative, descriptive design was used in order to gain deeper insights into how patients and students experienced themselves and their environments. The study includes two groups of informants receiving support from two different systems. Generalizations or causal inferences about the differences between the two groups cannot be drawn from a qualitative

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<sup>1</sup> For reasons of confidentiality, it is not possible to name the specific schools I visited or make references to their home pages.

study and small samples. However, it is still of interest to explore similarities and differences in the informants' narratives of their experiences in the two settings.

### **Informants and inclusion:**

*Fourteen patients* at two community mental health centres in Norway were included. Nine patients were interviewed twice (6 to 12 months apart) and five were interviewed once, for a total of 23 interviews. Initial interviews were conducted while the informants were inpatients in a short-term, open ward. At the time of the second interview, most were living at home and receiving different types of psychiatric outpatient treatment.

*Fifteen students* at two different schools for adults with mental health problems were interviewed. Since Norway does not have such schools, informants were recruited from two schools in Denmark. Nine students were interviewed twice and six were interviewed once, for a total of 24 interviews. All interviews were conducted at the schools.

*Inclusion criteria* were that informants have at least one diagnosis of severe mental illness, substantial impairment, and a condition persisting for at least two years, and be capable of being interviewed without undue distress.

At the wards, nurses asked patients who met the inclusion criteria if they were interested in participating. At schools, teachers asked students. In addition, the first author attended a morning gathering at the schools and informed the students about the study. Sign-up sheets were available in the cafeteria, so anyone who met the criteria and wanted to participate could register.

For *informants'* background details, see Table 1. All information is from the informants' own descriptions. Many had been given several different diagnoses, and some were unsure which diagnoses were still considered valid. All informants described severe problems including isolation, attempted suicide, and self-destructive behaviour.

- Insert table 1 here -

## Interview

A modified version of the "Form of Living Interview" (Haavind, 1987) was used. Informants were asked to describe a typical day and week. Follow-up questions were asked to elaborate the patient's interpretations of the events and their significance, and to trace experiences about development. We chose this method to avoid leading questions and to encourage participants to freely mention important events from their daily lives without suggestions from the interviewer.

## Ethics

The Danish Ethical Committee for research stated that their approval was not required for this study. The Regional Committee for Medical and Health Research Ethics and the Privacy Ombudsman of the health authority approved the study. Data from all informants were collected and stored according to regulations. Participation was voluntary and had no effect on access to treatment or schooling. All informants received oral and written information about the study and gave written informed consent.

## Qualitative data analyses

Interviews were audiotaped and transcribed by administrative assistants with the same native language as the informant. Analyses were inspired by principles of hermeneutic content analysis (Kvaale, & Brinkmann, 2009; Malterud, 2011). Interviews with patients and students were analysed separately, using NVivo software. For each group of informants, meaningful units were identified and grouped in sub-categories that were condensed several times before being abstracted into main categories.

- Insert table 2 here -

## Findings and interpretations

In the following presentations of findings and interpretations, citations from interviews are in *italics*.

Students: A nurturing environment

### **Well-being**

Students described how school improved their everyday lives in various ways and raised their quality of life. Many mentioned the importance of *structure*, having something to do every day, and escaping from loneliness and habits that could exacerbate their condition: *If I do not attend school, I get mentally ill, maybe I will sit at home all day, staring at the walls, and that will make me very sick.*

They also mentioned as important that the school supported a healthier lifestyle, with meals offered and the opportunity to attend fitness classes in a safe environment.

Some of the students also received support or treatment outside the school; this could be therapy, medication, or home visits from community nurses. Many students described needing extensive help earlier but now needing much less or no support. Several continued to use medication; others had stopped or stopped between the first and second interviews. Many described numerous earlier hospitalisations, but none described recent admissions. In general, it was observed that needs for treatment decreased after they had attended school for a period. Some still needed treatment but less than earlier (e.g. sheltered living rather than long-term hospitalization, or medications but no acute admissions). They also described being more actively involved in their treatment, and several said that teachers had been helpful in discussions with social services and assisted them in securing better services than earlier.

All students spoke a lot about joy and happiness, describing moments both in everyday life and on planned occasions. They emphasised the significance of sharing many joyful experiences: *I have experienced so much good, and met so many good people. That has changed me.*

Other important aspects of the students' well-being appeared to be freedom from pressure and the ability to attend school as long as needed: *This has been a long journey. When I started, I had it very difficult; (...) it was ok for me just to be. Then, I could build myself up again,*



*slowly. I did it myself, just like I myself decided to give up at one point, I also decided to get up again.*

### **Learning and reflecting**

All students described opportunities to learn new skills such as cooking, computer use, or a different language as important and said they appreciated opportunities to learn things they could use outside the school. Furthermore, new skills could lead to new experiences and further development. When they learned to cook, for example, they could invite a friend over. Knowing how to use a computer meant they could order films and books or engage in online discussions. Knowledge about poetry could make it possible to attend a poetry festival.

In addition to mastering practical skills, the students stated that the *process* of learning was important. They appreciated developing intellectually; becoming informed about politics, literature, philosophy, history, and other topics; and having opportunities to reflect upon the big questions in life: *Philosophy, I really like it. The teacher has some program, and then we talk about being human, identity, and more. I start to think different. Then we discuss what this means for us; I find myself through this.*

Students: Supporting the unique individual

### **Relations**

For all students, the social environment and opportunities to make lasting relations were highly significant.

All students liked their teachers. They mentioned them by first name, described them as “warm” and “competent”, and said, “*They care about me*”. The students also described it as important that teachers were readily *available* and that they spent a lot of time together, interacting in everyday situations. They described these conditions as different from traditional psychotherapy (with limited sessions at fixed intervals), and this difference appeared to be important for the students. Teachers functioned as role models, and the students had many opportunities to influence the quality and quantity of the interactions.

Many students described being lonely earlier and the importance of their relations with other students. They described typical aspects of friendship such as having fun together, helping with tasks, and discussing different topics. “Friend” was a word they used frequently. Many also mentioned that these relationships went beyond friendship: *It is like a family*.

Many students also emphasised the feeling of community and mutual responsibility. Some described the importance of knowing that the school existed. Even if they had not attended for long, students said it was easier to try new challenges knowing they could always come back to school.

### **Individual customization**

For all students, it seemed important to be treated as *individuals*. This included individual customisation, and schedules and lessons adjusted according to their needs, interests, and strengths. They also mentioned the importance of teachers remembering to ask about personal things (like holidays and appointments) and greeting them by name: *They know me by name*.  
*They know me*.

Many students described earlier experiences of *not* being respected, but all of them appreciated being accepted at school and recognised this respect in numerous daily situations:

*When you say something, they will listen to you, and take you seriously, instead of thinking,*

*“Well, you are not quite right anyway...”*

Patients: Discontinuity

### **Good care at wards and no care at home**

The patients described a chronic situation of discontinuity alternating between admissions and discharges. All patients perceived the ward as a secure place and described the importance of care and support, and good relations with the staff: *Safety. That is important for me. That there are people surrounding you, someone to talk to, that you can get help when you need it.*

They felt better at the wards and appreciated the safe and social environment. However, most of them thought the inpatient stays were too short and too infrequent: *I have been in and out of the ward several times. Last time ... I thought it went well, but after a few weeks, everything was like before admission.*

With few exceptions, the patients described life at home as very different from the wards. At home, they experienced anxiety, depression, loneliness, substance abuse, economic and practical difficulties, sleep problems, and suicidal thoughts: *It is like hell. Last night I did not sleep at all.* None used words like happiness, and many described somatic problems that affected their daily lives. Most were isolated, and many experienced scant and fragmented help. Even those most satisfied with their support at home received help only a few hours a

week; the rest of the time, they were alone. One patient summed it up this way: *“I exist. I do not live”*.

Regarding treatment in general, the patients expressed differences; some described good and useful treatment, especially at the wards. Conversations with psychologists or the staff were considered very important, and some benefited from therapeutic groups at the wards. A few patients described good treatment and support from therapists or psychiatrists outside the wards. Others said they received little or no treatment, or treatment that was not perceived as helpful or not adapted for their problems. All patients described medications as very important, even if many also described problems such as side effects or dependency.

Whether treatment was helpful or not, most patients described it as disjointed and haphazard. They described little collaboration between different agents in the system, no long-term plans for treatment, and little actual treatment for their illness.

### **Lack of lasting relationships**

A few patients described close relationships with and valuable support from their families. Others said they had little or no contact with their families. Most talked about loneliness, isolation, and a small fragile, destructive or non-existing network: *I want to get a new network. However, I guess it will be difficult...*

For most patients, their main network was professional and often characterized by limited resources and continuous discontinuity. Clinicians were constantly replaced, and patients had to connect with new therapists repeatedly. Effective treatment and helpful relations were often

broken. Some patients consider this a problem, and for others it was “*okay*”, since they were “... *used to it, and not bound with people anymore*”.

Two patients were exceptions of these general descriptions; they talked about lasting relationships and prolonged, systematic treatment outside the ward.

Patients: Little support for the individual

### **Adjusting to the system**

Most patients described having to adjust to the system in various ways, and that the system adjusted little to their needs. For instance, they described the importance of following rules made by professionals, especially at the wards, but also regarding other subjects, like their need for admissions or support at home. For some, the number of rules became a problem. For others, the rules felt inflexible or unsuitable for their needs. Many described days at the wards as boring or filled with meaningless activities.

### **Not taken seriously**

Most patients noted that the staff would not take their complaints seriously, for instance, not believing them when they said how sick they were. Since disease was the key for admission to the ward, the patients perceived this as a crucial problem resulting in less support: *I feel that they do not believe me, and then I do not get any help either.*

Others described not receiving help for somatic symptoms or practical problems or getting help not suitable for them. In general, many patients described a system providing good support sometimes, but said they had little influence and often experienced poor adjustment to their personal needs.

## Discussion

The aim of this study was to explore whether different environmental conditions would affect the narrative descriptions of informants with similar diagnoses and backgrounds. The students and patients described many similarities regarding background and earlier experiences, but they also described highly different life situations, suggesting that the differences could be related more to environmental conditions than to diagnoses.

Students described a manageable everyday life in which they had good experiences, were met and accepted as individuals, had opportunities to make their own choices, and had good relationships with teachers and other students. The patients described few lasting relationships, loneliness, little mastery, and little autonomy. Their primary focus was on getting treatment for their illness.

As mentioned, Slade distinguishes between clinical and personal recovery (Slade, 2009).

When describing their everyday lives, the students mentioned many of the core elements of personal recovery, such as personal and unique experiences, meaning, satisfaction, and hope (Slade, 2009). At the same time, some still experienced symptoms of mental illness, and not all would have a full clinical recovery.

Patients, by contrast, described few of the aspects related to either personal or clinical recovery. They generally described having little hope, meaningfulness, satisfaction, or other conditions related to personal recovery or quality of life. These findings and interpretations might suggest that the focus on treatment of the patients' illnesses and symptoms could lead to *less* focus on their well-being, and psychological and social conditions supporting well-being. The general assumption seems to be that, with fewer symptoms, the other factors (relationships, mastery, meaning) would come automatically, but the patients in the interviews could not describe anything supporting this assumption. In fact, the findings from the interviews with the students suggest an inverse connection: that better life conditions would have more impact on symptoms than symptoms have on life conditions.

A majority of patients described troublesome pain and somatic diseases leading to isolation and sleep disturbances. Somatic pain was not a focus in any of the interviews with students, although several also had somatic impairments. Of course, these differences can be coincidental. However, there might be a connection between satisfaction with life and perception of pain and somatic disease. Diener and Chan (2011) reviewed seven different types of evidence and found that higher subjective well-being indicated better health, even if the results did not indicate that subjective well-being could prolong the lives of persons suffering from certain diseases such as cancer. Therefore, it is possible that even if subjective well-being cannot predict the outcome of severe somatic disease, it may influence how pain is perceived. By contrast, it is of course possible that patients' perceived pain contributed to their low quality of life.

Differences in health could also be related to differences in lifestyle. Students described eating regular healthy meals at school, and most were engaged in physical activities, while

most patients described a rather unhealthy lifestyle when not admitted. Nome and Holsten (2012) showed that patients admitted to psychiatric hospitals suffered increased mortality compared to other populations. Their study has no clear explanation for these differences but suggested that possible causes might be excess medication combined with unhealthy lifestyles. This aligns with the differences described by students and patients, suggesting that environmental conditions at the schools make it easier for students to maintain better health.

Patients also described lack of individualized treatment and lack of control. They described that their opinions were not taken seriously and not being heard. Service users from New Zealand have stated that being taken seriously and being an active part of their treatment is crucial for change (Mental Health Commission, 2001). Again, this parallels students' descriptions but not patients' descriptions and might contribute to the described differences.

Both students and patients described relationships as important. This aligns with theories describing humans as social beings (Mitchell, 2000; Mead, 1936; Winnicott, 1965) and with knowledge about the importance of relationships for recovery. However, although both students and patients describe relationships as equally important, they describe their social *frames* for relationships and their environmental opportunities to develop relationships quite differently.

Students described spending many hours daily in mutual interaction with teachers and other students. They also described relationships lasting for years and a high level of control in their relationships. They could make contact with teachers and fellow students when they wanted to, and they enjoyed being together.

Patients, by contrast, described few personal relationships. They described relationships with nurses at the wards as essential and said that the most important treatment at the wards was



conversation with nurses and therapists. However, the nature of these relationships was strictly limited in quantity and duration, and had little focus on mutual interaction and more focus on the fact that patients were treated by professionals. There was much discontinuity in these relationships; professionals had most of the control over the nature of contact, and contact would be broken when the patient was considered not to need further treatment. Bronfenbrenner's (2001) ecological model of development emphasises the importance of interaction over time to promote the development of a life domain. The patients, however, described the opposite: that their interactions are constantly interrupted and limited in time and duration. Topor and Denhovd (2012) showed that such practices are common in psychiatry and that both working alliances and recovery are improved when patients receive more time and more stable relationships than psychiatry normally offers.

*Patterns* of interaction also differ between students and patients. Slade (2009) distinguishes among three different patterns for relationships; real relationships, partnerships, and detached relationships; and he recommends partnership with sharing of power for a recovery-oriented practice (Slade, 2009). This *partnership*, with sharing of power and mutual interaction, aligns with the students' experiences, while the patients' descriptions can best be described as *detached*, with most of the power held by the health professional.

Together, these factors might indicate that the patients had fewer environmental opportunities than the students to develop stable and lasting relationships and to benefit from such mutual interaction (Slade, 2009; Mead, 1936).

### **Clinical implications**

Although more research is needed, findings and interpretations suggest that, for some patients with severe mental illness, focusing on environmental conditions and on the development of

psychological and social well-being might be more effective and provide better quality of life than to focus solely on treatment of their symptoms. Important environmental conditions could include opportunities to develop lasting and mutual relationships, and to participate in meaningful activities, and an intervention that is intensive enough and of long enough duration to make a substantial difference.

### **Limitations of the study**

The qualitative design chosen was well suited for exploring the experiences of students and patients, and for revealing environmental factors important to them without any leading questions. However, the method also has limitations. Findings and interpretations indicate important differences between the groups, but because of the qualitative method, these findings must be considered tentative, and quantitative research design is needed to further explore the suggested differences between the groups.

Since patients were admitted at the time of the first interview, while most students had not been admitted for years, it might be argued that the patients were in more acute stages of their illness than the students were. However, most patients described being in a *chronic* acute situation lasting for years, with repeated admissions and relapses and little lasting recovery. Moreover, many of the students described being in similar situations earlier, before they started at school, and described significant differences between then and now. Therefore, it is possible that differences in the situation are not related to characteristics of the *individuals* but to different *environmental* conditions.

## Conclusion

Much of the research regarding severe mental illness focuses on the *disease* and the best treatment for it. In this study, students and patients had similar backgrounds and diagnoses known to affect daily life functioning and relationships with others. All students described that they *had* developed such relationships, while most patients described themselves as lonely. Students described being happier and more engaged, and having a higher quality of life. Very few patients described any signs of personal or clinical recovery, while most students described personal recovery, and some also described clinical recovery.

This suggests that the patients' main problem might *not* be their diagnoses or their backgrounds but the environmental conditions offered to cope with their challenges. In an environment that stimulates relationships and personal growth, patients might have opportunities for better lives and for personal growth and development. More research is needed to draw causal inferences, but findings in this qualitative study indicate that systems other than medical could be important in supporting development and personal recovery of persons suffering from mental illness.

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