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Received Date : 28-Jul-2016

Revised Date : 17-Feb-2017

Accepted Date : 27-Feb-2017

Article type : Original Article

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TITLE PAGE:

**Perceptions of oral health by those living with mental illnesses in the Victorian
Community - The consumer's perspective**

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Keywords: Oral Health, Public Health, Mental Illness, Dental Health, Qualitative, and
Collaboration

Submitted: June 2016

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/idh.12278](https://doi.org/10.1111/idh.12278)

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ABSTRACT

Objective: Understand the way people living with mental illness in an Australian community experience and define oral health.

Study population: People living with serious mental illness in the Victorian Community.

Methods: Qualitative methodologies were used in this study. Two focus groups and four semi-structured interviews were conducted. The data was transcribed and thematically analysed.

Results: Participants generally valued oral health and recognised that attending regular dental appointments played a key role in improving their oral health. Participants felt that their mental illness overwhelmed their ability to maintain good oral health. Coping, dental fear, stigma, financial barriers and communication were identified as issues around utilisation and access to care.

Discussion: Experiences of oral health were both positive and negative. Barriers and enablers, extending beyond participant oral health literacy for oral health were identified from the data and recommendations around personal, environmental and clinical supports were made.

Conclusion: This is a valuable study that provides new insight into a complicated issue. Recommendations to create a supportive dental environment and direction to improve the dental experience have been made to make oral health more accessible for people living with mental illness. Recommendations have also been made for community-based mental health organisations to aid the improvements in oral health with this group of people, thus building a collaborative approach to support oral health for this vulnerable group.

CLINICAL RELEVANCE

Scientific Rationale: A qualitative approach to this work was used because of its exploratory nature and the need to capture rich, lived experiences in order to understand the way people living with mental illness experience and define oral health, as limited information exists.

Principal findings: The data collected was insightful, and is presented to raise the clinician's awareness of oral health perceptions and issues in this group of people. Both positive and negative dental experiences are described so that clinicians are able to further their understanding.

Practical Implications: This study will give information to clinicians about some current perceptions of oral health among people living with severe mental illnesses, and inform clinicians and policy makers to improve clinical management and services in this group of people.

INTRODUCTION

A large body of literature supports the notion that individuals with mental illness are at a higher risk of developing chronic poor physical health conditions that include obesity, diabetes mellitus and cardiovascular disease [1-4]. Evidence has shown that this group of people have high rates of poor oral health and are affected by oral diseases such as dental caries and periodontal diseases [5-7]. When compared to the general population, this group of people are more likely to experience untreated dental problems, require emergency dental treatment and need more complex treatment as a result [8, 9]. Given that there is a strong correlation between oral health and physical health, where the relationship between oral health and physical health are intertwined, people living with severe mental illness are recognised as a priority group in need of support in improving oral health [7, 10].

The impact of mental illness can strongly shape a person's dental experiences [7, 11]. Various structures and circumstances within the social, economic and political environment of Australian society have created fundamental inequalities that not only contribute to the development of oral diseases, but also perpetuate adverse cycles of continued poor dental and oral health [12]. Coping with their lives, managing the impact of mental illness, having compromised education as a result of illness, and limited employment opportunities have been identified as determinants that affect oral health [6, 12, 13]. These social inequalities reduce the ability of people living with mental illnesses to access adequate dental care and improve oral health. Risk factors associated with poor oral health are highly prevalent in this group of people with higher rates of smoking, higher consumption of sweetened caffeinated drinks and prescribed medications which are known to cause diminished saliva levels further exacerbating the high risks of dental decay and periodontal disease [14-16].

Existing research surrounding the consumer's perspective on oral health is limited within Australia and internationally. Numerous studies document the substantial poor oral health among individuals living with mental illness [5, 6, 16, 17] and that current dental services inadequately address dental needs [18]. Happel et al (2013) investigated perceptions of nursing staff working in the field of mental illness on oral health [19] which highlights the poor access individuals face. Studies however lack information regarding the oral health

experiences from the consumer's perspective that may give personal direction to policy healthcare makers to address the unmet dental need.

This research is situated in a partnership project undertaken with a large national provider of community mental services in Australia known as Neami National. Neami National provides support services within a collaborative recovery framework to individuals living with serious mental illnesses in the community. Capacity building work around oral health has been undertaken as part of this project, however despite advice and referrals to dental clinics being made, many of their consumers did not go on to access dental care [20]. Understanding the barriers from the perspective of people with mental illnesses was considered to be the next important step in identifying appropriate supports and enablers both for Neami National support workers and dental practitioners. The aim of the project was to identify the barriers to oral health for people living with mental illness within an Australian community by exploring, among a group of Neami National consumers, the way they perceive and experience oral health and interact with oral health care services. Ethics approval for the study was granted by The Human Research Ethics Committee at the University of Melbourne.

STUDY POPULATION AND METHODS

People living with mental illness in the community who receive support from a large national provider of community mental services in Australia Victoria was the study population and were invited via their support workers, to participate in a focus group or a semi-structured interview. Participants self-selected based on their interest and were competent in everyday communication, living independently in the community. All participants were adults, over 18 years of age and thus able to provide verbal and written informed consent.

Two focus groups (denoted FG1 & FG2, with participants denoted as P1-P7 in results) and four semi-structured interviews (denoted I1-I4 in results) were conducted involving twelve participants; four males and eight females. One of the two focus groups included only two participants which resulted in data collection being conducted in a semi-structured interview style with the two participants listening to each other's answers. During the focus groups, the first author was the facilitator and the second author was the note taker. For the semi-structured interviews, the first author was the interviewer and a support worker was present. The focus groups were conducted on Neami National premises (familiar to the participants) and the interviews, according to the participant's preference; either arranged at the participant's home or on Neami National premises. Both the focus group and semi-structured interviews followed a guide, were digitally recorded and ran for 26 to 60 minutes.

Transcribing of the data from audio recording was undertaken within 24 hours [21], and transcriptions were randomly checked for validity by the other authors; participants names were replaced with codes to protect confidentiality. The data were manipulated using NVivo 10; and thematically analysed by the three authors based on grounded theory [22, 23]. Participant's transcripts were openly coded leading to keywords and then to the identification of common issues and themes among participants. Axial coding enabled the development of major themes and categories, which then underwent selective coding. There was evidence in the data of saturation along with some individually unique themes. The three authors met at regular intervals throughout data collection and analysis to discuss the themes that emerged from the data and were equally involved in the analysis process. This approach supported analysis triangulation and was designed to reduce researcher bias and increase reliability and validity [24].

RESULTS

Six key themes (self-perceived oral health status, fear, stigma, coping, financial issues, communication) emerged from the data. Within each theme, several descriptive issues were also identified and the results reported here are related to consumer perceptions and experiences of their own oral health. Additional papers by the same authors will report themes related to the provision of dental care and an evaluation of support provided by the mental health organisation. The ordered themes assist in understanding the experiences and barriers this group of participants faced and what supports are already in place. Illustrative quotes have been provided referenced by the coded identifiers.

Self-perceived oral health status

Most participants reported their oral health was poor. This description was often linked with the participant's current oral health behaviours and was usually based on experienced dental pain and/or being able to see dental decay.

“Oh look, the appearance of my teeth are dreadful, you know my front teeth... I have decay visibly showing.” (I1)

“It's pretty poor... I don't brush my teeth every day. I don't see a dentist regularly enough.” (I3)

Some participants who reported that their oral health was acceptable, had seen an oral health provider regularly or had maintained a regular preventive oral health routine at home.

“Well my dental hygiene is pretty good. You know, I brush twice a day. And well flossing is a bit – sort of – irregular.” (I2)

Coping with mental illness and self care

Living with a mental illness often overwhelmed actions for self-care, which was a common theme. Often participants explained they had the intention to maintain a preventive oral health routine, however coping with their mental health conditions and dealing with additional stressors in their lives made this challenging.

“I don’t clean my teeth often enough. I used to clean my teeth twice a day before... I got diagnosed. You know when you get depressed you just stop showering, you stop cleaning your teeth, you stop shaving. And then I got into the bad habit of cleaning my teeth when I was in the shower. So I don’t do it twice a day, I just do it when I get in the shower, and that could be every second day or sometimes every day, or even every third or fourth day. Depends on how I’m travelling at the time.” (I3)

“Also lack of self-care because we’re attending to our mental health needs...I mean if you’re not travelling well with your mental health... you’re just consumed by all of that, and things; eyesight and teeth on the list are deteriorating because you’ve sort of gone far off into the distance and just trying to manage everything else.” (FG1, P2)

“I became quite unwell last year so I wasn’t brushing my teeth for a period of time... I let self-care go” (FG1, P4)

One participant explored in depth the extent of the impact of mental illness on his oral health. He described his oral health as a physical representation of the mental illness he was coping with (I1).

“Part of me was seeking to destroy something that I highly valued. It was part of the whole self-sabotage phase I was going through. Part of me also wanted something; a physical symbol of the inner turmoil that I was going through. I just wanted something physical to show for it. ... Because I had nothing left that someone could point to that say that was real. External visuals validated it, and I wanted other people to look [at me] and say ‘that’s wrong, that’s bad’” (I1)

Motivation to improve oral health was associated with an individual's feeling of empowerment, autonomy and independence. This was often coupled with whether they had accessed positive oral health support.

"Probably before I started going and having some treatment on my teeth, it was just nope. I just never got around to it. No self-care things. Nope. But now that I want to keep my teeth, I am now more motivated to." (FG2, P2)

Regret was another common response among participants who had had negative experiences.

"I just wish I had looked after my teeth better. It would be nice to think that my teeth will stay in my head for the rest of life but... prevention would have been better than cure." (FG2, P2)

Fear

Dental fear and anxiety was a powerful theme that emerged from the data and was a significant barrier for many participants. Many participants acknowledged they had some form of dental fear. Anxiety often accompanied the dental fear, and was usually more notable when participants spoke about a negative or traumatic dental experience. In some instances the fear and anxiety was a significant barrier for the participant to access regular dental care.

"[I feel] terrified. Really, really anxious. I have to be very careful to watch my breathing, make sure I don't hyperventilate...I don't like the idea of people having their hands in my mouth... I probably won't sleep the night before the appointment. I find it difficult on the day of the appointment because I'm nervous. I'll probably spew." (I1)

"I pretty much go into fight or flight syndrome. And I'll always just fly out of my body." (FG1, P1)

"Going to the dentist is really traumatizing. Like I get to the stage where I

am screaming or crying or whatever 'cause I can't deal with it. I've always been like that and I've never liked the dentist. Even though they are a necessity." (FG1, P1)

"Two reasons for this. The first reason is social anxiety. The second reason would be because having to go and sit in the chair and get my teeth drilled out is scary. That makes me anxious. When I'm actually there I'm highly anxious." (FG1, P6)

"I think it's the smell and it's very clinical. I get very anxious." (FG2, P2)

Participants, despite their fear and anxiety often had individual ways of coping when undertaking a dental appointment. To reduce the sense of being vulnerable, one participant found that not lying down flat on the chair helped to ease the emotions associated with fear of dental treatment. One participant found his fear was mostly the fear of the unknown and once had overcome it, he became more comfortable with attending the dental appointment. Other participants had recommendations to improve their experience and this ranged from improving music choices played at the dental clinic to visual or environmental distractions.

"Well the chap that I see works from two rooms. One room is a window like this (points to a wide floor to ceiling window which allows for natural light to enter the room) and the other one is just 4 walls. And every time when I get called in, I always hope that we are in the room with the view. I mean, even though it looks over the roof of a shopping centre... it's a bit more to look at than the [other room]." (FG2, P2)

"I was pretty much like you. I was so terrified that after I got the last of my top teeth out I was so happy. I had intravenous Valium 'cause the guy wouldn't do it 'cause I was shaking so bad. So anyway... on the last session, something popped in my head, and you know how you go back like that? (Demonstrated lying back on the dental chair) I went, 'I don't want to go back like that, just put me like this' (demonstrated sitting up straighter)

and it instantly stopped that fear that I had. You know that feeling when you go back in a chair? That was the feeling that I had when I was going to the dentists. Fear of the dentist, thinking about dentists, people talking about teeth, I get that fear. And once I stopped the chair from going so horizontal and had it moved up a bit... that fear disappeared.” (FG1, P3)

Use of drugs and self-medication to reduce the fear and anxiety was also evident. One participant made strong recommendations to use Valium.

“I use Valium. I recommend Valium. It works!” (FG1, P3)

Stigma

Stigma was another important theme that emerged from the data. Participants were conscious about being judged or stigmatized by other people for their mental illness. Their experiences, however, often differed from one another. Experiences ranged from extremely negative, to participants being neutral or unaware of it, and to experiences of no negativity. Despite their past experience with stigma, participants appeared to be mindful of public responses about their mental health condition from dental reception staff and practitioners.

“The stigma! Like you know, you tell the dentist you have a mental health [illness]... they treat you so differently.” (FG1, P1)

“I think it could be fear, lack of education, and the influence of Hollywood through the media. The media is shaping the perceptions of what a mental health problem is. A lot of people still think that if you see a psychiatrist or a psychologist for example, you are just crazy and you kill people. Well it’s not like that at all” (FG1, P6)

“I haven’t [experienced stigma]... but sometimes I do think perhaps the receptionist because they are multifunctional in those big organizations. And you see so many of them so sometimes you wonder, have they looked at my file before?... And I always think, whenever I check-in that it must come

up like ‘bing-bing-bing’ on the computer showing I have priority” (FG2, P2)

Participants in Focus Group 1 raised the issue of disclosing their mental illness to the oral health provider during treatment. This included refraining from telling the practitioner what type of medication they were prescribed, as it would identify their mental health condition to the practitioner. Some participants were aware that some medications could interact with one another and appeared to have researched their medications to gain a better understanding of whether it was necessary to advise the oral health provider about their medication. Other participants, however, found no issue telling the oral health provider what medications they were taking.

Financial issues

The cost of dental treatment was well explored. Participants spoke about their inability to access dental services and their capacity to visit a dental practitioner for a regular examination being influenced by cost. Some participants explained that the affordability of dental care was such a barrier that they would often live with the dental pain rather than seek immediate dental treatment. Fear of being unable to pay a bill for care was also mentioned as a deterrent to seeking ongoing dental treatment.

“Haven’t been to the dentist for a few years because of financial reasons.” (FG1, P4)

“If I’ve got a sore tooth, I just battle through it. I just can’t afford to go to the dentist.” (I3)

“Not really. I don’t have to get any help [about my teeth]. I don’t know... I’ll just battle through it [the pain].” (I3)

“I guess one of the things is lack of information. I don’t know where to go I guess. I don’t really have any health insurance at the moment, so I don’t know what to do” (FG 1, P6).

Communication and Literacy

The level of oral health literacy among participants ranged widely. The results show, however that even among participants who had high levels of oral health literacy, miscommunication between dental practitioner and patient still occurred. Some participants also noted the language used sometimes made them feel uncomfortable.

“So I think with a lot of dentists, they know what they are talking about... but we don’t. We don’t understand what they’re talking about. So it’s a bit hard to understand what they’re talking about.... I mean the way they explain it. We don’t understand all these things. You know some of the terminology. If they showed a chart or something like that or they explained it a bit more in layman’s terms... it would be a lot easier... Well it’s your teeth. You want to know what is going on with your own mouth ‘cause you can’t see. So you want to be able to know what they’re seeing especially when they are poking and probing in you” (I4)

“Sometimes the language, I don’t understand what they are saying, and the medical language that they use. I don’t know what they mean when they say certain things and I’m like ‘does it mean I’ve got something wrong with my teeth?’ or ‘what are they going to do with me today?’” (FG2, P1)

DISCUSSION

This study has increased the understanding of the barriers faced by people living with mental illness in improving their oral health. It found that generally, people living with a mental illness valued their oral health. Many participants regarded oral health as important and understood that dental practitioners played a key role in improving and maintaining their oral health. The study found that the barriers to improving oral health were, however multi-factorial. Participants had identified more than one barrier to improving their oral health, and this was reflected within the responses they provided. Often the barriers were interconnected, but complex portraying a web of ecological barriers faced by people in everyday life.

Coping barriers

Participants found that managing their own lives and living with a mental illness was a significant barrier to improving oral health, and this resulted in competing priorities. Management of their priorities was usually depended on how well the participant had been managing their mental illness. Previous health behaviours such as periods of reduced self-care may have contributed to poorer oral health. Motivation to improve their oral health was associated with an individual's feeling of empowerment, autonomy and independence. Regret was another response noted among participants who had had negative experiences and included participants having self-described poor oral health and not being able to attain the oral health care needed.

Fear as a barrier

Dental fear and anxiety was a powerful theme that emerged from the data and was a significant barrier for many participants. Stress-induced fear associated with making a dental appointment and attending it was regularly highlighted. The use of drugs and self-medication to reduce anxiety was also evident among participants. There is evidence to show that fear and anxiety, like that induced by making a dental visit could have the capacity to induce a psychotic episode and challenge or compromise the recovery process. While this was not explored in the focus groups, it is feasible to suggest that concern about the risks of a psychotic episode induced by high levels of anxiety could act as barriers to attending for dental care among this population group [25, 26] .

Stigma as a barrier

Stigma was another theme that emerged from the data. Participants were mindful of disclosing their mental illness to the general public and were fearful of being stigmatized or judged for their mental health condition. Participants were aware that they could be stigmatized or judged by the dental team, including the receptionist, dental assistant and dental practitioner. This finding is not surprising in a sense that people living with mental illness often do not tell employers and colleagues about their mental illness for the same reasons [27]. Similarly, some participants advised that they would not disclose information about their medications to the dental practitioner, as it would identify their mental illness and therefore may cause stigma.

Financial barriers

Cost was described as a major barrier for people living with mental illness in accessing dental care. In Victoria, consumers with a healthcare concession card or pension card are eligible to access public dental services [28]. Public sector services offer people living with mental illnesses priority for dental treatment at a government-subsidized fee that make treatment more accessible, however not necessarily more affordable [29]. Financial barriers were evident and participants were not always aware that they were eligible for public dental assistance and the embarrassment about being unable to pay a bill for care was a deterrent to seeking dental treatment.

Communication and literacy as a barrier

Communication was another key barrier to improving oral health regardless of the level of oral health literacy. While some participants showed a good understanding of oral health terms, it was clear that miscommunication and misunderstanding about dental language was clear. Participants noted that it was difficult to understand the dental practitioner at times, and the terminology used caused some confusion about their oral health and the proposed treatment. This often led to feelings of disempowerment and an inability to take control of their oral health. Some participants had indicated they used online tools to gain information and inform themselves. This appeared to improve the participant's literacy but also produced misconceptions about their oral health.

People living with mental illness will have varied oral health literacy depending on past experience and educational background and varied ability to understand and use information

to improve their oral health. Our participants were keen to be able to take control of these conditions themselves and also to undertake preventive care. But that was often compromised by their mental illness. Fear and anxiety posed significant additional challenges for people managing existing mental illnesses. It is clear also, that people may not disclose their mental illnesses or the medications prescribed to manage them out of fear of stigmatisation. This poses additional challenges for practitioners, and for mental health support workers in both enabling referrals and appropriate treatments and in accessing priority listed public dental health services.

Although this study produced a number of useful findings, it also raised further questions about whether a participant's barriers were linked to their specific mental illness diagnosis. As an example, are the experiences or perceptions of people diagnosed with schizophrenia different to those with bi-polar, depression or addiction recovery? It will also be important to understand the recovery cycle and identify optimum phases for providing dental care. Additionally, researchers were interested in whether traumatic dental experiences could trigger psychotic episodes after the dental appointment. While this was not explored in the focus groups or semi-structured interviews, there were perceptions that negative dental experiences could hinder the mental health recovery process. Based on this reasoning, it is recommended that further research with this group of people should explore the impact of anxiety related to, or negative experiences of, dental treatment and the impact this has on mental health status and recovery processes.

This study had a number of limitations. Recruitment proved difficult resulting in a relatively small sample size, and while the combined sample size was sufficient from which to draw clear themes, larger numbers would provide a stronger basis for conclusions. Data saturation was evident and may have been achieved; however it was not certain and further sampling was constrained by time and resources.

Mental illness is an umbrella term that encompasses a variety of illnesses of different severities such as bi-polar and schizophrenia. In this research, participants were not asked to disclose the illness they were living with. The type of mental illness could have influenced the data collected. Participants were self-selected via consumer interest only, and this may have selectively chosen certain types of participants with some control over their illness and may have excluded people living with extreme cases of mental illness or those who were

more socially disadvantaged. The findings of the study, for these reasons, lacks generalizability to all people living with a mental illness, particularly those with severe mental illness.

While we acknowledge these limitations, the sampling did identify participants who were likely to be seen by an oral health provider in a general practice or at a public dental clinic with no specialty training. Although it is acknowledged that some individuals may need to be seen by dental specialists in more supported settings, it is likely that many more will attend general practices. A different study design to accommodate the needs of people with particularly severe mental illness is recommended to explore the barriers to oral health for this group of people. Furthermore, it may be important to consider exploration of specific mental illnesses to enable comprehensive recommendations related to people with specific mental illnesses.

CONCLUSION

People living with mental illness face a range of barriers to improve and/or maintain their oral health. The information obtained from the research was designed to understand how people living with mental illnesses experience oral health. The impact of mental illness and past experiences associated with dental treatment were likely to define the oral health experiences of people living with mental illness. Barriers to accessing dental services and achieving oral health were found to be multi-factorial and complex. This included coping ability, fear and anxiety, stigma, financial issues, knowledge and communication barriers. Evaluation of the community-based mental health organisation's oral health support was also conducted and found to have a positive impact on the participants in this study. Support workers are recognised as playing an important role in supporting and referring consumers in their interactions with oral health care providers. Further research into the experiences of people living with mental illness is also recommended to review whether any further data and barriers may emerge, whether people living with a specific mental illness define and experience oral health differently, and whether traumatic dental experiences have the capacity to influence psychotic episodes.

While it lacks generalizability, the research has consisted of in-depth and rich information. The study findings will be used to inform training packages and service models for mental and oral health providers to support and thereby improve the oral health status of people living with severe mental illness. Finally, the research was aimed to provide evidence for oral health promotion planning for other organisations interested in improving the oral status of those living with mental illness as there is currently little literature or evidence that suggests or recommends on how to approach this. Recommendations for both dental practitioners and community-based mental health organisations are being prepared for publication.

ACKNOWLEDGEMENTS

This work was supported collaboratively by Oral Health CRC, Neami National and the University of Melbourne Dental School.

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Title:

Perceptions of oral health by those living with mental illnesses in the Victorian Community - The consumer's perspective

Date:

2018-05-01

Citation:

Ho, H. D., Satur, J. & Meldrum, R. (2018). Perceptions of oral health by those living with mental illnesses in the Victorian Community - The consumer's perspective. INTERNATIONAL JOURNAL OF DENTAL HYGIENE, 16 (2), pp.E10-E16. <https://doi.org/10.1111/idh.12278>.

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