



EMPIRICAL STUDIES

Barriers and facilitators for dental care among patients with severe or long-term mental illness

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Abstract

Background: Persons who struggle with severe or long-term mental illness (SMI) have a higher prevalence of oral health problems than the general population. Obtaining and continuing dental treatment is challenging for this patient group for many reasons, and many drop out of active treatment. Our study aimed to explore perceived barriers to obtaining optimal dental health care for patients with SMI. Further, we sought to identify possible ways to facilitate for providing true access to dental services for this population.

Methods: The study utilised a flexible qualitative design with data collected during ordinary clinical practice in a public dental clinic in Norway. We conducted semi-structured face-to-face interviews with 51 persons with SMI twice: an initial interview before dental treatment and a final one after dental treatment. We applied the thematic analysis method.

Results: Thematic analysis revealed two key themes in the participants' experiences of access to dental health services: *practical conditions* and *relationship with the dentist*. Patients reported barriers and facilitators for access to care as factors associated with patients (patient factors), with the dentist (dentist factors) and with healthcare services (system factors).

Conclusions: Our study indicates that persons with SMI appreciate oral health and want to obtain needed oral care and dental treatment, but they encounter barriers on several fronts. The participants offered suggestions for how to facilitate attendance and adherence. Our findings suggest that dental healthcare services require reorganisation to meet the needs of patients with SMI.

KEYWORDS

dental health services, health services accessibility, mental disorders, qualitative research

BACKGROUND

Oral health is an important part of general health and affects physical health, mental health, quality of life and general

well-being (1). Poor oral health can also negatively affect eating, speech and one's social and intimate interaction with others (2). Oral health should therefore be considered relevant and important wherever health issues and quality of life are addressed.

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Mental health problems are common both globally and in developed countries and cause a considerable burden of disease and years lived with disability (3, 4). In Norway, for instance, estimates reveal that half of the population experience depression or anxiety during their lifetime (5). The most common problems are mild and transient conditions, but consequences of severe and long-term mental illness (SMI) create a severe burden for individuals, families and society (6). Mental illness is thus the most common cause of disability benefits in Norway, accounting for 35% of all disabilities (7).

Persons who struggle with severe or long-term mental illness (SMI) have a higher prevalence of oral health problems than does the general population (8, 9). Further, despite the prevalence of poorer oral health among persons with SMI, this specific patient group underutilises dental health services (10, 11). Access to dental services is reportedly poor, and many miss or drop out of active and systematic treatment (11). Consequently, persons in this patient group tend to postpone treatment until pain is severe (12).

Despite the growing attention that has focused on the poor oral health of people with SMI (2, 13), little is known about why this patient group misses necessary dental treatment. Further, research on how persons with SMI perceive and experience barriers to obtaining oral healthcare services and how this patient group would prefer that services be designed in order to improve their accessibility and usefulness is scarce.

Our study aimed to explore the experiences and views of patients with SMI in oral healthcare services and especially perceived barriers to obtaining optimal dental health care. Further, we sought to identify possible ways to facilitate providing true access to dental health services for this population. Our ultimate goal was to develop and improve adequate oral health services for persons with SMI.

METHODS

The study is part of a longitudinal mixed-methods project addressing oral health and dental treatment for persons with severe or long-term mental illness (SMI) (14). The research project has been implemented as part of ordinary clinical practice in a public dental clinic in Western Norway. The Regional Committee for Medical Research Ethics approved the study (Reg no 2015/1724-1). Participation in the study was voluntary, and the patients were informed that they could receive dental treatment regardless of whether they participated in the study. All participants provided their written informed consent to participate prior to inclusion.

The present study applied a flexible qualitative method for identifying, analysing and reporting patterns (themes) within data (15) collected in semi-structured interviews. The procedures adhered to consolidated criteria for reporting qualitative research (COREQ) (16).

Participants and setting

The Oral Health Centre of Expertise in Western Norway initiated and conducted the study in collaboration with the public dental clinic and the Community mental health services in a Norwegian municipality (18 000 inhabitants). The Community mental health services recruited the participants. At the outset of the research project, the contact persons in the team (all psychiatric nurses) were individually assigned to each service user ($n = 82$) who received individual support from the Community mental health team. Participation was based on informed and written consent. Participation in the study involved an intake interview by the first author, a dental examination by the second author and several questionnaires on issues relevant to oral health. After identifying the patients' treatment needs in the oral examination, the dentists provided dental treatment to all patients according (as far as possible) to their own preferences.

Norwegian authorities have stated that all citizens have an equal right to good oral health. Thus, under certain conditions, vulnerable groups—including persons with SMI—have a right to free dental treatment. That is, persons who receive home-based nursing at least once a week for at least three months, and persons who are hospitalised for a minimum of three months have a right to free dental treatment. All service users in the collaborating Community mental health service received invitations to participate regardless of whether they were entitled to free dental treatment. In all, 51 persons (33 women, mean age 43 years) agreed to participate in the study (Table 1). Of the participants, 34 (66.7%) had a right to free dental treatment. Participants received all dental services provided as part of the project free of charge. One of the psychiatric nurses in the Community mental health team served as a project employee in a 20% position; as a research team member, she provided support, transport and follow-up for the dental clinic.

The first author (JB) collected data in semi-structured interviews which she conducted. The interviews took place during the first meeting at the dental clinic and served two purposes: first, to explore the participants view and experiences with oral health care in general, and to enquire about perceived barriers and ways to facilitate providing oral healthcare services; second, to explore individual needs and preferences for their own treatment. The dentist later discussed this information with the participant. Participants were free to choose whether they wanted to come to this discussion alone or wanted to bring their psychiatric nurse as support. The interviews also enquired about background information, demographical variables and screening for the main categories of psychiatric disorders (17). Interviewers made note of the self-reported duration of severe mental illness, as well as information describing the person's general functioning at work and in social life. To explore the research questions further, we asked the following questions:

TABLE 1 Description of participants.

	Total (n = 51), 33 (65%) females
Mean age (SD)	42.6 (13.6), min = 22, max = 78 years
Diagnostic category	
Anxiety disorders	36 (70.6%)
Mood disorders	34 (66.7%)
Psychosis in bipolar disorder	16 (31.4%)
Severe traumatic experiences	28 (54.9%)
Cognitive disabilities	15 (29.4%)
Severe somatic illness (co-morbidity)	24 (47.1%)
Duration of mental illness	
<5 years	3 (5.9%)
5–10 years	5 (9.5%)
>10 years	15 (29.4%)
Since childhood	27 (52.9%)
Marital status	
Married/living together	19 (37%)
Single	32 (63%)
Education	
Primary school (9 years)	17 (33.3%)
Secondary school (12 years)	28 (54.9%)
University (15 years +)	6 (11.8%)
Occupation	
Working (part time, max 30%)	3 (5.9%)
Sick leave	17 (25%)
Disability pension, age pension	29 (42.6%)
Sheltered occupation	3 (4.4%)
Other (social benefits, unemployment benefits)	2 (3.0%)
The patient's chosen condition upon attendance at the dental clinic	
Comes alone	32 (62.7%)
Comes with support from psychiatric nurse	19 (36.5%)
In need of supported transport	22 (43.1%)

1. How is it for you to go to the dentist? (proposed answers were “all right”, “difficult, but doing it anyway”, “avoid as much as I can”, or the patient chose his/her own words)
2. If dental treatment is difficult for you, what do you experience as barriers to meeting your dental health service?
3. What is important to you when dealing with a dentist?
4. What kind of dental health service should be available to you in the best possible way?

A second interview followed completion of the dental treatment in order to validate the content of the first interview

and to provide the participants with an opportunity to add new information based on their experience from the dental treatment. Interviewers wrote notes immediately after each interview and transcribed statements verbatim. Notes also included the interviewer's (JB) reflections.

Data analysis

The study applied a flexible qualitative design, and the thematic analysis procedure described by Braun and Clarke served in analysing the responses (15). Procedures adhered to consolidated criteria for reporting qualitative research (COREQ) (16).

The analysis followed several steps as described by Braun and Clarke (15). First, the first two authors (JB and DH) read and reread their notes, both individually/separately and together, and discussed their initial impressions. The second step involved generating initial codes across the entire data set, where the authors coded all expressions relevant to the overarching research question. Thereafter, the authors collated the codes into potential themes, compiled all data relevant to each potential theme and, finally, defined and named the themes.

RESULTS

One-fourth of the patients (13 persons) reported that going to the dentist was all right for them. More than half (29 persons, 57%) reported that it was difficult, but they tried to do it anyway. Typically, persons in this group visited the dental clinic for an initial session, but dental treatment remained incomplete due to dropout or cancellation of subsequent sessions. Seven persons reported that they avoided dental health services as much as they could, but accepted the invitation this time because transport was arranged, the treatment was free or because it was highly needed due to pain. Two patients refused to answer according to the proposed categories, but emphasised that their thoughts and feelings associated with going to the dentist depended strongly on the personality of the dentist they were going to meet.

Two main themes identified in the patients' descriptions of dental services were *practical arrangements* and *relationship with the dentist*.

Reported barriers

Almost all (n = 50) of the participants identified barriers in meeting dental health services. Two participants identified a single barrier, which associated with poor economy,

while most participants reported several hindrances or challenges. These barriers exist on multiple levels and involve factors associated with the patients themselves, factors related to the dentist as a person, and factors associated with the dental healthcare system (Figure 1). We categorised these different barriers according to the two main themes: *practical conditions* and *relationship with the dentist* (Table 2).

Practical conditions as barrier

The participants reported several practical conditions as barriers to obtaining optimal dental health care. Many patients were concerned about their difficulties adhering to treatment, that is difficulties arranging appointments at the dental clinic, difficulties attending the actual session with the dentist

(organising transport and leaving home when “having a bad day”) and following up when several sessions in the dental clinic are needed. Participants emphasised that these difficulties are due to mental illness and not to physical inability:

An appointment at the dentist needs a lot of planning and is demanding to implement, especially when I have bad periods or when I am seriously depressed, and

I am fine with dental treatment when I first arrive; the challenge is making an appointment, transport and getting there in time.

Even if, under certain conditions, persons with SMI have a right to free dental treatment, most respondents reported poor economy as a significant barrier. Some reported that specified

TABLE 2 Participants' experience of barriers to achieving dental health care.

Barrier	Example	Relevant theme
Making appointments at the dental clinic	I postpone and avoid to make an appointment at the dental clinic, using the telephone scares me. I am unable to arrange an appointment myself. It is especially difficult if I failed to attend the previous session, I am so ashamed.	Practical conditions
Attending the session	It is hard for me to get out of my home, I postpone and sleep over If I am not clearly reminded. All this is due to depression, I do not want to be like this.	Practical conditions
Transport	The difficult part for me is transport and getting there. I have no car and using a bus is impossible for me. Taxi is far to expensive, I can not afford it.	Practical conditions
Support	I am far too anxious to go the dental clinic alone, I need support from a person who understands and can go with me	Practical conditions
Poor economy	I have cancelled appointments at the dentist several times due to finances. Poor economy is the main problem for me.	Practical conditions
Unsupportive dentist	My greatest fear is to meet an unsupportive dentist who is busy and wants to get things done. I get more nervous and feel so small. Treatment is not going well. I feel criticised and misunderstood.	Relationship with the dentist
Shame	I feel ashamed of my teeth and feel afraid to smile, talk and be with others. I always feel inferior when meeting others, especially people I do not know well. I expect being criticised or humiliated, and try to behave in ways to be as invisible as possible.	Relationship with the dentist
Respect	I have mental health problems, but I am a grown up person. I hate being spoken to as a child when in the dental chair. I need a dentist who knows me and shows respect.	Relationship with the dentist
Threat of violation	Proximity in the dental chair is difficult to me due to traumatic life history. I feel unsafe with people I do not trust	Relationship with the dentist
Anxiety	Dental anxiety depend on the context, I panic when predictability is low.	Relationship with the dentist
Mental illness	I have days and weeks when my mental illness is worse and I feel terrible, but dental health personell perceives me as difficult and unmotivated. Then I feel worse, frustrated and vulnerable.	Relationship with the dentist
System	I lost the right to free dental treatment because my mental illness got worse and I needed treatment in the specialist mental health services. The rules do not make sense.	Practical conditions

conditions went unmet, whereas others reported worrying about unpredictability, as the right to free treatment applies for one year at a time and can be lost:

I have had free dental treatment this year, but the rules will not apply to me next year. I have to save money to afford going to the dentist next year. I wonder if I will have to pay for dental health care when I reach retiring age as well.

Several participants reported difficulties with adherence due to their mental health symptoms, such as periods of malfunction with panic-related anxiety and severe depression.

On days when you feel hopeless and think of ending your life, you forget both to brush your teeth and to go to the dental clinic.

The patient may have needed hospitalisation or other specialised care. Several participants reported missing sessions and that nobody contacted them about it or asked if they needed a new session:

My mental illness causes me to have bad periods when I need hospitalization. Then I forget appointments at the dental clinic and risk falling out and losing my treatment. The dentist thinks that I do not care or that I am a difficult person, and I feel ashamed.

As the last quotation illustrates, participants reported that they care about their oral health, but encounter barriers to obtaining dental health care. Generally, they asked for visits at the dental clinic as a matter of routine every year, but regretted the barriers they encountered on different fronts.

Relationship with dentist as barrier

The results indicate that an important aspect of enduring mental illness is feeling inferior and vulnerable. Most participants reported feeling shame about oneself in one way or other, that is shame about exposing one's teeth, shame about exposing one's life situation, and a general feeling of inferiority and vulnerability. Many patients reported fear that the dentist might criticise, humiliate or harm them, as the following two quotations illustrate:

I experience shame more than anxiety at the dentist and expect to be ridiculed or criticized. I have been bullied before and always expect it to happen again. Trust is difficult.

I have been committed to mental hospital many times, and several times compulsory means were used. I think that's why I react when people come close to me. My body gets scared. Proximity in the dental chair is difficult for me.

Some patients reported fear of disappointing the dentist, as they are generally concerned about not disappointing people. Participants associated this feeling with fear of burdening others, including the dentist. In order not to disappoint the dentist, several participants felt it was important not to complain or share their own opinions:

The dentist sometimes asks me what I prefer, but I never tell. I am afraid of the reaction from the dentist if I tell my own needs. Another patient reported:

I never dare to tell my own needs; in fact I do not know what they are.

Shame is interpersonal, and several participants reported how the dentist amplifies or attenuates their shame, that is how the dentist's perceived impatience, criticism or preoccupation reinforces their feelings of shame or inferiority:

If the dentist is impatient, it is very difficult for me to relax. I fear that I'm using someone else's time, that I am a difficult person and a burden to others.

Several participants described missing a treatment session due to mental illness as a particularly critical incident. They assume, however, that staff at the dental clinic perceive and believe that they lack motivation, are lazy or do not care. Consequently, making a new appointment after failing to adhere once is even worse, as they feel shameful and expect criticism or humiliation. A reported consequence is to postpone dental treatment, which risks the deterioration of oral health.

Further, some participants reported that the dentist lacks understanding of or interest in their situation. For most participants, shame and inferiority associated with reported previous experiences of therapists and other authority figures not taking them seriously. Consequently, they carry a fear that the hurt will happen again. Respect is therefore important, and several patients pointed out that health professionals who try to be helpful are not always respectful:

I hate being spoken to like a child. I know that I have problems, but I am a grown up and not a child. So, don't patronize me; it makes me feel more shameful and very frustrated.

Reported facilitators

Participants suggested practical ways to facilitate obtaining dental health care (Table 3). Practical arrangements comprised various combinations of reminders, support and transport. Some participants pointed out that they needed support from professional contacts to facilitate access to dental health care on a continuous basis, whereas others needed support during periods when life is particularly difficult and their ability to function independently is diminished.

Several participants reported that attending the interview and the dental examination would be impossible without support from their psychiatric nurse:

Without ES (nurse), I would never have been here today. She called me an hour before picking me up and came together with me.

A commonly reported facilitator associated with economic predictability:

Going to the dentist is very expensive. As I have never had an ordinary job and my income as a disabled person is low, long-term decisions of free dental treatment would be an important facilitator for me.

Most participants reported factors associated with the dentist as a person and their relationship with the dentist as crucial facilitators affecting their use of dental health services (Table 3). Important themes included feeling safe and that the dentist understood and respected them. Meeting the same dentist and the same dental team gave a sense of predictability, and patients did not need to explain their difficulties or needs repeatedly. Time is important, as most participants emphasised that calmness and patience counteracted their sense of shame and vulnerability:

DISCUSSION

This study aimed to investigate the experiences and views of patients with SMI in oral healthcare services. In particular,

Suggestion	Example	Relevant theme
Arrangements of appointments and transport	Dentist and mental health services need to cooperate. Then appointments, reminders and transport can be arranged and it is possible for me to attend at the clinic	Practical conditions
Support person available	When E (psychiatric nurse) can pick me up and go to the dental clinic together with me, my day is saved. Then I can manage dental treatment. Without E, I would never have been here (dental clinic) today.	Practical conditions
Predictable and affordable costs	I need to know if rules for free dental treatment applies to me, and I need to know how much I have to pay myself. I need to plan future costs.	Practical conditions
Keep the same dentist over time	I have a GP who knows me over time and whom I trust. I want «my own» dentist as well! Having a dentist who understands my needs and shows respect is of great help.	Relationship with the dentist
Knowledge	The dentist must have some knowledge of mental illness and how the disease affects me.	Relationship with the dentist
Respect	The dentist as a person is the most important facilitator for me. She meets me with respect and understanding. We cooperate in dental treatment and I feel safe enough to tell my own needs.	Relationship with the dentist
System	The regulations regarding the rights to free dental care must be upgraded. And the system must ensure that those who have rights under the law are guaranteed the health care they are entitled to.	Practical conditions

TABLE 3 Participants' suggestions for how to facilitate attendance to dental health care.

we sought to explore perceived barriers to obtaining optimal dental health care and to identify possible ways to facilitate providing true access to dental health care for this patient group. The study sample comprised persons with severe or enduring mental illness who received individual support from the Community mental health team in a municipality in Western Norway.

The study revealed a gap between patients' needs that must be met in order for them to benefit from the dental health services available to them. Participants reported barriers to attendance and adherence to treatment due to their mental illness, such as arranging appointments by phone, planning transport, actually visiting the clinic and cancelling an appointment due to illness. Dental health services generally rely on an adult's personal ability to initiate contact and to follow up over time. Our study suggests that this responsibility is too much for many patients with SMI, at least during especially difficult periods. The results suggest that measures are needed to (close or) bridge the gap between this patient group and dental health services, as Bjørk et al. (18) also reported in a study of access to somatic health care for persons with SMI. The participants in our study emphasised the importance of the practical and emotional support from the psychiatric nurse, and the availability of transport when needed. Such measures require close collaboration between dental health services and mental health services. However, to identify and follow up on the patient's needs for support with oral health care, mental health services must view oral health as a natural part of general health (2). Collaboration between mental and dental health services must be strengthened to provide for oral health needs, as oral health is an important contributor to general health and quality of life (13).

Most participants in our study reported shame or perceived inferiority as barriers, often accompanied by mistrust of ward members. Patients in our study also feared not being taken seriously, which comports with previous research (8, 18, 19). In our study, participants reported fears of burdening or disappointing the dentist and therefore suppressed their own needs while enduring dental treatment in a state of emotional distress. This kind of therapeutic relationship maintains the patient's fear and, in a sense, confirms the patient's expectation that they will not be understood (19). Shame or self-stigmatisation (20) correlates negatively with adherence to treatment (21) and must be taken into account when developing interventions aimed at increasing access to health care for patients with SMI (18). As Abrahamsson et al. (19) conclude, cultivating a good relationship between patient and caregiver is crucial when interacting with vulnerable patient groups. The results from our study underpin this argument, as participants claim that a relationship of trust with the dentist alleviate shame.

The participants in this study offered a clear suggestion for improving access to dental services: providing a stable and continuous programme where patients in this group can meet dental professionals with expertise and interest in this field, and who can become familiar with the patients over time. Such a programme could strengthen patient attendance and collaboration with dental healthcare providers over time and prevent unnecessarily postponing treatment, and the need for emergency treatment that such delays may lead to. A possible solution could be to establish specialised teams with employees who have both the expertise and resources to offer these services. More importantly, service users should be involved at all levels in the process of improving dental services. User involvement is a key component of a movement within mental health care in the direction of recovery-oriented practice (21, 22). In recovery-oriented services, service users' understanding and competence takes precedence and must be taken seriously by professionals involved (23). The results from our study suggest that this type of user involvement also needs to gain access to dental health services.

Furthermore, user involvement is required to discuss important issues related to privacy. Interdisciplinary collaboration and support should never interfere with patients' right to personal autonomy (17, 12). Patronising or moralising never builds a respectful relationship, and empowerment to participate and make one's own choices in life is an important human right. Support must be available, but never intrusive. Thus, participants ask for support *when needed*, in accordance with what is known as voluntary chosen dependency (18).

In today's Norwegian healthcare system, patients with severe or chronic mental disorders are, under certain conditions, entitled to free dental health care. Our results indicate that protecting patients' rights under the law alone is insufficient, as for some patients the barriers are so high that they find themselves unable to exercise their rights. Others fail to exercise their rights for various reasons, citing financial conditions as a major barrier. Although patients with serious or enduring mental illnesses are considered a prioritised group within the Norwegian dental health services, the praxis does not fully meet the authorities' intentions. Organising dental health care for persons with SMI needs further improvement.

The present study included persons with severe mental illnesses. To ensure that these patients were able to consent to their participation, their Community mental health team participated in the recruitment and data collection. Although the recruitment procedure may have influenced the patients' willingness to participate, we considered the recruitment procedure the best way to create a safe setting where the participants could discuss questions about their participation with a familiar mental health team contact person. The participants also had ongoing contact with the Community mental health

services during data collection. All service users (N = 82) receiving individual support from the Community mental health team received information about the study and invitations to participate so as to secure rich and diverse data from participants in the target group.

One limitation of our study could be that we did not make audio recordings of the interviews (16). We discussed with our collaborating partners in the Community mental health services the question of whether to make audio recordings already in the planning phase, but opted against it because it would likely have posed a barrier to participation, especially for persons with severe mental disorder and paranoia. Our goal was to create a safe space for respectful conversation while ensuring the data were valid. The longitudinal study design enabled participants to meet the researchers several times, and the second interview provided an opportunity not only to validate the information participants provided in the first interview, but also for them to provide new information throughout the dental treatment process.

The study design suggests interpreting the results with some caution, as the sample comprised only 51 persons in a single Norwegian municipality. The strength of the study is that the data reflect a variety of perspectives, as participants have a wide range of mental health problems and various experiences in dealing with dental health services. The study is conducted in an average public dental clinic strengthening the ecological validity of the study. Further, the reported barriers to dental treatment are generally in line with the results of previous research, and healthcare planners and politicians should take them into account. Nevertheless, more research is needed to gain knowledge of oral health and dental treatment for persons with SMI in welfare states like Norway, for example quantitative studies to explore oral status and dental treatment among persons with SMI in comparison with the general population.

CONCLUSIONS

Our findings suggest that meeting the needs of patients with severe or long-term mental illnesses will require some re-organisation of dental healthcare services. Filling the gap between patients' dental healthcare needs and the current dental health services will also require strengthening cooperation between several healthcare services. This cooperation must identify and follow up on patients' needs for practical and personal support. Further, the dental health team needs knowledge, competence and guidance on how to recognise the individual needs of patients with SMI, as well as how to establish a confidential and functional relationship with them while facilitating good dental treatment. Dental health services for persons with SMI require interdisciplinary collaboration within the dental clinic.

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AUTHORS' CONTRIBUTION

Bjørkvik J and Henriquez D were responsible for collecting and analysing the data, and conceptualised the results with support from the other authors. All authors contributed to the study design and development, and writing the manuscript.

ETHICAL APPROVAL

All participants provided written informed consent to participate prior to inclusion. Approval for the study by the Regional Committee for Medical Research Ethics was applied for (Reg no 2015/1724-1). Before the interview, all participants were informed that participation in the study was voluntary. They were also informed that they were offered dental treatment regardless of participation in the study. In the present study, we have included persons suffering severe mental illness. In order to ensure that the patients were able to provide consent to their participation, their Community mental health team was engaged in the recruitment and research process. Participants also had an ongoing contact with Community mental health services while data collection was going on.

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