Oral health experiences and needs among young adults after a first-episode psychosis: a phenomenological study

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Accessible summary

What is known on the subject?
- Substance abuse, poor lifestyle and side effects of medication often occur and cause oral health problems in patients diagnosed with severe mental illness (SMI). Oral health in SMI is related to quality of life, self-esteem, and daily functioning. Despite its importance, oral health in mental health care is still a postponed healthcare pathway. Treatment guidelines on patients after a first episode psychosis (FEP) indicate that interventions are recommended, but clinical advice is lacking. However, no research on the experiences of young adults’ oral health after FEP has been conducted.

What does this paper add to existing knowledge?
- This study is the first study to gain insight into most important experiences in patients after FEP regarding oral health. After FEP, participants experience many risk factors, for example substance use, poor diet and financial problems, and participants are not able to adequately attend to their oral health. There is a lack of awareness among participants after FEP about oral health and participants do have high burden. After FEP, participants need support and help from their environment to maintain their oral health.

What are the implications for practice?
- In FEP, oral health needs more attention to avoid the negative consequences in a later phase of the illness. To fill the gap between patients’ needs regarding oral health care and the attention of mental healthcare professionals, the awareness of patients and mental health professionals concerning oral health should be heightened, and clinical interventions to support these needs should be developed.

Abstract

Introduction: Oral health affects quality of life, self-esteem, physical health and daily functioning. Treatment guidelines on patients after first episode psychosis (FEP) recommend interventions, but clinical interventions are lacking. No research on the experiences of young adults’ oral health after FEP has been conducted.

Aims: This study aimed to explore the lived experiences and needs of patients after FEP with regard to their oral health.

Design and Methods: Single-centre phenomenological study using open interviews (N = 30). Data were analysed using the Colaizzi method.
Results: Patients reported oral health problems since their FEP. The problems that patients encountered were dental care in general (e.g., a lack of awareness), risk factors (e.g., substance use, poor diet and financial problems), overall experiences with dentists/dental hygienists and the gap between needs and interventions.

Discussion: There is a lack of awareness among patients after FEP about oral health while patients are not able to adequately attend to their oral health and patients have high burden on this topic.

Implications for mental health nursing: To bridge the gap between patients’ needs regarding oral health, the awareness of patients and mental health professionals should be heightened, and patients should be better supported by mental health professionals.

KEYWORDS
Awareness, first episode psychosis, nursing, oral health, oral health assessment, prevention

1 | INTRODUCTION

The importance of attention to oral health care in psychiatric patients diagnosed with severe mental illness (SMI) is well described and has been shown to be poor (De Hert et al., 2011). A decrease in mental health is associated with an increased need for dental care (Persson, Axtelius, Söderfeldt, & Östman, 2009). Kilbourne et al. (2007) demonstrate that 61% of patients diagnosed with SMI reported poor oral health and that over 34% of patients stated that oral health problems made it difficult to eat. Poor oral health impacts daily living (e.g., eating, social acceptance, self-esteem, feeling comfortable) and is also associated with chronic disorders, for example diabetes, high blood pressure, respiratory disease and coronary heart disease in patients diagnosed with SMI (Cormac & Jenkins, 1999; Montebugnoli, 2004). Kisely, Baghaie, Lallo, Siskind, and Johnson (2015), Kisely, Ehrlich, Kendall, and Lawrence (2015) states that poor oral health in this group also contributes to avoidable admissions to a general hospital and that dental conditions are a common cause of acute avoidable admissions. This finding shows that oral care is an important part of general health in patients diagnosed with SMI (and a chronic disorder, e.g., diabetes, high blood pressure, respiratory disease and coronary heart disease). Risk factors for poor oral health are also known, and inferences can be made from syntheses of the literature. These risk factors include the type and stage of mental illness; a lack of motivation and low self-esteem; a lack of perception of oral health problems; lifestyle (e.g., eating, substance use) and the ability to sustain self-care and dental attendance; socio-economic factors (e.g., low income or low education); and the oral side effects of medication (British Society for Disability and Oral Health, 2000; McCreadie et al., 2004; Kisely, Baghaie, et al., 2015; Kisely, Ehrlich, et al., 2015).

1.1 | Rationale

Awareness of and support regarding oral health for patients diagnosed with SMI are of great importance. To prevent poor oral health, with all its consequences, it would be of great interest to intervene in an earlier stage, such as the first episode psychosis (FEP). However, no research on the experiences of young adults’ oral health after FEP has been conducted.

The British Society for Disability and Oral Health (2000) has published recommendations for oral health care for people with mental health problems, but the suggestions were not practical. In the Netherlands, multidisciplinary guidelines for patients after FEP describe that “during somatic screening it is important to check oral health” (Veling et al., 2017; p.140) and “during lifestyle screening it is important to check oral health hygiene” (Veling et al., 2017, p.183). Clinical interventions are lacking, and therefore, there is a significant risk that nothing will be taken. As Crow (1999) states, “If mental health nursing practice is a patient-centred partnership, as many of our nursing standards suggest, then nursing’s focus should be on the patient’s experience rather than the psychiatric diagnosis with which the experience is attributed. Mental health nurses need to turn to service users to learn how best to help” (p.125).

1.2 | Research question

The research question in this study was the following:

How do patients experience their oral health after FEP, and which needs regarding their oral health do they have?

1.3 | Aim

The current paper aims to gain insight into the lived experiences and needs of young adults after FEP regarding their oral health using an interpretive phenomenological approach.

2 | STUDY DESIGN

2.1 | Theoretical framework

In this study, a descriptive, interpretative phenomenological approach was used to gain insight into the lived experiences portrayed by the patients.
The first aim of this study was to explore the experiences and needs of oral health behaviour among patients between 18 and 35 years after FEP.

2.2 | Participant selection

The study population consisted of patients after FEP treated by the Early Intervention Service of the Friesland Mental Health Care Services in the Netherlands. Patients were asked by their psychiatric nurses to participate and were approached face-to-face. A convenience sample based on availability and willingness to participate was assembled. In this study, thirty patients between 18 and 35 years were included. Patients in a period of “florid” psychosis were excluded from the interviews.

2.3 | Data collection

The data were collected through in-depth and open-ended interviews between April and October 2016. During the interviews, an aide mémoire in the form of a list of relevant topics was used to provide flexibility during the interviews (Table 1). The interviews started with a broad and open-ended question to address lived experiences: “What does oral health mean to you, how do you report your oral health, and do you have needs to improve it?” Follow-up questions were then asked on the basis of the information provided by the patients. Due to the characteristics of the interview approach used, issues were less standardized, and the patients had the opportunity to provide their perspectives.

The interviews were conducted by nursing students (bachelor students in the final phase of their study) under the supervision of a research team (SK. and NB.). After written informed consent was given, the interviews were documented using a voice recorder. The duration of the interviews was between 30 and 90 min. The iterative process of sampling, data collection and analysis was continued until data saturation was reached; no new codes were found in the last five interviews.

2.4 | Data analysis

The research team, consisting of two experienced nurses, analysed the data and coded them independently. In the current study, we used Colaizzi’s seven-step phenomenological method (1978), Bracketing by maintaining a reflective log file was common in the phase of analysing the data. During this phase, peer debriefing was conducted following each step in the coding process. The data discovered were compared with the literature to substantiate our findings. Each theme was described in the findings, and notable quotes were used to clarify the findings. Table 2 provides a short summary of the analysis technique of Colaizzi’s strategy used in this study.

2.5 | Ethical considerations

For this study, the research proposal was submitted to the ethics committee (Leeuwarden, the Netherlands) although formal approval was unnecessary. The committee confirmed the approval, registered under no.RTPO979a. Informed consent was given in writing: the principle of justice was followed by providing oral and written information about the research, confidentiality, voluntary participation, guaranteed anonymity, the possibility to quit participation at any time and consent to the audio recordings. The recordings of the interviews are retained, according to the international safety regulations for the storage of data, at the NHL/Stenden University of Applied Sciences and are accessible only to the researchers.

2.6 | Assessing the rigour of this study: Trustworthiness and authenticity

There were four criteria to establish trustworthiness: credibility, transferability, dependability and confirmability (Bryman, 2012; Lincoln & Guba, 1985). Establishing the credibility of findings entails both making every effort to ensure that research is carried out according to the canons of good practice and, where appropriate, submitting the research results to the patients who were studied for confirmation that the researcher had correctly understood their world. This technique is referred to as respondent validation (Bryman, 2012). In this research, the research group fed back (in Dutch) to the interviewees its impressions and findings of the discussions. In this study, transferability was strengthened by comparing the data discovered to the literature on this subject to substantiate the findings. Dependability requires trying to ensure that complete records and an audit trail of all phases of the

<table>
<thead>
<tr>
<th>TABLE 1 An aide mémoire</th>
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<tbody>
<tr>
<td>Oral health</td>
</tr>
<tr>
<td>Is defined as: “Is multi-faceted and includes the ability to speak, smile, smell, taste, touch, chew, swallow and convey a range of emotions through facial expressions with confidence and without pain, discomfort and disease of the craniofacial complex. Oral health is a fundamental component of health and physical and mental well-being. It exists along a continuum influenced by the values and attitudes of individuals and communities; reflects the physiological, social and psychological attributes that are essential to the quality of life; is influenced by the individual’s changing experiences, perceptions, expectations and ability to adapt to circumstances” (Glick et al., 2016; P322)</td>
</tr>
<tr>
<td>Patients experience</td>
</tr>
<tr>
<td>Patients diagnosed with SMI report many problems, for example eating, social acceptance, self-esteem, feeling comfortable (Kilbourne et al., 2007)</td>
</tr>
<tr>
<td>Risk factors</td>
</tr>
<tr>
<td>Risk factors for poor oral health in patients diagnosed with SMI were, for example type and stage of mental illness; a lack of motivation and low self-esteem; a lack of perception of oral health problems; lifestyle (e.g., eating, substance use, smoking, and nutrition) and the ability to sustain self-care and dental attendance; socio-economic factors (e.g., low income or low education); and the oral side effects of medication (British Society for Disability and Oral Health, 2000: McCreadie et al., 2004; Kisely, Baghaie, et al., 2015; Kisely, Ehrlich, et al., 2015)</td>
</tr>
</tbody>
</table>
**TABLE 2** A summary of the steps using Colaizzi’s strategy as employed in this study

<table>
<thead>
<tr>
<th>Step</th>
<th>What and result</th>
</tr>
</thead>
</table>
| Step 1 Obtain an overview of the data | - Interviews were transcribed verbatim  
- Read and re-read to gain a feeling for and to make sense of the patients’ lived experiences regarding oral health |
| Step 2 Extracting significant statements | - Significant statements of the participants experiences, meanings and needs were extracted  
- Coding in Atlas TI V 7.5.12 software package |
| Step 3 Compare and discussion | - Compared the original quotes with the formulated meanings to achieve consistency  
- We illuminated experiences and meanings that were hidden in various contexts of the phenomenon. Minimal differences were found within the research group, and there was a discussion to reach a solution, when necessary  
- 458 Quotes classified into 458 significant meanings |
| Step 4. Categorize | - Categorizing the meanings into codes that reflect a vision to form a code  
- 40 Codes were obtained from 458 meanings  
- 40 Codes were incorporated into 5 themes |
| Step 5. Describe | - Provided a sufficient description of the experiences, meanings and needs of the patients. The formulated themes were integrated in a description of the phenomenon under study |
| Step 6. Clear relationships | - Generate clear relationships between the themes, it also included eliminating some ambiguous structures that weaken the whole description |
| Step 7. Validation | - “Member check technique” was used to validate the findings within participants  
- Discussion about participants feedback and changes were incorporated |

Research process were kept (Bryman, 2012). It should be evident that personal values or ideological inclinations have not been allowed to sway the performance of the research and the findings deriving there from (Bryman, 2012). In this study, two members of the research team (SK. and NB.) led and monitored this research and gave feedback during the study.

Guba and Lincoln (1994) suggest criteria of authenticity, and these standards raise a wider set of issues. This research fairly represents the experiences, and needs of the patients, and every effort was made to serve the patients. The ontological authenticity of this study can be formally assessed upon completion, but in this regard, an indication was gained from the responses to the feedback sessions, which indicated that the patients felt they had increased their awareness and understanding of the phenomena.

### 3 | FINDINGS

Interviews were carried out between April and October 2016. The themes of oral health experiences emerged from an analysis of approximately 23 hr of audio (range: 30–90 min), transcribed in 146 pages, from 30 patients after FEP who ranged in age from 18 to 35 years (mean 26.9). Table 3 illustrates the participant demographics and their medications (in groups) and diagnoses. Most frequent reported antipsychotics were Olanzapine (N = 13), Risperidone (N = 5), Aripiprazole (N = 4) and Sulpiride (N = 2).

Within the theme of oral health experiences and needs, we further categorized and coded the data with regard to dental care in general, risk factors, the financial situation, experiences and needs for interventions of the participants. These themes were inextricably linked. Table 4 gives an example of the phenomenological process.

#### 3.1 | Dental care in general

The patients were asked to describe what oral health mean to them, but the patients’ answers remained superficial, or the patients described their current state. This question was difficult for the patients to answer. The patients were not aware of the meaning and importance of oral health.

I do not know, as long as my mouth looks fresh and does not hurt. [part. 1]

I have had a root canal. My right front tooth is fake. When I was young, it broke off. And, now, with so much time, it gets stuck again because it often falls off. [part. 2]

All patients were using devices for dental care. Most frequently, the patients named a toothbrush (electric or manual) and toothpaste. One-third of the patients used a toothpick or dental floss. Seven patients brushed their teeth irregularly and not twice a day. Some of the patients only brushed when they remembered or thought about it, meaning that the frequency with which they did so could be only once or twice a week. The patients were hindered by many mental health problems, and as a result, they thought less about cleaning their teeth. The patients stated that for regularly cleaning their teeth, awareness is the most important factor, and it is precisely this awareness that they do not have.
3.2 Risk factors that affect oral health

The patients’ experiences and knowledge of risk factors was discussed. The risk factors were also important factors that the patients experienced when trying to take care of their oral health. Twenty-one patients (70%) reported that they use or used drugs, some recently and some in the past. The most frequently used drugs were marijuana, cocaine, speed and MDMA.

### TABLE 3 Participant demographics and self-reported medications and diagnoses

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age group</th>
<th>Residential status</th>
<th>Marital status</th>
<th>Self-reported medications</th>
<th>Diagnoses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>18–21</td>
<td>With parents</td>
<td>Not married</td>
<td>-</td>
<td>FEP, PTSS, Drug abuse</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Asperger, PDD, Drug abuse</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>18–21</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>-</td>
<td>FEP, ADD, Drug abuse</td>
</tr>
<tr>
<td>4</td>
<td>Male</td>
<td>18–21</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>-</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>5</td>
<td>Male</td>
<td>18–21</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication, Anti-Anxiety Medications</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>6</td>
<td>Female</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
</tr>
<tr>
<td>7</td>
<td>Male</td>
<td>31–35</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, ADHD, Drug abuse</td>
</tr>
<tr>
<td>8</td>
<td>Male</td>
<td>26–30</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>-</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>9</td>
<td>Male</td>
<td>26–30</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication, Anti-Anxiety Medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>26–30</td>
<td>With partner</td>
<td>Living together</td>
<td>Antipsychotic medication, antidepressants, Anti-Anxiety Medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>12</td>
<td>Male</td>
<td>22–25</td>
<td>Single</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>13</td>
<td>Female</td>
<td>26–30</td>
<td>With parents</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>14</td>
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<td>26–30</td>
<td>With parents</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
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<td>15</td>
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<td>Antipsychotic medication</td>
<td>FEP</td>
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<tr>
<td>16</td>
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<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>17</td>
<td>Female</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>18</td>
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<td>26–30</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>19</td>
<td>Female</td>
<td>31–35</td>
<td>With partner</td>
<td>Living together</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
</tr>
<tr>
<td>20</td>
<td>Female</td>
<td>31–35</td>
<td>Single</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
</tr>
<tr>
<td>21</td>
<td>Male</td>
<td>31–35</td>
<td>Single</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP</td>
</tr>
<tr>
<td>22</td>
<td>Male</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Living together</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>23</td>
<td>Female</td>
<td>22–25</td>
<td>Single</td>
<td>Not married</td>
<td>Antipsychotic medication, antidepressants, Mood Stabilizer</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>24</td>
<td>Male</td>
<td>31–35</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>25</td>
<td>Female</td>
<td>22–25</td>
<td>Single</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>26</td>
<td>Male</td>
<td>31–35</td>
<td>With parents</td>
<td>Not married</td>
<td>Antipsychotic medication, Anti-Anxiety Medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>27</td>
<td>Male</td>
<td>26–30</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication</td>
<td>FEP, Drug abuse</td>
</tr>
<tr>
<td>28</td>
<td>Male</td>
<td>22–25</td>
<td>Sheltered living</td>
<td>Not married</td>
<td>Antipsychotic medication, mood stabilizer</td>
<td>FEP, Bipolar, Drug abuse</td>
</tr>
<tr>
<td>29</td>
<td>Female</td>
<td>26–30</td>
<td>With partner</td>
<td>Living together</td>
<td>Mood stabilizer</td>
<td>FEP, Bipolar</td>
</tr>
<tr>
<td>30</td>
<td>Female</td>
<td>31–35</td>
<td>With partner</td>
<td>Living together</td>
<td>Antipsychotic medication, antidepressants</td>
<td>FEP</td>
</tr>
</tbody>
</table>

ADD: Attention deficit disorder; ADHD: Attention deficit hyperactivity disorder; FEP: First episode psychosis; PDD: Pervasive Developmental Disorder; PTSS: Post-traumatic stress syndrome.
TABLE 4  Oral health in patients after FEP: Examples of the phenomenological process using Colaizzi's strategy

<table>
<thead>
<tr>
<th>Quotes</th>
<th>Significant meanings</th>
<th>Codes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>I did not go to the dentist for over 3 or 4 years. Because of my debts, I am in debt restructuring; I cannot really pay the dentist. (part.7, line 61–63)</td>
<td>Patient realizes that he has not been to the dentist for a long period of time because of his debts and the financial consequences thereof.</td>
<td>No dental control/no insurance</td>
<td>Risk factors</td>
</tr>
<tr>
<td>I do not have insurance for the dentist because I am €15,000 in debt. Moreover, I cannot pay the bill. (part. 3, line 75)</td>
<td>Patients have difficulties paying bills because of their debts, and they do not have the money to pay for insurance.</td>
<td>Debts</td>
<td></td>
</tr>
<tr>
<td>I have had a mentor for over a year, but I do not have insurance for the dentist. I still need debt restructuring, but the system works very slowly, and it takes a long time before everything is settled. (part.7, line 193–201)</td>
<td>Patients state that the debt structuring system does not work.</td>
<td>System does not work</td>
<td></td>
</tr>
<tr>
<td>When I have used drugs I think often, I do not mind, and I do not care about anything. This includes dental care. (part.1, line 30)</td>
<td>Dental care is not a priority for patients when they have used drugs.</td>
<td>Consequences of drug abuse</td>
<td>Risk factors</td>
</tr>
<tr>
<td>When I have used drugs, I often forget and do not feel like it. Everything is bullshit. I am basically continuously making excuses for not doing things. (part.2, line 92)</td>
<td>Patients who often used drugs forget things or do not feel like doing something.</td>
<td>Not on mind</td>
<td></td>
</tr>
<tr>
<td>When I was using drugs, I was only busy doing blow, and I did not feel like brushing my teeth and did not think about it. (part.3, line 38–39)</td>
<td>Dental care is not on the mind of patients using drugs.</td>
<td>Not on mind</td>
<td>Interventions</td>
</tr>
<tr>
<td>I am continuously so tired that I forget, and besides that, I do not feel like it. The psychosis and drugs make a person very confused. (part.5, line 43)</td>
<td>Patients feel chaotic in and after a first episode psychosis, which, together with drugs, makes the world confusing.</td>
<td>Not on mind</td>
<td>Risk factors</td>
</tr>
<tr>
<td>I have a lot on my mind, and brushing my teeth is not a priority (part.5, line 74)</td>
<td>Patients have many things on their mind after a first episode psychosis; dental care is not one of them</td>
<td>Lack of structure</td>
<td></td>
</tr>
<tr>
<td>Because of the medication I used for my psychosis, I feel hungry, and I eat a lot. I have gained many pounds since then. (part.6, line 300–306)</td>
<td>Patient feels hungry because of the use of medication for psychosis. Weight gain</td>
<td>Side effect of medication</td>
<td></td>
</tr>
<tr>
<td>I receive an email from the dentist when it is time to make an appointment. (part.18, line 34)</td>
<td>Losing a reminder card from the dentist makes it hard for patients to remember that they have to make an appointment.</td>
<td>Losing memories</td>
<td>Interventions</td>
</tr>
</tbody>
</table>

These patients commonly indicated that the misuse of drugs caused many problems. They described that the chaotic feelings in and after FEP combined with drug use make their world more complicated.

Well, I do know the importance of oral health, but I did not care, and I did not think about it and did not feel like doing anything with that. I was busy using drugs and alcohol. [part. 3]

I had a lack of motivation, and oral health was not in my system. [part. 7]

The patients who have used drugs state that they often forget things and do not feel like doing anything. All patients state in common that dental care is not prioritized (N = 30).

When I was 17 years old, I was really lazy, and especially when I smoked marijuana, I did not think about oral health or brushing my teeth. [part. 1]

My thoughts were completely somewhere else. I lived in my own world. My thoughts were not about taking care of my teeth and such things. [part. 25]

All patients portrayed cognitive difficulties such as a lack of fluency, working memory and flexibility. In addition, there was no motivation for the patients to take care of themselves. Most patients frequently reported a lack of structure and a lack of planning in daily life as a result of abusing drugs and alcohol, and the patients did not link this aspect directly to FEP. After quitting drugs, the patients became more aware of their health problems. More than half of the patients smoke, but they did not link smoking to their oral health.
Nutrition was indicated as a risk factor by the patients. It was connected not only to a period of drug abuse but also to the side effects of medication. The patients stated that dental problems also affect the intake of nutrition. Binge-eating and an unhealthy food pattern were common for half of the patients. All patients linked drinking sugary beverages (e.g., redbull or cola) to a dry mouth as a side effect of medication; some patients also linked it to a period of drug abuse.

In a period of drug use, I hardly ate. If I was hungry, I got a bag of crisps; I did not care. [part. 1]

Because of the medication I used for my psychosis, I feel hungry, and I eat a lot. I have gained many pounds since then. In the last half year, I became ten kilograms heavier after starting medication. [part. 6]

All patients mentioned the side effects of medication as part of reduced oral health. Xerostomia, somnolence, reduced responsiveness, pain, concentration problems and weight gain were the most reported experiences as a consequence of the side effects of medication. All patients felt that their teeth became worse as a result of the use of medication, and the patients were not aware of other factors that influence oral health.

The patients mentioned their financial situation as an important reason why they will not go to the dentist. They were often in debt; debts were incurred during FEP. The patients could not afford to pay for insurance for dental care. Because of their mental illness, almost all patients could not work for a period. Twelve patients incurred heavy debts at the time of their psychosis, and most patients had marginal incomes. The patients who were in this situation felt very uncomfortable. Their financial situation was directly affecting their ability to pay for dental health care.

I do not have insurance for the dentist because I am €15,000 in debt. I cannot pay the bill. [part. 3]

In the Netherlands, people with a diagnosis of psychosis are sometimes supervised by a financial administrator who manages their debts, and when the financial situation is stabilized, debt structuring is an option. The patients stated that this system is slow, and they became desperate. The distance to dental care is increased by not going to the dentist for many years. The patients stated that they entered a vicious circle and could not solve this problem themselves.

After FEP, a period of recovery was experienced as complicated, and the patients reported insecurity about their appearance. Insecurity about themselves was linked to a decrease in overall well-being after FEP. For some patients, insecurity was a reason for using drugs and drinking alcohol.

3.3 | Experiences with dentists and dental hygienists

The patients were questioned in regard to their experiences with dentists and dental hygienists. Early in life, almost everybody went to the dentist twice a year, the standard in the Netherlands. There were no negative experiences. One of the grew up without a dentist in Indonesia. The period no longer going to appointments started while using drugs and during the FEP. This aspect is linked to the period of overall neglect. In this stage, there was no ability for the patients to take care of themselves, nor did they pay attention to doing so. Going to a dentist or dental hygienist is linked to their financial situation. Having insurance indicates that the patients go to the dentist twice a year, but doing so is "conditional on remembering."

A few patients had experiences with a dental hygienist. The patients had no bad experiences. Fear of dentists or dental hygienists was discussed, but in general, it was not an issue.

3.4 | Needs and interventions to increase oral health

All patients confirmed that they require more structure in their daily life so that they can have more insight into their day-to-day activities. They described this aspect as a helping intervention. The patients explained that more structure is necessary to reintroduce things such as brushing their teeth into their system. Additionally, the patients mentioned help with planning daily activities such as taking care of themselves and making appointments.

I think I can improve my oral health by drinking fewer sugary drinks and brushing more often. I had alcohol-and drug abuse. But, really, I do not like to do that, and I am not motivated. When I hear those voices, then there is even more lack of motivation. I live with my partner, I can ask her, but I do not know if that would work. [part. 11]

I need help with planning; it is not that I do not think it is important, but I forget many things I have to do. It takes much effort, and I would like to have someone to tell or remind me to brush my teeth. [part. 23]

To obtain more structure and better planning, the patients suggested placing all their appointments in a digital agenda or app. A frequent reminder prevents forgetting appointments.

I got a reminder by post from the dentist, but I lost it. [part. 16]
A week before the appointment, the dentist called me to remember. That was helpful. [part. 20]

Despite reminders from the dentist, the patients forgot their appointments often because they were preoccupied with something else. The patients experienced support from the environment, especially parents.

My mother is important for giving structure to my daily activities. [part. 6]

If my parents were not there, I probably never would have gone to any appointment in that period. [part. 24]

All patients reported a lack of knowledge of oral health and oral health care. In particular, there was a lack of knowledge on the influence of risk factors on oral health. There was no difference between patients regarding whether they used drugs or not. There was also a lack of knowledge of the consequences of not taking care of their teeth. It seemed hard to motivate the patients, especially when they used drugs. Nevertheless, in all patients, there was no reported need for health promotion. The patients stated that interfering is not desirable and will only generate resistance. The patients felt stigmatised as though they were children and could no longer think for themselves. Moreover, they believed that they know how to take care of their oral health. This belief is in contrast to the statement from one patient earlier: "awareness is critical."

4 | DISCUSSION

This phenomenological study in the Dutch context is unique, and it gives insights into the lived experiences and needs regarding oral health among patients between 18 and 35 years after FEP. The WHO (2004) recommends that more investment in under-funded areas of health research were needed and also recommends to translate knowledge into actions to improve oral health (Petersen, 2005). Therefore, it was important to explore the experiences and needs of patients after FEP. This study is the first to explore patients’ experiences in four themes.

Overall, participants were satisfied with their oral health before the occurrence of psychotic symptoms, and they stated that a decrease in oral health started after that period. In total, four themes were reported based on the lived experiences and needs of the patients: dental care in general, risk factors, experiences, needs and interventions. These four themes were linked to each other. All participants had difficulties in managing their oral health; they were unaware of the consequences of the risk factors and reported the importance of others in helping them.

With regard to dental care in general, the participants were not aware of the importance of oral health. A study among patients after FEP and patients after multiple episodes shows that there is less awareness among patients after FEP than among patients after multiple episodes (Thompson et al., 2001). These findings indicate the importance of using psychoeducational approaches to improve awareness in patients after FEP. In practice, patients receive psychoeducation, but the psychoeducation is focused on specific topics, for example sports or lifestyle, or psychotic symptoms and the effect of cannabis use (Edwards et al., 2006). To date, studies among psychoeducation have not taken oral health into account, and it is not known in what way psychoeducation on oral health is effective in patients after FEP.

Here, the question of nurses’ oral health awareness arises. Research shows the overall lack of oral health awareness among nurses. Gillam, Williams, and Gillam (2016) tested a questionnaire on oral care knowledge and awareness in nurses and identified deficiencies in their knowledge of oral care and concluded that a basic awareness of conditions and medications that may affect the mouth would be of great value. This current research shows the importance of teaching oral care to nurses, which would enable nurses to provide a higher standard of oral care to patients.

In this study, all participants were confronted with many risk factors (e.g., substance use, poor diet and financial problems) and experienced the consequences of bad oral health (e.g., pain and feeling insecure). Our research explored lived experiences and was not focused exclusively on assessing risk factors. The participants stated that there are financial problems, and the participants did not always have insurance. This was directly affecting their ability to pay for dental health care. The evidence showed that inappropriate decisions were a consequence of poverty and a scarcity mentality. Moreover, these consequences have a large cognitive impact on, for instance, working memory and flexibility (executive functioning) (Mani, Mullainathan, Shafir, & Zhao, 2013). Participants were restricted by their short-term memory; long-term perspectives and appropriate long-term aims were limited. It is known that people stricken by poverty use less preventive health care, fail to adhere to drug regimens, are less likely to keep appointments and are worse managers of their finances. This study confirms that patients after FEP are a high-risk group for whom support is necessary. This fits in the approach of the WHO, the importance of promotion of oral health to reduce burden and disability in poor and disadvantaged populations (Petersen, 2010).

The participants in this study showed no negative experiences regarding dentists/dental hygienists. We believe that it is important to realize that fear can be a reason for not going to the dentist. There is evidence in patients diagnosed with SMI: “One half of all dental patients experience some anxiety about their dental visits, and in some cases this leads to dental phobia” (Kisely, 2016, p.278). In our study, fear was not an issue for patients after FEP.

With regard to needs and interventions, the participants stated the importance of support from others. This support could be in the form of a reminder for an appointment to prevent missing appointments. In sending reminders, there is a difference between dentists and dental hygienists. The results of our study showed
that participants report a lower level of non-attendance when they receive a message the day before and the day of the appointment. Studies reporting the needs and interventions of patients diagnosed with SMI support the sending of reminders for their appointments, for example, studies focusing on medication adherence using text messages (Pijnenborg et al., 2010). To date, however, studies have not taken oral health into account, and it is not known whether these outcomes are feasible in patients after FEP.

The participants reported the importance of others in helping them remember their daily oral health routine and remember to visit the dentist. This finding raises questions about who is responsible for oral health care for patients after FEP, particularly to prevent problems. Oral health prevention is primarily the responsibility of dentists/dental hygienists, but there is a role to be played by mental health nurses. Mental health nurses have contact with patients on a regular basis, and therefore, they have the opportunity to support patients diagnosed with their oral health, just as they also do in regard to physical health and healthy eating habits. Because of the lack of concrete tools, the Oral Assessment Guide for Psychiatric Care (OAG-PC) can be appropriate to methodically coordinate, assess and evaluate patients’ oral health (Sjögren & Nordström, 2000). The WHO recognizes oral health as a part of integrated care (Petersen, 2010). Using an oral health assessment guide, for example during somatic screening, should be incorporated to integrate oral health into daily care, but, studies among integrated care have not taken oral health into account, and therefore, it is not known if an Oral Assessment Guide will increase oral health in patients after FEP.

This study was carried out with a small sample size of 18 men (60%) and 12 women, and although the ratio is not equal, the results were comparable, and no gender issues were found. Of thirty participants, 21 participants used drugs, often cannabis, at some time in their life (70%). The prevalence of substance use among people with FEP is in line with previously published data in Canada (Van Mastrigt, Addington, & Addington, 2004) and Australia (Wade et al., 2006), which indicates that the high prevalence of abuse in these authors’ studies in patients after FEP is particularly notable. Therefore, we conclude that the sample used in this study is representative of patients who experienced FEP. However, in our findings, there was no particular difference between participants who used or did not use drugs regarding their oral health or other specific mental health-related issues. The implication is that the findings are more related to problems after FEP than they are related to problems after a drug-induced psychosis.

5 | STUDY LIMITATIONS

This research is a single-centre study in the northern Netherlands, and replication of this study in a multiple-centre design with a comparable population can be suggested. However, there are no direct indications to assume that there are substantial differences between the studied sample and the patients of other mental health organizations: the sample used in this study is not distinct in gender or age.

Nevertheless, this research has given new insights into the experiences and needs of patients and research can be continued.

6 | IMPLICATIONS FOR MENTAL HEALTH NURSING

For many years, research on oral health among patients diagnosed with SMI has been conducted. Interestingly, however, no research the poor oral health of patients after FEP is available, and poor oral health still remains a major forgotten problem. This phenomenological study gains insight into the experiences of patients after FEP regarding their oral health and demonstrates that oral health among patients after FEP is associated and linked with other phenomena and that there is a need for care. The problems in oral health in patients after FEP are enormous, and it is preferable to indicate this priority.

For mental health nurses and other professionals, to assess patients’ oral health, the consideration of using an oral health assessment guide should be part of a somatic or lifestyle screening. The contribution of risk factors (financial problems included) should be monitored and managed. To methodically coordinate, assess, plan, implement and evaluate patients’ oral health, the OAG-PC can be appropriate and is available. Nurses and other mental health professionals should play their role. Our study shows the lack of awareness among patients and nurses. Oral health integrated in psychoeducation after FEP can be appropriate, but conditionally, nurses have to be properly trained. In this regard, it is important to start with students in nursing schools.

Oral health has many consequences for patients after FEP, and therefore, prevention is needed, as patients encounter many risk factors after FEP that decrease oral health, for example oral health education to create awareness. There is a need to develop evidence concerning oral health care after FEP with regard to practical interventions.

After FEP, patients might not be able to adequately attend to their oral health, and patients need help planning and remembering daily activities with regard to dental care. It is important to develop evidence to prove that remembering to address oral health care can help increase oral health (e.g., oral health adherence), and it is worth focusing on this topic in future research.

An integrated approach between mental health professionals and dentists and dental hygienists to improve oral health for patients after FEP is indicated; this approach includes psychoeducation and promotion.

Policy and decision makers should consider providing free dental care for people with mental illness, given the importance of oral health for overall health. The government and municipalities together with health insurance agencies should work on adjusted services with regard to insurance plans and financial problems for this vulnerable group of young patients.
There is no health without oral health. It is important for mental health professionals to know what the experiences and needs of patients are. There is a lack of awareness among patients and nurses in mental health care, and both should be aware of the importance of oral health for overall health, especially in patients who are vulnerable (e.g., after FEP). Psychoeducation and interventions (e.g., oral health adherence) can be developed, with oral health being integrated.

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CONFLICTS OF INTEREST

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AUTHORSHIP STATEMENT

In keeping with the latest guidelines of the International Committee of Medical Journal Editors, SK contributed to the data collection, analysis and interpretation, drafted the initial paper, provided intellectual content and revised subsequent drafts to final submission, SC wrote and reviewed the manuscript and discussed the results; AM reviewed the manuscript; LK wrote and reviewed the manuscript; NB contributed to the conception and design of the research, undertook data analysis and interpretation of data, revised drafts of the manuscript for intellectual content. All authors read and approved the final manuscript, and are all in agreement with the manuscript. The authors listed all and meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors.

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