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THE SCHIZOPHRENIA COPING ORAL HEALTH PROFILE. DEVELOPMENT AND FEASIBILITY

Francesca Siu-Paredes[1,2],
Nathalie Rude[2],
Corinne Rat[3],
Matthieu Reynaud[3],
Mohamad Hamad[2],
Sahar Moussa-Badran[1],
Frederic Denis[3,4*]

[1]Université Champagne Ardenne. Faculté d'Odontologie de Reims, 2 rue du Général Koenig 51100 Reims

[2]EA 481 Integrative Neurosciences and Clinical, University Hospital of Besançon, F-25000 Besançon, France

[3]Clinical Research Unit, La Chartreuse Psychiatric Centre, 21033 Dijon, France

[4]EA 75-05 Education, Ethique, Santé, Université François-Rabelais Tours, Faculté de Médecine, 37032 Tours, France

Abstract

Background: The aim of this work was to present the creation of appropriate tools to evaluate the coping strategies in Oral-Health-related Quality of Life (OHrQOL) implemented by persons with schizophrenia (PWS), the Schizophrenia Coping Oral Health Profile (SCOOHP), and the results of a feasibility study.

Methods: A qualitative investigation was conducted between June 2016 and May 2017.

The first step included 26 semi-structured individual interviews, 20 with PWS and 6 with health professionals (HPs), and 2 focus groups (PWS and HPs) to explore the experiences of the participants and how they felt about coping strategies in OHrQOL. The second step was a feasibility study involving a statistical analysis to test the acceptability and internal consistency (Cronbach's α) of the SCOOHP.

Results: The analysis of these interviews allowed for us to obtain 277 items from 3545 verbatim transcriptions related to various dimensions of OHrQOL. We presented the items selected in coping concepts in this study. After selecting items in several stages, we drew up the SCOOHP scale with 23 items (15 items for positive coping and 8 items for negative coping). The feasibility study showed good acceptability, good understanding of the items and good consistency reliability (α = 0.59).

Conclusions: This is the first study that has enabled us to draw up a specific tool to assess coping strategies in OHrQOL of PWS. A multicentre study involving a larger sample of PWS is underway in order to perform the psychometric validation of the SCOOHP.

Trial registration: Clinical Trials Gov NCT02730832. Date registered: 21 March 2016.

Introduction

Schizophrenia is a serious and a complex mental illness that affects 1% of the population [1]. It is characterized by the presence of positive or negative symptoms. Positive symptoms are characterized by mental dissociation, delusion (false unshakable belief based on illogical grounds), hallucinations (false perception without a stimulus), dampened or inappropriate emotions, and episodic or continuous progression [2]. Schizophrenia is a chronic disease that requires long-term medical treatment, which can result in physical, psychological, and social problems related to both the disease and the potential side effects of treatment [3]. Previous studies have shown that persons with schizophrenia (PWS) neglect their self-care and have high

rates of physical ill-health, such as heart disease or oral health, and a high mortality rate (life expectancy is reduced by 20%) [4,5]. One of the most visible elements of poor oral health in PWS is edentulousness and a large number of missing or decayed teeth [6]. A combination of dental caries, periodontal or infectious diseases and metabolic disturbances induced by antipsychotic treatments (including diabetes, obesity, and xerostomia), poor diet and lifestyle behaviours (diet rich in sugars, use of psychoactive substances such as tobacco, and inadequate oral hygiene) lead to poor health [7,8]. Difficult relationships with professional caregivers (such as fear of mental illness and lack of training) and the health system in general (including difficulties in gaining access to private practice, environment, and cost) are additional

obstacles contributing to deficient somatic care [9]. Currently, oral health prevention and promotion programmes, based on knowledge in the general population and transposed for persons with severe mental disorders, have not proven to be very effective. The specific profile of persons suffering from schizophrenia must be taken into account [10].

The neglect of self-care by PWS appears to be influenced predominantly by negative symptoms of schizophrenia, such as lack of initiation, a lack of concern for personal health, social withdrawal and a lack of motivation [11,12].

For oral health, negative symptoms and low socioeconomic and educational status are risk factors common to tooth decay and periodontal disease [13]. These factors are aggravated by stigmatization and discrimination [14], which

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* E-mail: frederic.denis@chlcdijon.fr

can partly explain why the physical health of PWS is neglected. Deterioration in oral health or Oral-Health-related Quality of Life (OHrQOL) can also be attributed to the medications used to manage schizophrenia. Antipsychotics may induce hyposalivation (xerostomia) or hypersalivation, and first-generation antipsychotics may lead to oral dyskinesias [6]. Oral health has both social and functional impacts as it affects the ability to pronounce words and the ability to eat. Tooth loss is a symbol of vital physical decline and leads to functional and psychological consequences in terms of communication skills and physical appearance [15]. Finally, poor oral health affects quality of life [16]. Conversely, good oral health is a positive factor in a person's general state of well-being and self-esteem [17].

A better understanding of the interest or disinterest in the act of self-care is needed to help PWS to improve their OHrQOL. Research should focus on assessing coping strategies for physical and mental health issues to develop appropriate strategies and to encourage financial support for OHrQOL healthcare studies.

Indeed, strategies in public health have used OHrQOL measures combined with clinical indicators to identify patient symptoms due to oral diseases, as well as patient ability to perform daily activities [18]. However, clinical indicators or measurement of OHrQOL do not explain why PWS rarely consult a dentist, are more likely to delay seeking care, and are less likely to adhere or receive adequate treatment than the general population. Determining the coping strategies used by PWS in daily life, for example, when making a dentist appointment or brushing their teeth regularly, is an issue that warrants being addressed. The information garnered would contribute to a better understanding of why PWS fail to use the healthcare system and good oral health practices.

Studies show that schizophrenia interferes with a person's ability to manage their emotions and make decisions in daily life [19,20]. Coping strategies play a crucial role in the recovery process of PWS; they can be considered as the capacity to cope with and to gain insight into the illness or to solve a problem [20].

The mechanisms of this involvement should be clarified to identify the capacity of PWS to cope with essential self-care on a day-to-day basis for good OHrQOL. Coping strategies play a crucial role in the recovery process of schizophrenia patients, particularly when the person has to address impediments to accomplish their goals [21]. Coping strategies are conscious efforts used to solve problems or to fulfil needs in daily life. Coping strategies are associated with both subjective (self-esteem and hopelessness) and objective (symptom severity) domains of recovery [22]. The effectiveness of the coping effort depends on the symptoms of the mental illness, such as stress; the individual; and the circumstances [19]. Coping strategies are considered as the evaluation of a transaction between the person and his environment, where certain perceptive, emotional or behavioural processes can help with the management of stressful events [23]. Problem-based coping (changing the problem that causes stress through a combination of efforts to cope with the situation) and emotion-focused coping (regulating the emotional responses to the problem that generates the stress) are two types of coping strategies [20]. Of these two strategies, PWS use more passive emotion-focused strategies, such as avoiding, ignoring and not thinking about the problem [23].

Schizophrenia symptoms often involve the loss of basic skills involved in daily life such as personal hygiene and grooming, budgeting or employment, independent living and time management. Recovering these basic skills is both an indicator of wellness and a toolkit to aid further progress [24]. By identifying simple goals and using proven strategies for achieving them, a higher quality of life can be attained; thirty percent of patients with schizophrenia manage without antipsychotic medicines after ten years of the disease, without falling back into a psychosis [25].

As far we know, coping strategies used by PWS to adapt to poor OHrQOL, which lead to neglect in oral health, have never been explored.

We hypothesized that a self-administered questionnaire for PWS that focuses on oral health coping should contribute to a better understanding of oral health needs. For caregivers, this information could inform care strategies to encourage positive behaviour in oral health and improve OHrQOL of PWS.

The aim of this work was to present appropriate tools developed to evaluate the coping strategies in OHrQOL implemented by the patients and a feasibility study.

METHODS

Design
A qualitative investigation was conducted between June 2016 and November 2018.

The first step included a semi-structured individual interview [26] and a focus group (FG) interview [27] to explore the experience of the participants and their feelings regarding OHrQOL and, more specifically, the coping strategies in OHrQOL. The second step was a feasibility study involving statistical analysis to test the acceptability of the Schizophrenia Coping Oral Health Profile (SCOOHP). The design of this study was used in a previous study by our team [28].

Participants
PWS and health professionals (HPs) were recruited from the administrative database of the Chartreuse Hospital (Dijon, France) by telephone for outpatients or face-to-face for inpatients. PWS were eligible to participate if they were at least 18 years old, they had a diagnosis of schizophrenia (according to the International Classification of Diseases 10th Revision: ICD-10) [29], they provided informed consent to participate in the study, and French was their native language. The exclusion criteria were a diagnosis other than schizophrenia, individuals who were unstable from a psychiatric perspective, serious physical illness, and intellectual disability.

In accordance with the guidelines published by Lancaster et al., 30 PWS were included in the feasibility study [30].

All PWS were offered financial compensation for their time (€20 for the first step of the study and €10 for the feasibility study). No relationship was established with the PWS prior to the initiation of the study.

Ethics

This study was approved by the Committee for the Protection of Persons of Eastern France

(Registration number: 2015-A01741-48). After providing the participants with a complete description of the study, written informed consent was obtained from each participant (or from their legal guardians for individuals under guardianship).

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

Generation of items for coping in oral health

Semi-structured interviews with 20 PWS and six health professionals (one dentist, one doctor, one psychiatrist, one psychologist, and two nurses) [26] and two FGs [27] were conducted with eight different individuals (1 FG with 4 PWS and 1 FG with the 4 HP) to collect qualitative data. Semi-structured interviews and FGs were drawn up by a psychologist who was experienced in managing individuals with mental health issues. The psychologist used an interview guide covering several specific areas of OHrQOL for PWS. These guides were based on the literature, our recent studies [31-34], and consensus meetings with experts from the work group (WG) (one dental researcher, one psychosociology researcher, one methodologist, one nursing researcher, and one PWS). The goal of qualitative research is to provide in-depth understanding; therefore, it targets a specific group or type of individual. It is not possible for researchers to collect data from everyone in a community. The aim of our study was to include all issues relating to OHrQOL and to obtain a "point of saturation" [35] regarding the themes addressed by the PWS and the HP who managed patient care. Thirty-four individuals participated in the study. The sample size was sufficient to obtain a "point of saturation" for the data [35]. Data for the semi-structured interview and the FG were compiled at a site of the Chartreuse Hospital that was conducive to discussion.

All individual interviews and FGs were audio recorded, transcribed by an administrative assistant, converted into verbatim accounts, and analysed using a reading grid. Our aim was to identify emergent or repetitive themes and patterns throughout the transcript and to interpret data accurately from the participants' perspectives and selected potential items, e.g., assertions likely to be included in the self-report questionnaire [36].

All transcripts were analysed by the psychologist who had recorded the semi-structured interview and conducted the FG. In the first selection, duplicate words for word items were eliminated. However, if a sub-theme was cited at least once, the repeated item was retained and referenced. Double negatives and negative words were avoided through rewording.

A consensus meeting was held with the WG to seek evidence of the respective views until all themes and sub-themes were agreed upon. Only items related to the concept of coping in OHrQOL were validated.

Feasibility Study
Acceptability questionnaire

A feasibility study was conducted with another group of 30 PWS recruited at Chartreuse Hospital. We used the same inclusion-exclusion criteria as that used for the SCOOHP. Sociodemographic data were collected, and the purpose of the feasibility study was to determine whether the patients found the SCOOHP questions clearly understandable, awkward, disturbing or surprising. We also sought to establish if certain questions could be added or if certain individuals had problems answering this questionnaire. Acceptability criteria, such as the time taken for completion, the amount of missing data, and the number of patients who did not return or who refused to participate were equally assessed.

The SCOOHP was a self-administered questionnaire with five possible answers for each item. These were matched with scores from 1 to 5, where "1" meant "strongly disagree" and "5" meant "strongly agree". Scores from the positively worded questions were reversed to calculate the overall score so that the direction of all responses was the same. We used smileys to help the PWS answer the questions.

Item-level analysis

Descriptive statistics included frequency distribution, means, standard deviation (SD), ceiling and floor effects. Items with a low response rate, as well as redundant items (i.e., high inter-item correlations, r > 0.4: n=30), were removed. Items with ceiling or floor effects (i.e., $0.70 \leq SD \leq 1.44$) were discussed further [37].

Internal consistency was assessed by Cronbach's α by evaluating the degree of internal consistency and homogeneity between items [38]. Cronbach's α value > 0.75 indicates excellent reliability, whereas values between 0.40 and 0.75 show fair to good reliability, and values <0.40 indicate poor reliability [38].

The SAS® software was used for statistical analyses.

The translation process of the SCOOHP in English (Figure 1)

The following protocol was used. Initially, two translations (French to English) were made independently by two bilingual translators in accordance with standard recommendations described in the literature [39,40]. Both translators
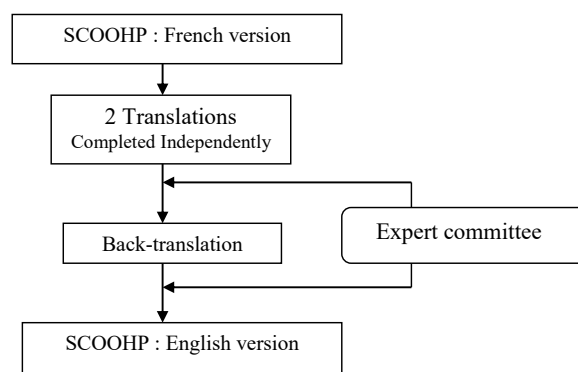

Figure 1: Flow chart of the translation validation process

were native French speakers, were fluent in English and had significant experience in qualitative studies. To determine the concept and equivalence of items, both translated versions were evaluated by an expert committee composed of two specialists in oral health, two specialists in schizophrenia, and one PWS. These individuals were also native French speakers fluent in English and had experience in oral health research. Attention was given to the identification of possible shortcomings in the understanding of the questionnaire's items. Following discussion, the committee of specialists drafted a summarized version of the questionnaire in English. The summarized version of the questionnaire was translated back into French by a native English translator who was blinded to the original instrument and who was not previously involved in the study. Finally, the expert committee evaluated the back-translated version.

Results

Population Characteristics
The characteristics of the 20 PWS in the first step of the study and the 30 PWS in the feasibility study are shown in Table 1.

Generation of items for coping in oral health
The interview guides used for the semi-structured interviews and the FGs are shown in Table 2.

The individual semi-directive interviews and the FG interviews yielded 3245 verbatim accounts. An initial analysis of the thematic content provided 837 remarks and 166 subthemes or dimensions. The transcript yielded no new codes, indicating data saturation. We retained 277 items labelled as "information related to OHrQOL for PWS".

The distribution of all 277 items brought up by the PWS and HPs show that 65% (180 items) were brought up by PWS and 10% (28 items) by HPs during the semi-structured interview process. Only 9% items (25 items) were brought up by FG patients and 5% (14 items) by FG professionals. We observed that 11% items (30 items) were common to patients and health professionals.

Table 1. Characteristics for the 20 PWS in the first step of the study and the 30 PWS in the feasibility study

Variables	First step N %	Mean (SD)	Feasibility N %	Mean (SD)
Gender				
Male	12 (60)		17 (56.7)	
Age (years)		45.8 (9.5)		44.6 (11.9)
≤34	2 (10)		6 (20)	
35-44	7 (35)		10 (33.3)	
45-54	6 (30)		9 (30)	
≥54	5 (25)		5 (16.6)	
In-patients	2 (10)		10 (33.3)	
Out-patients	18 (90)		20 (66.7)	

SD : Standard Deviation

Table 2. Interview guide used in semi-directive interviews with persons with Schizophrenia and in focus groups with health professionals

Interview guide (12 main themes) used in semi-directive interviews with persons with schizophrenia	Interview guide (11 main themes) used in focus group with health professionals
1. How are you? How do you feel?	1. What do you think affects the oral health-related quality of life of patients?
2. Can you describe which aspects of the oral health you like?	2. Can you tell me about the everyday difficulties patients encounter concerning their oral health?
3. As far the organization of your days is concerned, what time is troublesome? (night time, waking up, morning, lunch time, afternoon, evening, bed time)	3. Does oral health have repercussions on the state of mind of patients?
4. Does your oral health have repercussions on your state of mind?	4. Do they sometimes try to conceal problems with their oral health?
5. What are your relationships with your family circle or caregivers like? Do you feel understood and reassured by your family circle or caregivers?	5. Does their oral health status have repercussions on their relationships?
6. Are your social relationships disturbed because of your oral health?	6. What do you recommend for them when they are confronted with oral health problems? Or confronted with one particular problem?
7. Have you ever refused to do something, such as talking with others or eat something because of your oral health? If so, what?	7. What about you? What difficulties do you encounter when you are confronted with an oral health problem in these patients?
8. To sum up, what aspects of your oral health trouble you the most?	8. What attitude do you adopt? Do you adopt any attitude in particular?
9. What do you think could improve your oral health?	9. What could improve the oral health quality of life of the patients?
10. How important is your treatment to you?	10. What resources do you use to make your work easier or to make your relationship with patients easier?
11. What are you plans for the future?	11. Do you have solutions, ideas, or suggestions to provide them with better care?
12. How do you imagine the future?	

After exclusion of non-informative items, we retained 74 preselected items relating to OHrQOL in PWS, 32 potential items for coping strategies, and 19 potential items for satisfaction with oral healthcare. Of these 32 potential items for coping strategies, 9 were not retained because they were not informative enough. At the end of this step, the first draft of the SCOOHP questionnaire included 23 preselected items.

Second step: Feasibility Study and Item-level analysis

The average time needed to complete the SCOOHP questionnaire was 5.7 minutes ± 2.2 (min = 1; max= 10). There was a 100% return rate for the case-report forms (n = 30), and there were no refusals to participate. As reported by 93.3% participants, the "smileys" helped them answer the questionnaire. Nobody suggested adding new questions to the SCOOHP questionnaire or found that the questions were hard to understand. The SCOOHP was awkward or disturbing for 10% of the PWS, and 16.6% found one question to be surprising; however, they did not specify which one(s). The items were clearly understood and accepted. Ceiling effects were observed with six items (1, 4, 5, 11, 18, and 21). One floor effect was found with item 5. Frequency distributions for the responses of the SCOOHP feasibility study are presented in Table 3.

Cronbach's alpha (α = 0.59) showed good reliability, consistency, and homogeneity among the items (Table 4).

The translation process of the SCOOHP in English

The English version of the draft prototype of the SCOOHP questionnaire obtained by back translation was approved by the expert committee after some minor suggestions. The English version of the SCOOHP is shown in Table 5, and it was declared to the Institut National de la Propriété Industrielle (INPI) under the number DSO2018000112.

Discussion

The objective of this study was to present the stages of development and a feasibility study for the SCOOHP, a self-administered questionnaire to evaluate coping strategies in OHrQOL that takes into account the knowledge of OHrQOl in PWS. The interviews and FGs discussed the strategies used by patients to adjust to oral disease and thus better accept or improve it.

To capture the essential items of the coping concept in OHrQOL, our group explored comments made by patients and HPs in psychological and adaptive processes in OHrQOL [32,41]. The ability of PWS to discuss their condition remains an issue of debate in the psychiatric community [42], which can explain why most of the scales to explore perception in quality of life for PWS were generated either from the literature or expert opinions [42]. In our study, 65% of the items were produced by the PWS, and only 15% were produced by the HPs. PWS widely expressed their specific oral health problems:

"I have trouble biting firm meat because my teeth move when I chew"/ "I know I must brush my teeth every day, but when I do not feel well, I cannot do it"/ "I am afraid to visit the dentist"/ "Due to the yellowing of my teeth from tobacco use, I do not dare to smile "/ "I have a metallic taste in my mouth with my treatments".

However, the HP point of view is important and must be included in the selection process of the questionnaire. HP support and help is instrumental for patients to look after their own oral health and for managing the fear and anxiety induced by dental care. HPs have a good knowledge of the difficulties faced by PWS in OHrQOL and are able to provide solutions.

"Some do not even have a toothbrush"/ "We pay attention to whether they take showers every day when they are in hospital, but we do not pay attention to whether they brush their teeth!"/ "we should talk about diet to the dietician"/ "I accompanied Mr. X to the dentist, and it went very well; it had been at least ten years since he had gone to the dentist".

Coping strategies are cognitive and behavioural efforts to manage internal and external demands that tax or exceed the person's resources [43]. In OHrQOL, we observed that both positive and negative coping were highlighted in the questionnaire.

Negative coping was the strategy used by patients to adjust to the disease but not to improve OHrQOL. In contrast, positive coping was the strategy used by patients to improve their OHrQOL. Negative coping refers to four distinct problems that impacted oral health. Poor dietary habits included snacking (item 9), poor nutrition (item 10), and the frequent consumption of sweet foods (items 6). The second problem was poor oral hygiene (items 13 and 20); the third was comorbid substance use including tobacco, alcohol or psychostimulants (items 7); and the fourth was barriers to accessing dental care (items 23). Studies highlight that PWS are at a greater risk of oral diseases because of poor nutrition and oral hygiene; the heavy consumption of sugary drinks; comorbid substance misuse including tobacco, alcohol or psychostimulants; and financial or other barriers to accessing dental care [44,45]. Furthermore, PWS had low motivation for oral healthcare [46]. The positive coping strategies in OHrQOL were associated with well-being in daily life (items 1, 2, 3 and 5), daily efforts for good eating habits (items 8, 17, 18 and 21), good practice of oral health (items 11, 12, 14, 15 and 16) including the capacity to manage regular dental visits (item 22), and dealing with side effects of the treatment (item 19). Oral health is essential to general health and well-being at every stage of life. A healthy mouth not only enables nutrition of the physical body but also enhances social interaction and promotes self-esteem and feelings of well-being [47]. The PWS is in the best position to know how the disease interferes with his/her overall well-being. Well-being on a daily basis and the ability to make life plans emerged in our research as a positive outlook. In contrast, a negative outlook is related to depression and is associated with poor oral health [48,49].

Our results confirmed that coping strategies for schizophrenics play a crucial role in the mental health recovery processes [19] and in OHrQOL. We observed that the coping strategies were associated with both subjective (like self-esteem) and objective (negative symptoms) domains of recovery [22]. Poor diet and lifestyle behaviour (diet rich in sugar, use of psychoactive substances, and inadequate oral hygiene) contribute to poor health and

Table 3. Frequency distributions of the responses of the feasibility study

N° ITEMS	Strongly disagree (n,%)	Disagree (n,%)	More or less agree (n,%)	Agree (n,%)	Strongly Agree (n,%)	Total (n,%)	Missing data (n,%)	Theoretical dimension
1. I am looking for simple pleasures (walk, drink coffee, listen to music, watch TV ...).	0 0,0%	0 0,0%	3 10%	6 20%	16 53,3%	30 83,3%	5 16,7%	Positive coping
2. I go out of my home	5 16,7%	1 3,3%	5 16,7%	7 23,3%	11 36,7%	30 96,7%	1 3,3%	Positive coping
3. I eat for my pleasure	6 20%	0 0%	6 20%	8 26,7%	10 33,3%	30 100%	0 0%	Negative coping
4. I have a hobby (music, singing, drawing, movie, and ballads …)	4 13,3%	3 10%	3 10%	6 20%	14 46,7%	30 100%	0 0%	Positive coping
5. When I move, I feel good	1 3,3%	0 0%	4 13,3%	11 36,7%	14 46,7%	30 100%	0 0%	Positive coping
6. I feel trapped by my relationship with sugar.	7 23,3%	6 20%	5 16,7%	5 16,7%	7 23,3%	30 100%	0 0%	Negative coping
7. I have my own medicines to manage my health	11 36,7%	4 13,3%	4 13,3%	4 13,3%	7 23,3%	30 100%	0 0%	Negative coping
8. I have a balanced diet	2 6,7%	4 13,3%	10 33,3%	5 16,7%	9 30%	30 100%	0 0%	Positive coping
9. I snack between meals	6 20%	6 20%	4 13,3%	11 36,7%	3 10%	30 100%	0 0%	Negative coping
10. When I am stressed or don't feel good, I eat less, or I eat more	9 30%	8 26,7%	5 16,7%	4 13,3%	3 10%	30 97%	1 3,30%	Negative coping
11. I think about washing myself (shower, bath, cleaning)	1 3,3%	1 3,3%	1 3,3%	5 16,7%	22 73,3%	30 100%	0 0%	Positive coping
12. I brush my teeth and/or my denture	3 10%	0 0%	2 6,7%	13 43,3%	12 40%	30 100%	0 0%	Positive coping
13. I neglect my oral health	16 53,3%	9 30%	1 3,3%	3 10%	1 3,3%	30 100%	0 0%	Negative coping
14. I brush my tongue	8 26,7%	6 20%	3 10%	5 16,7%	8 26,7%	30 100%	0 0%	Positive coping
15. I take care of my mouth to have a good breath	2 6,7%	6 20%	3 10%	11 36,7%	8 26,7%	30 100%	0 0%	Positive coping
16. I take care of my mouth to have a good dentition	4 13,3%	2 6,7%	3 10%	12 40%	9 30%	30 100%	0 0%	Positive coping
17. I eat healthy food	3 10%	4 13,3%	9 30%	6 20%	8 26,7%	30 100%	0 0%	Positive coping
18. I think about drinking water (normal or sparkling) when my mouth is dry	2 6,7%	1 3,3%	2 6,7%	11 36,7%	14 46,7%	30 100%	0 0%	Positive coping
19. I can coordinate the movement of my hands in order to brush my teeth	4 13,3%	1 3,3%	4 13,3%	11 36,7%	10 33,3%	30 100%	0 0%	Positive coping
20. I forget to brush my teeth	13 43,3%	5 16,7%	4 13,3%	5 16,7%	3 10%	30 100%	0 0%	Negative coping
21. Alcohol, tobacco, drugs have negative effects on the oral health	5 16,7%	2 6,7%	1 3,3%	8 26,7%	14 46,7%	30 100%	0 0%	Positive coping
22. I manage to visit my dentist	6 20%	4 13,3%	1 3,3%	8 26,7%	11 36,7%	30 100%	0 0%	Positive coping
23. I'm afraid to go to the dentist	10 33,3%	3 10%	4 13,3%	6 20%	7 23,3%	30 23,0%	0 0%	Negative coping

Table 4: Inter-item and item-scale for the SCOOHP items

SCOOHP item	1	2	3	4	5	6	7	8	9	10	11	12
item-scale	.0599	0.433	0.315	0.599	0.550	0.323	0.358	0.509	0.249	0.326	0.789	0.789
SCOOHP item	13	14	15	16	17	18	19	20	21	22	23	
item-scale	0.737	0.630	0.674	0.674	0.507	0.509	0.765	0.360	0.368	0.550	0.279	

Cronbach's α=0.59

diminished sociality, thus impacting self-esteem and mental health [6].

Coping strategies are described as the evaluation of a transaction between the person and his environment, where certain perceptive, emotional or behavioural processes can help the person cope with stressful events [23]. Generally, dental visits or accessibility to dental care generate major stress for PWS, which is one reason for their infrequent dentist visits [50]. The cost of dental care, difficult relationships with professional care givers, or general obstacles related to the health system in terms of access to private care are evoked as stress-causing factors for persons with severe mental illness. In this case, a rational presentation of the causal links between stress factors is sorely needed if we wish to treat patients successfully over a long term [51].

The selection of items of the SCOOHP questionnaire is in accordance with Gronholm et al. [52]. There are different types of coping when PWS have been under significant stress. PWS can avoid and deny the stressful situation, in which case, coping is centred on emotion in the SCOOHP (for example, items 13 and 20). If PWS seek support from others, coping is centred on the search for social support (items 1, 2, 3, 5 and 22), or if PWS analyse the situation, coping is centred on the problem (items 12, 15, 16 and 21).

During the feasibility study, we observed good reliability, consistency, and homogeneity between items (α = 0.59). However, this result should be interpreted cautiously and should be confirmed in a large sample with psychometric validation. During the psychometric validation process, some items of the initial version of the SCOOHP questionnaire can be removed. Indeed, some items may not be informative or meaningful enough for PWS.

The method used to translate the questionnaire into English was carefully guided by standard recommendations described in the literature [39,40]. The participation of one PWS in the expert committee helped to increase the strength of the English version of the SCOOHP.

Strengths and limitations

One strength of this study is its systematic use of knowledge provided by PWS through the individual semi-structured interviews, FG interviews and the WG. Each step of this study reduced the risk that measurement or observation biases could affect the quality of the questionnaire we developed. 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.

Although the included PWS were stable from a psychiatric perspective, the potential unreliability of the information elicited from the patients was one of the challenges of this study. Psychiatric diagnoses may be especially vulnerable to instability over time [53], and an experienced psychologist conducted the interviews to differentiate certain delirious remarks by patients.

Conclusions

To our knowledge, this is the first study that has sought to draw up a specific tool to assess coping strategies in OHrQOL of PWS. The SCOOHP self-administered questionnaire was established by analysing the content of semi-structured individual and group interviews with PWS and HPs. The scale was well-accepted and understood with negligible levels of missing data. It allows practitioners to target all dimensions of the concept studied.

A multicentre study involving a larger sample of PWS is underway in order to perform the psychometric validation of the SCOOHP scale.

Conflict of interest

The authors report no conflicts of interest.

Authors' contributions

FS was the signatory investigator on the study. FD and NR contributed to the concept and design of the study. All authors contributed to the interpretation of the data, revised the manuscript, and approved the final content of the manuscript.

Table 5. The SCOOHP questionnaire in the final version
Could you please fill out this questionnaire which aims to inform us about your daily life and your health in order to improve your support.
Check for each question the box that **most closely matches what you are currently feeling**.
We wish the most sincere answers possible; there is no good or bad answer.

Fill in the start time of filling in the questionnaire
|__|__| h |__|__| mn

	Strongly disagree	Disagree	More or less agree	Agree	Strongly Agree

Tell us about your feelings now, and over the past 2 weeks

	Strongly disagree	Disagree	More or less agree	Agree	Strongly Agree
1. I am looking for simple pleasures (walk, drink coffee, listen to music, watch TV ...).	1	2	3	4	5
2. I go out of my home	1	2	3	4	5
3. I eat for my pleasure	1	2	3	4	5
4. I have a hobby (music, singing, drawing, movie, and ballads …)	1	2	3	4	5
5. When I move, I feel good	1	2	3	2	5
6. I feel trapped by my relationship with sugar.	5	4	3	2	1
7. I have my own medicines to manage my health	1	2	3	4	5
8. I have a balanced diet	1	2	3	4	5
9. I snack between meals	5	4	3	2	1
10. When I am stressed or don't feel good, I eat less, or I eat more	1	2	3	4	5
11. I think about washing myself (shower, bath, cleaning)	1	2	3	4	5
12. I brush my teeth and/or my denture	1	2	3	4	5
13. I neglect my oral health	5	4	3	2	1
14. I brush my tongue	1	2	3	4	5
15. I take care of my mouth to have a good breath	1	2	3	4	5
16. I take care of my mouth to have a good dentition	1	2	3	4	5
17. I eat healthy food	1	2	3	4	5
18. I think about drinking water (normal or sparkling) when my mouth is dry	1	2	3	4	5
19. I can coordinate the movement of my hands in order to brush my teeth	1	2	3	4	5
20. I forget to brush my teeth	5	4	3	2	1
21. Alcohol, tobacco, drugs have negative effects on the oral health	1	2	3	4	5
22. I manage to visit my dentist	1	2	3	4	5
23. I'm afraid to go to the dentist	5	4	3	2	1

References

[1] Jablensky A. Epidemiology of schizophrenia: the global burden of disease and disability. Eur Arch Psychiatry Clin Neurosci. 2000; 250:274- 85.

[2] Kurtz MM, Wexler BE, Fujimoto M, Shagan DS, Seltzer JC. Symptoms versus neurocognition as predictors of change in life skills in schizophrenia after outpatient rehabilitation. Schizophr Res. 2008;102:303-311.

[3] Kwong VW, Chang WC, Chan GH, Jim OT, Lau ES, Hui CL, Chan SK, Lee EH, Chen EY. Clinical and treatment-related determinants of subjective quality of life in patients with first-episode psychosis. Psychiatry Res. 2017; 249:39-45.

[4] Wildgust HJ, Hodgson R, Beary M. The paradox of premature mortality in schizophrenia: new research questions. J Psychopharmacol Oxf Engl. 2010;24:9–15.

[5] Brown S, Inskip H, Barraclough B. Causes of the excess mortality of schizo- phrenia. Br J Psychiatry J Ment Sci. 2000; 177:212–7.

[6] Arnaiz A, Zumárraga M, Díez-Altuna I, Uriarte JJ, Moro J, Pérez-Ansorena MA. Oral health and the symptoms of schizophrenia. Psychiatry Res. 2011;188:24–8.

[7] Thomas A, Lavrentzou E, Karouzos C, Kontis C. Factors which influence the oral condition of chronic schizophrenia patients. Spec Care Dent Off Publ Am Assoc Hosp Dent Acad Dent Handicap Am Soc Geriatr Dent. 1996;16:84–6.

[8] Joukamaa M, Heliövaara M, Knekt P, Aromaa A, Raitasalo R, Lehtinen V. Schizophrenia, neuroleptic medication and mortality. Br J Psychiatry J Ment Sci. 2006;188:122–7.

[9] Kisely S, Smith M, Lawrence D, Cox M, Campbell LA, Maaten S. Inequitable access for mentally ill patients to some medically necessary procedures. CMAJ. 2007;176:779–84.

[10] Khokhar WA, Clifton A, Jones H, Tosh G. Oral health advice for people with serious mental illness. Cochrane Database Syst Rev. 2011;11:008802.

[11] Persson K, Olin E, Ostman M. Oral health problems and support as experienced by people with severe mental illness living in community-based subsidised housing a qualitative study. Health Soc Care Community. 2010; 18:529- 36.

[12] Kilbourne AM, Horvitz-Lennon M, Post EP, McCarthy JF, Cruz M, Welsh D, et al. Oral health in Veterans Affairs patients diagnosed with serious mental illness. J Public Health Dent. 2007; 67:42- 8.

[13] Lencová E, Broukal Z, Dusková J. Psychosocial, behavioural and oral health indicators--review of the literature. Prague Med Rep. 2006; 107(3): 305-16.

[14] Moore S, Shiers D, Daly B, Mitchell AJ, Gaughran F. Promoting physical health for people with schizophrenia by reducing disparities in medical and dental care. Acta Psychiatr Scand. 2015; 132:109–21.

[15] Wey MC, Loh S, Doss JG, Abu Bakar AK, Kisely S. The oral health of people with chronic schizophrenia: a neglected public health burden. Aust N Z J Psychiatry. 2016; 50:685–94.

[16] Wartelsteiner F, Mizuno Y, Frajo-Apor B, Kemmler G, Pardeller S, Sondermann C, et al. Quality of life in stabilized patients with schizophrenia is mainly associated with resilience and self-esteem. Acta Psychiatr Scand. oct 2016; 134(4):360-7.

[17] Chu K-Y, Yang N-P, Chou P, Chiu H-J, Chi L-Y. Comparison of oral health between inpatients with schizophrenia and disabled people or the general population. J Formos Med Assoc. 2012; 111:214-9.

[18] Lazarus RS, Folkman S. Stress, Appraisal, and Coping. New York: Springer Publishing Company, Inc.;

[19] Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: A theoretically based approach. J Pers Soc Psychol 1989, 56, 267-283.

[20] Grisso T, Appelbaum PS. Comparison of standards for assessing patients' capacities to make treatment decisions. Am J Psychiatry. 1995; 15:1033–7. 1984.

[21] Carver CS, Connor-Smith J. Personality and Coping. Annu Rev Psychol. 2010; 61:679–704.

[22] Hofer A, Mizuno Y, Frajo-Apor B et al. Resilience, internalized stigma, self-esteem, and hopelessness among people with schizophrenia: cultural comparison in Austria and Japan. Schizophr Res 2016;171:86–91.

[23] Aghevli, MA, Blanchard, J.J., Horan, W.P., 2003. The expression and experience of emotion in schizophrenia: a study of social interactions. Psychiatry Res. 119, 261-270.

[24] Alex Kopelowicz, Robert Paul Liberman, and Roberto Zarate. Recent Advances in Social Skills Training for Schizophrenia. Schizophr Bull. 2006 Oct; 32(Suppl 1): S12–S23.

[25] Wils RS, Gotfredsen DR, Hjorthøj C, Austin SF, Albert N, Secher RG, Thorup AA, Mors O, Nordentoft M. Antipsychotic medication and remission of psychotic symptoms 10years after a first-episode psychosis. Schizophr Res. 2017 Apr;182:42-48.

[26] Hesse-Biber SN, Leavy P. Designing qualitative approach to research. The Pratice of Qualitative Research. Sage Publication, 2010.

[27] Krueger RA, Casey MA. Focus Groups. A Practical Guide for Applied Research. Thousand Oaks CA: Sage Publications, 2000.

[28] Baroin A, Mokadym H, Chopard G, Lavier A, Berger E, Rumbach L,Rude N. Establishing an evaluation scale for the perception of quality of life related to relapsing-remitting forms of multiple sclerosis and feasibility study. Int J of Neurosci. 2012;122:9-16.

[29] OMS Classification CIM-10 des troubles mentaux et des troubles du comportement [Internet]. WHO. [cited 2015 Oct 11]. Available from: http://www.who.int.com

[30] Lancaster GA, Dodd S, Williamson PR: Design and analysis of pilot studies: recommendations for good practice. J Eval Clin Pract. 2004;10:307-12.

[31] Denis F, Hamad M, Trojak B, Tubert-Jeannin S, Rat C, Pelletier JF, Rude N. Psychometric characteristics of the "General Oral Health Assessment Index (GOHAI) » in a French representative sample of patients with schizophrenia. BMC Oral Health. 2017; 17, 75. doi:10.1186/s12903-017-0368-3.

[32] Baroin A, Mokadym H, Chopard G, Lavier A, Berger E, Rumbach L,Rude N. Establishing an evaluation scale for the perception of quality of life related to relapsing-remitting forms of multiple sclerosis and

feasibility study. Int J of Neurosci. 2012;122:9-16.

[33] Denis F, Millot I, Abello N, Carpentier M, Peteuil A, Soudry-Faure A.Study protocol: a cluster randomized controlled trial to assess the effectiveness of a therapeutic educational program in oral health for persons with schizophrenia. Int J Ment Health Syst. 2016;10:65 DOI 10.1186/s13033-016- 0096-0.

[34] Pelletier JF, Lesage A, Boisvert C, Denis F, Bonin JP, Kisely S. Feasibility and acceptability of patient partnership to improve access to primary care for the physical health of patients with severe mental illnesses: an interactive guide. Int J Equity Health. 2015;14:78.

[35] Hesse-Biber SN, Leavy P. Designing qualitative approach to research. The Pratice of Qualitative Research. Sage Publication, 2010.

[36] Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77-101.

[37] Berzon R, Hays RD, Shumaker SA. International use, application and performance of healthrelated quality of life instruments. Qual Life Res. 1993; 2:367-368.

[38] Bland JM, Altman DG. Cronbach's alpha. BMJ. 1997;314:572.

[39] Herdman M, Fox-Rushby J, Badia X. 'Equivalence' and the translation and adaptation of health-related quality of life questionnaires. Qual Life Res. 1997;6(3):237–47

[40] Gjersing L, Caplehorn JR, Clausen T. Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. BMC Med Res Methodol. 2010;10:13.

[41] Rat AC, Pouchot J, Guillemin F, Baumann M, Retel-Rude N, Spitz E, Coste J. Content of quality of life instruments is affected by item generation methods. Int J Qual Health Care. 2007;19:390-398.

[42] Trauer T, Mackinnon A. Why are we weighting? The role of importance ratings in quality of life measurement. Qual Life Res. 2001;10:579-585.

[43] Lazarus R. Psychological Stress and the Coping Process. New York (NY): McGraw-Hill; 1996.

[44] Kisely S, Baghaie H, Lalloo R, et al. (2014) A systematic review and meta-analysis of the association between poor oral health and severe mental illness. Psychosomatic Medicine 77: 83–92.

[45] Denis F, Pelletier JF, Chauvet-Gelinier JC, Rude N , Trojak B. Oral Health Is a Challenging Problem for Patients with Schizophrenia: A Narrative Review. Iran J Psychiatry Behav Sci. 2018 January; 12(1):e8062. doi: 10.5812/ijpbs.8062.

[46] Tang LR, Zheng W, Zhu H et al. Self-Reported and Interviewer-Rated Oral Health in Patients With Schizophrenia, Bipolar Disorder, and Major Depressive Disorder. Perspect Psychiatr Care. 2016;52(1):4-11.

[47] Kisely S. No Mental Health without Oral Health. Can J Psychiatry. 2016;61(5):277-82

[48] Toombs SK. The temporality of illness: four levels of experience. Theor Med. 1990;11:227-241.

[49] Baron-Epel O, Dushenat M, Friedman N. Evaluation of the consumer model: relationship between patient's expectations, perception and satisfaction with care. Int J Qual Health Care. 2001;13:317-323.

[50] Nielsen J, Munk-Jorgensen P, Skadhede S, et al. Determinants of poor dental care in patients with schizophrenia: a historical, prospective database study. J Clin Psychiatry. 2011;72(2):140–143.

[51] Roccaforte R, Demers C, Baldassarre F, TeoK, Yusuf S. Effectiveness of comprehensive disease management programmes in improving clinical outcomes in heart failure patients. A meta-analysis. Eur J Heart Fail. 2005; 7: 1133-1144.

[52] Gronholm PC, Thornicroft G, Laurens KR, Evans-Lacko S. Conditional Disclosure on PatHPays to Care: Coping Preferences of Young People at Risk of Psychosis. Qual Health Res. 2016 Doi: 10.1177/1049732316680337.

[53] Gjersing L, Caplehorn JR, Clausen T. Cross-cultural adaptation of research instruments: language, setting, time and statistical considerations. BMC Med Res Methodol.2010;10:13.