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A qualitative study on experiences of persons with schizophrenia in oral-health-related quality of life

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Abstract: Our study aimed to explore the views and experiences in oral health and oral-health-related quality of life (OHRQoL) of persons with schizophrenia (PWS) in order to expand the understanding of the factors that either limit or facilitate their healthcare pathway, which can ultimately optimize their oral health and/or OHRQoL. A qualitative study was conducted in France in the Côte d'Or department (530 000 in habitants) centered on PWS's perceived meanings regarding oral health or OHRQoL, and semi-structured individual interviews were used. A conventional content analysis approach was chosen in order to highlight unrevealed themes. A sample of 20 PWS (12 males; 8 females) with a median age was 45.8 (± 9.5) were recruited to assess views and experiences regarding OHRQoL, which were focused on three dimensions: an individual dimension related to experience of "oral symptoms", a second dimension related to experience of "stress and its management", and a third related to "Autonomy dimension in oral health". We showed that PWS clearly expressed their mental representations of oral health and OHRQoL. This study supports that PWS were able to define their needs and had the ability to discuss their oral health and OHRQoL. These finding could be used to support specific interventions for this population to better manage the negative impact of antipsychotics and help them to consult dentists on a regular basis.

Keywords: Oral Health; Schizophrenia; Mental Health.

Introduction

Schizophrenia is a chronic and severe mental disorder that affects how a person thinks, feels, and behaves.[1] People with schizophrenia (PWS) may appear to have lost touch with reality and are commonly overwhelmed by significant cognitive and emotional disruptions. The symptoms of schizophrenia fall into three categories: positive symptoms, negative symptoms, and cognitive symptoms. Positive symptoms are psychotic behaviors, as in hallucinations or thought disorders (unusual or dysfunctional ways of thinking). Meanwhile, negative symptoms are associated with disruptions to emotions and behaviors. Lastly, cognitive symptoms manifest through difficulties with comprehension, impaired decision-making, issues with concentration and attention, and loss of

the ability to use information immediately after learning it.[2] Schizophrenia disturbs many aspects of a patient's life and can lead to deficits in daily life functioning including the ability and desire to perform preventive oral hygiene.[3]

Schizophrenia affects 0.7% to 1% of the global population and 600,000 individuals in France.[4] Schizophrenia requires long-term medical treatment[2] and PWS have at least one associated somatic condition, which may include cardiovascular, gastrointestinal, respiratory, neoplastic, infectious, endocrine, and oral disorders.[5]

Kisely et al.[6] reported the reasons for poor oral health in persons with severe mental illness and its impact on general health. These reasons include dental caries, periodontal or infectious diseases that interact with metabolic disturbances induced by antipsychotic treatments (diabetes, obesity), and poor diet and lifestyle behaviors (high-sugar diet, use of psychoactive substances such as tobacco, and inadequate oral hygiene). Specifically, dental caries and periodontal measurement indexes often reach twice the level found in the general population.[7]

In a recent national survey, we highlighted that PWS are less likely to have tooth scaling and dental treatments but more likely to have dental extractions than the general population, which clearly expressed poor oral health-related quality of life (OHRQoL).[8] The difficult relationship between PWS and caregivers and the health care system in general is a major reason for poor oral health. For example, fear of mental illness, difficult access to private practice, and the high cost of dental care are additional barriers that contribute to poor oral health and OHRQoL.[9] Oral health programs, although presenting statistically significant results, have little clinical impact on oral health.[10] Khokhar et al.[11] studied schizophrenics and found no study with a sufficiently high level of proof to support current practices in oral health education for PWS. In this context, further studies are needed to improve the management of their oral health and OHRQoL, potentially with the use of specific prevention and education programs. The challenge is to identify people who are not willing to care for themselves and identify the importance that they place on their quality of life including treatments,[12] dental pain management,[13] or OHRQoL[14] to expand the understanding of the factors that limit or facilitate the healthcare pathway. In other words, determining the significance that PWS place in oral health and OHRQoL warrants investigation.

Nowadays, we increasingly recognize that patients are as well positioned as their doctors in knowing their healthcare needs. As such, valuing the experiential knowledge acquired by the patient during his illness is the basis of person-centered care approaches.[15] With this model in mind, patients' views were central to the present research regarding person-centered care in dentistry; furthermore, no research has yet investigated these patients' views in terms of their oral health and OHRQoL. Thus, the present study aimed to explore the views and experiences in oral health and OHRQoL of PWS.

Methodology

Design

A qualitative study that explored the views and experiences in oral health and OHRQoL of PWS was conducted in the Côte d'Or department (530,000 inhabitants). In particular, semi-structured individual interviews were used. Participants were encouraged to provide accounts of their experiences and elaborate on the problematic issue.[16]

Participants

A sample of 20 PWS (both inpatient and outpatient) registered in the administrative database of the Chartreuse Hospital (Dijon, France) were recruited on a voluntary basis, using telephone invitations for outpatients and face-to-face invitations for inpatients. Inclusion criteria were as follows: native French-language speakers aged > 18 years with a diagnosis of schizophrenia (according to the International Classification of Diseases, 10th Revision: ICD-10).[17] Furthermore, participants had to sign an informed consent to participate. Exclusion criteria were as follows: diagnosis other than schizophrenia and unstable individuals from a psychiatric perspective with decompensated organic diseases or mental retardation. In qualitative research,

little new information is generated after interviewing 20 people,[18] and a minimum of 15 can offer data saturation.[19] A sample of 20 PWS is a priori sufficient with the theoretical saturation model related to grounded theory methodology to obtain a "point of saturation".[18,19]

All PWS were offered a financial compensation (€20) for the time and energy spent participating in the research.

Ethics

This study was approved by the Committee for the Protection of Persons of the Eastern French region (registration number: 2015-A01741-48). After providing participants with a complete description of the study, informed consent was obtained from each participant or from their legal guardians for individuals under guardianship. In the latter case, patient's legal guardian(s) signed the informed consent.

The study was registered on www.ClinicalTrials.gov under the number NCT02730832.

Generation of items

Interview guide

The individual interviews were conducted with an interview guide generated to explore several specific areas of oral health and OHRQoL in PWS. This guide was written based on the results of a narrative review conducted by our group on the subject until 2016.[20] The work is complemented by the most relevant literature to date. A literature search was conducted using the terms schizophrenia, oral health, and OHRQoL on PubMed as well as a grey literature search on Google Scholar. The search was done by experts on schizophrenia (two psychologists, two dentists, two psychiatrists, and two nurses). They screened 46 papers, selected nine (8,12,14,21-26), and engaged in discussion until a consensus was reached at the end of the third meeting. This process involved 3 consensus meeting. The items in the interview guide are available in Table.

Individual interviews

With the assistance of the interview guide, a psychologist with extensive experience in managing individuals suffering from mental health issues was fully equipped to carry out all face-to face interviews.

These semi-structured interviews were used to collect qualitative data, and spontaneous reactions were particularly explored to capture participants' experiences and to better understand the meaning that they attributed to oral health and OHRQoL. The second stage consisted of completing open-ended questions and follow-up questions. The interviewer reworded, reordered, or clarified the questions when necessary to better investigate new topics introduced by respondents.

Interview content analysis

Given the lack of previous knowledge on this particular matter, a conventional content analysis approach was chosen in order to highlight unrevealed themes.[27] The coding process was performed manually and independently by two researchers in order to limit

Table. Interview guide used in semi-directive interviews with persons with schizophrenia.

1. How are you? How do you feel?
2. Can you describe which aspects of the oral health you like?
3. Does your oral health have repercussions on your state of mind?
4. What are your relationships with your family circle or caregivers like? Do you feel understood and reassured by your family circle or caregivers?
5. Have you ever refused to do something, such as talking with others or eat something because of your oral health? If so, what?
6. Are your social relationships disturbed because of your oral health?
7. To sum up, what aspects of your oral health trouble you the most?
8. What do you think could improve your oral health?
9. How important is your treatment to you?

personal bias in the interpretation of participants' responses. Codes were then discussed and organized in themes in an inductive way. Interviews were coded consecutively, when they were available, allowing the investigator to compare them during the process of data collection. Saturation was considered to have been reached when no new themes could be extracted from the last interview. At this step, multiple readings of the interviews were performed in order to verify key themes and identify recurrences and differences among the interviews. Collective discussions finally allowed to confirm key themes and regroup them into broader dimensions.

Results

Participants

Interviews were conducted with 20 PWS. The mean age of the sample was 45.8 (±9.5) with a sex ratio of 12:8 for males and females, respectively. Most participants were outpatients (90%). Interviews were 20 to 40 minutes in length. No one involved expressed difficulty in understanding the questions of the interview guide.

Analysis of the interview content

The data showed that oral health and OHRQoL for PWS were the outcomes of dynamic interactions between multiple domains.

The content analysis of the interviews permitted to highlight three dimensions concerning views and experiences in oral health and OHRQoL of PWS's: an individual dimension related to experience of oral symptoms, a second dimension related to experience of stress and its management, and a third related to "Autonomy in oral health".

Themes

Experience of oral symptoms

Dental and facial pain

Participants reported experience with dental and/or facial pain and/or oral dysfunctions or discomforts with side effects of the treatments.

In this study, PWS clearly expressed complaints about pain due to dental disease or injuries. They also expressed pain, suggesting poor oral health (tooth decay or periodontal disease) and sensitivity to heat and cold.

> *My teeth hurt… My mouth is sensitive to hot and cold sensations… It hurts when I brush my teeth…*

In the corpus analysis, we found that these persons also expressed facial pain, particularly when antipsychotics treatments were implemented.

> *My jaw hurts and I have muscular pain in my face… I grind my teeth…*

Oral dysfunctions

Participants pointed different oral dysfunction when swallowing, chewing, and talking as potential disabilities affecting their OHRQoL.

> *I find it hard to swallow comfortably… I have difficulty chewing… The joint of my jaw is stiff, my jaw is clenched… I can't articulate sounds correctly… I have trouble articulating when I speak… My jaw and my teeth do not feel right.*

Side effects of treatments

Participants spontaneously expressed side effects of antipsychotic treatments in their OHRQoL.

> *My mouth feels dry or sticky… I have a burning sensation in my throat… My mouth is dry or pasty… I salivate more… The taste of food has changed since the change in my antipsychotic treatment.*

One of the most serious side effects from long-term use of both older and newer antipsychotics is a movement disorder called tardive dyskinesia. This disorder causes facial, tongue, hand, and neck muscles to move uncontrollably, and may be permanent once initiated; the PWS clearly expressed this problem.

> *I can't move my hand normally without shaking. It's hard for me to brush my teeth...*

Participants also reported that antipsychotics come with other side effects, such as weight gain and drowsiness, which impacted their quality of life.

I gain weight… At the end of meals… I am still hungry… I sleep more.

Stress and attitude about OHRQoL

Stress created by dental care

Out of the recognized comorbid anxiety disorders in PWS, the most frequent one is phobia regarding caregivers and providers. PWS expressed anxiety and stress about dental care, while showing interest in OHRQoL.

I have anxiety attacks at the dentist office… I do not take things easy and feel stressed when I have dental pain… I am afraid to go to the dentist… I have difficulties in managing my visit to the dentist.

Attitudes about OHRQoL

Positive attitudes in oral health and OHRQoL were associated with seeking for well-being, while negative attitudes, which were often shown by PWS, were aimed to adjust to oral disorders instead of caring for oral health or OHRQoL.

Positive attitudes

Positive attitudes were associated with compensated psychiatric disorders in the rehabilitation and empowerment processes to improve well-being in daily life.

I am looking for simple pleasures (walking, drinking coffee, listening to music, watching TV, etc.) … I go out of my home… I eat for pleasure… I have a hobby (music, singing, drawing, watching movies, writing ballads, etc.).

Positive attitudes were reported as daily efforts for good eating habits and were associated with good practices in oral healthcare.

I have a balanced diet… I eat healthy food… I brush my teeth and/or my dentures… I brush my tongue… I take care of my mouth to have good breath… I take care of my mouth to have good dentition.

Other positive attitudes included the awareness of adverse health effects from psychoactive drugs and substances, and the capacity to manage regular dental visits and side effects of dental treatment.

Alcohol, tobacco, drugs, etc. have negative effects on oral health… I manage to visit my dentist… I can coordinate the movement of my hands in order to brush my teeth… I consider drinking water when my mouth is dry.

Negative attitudes

We identified that negative attitudes refered to distinct problems that hinder oral health, which included poor dietary habits, such as snacking, and poor nutrition.

When I am stressed or don't feel good: I eat less or more, I snack between meals, and I feel trapped by my relationship with sugar.

The second most common problem was poor oral hygiene.

When I am stressed, I neglect my oral health, and I forget to brush my teeth.

Lastly, comorbid substance use, which includes tobacco, alcohol, or psychostimulants emerged as a negative attitude.

When I am stressed or I do not feel good, I have my own medication or substances to manage my health.

Autonomy dimension in oral health

The autonomy dimension included self-direction, free will, and empowerment. In oral health and OHRQoL for PWS, this dimension emerged during interviews as the following:

I pay attention to my breath… I am motivated to brush my teeth… I need to care for my oral well-being (for my oral and dental health).

The autonomy dimension was also expressed by the capacity to ask for help given certain needs and awareness of their personal capacities.

I need help managing my feelings… I need help managing my health…
I have bad breath… I am worried about my oral health… I have yellow teeth… I dare not smile.

Discussion

This qualitative study explored the views and experiences of PWS regarding oral health and OHRQoL. PWS reported poor oral health and OHRQoL, which allowed many themes to emerge. We were sensitive to the answers and experiences of each individual without prejudice. Given these conditions, participants were able to convey strong messages about their experiences with mental illness and their quality of life related to oral health. Our findings confirmed that even individuals with cognitive impairment are able to define their needs and that PWS have the ability to discuss their oral health and OHRQoL conditions, despite the fact that this ability is an issue of debate in the psychiatric community.[28]

For a long time, PWS were considered to be pain-insensitive.[29] However, it is safer to assume that pain experience in schizophrenia is disturbed or distorted rather than absent, and the cause of hypoalgesia in patients with stable mental states is unknown.[30] In our study, PWS clearly expressed their experience with oral or facial pain and highlighted a little-known problem of pain in relation to trismus and myasthenia induced by antipsychotics drugs.

The impact of anticholinergic drugs on OHRQoL oral diseases is a well-known matter, particularly among older people,[31] but it is often overlooked among people who suffer from severe mental illness, such as schizophrenia. In our study, this impact was clearly expressed. Furthermore, anticholinergic adverse effects increase with increased doses, and multiple low-level anticholinergic drugs can add up to the same burden (or more) than a single high-level drug.[32] The harmful potential increases with frailty and age, and anticholinergic drug use is closely related to serious negative[33]. The side effects of antipsychotic drugs on OHRQoL in PWS should receive more consideration by caregivers.

Phobia of dental care affects 5 to 20% of adults in industrialized countries.[34] The rates are unknown for PWS but this dimension emerged during interviews. Nevertheless, anxiety during oral management, which can take the form of either a panic attack or situational anxiety, and a predisposition to such crises can lead to avoidance of dental care.[35] Negative symptoms like anxiety symptoms can occur in up to 65% of patients with schizophrenia.[35] Thus, diagnosis and treatment of anxiety symptoms and disorders in schizophrenia is an important and often neglected aspect of schizophrenia management, especially for promoting dental care.[30]

The autonomy and coping themes emerged in the interviews with PWS, as they exhibited willingness to share their experiences, difficulties encountered, and strategies that both limit the effects of poor oral health and optimize OHRQoL in their daily lives. The findings highlighted a potential to build and develop new global therapeutic strategies around empowerment and positive support in somatic care, such as dental care and dental self-care.[36] Empowerment is becoming a fundamental concept in health promotion, as it aims to increase the power to act and the ability to steer one's life in medical and social spheres. It is a shift from a paternalistic and stigmatizing approach to emancipatory and rewarding dynamics.[37] Thus, several perspectives can be considered: a clearer view of oneself and one's ill health, better use of the healthcare system's support services, improved management of life changes, and finally, more deft use of adjustment strategies to integrate ill health and therapy into one's daily life.

Limitations

This study does have a few limitations. First, we offered a payment to the PWS to compensate them for their contribution to the research. This choice could be considered on ethical grounds to be coercive, unduly influential, and could have induced selection bias in our sample.[38] However, we believed a payment was necessary to demonstrate respect for research participants.

Second, we only included patients with stable schizophrenia (without positive symptoms) because unstable people need specific psychiatric care; getting cooperation from an unstable cohort is too

difficult. However, one must keep in mind that psychiatric conditions may be unstable over time.[39] It was sometimes difficult to differentiate certain delirious remarks from the patients and some quotes taken verbatim should be interpreted with caution. Moreover, it was difficult to specify the influence of different categories of symptoms (cognitive, positive, or negative) in the expression of their perception in oral health and OHRQoL. Schizophrenia is a complex continuum of intersecting symptoms.[17]

Third, PWS may have shared stories that made their decisions and perceptions seem more favorable during an interview. However, the flexible and responsive interviewing style enabled participants to discuss aspects of their experience that were relevant to them and minimized the risk of biasing the participants' responses.

Finally, participants were rather young (45.8 ± 9.5). The experience of older subjects should be evaluated in the future to represent their perspective in oral health and OHRQoL.

Perspectives

In recent years, there has been increased recognition on the experiential knowledge of healthcare users[34] and their ability to adapt professional knowledge to the requirements of everyday life. In this model, the experiential knowledge acquired by the patient during his illness is at the center of approaches that promote the empowerment concept.[37] Further, such approaches are important, as disagreement between doctors and patients can be as high as 50%, as stressed by Janse et al.[40] Whereas doctors pay attention primarily to clinical signs and symptoms, patients are interested in how they feel and their ability to meet their needs and desires. However, in clinical practice, clinicians, rather than the patients themselves, make decisions about the type of social skill training that the patients will receive. This reality indicates a gap between what clinician's think is timely and appropriate for patients and what the patients themselves think they need.[35] This study was specifically aimed at reducing this misunderstanding. The results of this study should be confronted with the point of views of caregivers.

Conclusion

PWS' views and experiences on oral health and OHRQoL were centered on dimensions related to experience of oral symptoms, experience of stress and its management, and "Autonomy dimension in oral health". PWS clearly expressed their thoughts and mental representations about their oral health and OHRQoL. Thus, this study supports that PWS are able to define their needs and have the functional ability to discuss their oral health and OHRQoL.

In the future, results of this study could be used to build tools to support patients with their daily oral hygiene, help them better manage the negative impact of antipsychotics and help them consult dentists on a regular basis.

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