

Oral health and psychosis:
**An exploration of oral health related outcomes and
experiences**

A thesis submitted to the University of Manchester for the degree of Doctor of Clinical
Psychology (ClinPsyD) in the Faculty of Biology, Medicine, and Health

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Abbreviations

BSDH: British Society of Disability and Oral Health

CLG: Community Liaison Group

CMA: Comprehensive Meta-Analysis

CMHT: Community Mental Health Team

DSM: Diagnostic Statistical Manual

DMFS: Decayed missing or filled surfaces

DMFT: Decayed missing or filled teeth

EPHPP: Effective Public Health Practice Project

EIS: Early Intervention Service

ICD: International Classification of Disease

IPA: Interpretative Phenomenological Analysis

MSc: Master of Science

NICE: National Institute for Health and Care Excellence

NHS: National Health Service

OCD: Obsessive Compulsive Disorder

OHIP-14: Oral Health Impact Profile Short Form 14

OR: Odds ratio

PIS: Participant information sheet

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

REC: Research Ethics Committee

RR: Risk ratio

SMI: Serious Mental Illness

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Paper 1: 3909

Paper 2: 4222

Paper 3: 4319

Abstract

The thesis explored oral health in people with experiences of psychosis. The thesis included three papers: 1) systematic review and meta-analysis 2) qualitative empirical study 3) critical reflection.

The systematic review (paper one) aimed to investigate the rate of oral health self-care behaviours in people diagnosed with a serious mental illness. Meta-analysis was used to synthesise the magnitude and consistency of effects in people with a serious mental health problem in comparison to non-clinical comparator groups. A narrative synthesis was conducted to summarise the wider literature. Thirty-three studies were included in the review. The quality of the studies were mixed. Results indicated that people with a serious mental illness are less likely to visit the dentist (OR 0.46, 95% CI 0.32-.065, $p>0.001$) or engage in toothbrushing (OR 0.19, 95% CI 0.08-0.42, $p<0.001$) in comparison to non-clinical samples. Other oral health self-care behaviours (e.g. flossing/ use of mouthwash) were also found to be low in people with a serious mental illness. The review indicated that further research was required to investigate why rates of oral health self-care behaviours are low in this population.

The empirical study (paper two) aimed to qualitatively explore the perceived relationship between oral health and psychosis in a service user sample using reflexive thematic analysis. The study recruited nineteen service users with experiences of psychosis and data was gathered in the form of semi-structured interviews. Analysis resulted in three themes: 1) Psychosis creates barriers to good oral health 2) The impact of poor oral health in psychosis 3) Systems for people with psychosis influence oral health. Findings suggested a perceived two-way relationship between oral health and psychosis. Self-identity and relationships with others were affected by poor oral health. Formal and informal support systems had the potential to influence oral health in people with psychosis. The results indicated a role for mental health services to routinely assess oral health needs and provide practical and psychological support to promote good oral health in this population. Informal networks were also considered important and should be supported and encouraged by services.

The critical reflection (paper three) focused on appraising the research, highlighting the strengths and limitations of the systematic review and empirical study. This paper also

provided personal reflections on the process of undertaking a large-scale research project.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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The author

I am a trainee clinical psychologist with over ten years of clinical and research experience working in the National Health Service. My first assistant psychologist post was working in an Early Intervention for Psychosis service. I then went on to work as an assistant psychologist in an acute inpatient setting. Following this role I worked as a research assistant at the Psychosis Research Unit whereby I worked on a large multi-site trial investigating the efficacy of a lifestyle intervention for people who take anti-psychotic medication. This sparked my interest in health inequalities and I undertook a Master of Science in Health Psychology whilst working as an assistant psychologist in an older adult inpatient unit. My clinical and research experiences have made me passionate about reducing health inequalities in people with mental health problems. My specialist placement on clinical training is in a medium secure forensic setting and within this role I advocate for supporting physical health needs alongside mental health needs. My research project was chosen due to this interest coupled with a genuine enthusiasm in working with people with experiences of psychosis.

Paper One: Oral health self-care behaviours in serious mental illness: A systematic review and meta-analysis

Word count: 3909 (excluding abstract, tables, figures and references)

232 (abstract)

The following paper has been published by *Acta Psychiatrica Scandinavica*. See Appendix A for author guidelines. Please note, there have been some deviations from the guidelines in the version presented here to ensure consistency throughout the thesis.

Oral health self-care behaviours in serious mental illness: A systematic review and meta-analysis

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Word count: 3909 (excluding abstract, tables, figures and references)

Summations

- People with a serious mental illness were less likely to visit the dentist.
- They were also less likely to brush their teeth.
- There was limited evidence around the use of dental floss and mouthwash

Limitations

- The quality of the available literature was variable.
- Few studies explored the use of dental floss and mouth wash.

- Research typically did not distinguish between routine and emergency dental visits.

Abstract

Aim To systematically review the rates of oral health self-care behaviours in people with a serious mental illness using meta-analytic methods and a narrative synthesis of available literature.

Method The review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines [PROSPERO reference: CRD42020176779]. Search terms pertaining to serious mental illness and oral health were entered into EMBASE, PsycINFO, Medline and CINAHL. Eligible studies included a sample of people with a serious mental illness and a quantitative measure of an oral health self-care behaviour (e.g. dental visits, toothbrushing). The Effective Public Health Practice Project tool was utilised to appraise the quality of the literature. Studies in the meta-analysis contained a non-clinical or general population comparator sample.

Results People with a serious mental illness were significantly less likely to visit the dentist (OR 0.46, 95% CI 0.32-.065, $p>0.001$) or brush their teeth (OR 0.19, 95% CI 0.08-0.42, $p<0.001$) when compared to non-clinical comparator samples. Few studies explored other oral health self-care behaviours (e.g. flossing, mouth-washing etc.), but uptake was generally low in people with a serious mental illness. The study quality of included studies was variable.

Conclusions The research showed a reduced uptake of oral health self-care behaviours in people with a serious mental illness. Sub-optimal oral health can negatively impact on physical, social and psychological functioning. Further research is needed to understand the reasons for low rates of oral health self-care behaviours in this population.

Key words: Oral health, psychotic disorders, bipolar disorders, dental care.

Introduction

There is evidence that people with a serious mental illness (SMI; i.e. psychosis, bipolar disorder) experience worse oral health outcomes than the general population.¹ For example, past research has indicated that people with SMI are 2.8 to 3.4 times as likely to be edentulous (complete loss of all teeth) and have significantly higher rates of decayed, missing or filled teeth (DMFT) or surfaces (DMFS) in comparison to the general population.²⁻⁴ Suboptimal oral health can have a detrimental impact on physical and psychological functioning.⁵ The oral cavity plays a crucial role in the overall well-being of a person and damage thereof can cause considerable suffering by affecting basic and essential functions like eating and speaking.⁶ Severe caries (tooth decay) leads to pain, discomfort, disfigurement, acute and chronic infections, and eating and sleeping disruption as well as a higher risk of hospitalisation, high treatment costs and lost workdays.⁷ Research suggests that there is a link between poor oral health and chronic disease, such as diabetes and cardiovascular diseases.^{8,9} The ability to smile can also be affected⁵, which can impact on self-esteem¹⁰ and the ability to socialise with others.⁶

The reasons for poor oral health outcomes in people with SMI are likely complex and may include higher rates of drug misuse,¹¹ smoking,¹² and medication side effects (e.g. xerostomia).¹³ Poor oral health in this population may also be due to reduced levels of oral health self-care behaviours (e.g. dental care, toothbrushing). Some, but not all, studies have suggested that people with a SMI are less likely to attend routine dental visits and, when they do, are more likely to have teeth extracted rather than filled.²⁻⁴ This could explain the high rate of edentulous in this population. An increased focus on preventative practices has improved oral health outcomes in the general population.¹⁴ Further research is needed to understand levels of oral health self-care behaviours in people with SMI, which could inform future prevention and intervention strategies, leading to better outcomes. It may help to understand oral health inequalities in people with SMI.

Aims of the study

The aim of this review was to investigate the rates of oral health self-care behaviours in people with a SMI. It used meta-analytic methods to synthesise the size and consistency of differences in oral health self-care behaviours between people with a SMI and non-clinical comparator samples. It also aimed to narratively review studies without a non-clinical comparator sample to better summarise the existing literature.

Material and methods

This review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-analyses standards with a protocol published on PROSPERO [CRD42020176779].

Eligibility criteria

The inclusion criteria were: i) a case-control, cohort, cross-sectional, longitudinal and epidemiological design study; ii) publication in an English language peer reviewed academic journal; and iii) a quantitative measure of an oral health self-care behaviour. We defined oral health self-care behaviours as actions that individuals take to improve or preserve good oral health.¹⁴ This included but was not restricted to owning a toothbrush, dental care attendance, and frequency of tooth-brushing.

Studies were required to include a sample of at least 75% of people diagnosed with a SMI in accordance with the Diagnostic and Statistical Manual (DSM-III or later) or International Classification of Disease (ICD-9 or ICD-10) criteria. SMI is a contentious, but widely used term often including a range of diagnoses such as personality disorders, major depression disorder and dementia.^{2,3} However, for the purpose of this review SMI has been defined as the collective term for people with a diagnosis of a psychotic or a bipolar spectrum disorder to maintain consistency with the UK-based National Institute for Health and Care Excellence (NICE) guidance and the majority of past literature¹⁵ Specific diagnostic criteria included schizophrenia, schizophreniform, schizoaffective disorder, delusional disorder, bipolar I and bipolar II. Participants who met the operational criteria for an early intervention service for first episode psychosis were included to allow for diagnostic uncertainty in younger age groups. For the purpose of the meta-analysis, eligible studies

were required to include valid comparator group (e.g. general population sample, non-clinical comparator).

Screening Procedure

Systematic searches were conducted in Medline, EMBASE, PsycINFO and CINAHL to identify peer-reviewed articles published between January 1980 and April 2020. Search terms were entered in blocks relating to serious mental illness (severe mental or serious mental or chronic mental or schizo* or psychoti* or psychos* or hallucinat* or paranoi* or bipolar or mania or manic) and oral health (oral health or oral hygiene or tooth* or teeth* or dent*). The search terms were developed based on the authors' clinical experience and relevant past reviews.^{2-4, 16} In cases where papers were unavailable or the data was insufficient to confirm eligibility or generate an effect size, information was requested from the primary or corresponding author. The first author (ET) screened the reference lists of eligible articles, citing articles, and relevant reviews.^{2-4, 16} Ten percent (805 studies) of titles and abstracts were double rated by another author (TV), with high levels of agreement ($k= 0.84$). At least two of the authors screened each of the full articles to confirm eligibility with discrepancy resolved through consensus.

Data extraction

Relevant study information (e.g. study design, sample size, type of sample) was extracted by the first author (ET). For the meta-analysis, outcome data was independently extracted by two authors (ET and JPC) to calculate an effect size (ICC = 0.95, $p>0.001$). If multiple time points were presented (e.g. dental visit within one year and dental visit within two years), the lower timescale analysis was selected to ensure consistency. When possible, we extracted analyses that controlled for covariates (e.g. adjusted odds ratios).

Quality assessment

An adapted version of the Effective Public Health Practice Project (EPHPP) tool¹⁷ was used to evaluate the overall quality of the included articles due to its suitability for assessing public health focused quantitative studies. The EPHPP has demonstrated good construct and content validity and interrater reliability.¹⁸ Consistent with previous review papers,¹⁹²⁰ the tool was adapted to account for the observational design of eligible studies.

Domains that were not considered relevant (design; blinding; intervention integrity; withdrawals and drop-outs) to the included studies were omitted. The design domain pertained to randomisation procedures for intervention evaluations and was therefore not relevant to the reviewed literature and excluded.

The adapted version of the EPHP consisted of four domains: selection bias, confounders, data collection methods and analyses. Each domain was rated as strong, moderate or weak and from this, a global rating was derived based on ratings in each domain. In the original EPHP, analyses ratings were not used to calculate the global rating. However, consistent with previous adaptations²¹ a decision was made to include analyses scores in the overall global rating as appropriateness of analysis was deemed to be integral to the quality of the study. Articles were rated by two authors (ET and TV; 79% agreement) and, in cases of discrepancy, consensus was reached with input from a third author.

Meta-analysis

We used Comprehensive Meta-Analysis (CMA, v3)²² to generate effect sizes and conduct analysis for all outcomes with $K > 3$. Study effect sizes were transformed into odds ratios and a random effects model was utilised as statistical heterogeneity was expected across studies.²³ Heterogeneity was explored through use of the Q-test and I^2 statistic and a sensitivity analysis was conducted to assess whether any individual study had great influence over the overall effect size.

Narrative synthesis

In order to appraise the wider literature in this area, all studies without a comparator group were narratively synthesised using the Synthesis Without Meta-Analysis (SWiM)²⁴ guidelines. Outcomes were grouped according to oral health self-care behaviours and the corresponding literature was tabulated using the population, intervention, comparator and study type (PICOS) framework to summarise the literature and explore clinical heterogeneity. A weighted average was calculated for key outcomes, using all available data, even those without a clinical comparator.

Results

The PRISMA flowchart (Figure 1.) displays the screening process. Thirty-three studies²⁵⁻⁵⁷ were eligible for inclusion. The total sample comprised of 446,932 people with a SMI and 6,284,176 controls. Further information was provided by seven authors^{26, 29, 35, 38, 44, 48, 57} to either confirm eligibility or produce an effect size. Table 1 displays the descriptive information on the included studies.

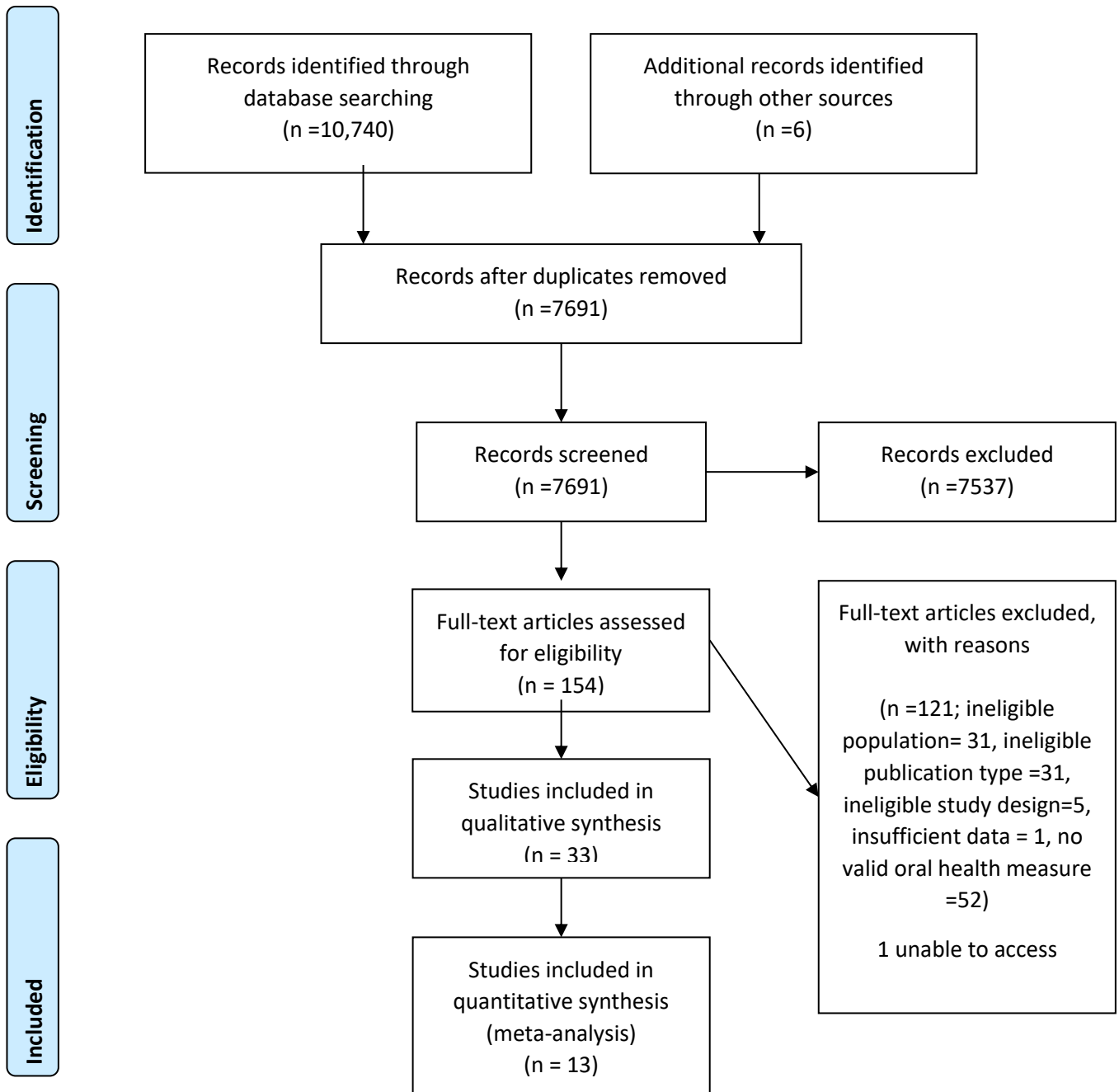


Figure 1.

PRISMA Flow Diagram of article screening.

Table 1.

Descriptive information on included studies.

Study ID	Study design	Population-Diagnosis	Status	Country	Sample size	Comparator Type	Outcome
Adams 2017	Clustered RCT, baseline data	First episode psychosis	Outpatient	UK	Case: 1248 Control: 17849	Adult Dental Health Survey (ADHS)	Dental service use, toothbrush frequency, technique and ownership
Agarwal, 2019	RCT, Baseline data	Schizophrenia	Outpatient	India	111	N/A	Toothbrushing frequency, technique, maintenance of toothbrush, aid for cleaning tongue and mode for cleaning teeth
Corridore, 2017	Cross-sectional	Schizophrenia, schizoaffective, borderline	Therapeutic community	Italy	67	N/A	Dental service usage and toothbrushing frequency

Cunha 2017	Case-control	personality disorder Bipolar disorder	Outpatient	Brazil	Case: 176 Control: 176	Existing study datasets	Dental service use
Denis, 2017	Cross-sectional	Schizophrenia	Inpatient and outpatient	France	90	N/A	Dental service usage and toothbrushing frequency
Denis, 2019	Cross-sectional	Schizophrenia	Inpatient and outpatient	France	109	N/A	Dental service usage and toothbrushing frequency
Denis 2020	Epidemiological	Schizophrenia	Inpatient and outpatient	France	Case: 2,213 Control: 578,006	General population database	Dental service usage (scaling)

Dickerson, 2003	Case control	Schizophrenia, schizoaffective disorder	Outpatient	US	Case: 100 Control: 2705	National health and nutrition survey	Dental service usage
Djordjevic, 2019	Case control	Schizophrenia	Inpatient	Serbia	Case: 190 Control: 190	Community sample of patients with localised or generalised chronic periodontitis	Toothbrush frequency and technique
Eltas, 2013	Cross-sectional	Schizophrenia	Outpatient	Turkey	53	N/A	Toothbrush frequency
Eskelinen, 2017	Cross-sectional	Schizophrenia, schizoaffective disorder, other schizophrenia spectrum disorder	Outpatient	Finland	275	N/A	Dental service use

Gandre, 2020	Epidemiological	Psychotic and bipolar disorder	Outpatient and inpatient	France	Case: 413,437 Control: 1,240,311	French national health data system	Dental service use
Gurbuz, 2011	Cross-sectional	Schizophrenia	Inpatient	Turkey	330	N/A	Toothbrushing frequency
Hede, 1992	Case-control	Schizophrenia, reactive psychosis, manic depression	Outpatient	Denmark	Case: 84 Control: 2548	General population survey	Dental service use and toothbrushing frequency
Hsieh, 2011	Pre-test post-test design, baseline data	Schizophrenia	Inpatient	Taiwan	100	N/A	Toothbrush frequency and maintenance of toothbrush
Janhardanan, 2011	Case control	Schizophrenia	Outpatient	US	Case: 198 Control: 113	Community comparison group	Dental service usage

Jovanovic, 2010	Case-control	Schizophrenia, NOS psychosis, schizoaffective disorder, persistent psychotic disorder, bipolar disorder	Inpatient	Serbia	Case: 186 Control: 186	Community comparison group	Dental service use, toothbrush frequency, technique and maintenance of toothbrush
Lynch , 2005	Cross-sectional	Schizophrenia, other	Inpatient	Northern Ireland	65	N/A	Toothbrush ownership
McCreadie, 2004	Case-control	Schizophrenia	Outpatient	Scotland	Case: 93 Control: 28,471	General population survey	Dental service usage, toothbrushing frequency, flossing, mouthwash use
Nayak, 2020	Cross-sectional	Schizophrenia, mania	Outpatient	India	250	N/A	Toothbrush frequency

Ngo, 2018	Cross-sectional	Schizophrenia, Intellectual Disability, other	Inpatient	Singapore	191	N/A	Toothbrushing frequency
Nielson, 2011	Epidemiological	Schizophrenia	Inpatient and outpatient	Denmark	Case: 21,417 Control: 3,790,446	National health insurance database	Dental service use
Pelletier, 2015	Cross-sectional	Schizophrenia, schizotypal disorder, delusional disorder	Outpatient	Canada	146	N/A	Toothbrushing frequency
Patrick, 1996	Cross-sectional	Schizophrenia	Outpatient	US	353	N/A	Dental service use
Salsberry, 2005	Cross-sectional	Schizophrenia, schizophreniform, schizoaffective	Outpatient	US	230	N/A	Dental service use

		disorder, delusional disorder, ICD-9 – Paranoid disorders					
Singh, 2017	Cross-sectional	Schizophrenia	Outpatient	India	71	N/A	Dental service use, toothbrushing frequency, mode and material for cleaning teeth
Singh, 2019	Cross-sectional	Schizophrenia	Outpatient	India	156	N/A	Dental service use, toothbrushing frequency, mode and material for cleaning teeth
Stiefel, 1990	Case control	Schizophrenia, bipolar disorder, other non- organic,	Outpatient	US	Case: 37 Control: 29	Community comparison group	Dental service use, toothbrushing frequency and flossing.

Tani, 2012	Cross-sectional	personality disorder Schizophrenia, schizoaffective disorder, delusional disorder, acute and transient psychotic disorder	Inpatient	Japan	523	N/A	Toothbrushing frequency
Teng, 2016	Epidemiological	Schizophrenia, delusional disorders	Inpatient and outpatient	Taiwan	Case: 4298 Control: 623,175	National insurance research database	Dental service use
Tredget, 2019	Cross-sectional	Schizophrenia	Outpatient	Wales	106	N/A	Dental service usage, toothbrush frequency and mouthwash use

Wieland, 2010	Cross-sectional	Schizophrenia, schizoaffective disorder, bipolar disorder, schizotypal personality disorder	Outpatient	Australia	20	N/A	Dental service use, toothbrushing frequency, flossing and mouthwash use
Xiong, 2010	Cross-sectional	Bipolar, psychotic disorder	Outpatient	US	170	N/A	Dental service usage

Quality appraisal

Findings from the quality assessment are summarised in Table 2. Six studies obtained strong scores, seven moderate and 20 weak. Limitations of the methodology predominantly related to data collection as outcome measures used were typically not validated and the reliability of the measures was poor. Studies tended to have a broader focus than oral health self-care behaviours. Therefore, the analysis in this area tended to be basic (e.g. percentages) and did not account for confounders, leading to higher rates of weak ratings.

Table 2.

Quality assessment					
Study ID	Selection Bias	Confounders	Data collection	Analysis	Global rating
Adams, 2017	Moderate	Weak	Weak	Moderate	Weak
Agarwal, 2019	Moderate	Moderate	Weak	Strong	Moderate
Corridore, 2017	Weak	Weak	Weak	Moderate	Weak
Cunha 2017	Moderate	Moderate	Weak	Strong	Moderate
Denis, 2017	Moderate	Strong	Weak	Strong	Moderate
Denis, 2019	Weak	Strong	Weak	Strong	Weak
Denis 2020	Strong	Strong	Strong	Strong	Strong
Dickerson, 2003	Moderate	Strong	Moderate	Strong	Strong
Djordjevic, 2019	Moderate	Moderate	Weak	Strong	Moderate
Eltas, 2013	Moderate	Weak	Weak	Moderate	Weak
Eskelinen, 2017	Moderate	Weak	Weak	Strong	Weak
Gandre, 2020	Strong	Strong	Strong	Strong	Strong
Gurbuz, 2011	Moderate	Moderate	Weak	Moderate	Moderate
Hede, 1992	Moderate	Weak	Weak	Weak	Weak
Hsieh, 2011	Weak	Weak	Weak	Weak	Weak
Janhardanan, 2011	Moderate	Strong	Weak	Moderate	Moderate
Jovanovic, 2010	Moderate	Weak	Weak	Strong	Weak
Lynch, 2005	Weak	Weak	Weak	Weak	Weak
McCreadie, 2004	Moderate	Weak	Weak	Weak	Weak
Nayak, 2020	Weak	Weak	Weak	Moderate	Weak
Ngo, 2018	Strong	Weak	Weak	Moderate	Weak
Nielson, 2011	Strong	Moderate	Strong	Strong	Strong
Patrick, 1996	Weak	Weak	Weak	Moderate	Weak
Pelletier, 2015	Weak	Weak	Weak	Weak	Weak
Salsberry, 2005	Strong	Strong	Strong	Moderate	Strong
Singh, 2017	Moderate	Weak	Weak	Strong	Weak
Singh, 2019	Moderate	Weak	Weak	Strong	Weak
Stiefel, 1990	Moderate	Weak	Weak	Moderate	Weak

Tani, 2012	Moderate	Weak	Weak	Strong	Weak
Teng, 2016	Strong	Strong	Strong	Strong	Strong
Tredget, 2019	Moderate	Weak	Weak	Weak	Weak
Wieland, 2010	Weak	Weak	Weak	Weak	Weak
Xiong, 2010	Moderate	Strong	Weak	Moderate	Moderate

Dental service use

Twenty-three studies reported data on dental visiting behaviour. These studies were of mixed quality. However, more than half of the studies entered into the meta-analysis were of strong quality. Studies were conducted in Europe (52%, K=12), North America (26%, K=6), Asia (13%, K=13), South America (4%, K=1) and Australasia (5%, K=1). Sixteen studies focused on people with a psychotic disorder, one on bipolar disorder and six on mixed SMI samples. A weighted average of data from eight^{28, 33, 40, 41, 43, 45, 52, 57} cross-sectional and case control studies indicated that 34% of participants with SMI had visited the dentist in the previous year. One epidemiological study⁴⁷ indicated that 43% of participants had visited the dentist within one year.

Two studies had higher rates of dental attendance compared to the rest of the literature, potentially explained by their samples of people with early psychosis²⁵ (80% within 2 years) and bipolar disorder²⁹ (85% within 2 years). Data was split into diagnostic groups (psychotic disorders and bipolar disorder) in one study³⁷, which looked at dental attendance across a five-year period. Although levels of attendance were high across both groups, they were greater in bipolar disorder (79% in comparison to 68%). One small-scale cross-sectional study⁵⁷ explored the impact of a partnership between mental health and dental services and found that 90% of individuals with a SMI had attended the dentist within one year. Baseline data was not provided to explore the difference between outcomes before and after the integration of services.

Dental service use meta-analysis

Nine studies^{29, 30, 33, 36, 41, 43, 47, 52, 55} of mostly strong quality explored dental service usage in comparison to a non-clinical comparator and were analysed using random effects meta-analysis (Figure 2). One study²⁵ was omitted from this analysis as the measure of dental service use was not consistent across the case sample and non-clinical comparator. The analysis (Figure 2) showed an overall OR of 0.46 (95% *CI* 0.32-.065, $p > 0.001$), indicating that individuals with a SMI were significantly less likely to access dental services in comparison to non-clinical controls. Separate analyses were conducted to explore differences between case-control and epidemiological studies. Although, statistically there was no significant difference in the strength of effect sizes between the two types of study ($Q(1) = 0.70$, $p = 0.400$), the five case-control studies (OR 0.32, 95% *CI* 0.08-1.29, $p = 0.109$) indicated no significant difference in dental service usage between SMI in comparison to non-clinical controls, whereas the four epidemiological studies (OR 0.60, 95% *CI* 0.38-0.96, $p = .003$) did show a significant difference between these populations.

The Q-test and I^2 statistic were used to explore statistical heterogeneity. Results indicated high levels of statistical heterogeneity across studies ($Q(8) = 2097.61$, $p < .001$, $I^2 = 99.62$), suggesting that the strength of the relationship between SMI and dental service use was highly variable across studies. A sensitivity analysis, which removed each study in turn to explore the impact on the overall effect size, the results indicated that one study⁴³ exerted some influence over the overall effect size (OR 0.65, 95% *CI* 0.46-0.93, $p = .019$).

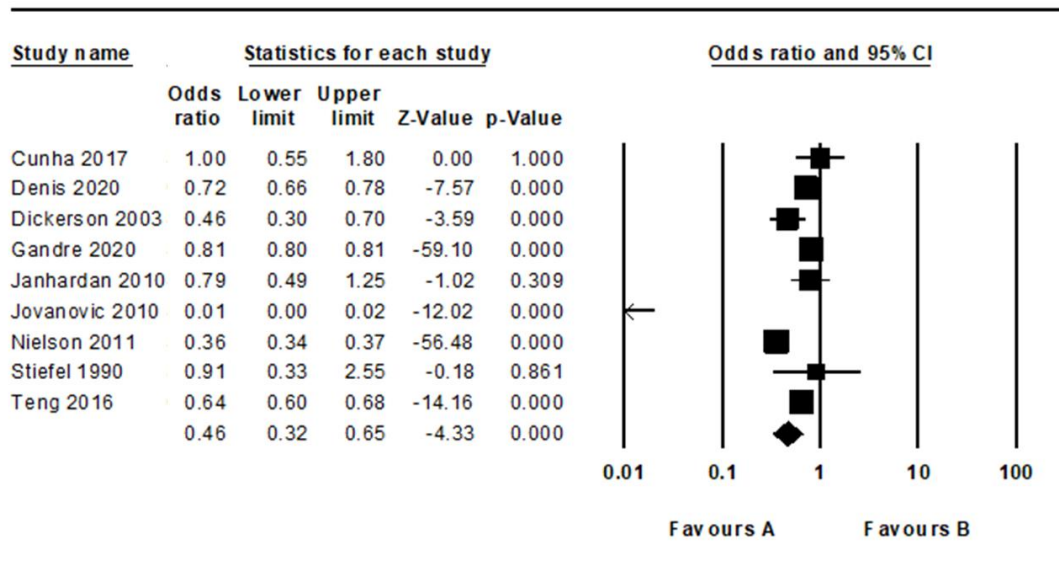


Figure 2.

Forest plot with individual effect sizes for studies comparing access to dental services in people with severe mental illness to non-clinical comparator samples.

Toothbrushing frequency

Twenty-one studies provided data on toothbrushing frequency. An even proportion of studies were conducted in Europe and Asia (43%, K=9) and the remaining studies were conducted in North America (9%, K=2) and Australasia (4%, K=1). Fifteen studies were conducted in people with a psychotic disorder only (75%, K=15), whereas six (25%, K=6) studies were conducted in mixed SMI samples. A weighted average of 10 studies^{25, 26, 39, 40, 43, 51-54, 56} indicated that only 39% of people with a SMI brushed their teeth twice a day.

The results and measures used to assess toothbrushing frequency were greatly variable. Results indicated that toothbrushing habits were often reduced in inpatient samples of people diagnosed with schizophrenia. Two studies^{38, 56} found that the uptake of toothbrushing behaviours was low in 50% of participants. Similarly, in one study, “habitual brushing” (undefined) was recorded in only 22% of participants.²⁷ In mixed SMI inpatient samples^{43, 46, 54} participants were more likely to clean their teeth. Studies of better quality^{38, 56} were more likely to report reduced toothbrushing behaviours.

Toothbrushing frequency meta-analysis

Five case-control studies^{25, 39, 43, 52, 56} of predominantly weak quality included a non-clinical comparator group and were entered into a random effects meta-analysis (Figure 3) to produce an overall effect size. Outcomes for two studies were dichotomised to generate an effect size.^{43, 56} The overall effect size (OR 0.19, 95% CI 0.08-0.42, $p < 0.001$) suggested that people with a SMI were significantly less likely to brush their teeth than controls.

The Q-test and I^2 statistic ($Q(4) = 23.13$, $p < .001$) indicated high levels of heterogeneity. 82% of the variance was due to statistical heterogeneity. A sensitivity analyses was conducted to identify outliers. The results indicated that two studies^{25, 39} exerted some influence over the overall effect size. When one study²⁵ was removed the effect size reduced to OR 0.07, CI 0.01-0.55, $p = 0.012$. Similar effects were observed when the other study³⁹ was removed (OR 0.06 CI 0.01-0.44, $p = 0.005$). However, the effects of neither study were great enough to impact overall statistical significance.

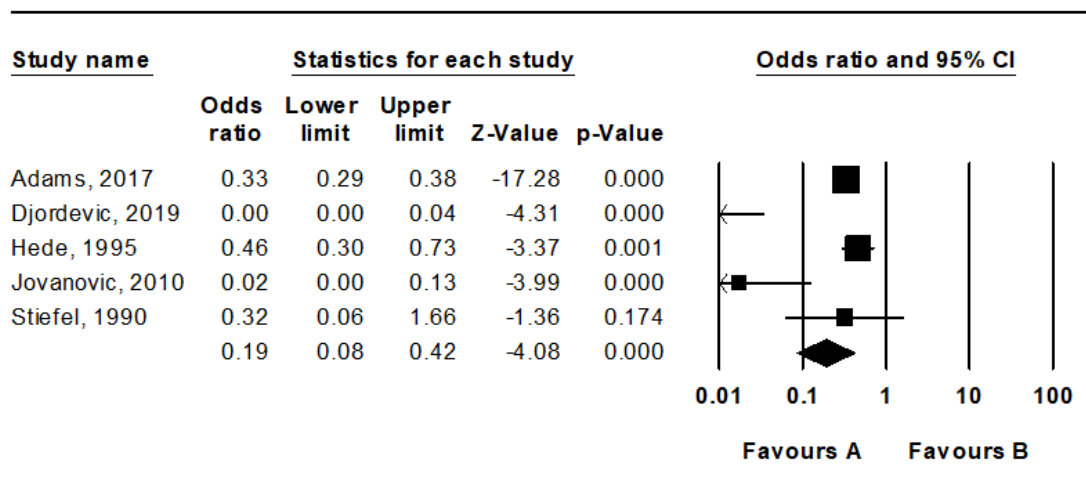


Figure 3.

Forest plot with individual effect sizes for studies comparing rates of toothbrushing in people with severe mental illness to non-clinical comparator samples.

Toothbrush ownership and maintenance

Two studies of weak quality reported on toothbrush ownership^{25, 44} and found similar levels in people with a SMI (70% and 66%). Results from three studies^{26, 27, 43} of weak to moderate quality indicated variable levels of toothbrush maintenance in people with a SMI. One study⁴³ suggested that only 1.8% of people with SMI changed their toothbrush every three months, but this was higher at 33% in a second study.²⁶ A key difference between these two studies was that one study⁴³ included an inpatient sample and the other²⁶ (which indicated a much higher rate of upkeep) included an outpatient sample. A third study of weak quality²⁷ found that 25% of subjects “maintained their hygiene tools” over an unspecified timescale.

Toothbrush technique

Three studies of moderate to weak quality investigated toothbrushing technique^{26, 43, 56} and found between 72.6% and 98.2% of people with a SMI used the incorrect brushing technique. Agarwal and colleagues²⁶ defined the correct technique as sulcular (also known as bass), which has been found to be more effective.⁵⁸ The other studies did not define the correct tooth brushing technique and are therefore difficult to interpret.

Materials used for oral health self-care behaviours

Two studies^{26, 50} of weak and moderate quality explored the uptake of oral hygiene tools in people with a SMI. Both were conducted in India with participants diagnosed with schizophrenia. Results indicated that 21.6% of participants used a tongue cleaning aid.²⁶ One study⁵⁰ highlighted that 34% of the sample used their finger to clean their teeth.

Flossing frequency

In three studies^{45, 52, 57} of weak quality, uptake of flossing behaviour ranged from 11%-20%. One study⁵² found that flossing behaviour was 50% lower in an sample with SMI compared to non-clinical controls. No studies investigated flossing technique.

Mouthwash

Three studies^{40, 45, 57} of weak quality explored the uptake of mouthwash in people with a SMI. In one study⁴⁰ 4.7% of participants reported that their oral care routine solely consisted of using mouthwash. One study⁴⁵ found that 23% of individuals with SMI used mouthwash as part of their oral care routine, which was similar to a non-clinical comparator group. A further study⁵⁷ found that 35% of people with a SMI used mouthwash, but there was no non-clinical comparator group.

Discussion

This is the first meta-analysis to comprehensively explore the uptake of oral health behaviours in people with SMI. We systematically reviewed 33 studies comprised of 446,932 people with a SMI and 6,284,176 controls. Findings indicated that people with SMI are significantly less likely to access dental services and frequently brush their teeth than the general population. There is also some tentative evidence to suggest that other behaviours such as flossing, mouth washing and ownership and maintenance of materials for oral health self-care behaviours are low in individuals with a SMI.

Recent research has suggested that people with a SMI are more likely to experience sub-optimal oral health in comparison to the general population.²⁻⁴ This review builds on existing literature by finding that oral health self-care behaviours are significantly reduced in people with a SMI. Results indicate that between 34-43% of people with a SMI visit the dentist at least annually. This is stark contrast to past research indicating that approximately 61% of the general population visit the dentist at least once per year.⁵⁹ Similarly, the finding that 39% of individuals with a SMI clean their teeth twice a day is much lower than what is typically recorded for the general population.⁶⁰ More research is needed to ascertain the difference between SMI and the general population when key confounders (e.g. socio-economic status, access to dental care) are considered. Two of the included studies.^{36, 55} controlled for income and access to dental care and found similarly low rates of dental service utilisation in SMI. Research in non-clinical samples has indicated an association between dental behaviours and outcomes.⁶¹ However, further research is required to establish whether the uptake of oral health self-care behaviours mediates the relationship between SMI and oral health outcomes.

Overall, the quality of the literature was variable with a high number of studies receiving a weak rating on the EPHPP tool. Outcomes of interest were seldom the focal point of included studies. Therefore, outcome measures were often unvalidated and analyses typically neglected to include key confounders (e.g. severity of illness, socio-economic status, access to dental care). It is also noteworthy that some studies used survey data as the comparator group and did not employ matching criteria. Although the quality of the

available literature was variable, we were able to extract descriptive data from the majority of identified studies.

In the available literature, mental health diagnoses were often retrieved from the medical notes and in some cases the method of confirming diagnoses was unstated. Further information was required from some authors to ascertain the diagnostic system used. Future studies should address this issue by ensuring that diagnoses are determined through more rigorous processes. Maintenance behaviours and dental attendance were poorly defined in the majority of studies. Most failed to distinguish between routine and emergency care. This is important given that people with a SMI may be more likely to utilise emergency care in crisis and less likely to attend routine dental visits.³⁰ Future research should carefully define dental visiting to provide a better understanding of pathways to care.

The literature predominantly focused on individuals with a psychotic disorder. However, one study²⁹ explored dental visiting behaviours in people with a diagnosis of bipolar disorder only, where there were high rates of dental attendance similar to the control group. High rates of dental attendance were also found across a longer time period in a study that separately assessed dental attendance in bipolar disorder and psychotic disorders.³⁷ It is possible therefore that dental visiting behaviours may not be as disrupted in people with bipolar disorder. No studies looked at toothbrushing in bipolar disorder, which poses as an important area for future research.

Only a limited number of studies could be statistically analysed using meta-analytic methods as the majority did not include a non-clinical comparator. Consequently, post-hoc analyses were not conducted to assess selection and publication bias.^{62, 63} Substantial levels of heterogeneity reduce confidence in the size of the effect produced. The observed heterogeneity may have been due to differences in methods and quality across the included studies. Study design had an impact on the dental visiting results. Statistically, there was no difference between case-control and epidemiological findings. However, when analysed separately, epidemiological studies indicated a significant difference between dental visiting in people with a SMI compared to controls, whereas case-control studies did not.

We restricted our inclusion criteria to peer-reviewed papers published in the English language which may have introduced bias. Studies with significant findings may be more

likely to be published, which could skew the results to significant findings.⁶⁴ Accessing English language publications may also reduce diversity across study samples. Requests for further information to confirm diagnoses or generate an effect size were sent to multiple authors and responses were only received by seven authors, which limited the ability to include some studies.

The disparity between the physical health of people with a SMI and the general population has been well documented.^{65, 66} Growing evidence suggests disparities exist in oral health.^{2-4, 67} The reasons for this are likely to be multifactorial and may include medication,^{68, 69} systemic issues,^{70, 71} and personal capability⁷². Literature indicates that education alone does not improve oral health outcomes in this client group, despite guidance published by the British Society of Disability and Oral Health (BSDH).⁷¹ One study²⁵ adapted the checklist from BSDH guidelines and found no significant improvements between the intervention and control group. Similarly, a Cochrane review¹⁰ did not provide evidence to suggest that education alone would improve outcomes in people with a SMI. National guidelines in the UK and Australia^{73, 74} have indicated a need for increased oral health support for people with complex and early psychosis promoting assessment, monitoring and additional support to maintain oral health. This review indicates that such guidelines should be adopted more broadly to include all people who experience psychosis. However, further research is needed to better understand what factors impact on oral health self-care behaviours to ensure interventions and support is targeted accordingly.

Conclusion

In conclusion, findings from this review indicate that oral health self-care behaviours are reduced in people with an SMI. Further research is needed to explore which factors affect the uptake of behaviours and how mental health difficulties are a risk factor for poor oral health outcomes. The recent Lancet Commission⁶⁵ called for better integration of mental and physical care. The results from this review indicate that this should also encompass dental care to meet the wide-ranging and complex needs of this client group to ensure effective early screening, monitoring and intervention in oral health.

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Paper Two:

**The perceived relationship between oral health and
psychosis: Qualitative analysis**

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202 (abstract)

The following paper will be submitted to the *British Journal of Psychiatry*. See Appendix B for author guidelines. Please note, there have been some deviations from the guidelines in the version presented here to ensure consistency throughout the thesis.

The perceived relationship between oral health and psychosis: qualitative analysis

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Abstract

Background

Individuals with psychosis are more likely to have poor oral health with higher rates of decayed and missing teeth. The relationship between oral health and psychosis is understudied and likely complex but may have important ramifications for improving health outcomes.

Aims To explore service user perspectives about the relationship between oral health and psychosis.

Method Qualitative reflexive thematic analysis of semi-structured interviews with service users with experiences of psychosis sampled from community mental health teams, early intervention for psychosis services and rehabilitation units.

Results The study recruited nineteen service users with psychotic experiences. Analysis resulted in three themes: 1) Psychosis creates barriers to good oral health 2) The impact of poor oral health in psychosis 3) Systems for psychosis influence oral health.

Conclusions: Findings indicated that psychosis impacted on adherence to oral health self-care behaviours and overall oral health. Poor oral health negatively impacted on mental health. Systemic and informal support was central to good oral health in this sample. The level of support provided by mental health teams was inconsistent. Everyone should have access to good oral health. Clinical recommendations indicate a whole team approach to assess and support oral health needs.

Introduction

Oral health is important for day-to-day functioning and plays a critical role in eating, smiling, and talking.¹ Conversely, poor oral health is detrimental to general health, self-esteem, and quality of life.² People diagnosed with psychotic disorders experience worse oral health outcomes than the general population, including higher levels of decayed and missing teeth.^{3,4} The prevalence of edentulousness (complete loss of teeth) and periodontal disease are also significantly higher in people diagnosed with psychosis.⁴⁻⁷ However, rates of filled teeth are significantly lower,⁸ which may indicate reduced access to dental care and increased extraction of teeth.

Reasons for sub-optimal oral health in people experiencing psychosis are likely complex and multifactorial. They may include individual influences such as motivation to seek treatment,⁹ chronicity of mental health problems,¹⁰ high risk behaviours,¹¹ and iatrogenic effects of psychiatric treatments.¹²⁻¹⁴ To protect limited National Health Service (NHS) resources, UK dentists expect patients to engage in preventative oral health self-care behaviours (e.g. regular flossing and toothbrushing) before the full range of treatment options are offered.¹⁵ However, the uptake of oral health self-care behaviours appear low in people with psychosis.¹⁶ Therefore, this population may find it difficult to engage in key preventative behaviours that could reduce the need for more intrusive or emergency treatments.¹⁷

The aim of this qualitative study was to explore the relationship between oral health and psychosis through consultation with service users with experiences of psychosis. By doing this, we sought to better understand the complex relationship and the unique challenges this population face to address unmet oral health needs. This is the first qualitative study to explore the relationship between oral health and psychosis in a service user sample.

Method

Sample and recruitment

A pragmatic qualitative approach¹⁸ was utilised to ascertain knowledge about the relationship between psychosis and oral health using semi-structured interviews. We aimed to recruit a sample large enough to develop a rich understanding of the research question.¹⁹ Clinical teams from two NHS Trusts referred service users meeting criteria for an International Classification of Diseases 10 (ICD) or Diagnostic Statistical Manual of Mental Disorders IV (DSM) diagnosis of a psychotic disorder (e.g., schizophrenia, schizoaffective disorder) or first episode psychosis (meeting operational criteria for an Early Intervention for Psychosis Service). See Table 3 for full inclusion criteria.

Table 3.

Criteria for inclusion	
Inclusion criteria	Exclusion criteria
18 years or over	Diagnosis of a known moderate to severe learning disability or organic disorder (e.g., dementia, acquired brain injury)
Under the care of an outpatient or inpatient team	Currently in crisis with known substantial risks to self / others
A diagnosis of schizophrenia, schizoaffective disorder, delusional disorder, schizophreniform or first episode psychosis (meeting criteria for entry into an Early Intervention Service)	
Able to give informed consent	
Able to speak English	

Ethics statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects were approved by [North-West – Greater Manchester East Research Ethics Committee, 19/NW/0723]. All participants provided informed consent to take part.

Data collection

The primary author (ET) conducted face-to-face ($n = 3$) or telephone ($n = 16$; during COVID-19 pandemic) interviews following a topic guide (see appendix C). The topic guide was developed with input from three people with lived experience of psychosis and one carer. Interviews ranged from 18 to 62 minutes (mean: 34, SD: 12) and were transcribed verbatim. Participants provided key demographic and clinical information prior to interview and completed the Oral Health Impact Profile-14 (OHIP-14)¹ and the Oral Health Survey²⁰ to assess their oral health related quality of life and knowledge of dental risk factors.

Analysis

The analysis process was both systematic and iterative, following guidance for reflexive thematic analysis outlined by Braun and Clarke.^{21,22} The lead author (ET) actively engaged with the dataset for familiarisation and completed line by line coding, which led to the development of preliminary themes. Authors LQ and VA coded a subsection of transcripts to provide other perspectives and the research team developed and refined these themes during regular multi-disciplinary discussions. Data was managed using NVivo²³ software.

Reflexivity statement

The primary author (ET) was a trainee clinical psychologist with an MSc in Health Psychology and experience of clinical working with psychosis. Such experiences impacted on the author's expectations about the relationship between service users and dental staff and beliefs about informed decision making when prescribed antipsychotic medication. This may have informed the way questions were asked and responded to. Therefore, other members of the research team reviewed a subsection of interviews and highlighted potential biases. ET engaged with the relevant research on dental literature prior to analysis, which informed deductive and inductive coding.²⁴ The research group comprised

of two clinical academics (KB & JPC), a non-clinical qualitative researcher (LQ), a dentist (VA), and a carer representative (DS). This diversity in perspectives supported a broader interpretation of the data.

Results

Demographic and dental visiting information is reported in Table 4, alongside results from the OHIP-14 questionnaire. Findings from the Oral Health Survey indicated variable knowledge of oral health related risk factors. Higher rates of correct responses were provided for questions pertaining to caries and erosion (51% and 47%, respectively). However, participants displayed poor knowledge of periodontal disease, with a correct response rate of 30%. Results from the OHIP-14 (see Table 4.) present the percentage of participants experiencing difficulties in each oral health-related quality of life domain. A high proportion of the sample reported difficulties in all domains of the OHIP-14. Table 5 includes further supporting quotes from the data.

Table 4.

Demographic information and dental data (n=19)		
Age		
	Median	44
	Interquartile range	19 (33-52)
Males (n/%)		
		12 (63%)
Ethnicity (n/%)		
White British		15 (80%)
Black British		1 (5%)
Asian British		1 (5%)
White Other		1 (5%)
White Irish		1 (5%)
Service (n/%)		
Community Mental Health Team		16 (84%)
Early Intervention in Psychosis Service		1 (5%)
Rehabilitation Unit		2 (11%)
Diagnosis (n/%)		
Schizophrenia		16 (84%)
Schizoaffective disorder		3 (16%)
No. of inpatient admissions		
	Median	3
	Interquartile range	7 (2-10)
Other diagnoses (n/%)		
Depression		6 (31%)
Anxiety Disorder		3 (16%)
Bipolar disorder		1 (5%)
Obsessive Compulsive Disorder		1 (5%)
Post-Traumatic Stress Disorder		1 (5%)
Dissociative Identity Disorder		1 (5%)
Eating disorder		1 (5%)
Autism Spectrum Condition		1 (5%)
Physical health difficulties (n/%)		

Back problems	2 (11%)
Diabetes	1 (5%)
Asthma	1 (5%)
Mobility problems	1 (5%)
Chronic obstructive pulmonary disease	1 (5%)
Arthritis	2 (11%)
Psoriatic arthritis	1 (5%)
Obesity	1 (5%)
High blood pressure	1 (5%)
High cholesterol	1 (5%)
Gray's Disease	1 (5%)
Sydenham's Chorea	1 (5%)
Anti-phospholipid Syndrome	1 (5%)
Registered with a dentist (n/%)	
Yes	16 (84%)
Last dental contact (n/%)	
<6 months	12 (63%)
<12 months	6 (31%)
<5 years	1 (5%)
Oral Health Impact Profile -14 results (n=18)	
Physical pain	(94%)
Psychological discomfort	(89%)
Psychological disability	(78%)
Functional limitation	(42%)
Physical disability	(53%)
Social disability	(56%)
Handicap	(72%)

Theme 1: Psychosis creates barriers to good oral health

This theme related to participants' perception of the ways in which psychosis directly and indirectly impacted on oral health. Many participants reported feeling like poor oral health was an inevitable consequence of psychosis despite attempts to maintain a healthy routine.

'I feel like I should have looked after them (teeth) more. I don't know how I would have done that, but, do you know what I mean?' P12

Table 5.

Additional supporting extracts for all themes.

Theme	Extract	Source
1.1	<i>Erm, couple of times, like I haven't brushed my teeth, like if I've been a bit poorly like, 'cos you don't really look after yourself do you, 'cos you don't, you're not really with it. When people are under stress which could be considered psychosis, it's like they've got too much on their mind to brush their teeth., I'd say it's like brushing your teeth seems to be kind of how do you say it, less a priority.</i>	P16
	<i>I'm not really there to be able to look after myself as well.</i>	P10
	<i>It's harder when you've got psychosis 'cos sometimes you don't know time of day kind of thing, you just try and do what you can to get through it.</i>	P12
1.2	<i>...they were related they were connected like the voice would play mind games with my tooth pain. So, it would be, they would be connected.</i>	P06
	<i>I felt like I was being talked about at the dentist. I felt like they were saying she stares or whatever and I didn't feel comfortable going in there, I felt like they were all talking about me in there.</i>	P09
	<i>Yeah I do get a bit sort of anxious you know with, in the waiting room because my voices start to flare up in that situation. I think I sort of get in my head that people can hear my voices, which is making me uncomfortable.</i>	P07
	<i>So it was interesting I had a friend who had this conspiracy theory of that the royal family put like a fluoride or something in the toothpaste to stop you, to prevent you from becoming awake and conscious and stuff and that played a bit on my mind. So as soon as then I used to take a minimum but like I say I'd do less because of that that but it's just paranoia.</i>	P06
	<i>I was just convinced there was something in the toothpaste. I was really paranoid at that stage, like I'm not paranoid anymore but apart from like small things like fluoride.</i>	P04

1.3 *I won't think twice about taking drugs and drinking alcohol because of my psychosis. Because of the way my psychosis, my general mood and wellbeing can sometimes be a bit low and a bit erm unstable that will drive me to drink alcohol and take drugs, So that won't help my mouth, my, that definitely doesn't help my teeth and mouth, you know.* P21

I started smoking it's something you know it's a lot of percentage of mentally ill people who smoke. I don't know the statistics. It's just something you think calms your nerves or whatever. Make me lose my teeth it was terrible and I didn't want, I didn't want to. It's against my will to smoke. P06

I was sort of like, drinking a lot and you know I did go through a little bit of stage, of a stage taking a few drugs and whatnot, erm, so, I presumed that it was something to do with that really. 'cos if you think about it, if you're taking drugs and that, you know, and you're up until like 5 and 6 o'clock in morning, you're not brushing your teeth before you go to sleep. P13

so when you're having a bad day with your psychosis and you want to escape it, you start taking smack, your teeth mouth and gums are affected. P18

Well the thing is, this medication knocks me out, at night-time I just go to sleep so I don't like, I want to go to sleep. P09

2.1 *Erm, it's ok, like it used to be one of the things that I only liked, like the only thing that I liked about myself, but I guess it's a bit different now, 'cos like they're not as good my teeth, but I just try and do what I can.* P10

I was quite upset when that happened, you know, even though the dentist said oh it looks great and everything. I suppose, you know, I suppose when it gets to that stage, you know, I, it did affect me quite a lot, but now, I'm quite used to it, so I've just accepted it really. P13

It made me feel like there was no point in me looking after myself because I was dirty anyway and there was no point in looking after myself because I couldn't make myself any better, any cleaner. P20

	<i>my gosh, they (the voices) don't half, put you down, you know, they're constantly at you all the time, they, you know, when me teeth were broken, they were constantly at me.</i>	P11
2.2	<i>I felt dirty. I wanted to feel very dirty because. I didn't wanna be attractive anymore. I didn't wanna be attracted by men, you know, it was a bit deeper than that so it was, yeah, I wanted to be unattractive.</i>	P11
	<i>..well basically, I knew I had bad breath at the time, so when I was talking to someone, I would talk under my breath instead of breathing out fully.</i>	P20
	<i>I mean nowadays I probably smile less because my teeth are yellow.</i>	P21
3.1	<i>I've got my community mental health team and they help me but I wouldn't ask them something that's totally out of reach.</i>	P18
	<i>It might have made a bit of difference. It might not have got out of hand if I'd had support with it. Cos it's not really talked about.</i>	P08
	<i>Well I've spoken to my support worker and he's told me he's gonna try get me into a dentist. I'm gonna have to ask (care co) as well to sort of get the ball rolling.</i>	P19
3.2	<i>My sister, my sister is my carer. She will always tell me to brush twice and use my mouthwash.</i>	P21
	<i>I think so yeah, you've got somebody next to you, you know if you need to talk you know but nothing specific but just somebody to sort of keep you calm before you go in.</i>	P02

1.1 A psychotic disconnect from self-care

This sub-theme referred to the all-encompassing nature of a psychotic episode that led to a disconnect with everyday activities, including oral health care. Participants talked about how psychosis brought about a temporary detached or dissociative state, which meant that self-care, like tooth brushing, felt distant and unobtainable. There was a complete preoccupation with their psychotic experiences, which made it impossible to maintain an oral health routine.

'Yeah, it's like listening to the voices and the hallucinations and you're wrapped up in that world. That's a complete delusional fantasy and you're not in the real world to brush your teeth.' (P19)

These feelings of disconnect from reality resulted in an inability to attend to oral health self-care behaviours (e.g., toothbrushing, flossing, dental visiting). This could trigger periods of overcompensating by overbrushing once acute psychosis subsided. Fluctuating patterns of attending to oral health suggested that people had an intrinsic sense of the importance of maintaining oral health, but that this was clouded by periods of psychosis.

'There's two sides to it really. You can either be, sort of, like obsessed about it and try and keep your mouth and your teeth as clean as possible, or when you're in a psychosis where time just goes without you realising, you know, hours and hours might pass, and you're not brushing your teeth.' (P13)

1.2 The threat of first rank psychosis to oral health

This sub-theme concerned the direct impact that hallucinations and unusual beliefs had on participants' oral health, often operating through fear and anxiety. Such experiences, acted as barriers to participants taking care of their mouth, teeth and gums making people worried about accessing treatment. For example, threatening command hallucinations sometimes directly warned of possible negative consequences if a person engaged in dental treatments, which impacted future dental attendance.

'One of the voices said if you take your wisdom tooth out, we're gonna bring more voices in your head and then they took my wisdom tooth out and 3 more voices came.' P01

Conversely, psychotic beliefs did not always impact adversely on dental health care. One participant expressed that their self-reported unusual beliefs, which appeared to be more grandiose in nature, enhanced their visits to the dentist. This suggests that it was also possible for psychotic symptoms to have a positive impact on oral health and potentially increase the likelihood of dental visiting.

'I think because I'm important, they [dental staff] like seeing me and they're very polite to me and they like seeing me 'cos I'm a bit of a VIP.' (P15)

1.3 Chemical inevitability

This theme concerned the perceived impact that substances have on oral health. People considered side effects from antipsychotic medication to be damaging to oral health and described finding it difficult to maintain a regular oral health routine because of tiredness and fatigue, with night-time routines being particularly challenging. Direct damage was thought to be caused by other side effects, including dry mouth and cravings for sugary food. Perceived control over taking medication was low. There was also some recognition that antipsychotic medication could positively impact oral health routines by minimising preoccupation with psychotic experiences.

'I think it's a really bad side effect. You need saliva and that to keep your teeth in good order, good working order sort of thing, it's a really bad side effect.' (P08)

The loss of routine and direct damage from medication was mirrored in the effects described by participants who used illicit substances. This included illegal drugs, alcohol, caffeine, and tobacco. Participants described these substances going *'hand in hand'* (P18) with psychosis. They attributed their use of substances to escapism and distress management. There was some overlap with theme 1.1 (a psychotic disconnect from self-care), as participants voiced experiencing a detachment from the real world when intoxicated, which impacted on their ability to attend to oral health self-care behaviours. Typically, participants recognised that substances negatively affected their oral health either by hindering their routine or by directly causing damage. Despite this, participants

stated that using illegal substances had often taken priority over self-care because of the power of addiction and beliefs about substances reducing mental distress.

'To be honest it was probably the same time when I was smoking crack, so probably drugs over dentist.' P04

Theme 2: The impact of poor oral health in psychosis

This theme represented the ways in which participants' thought that their oral health affected self-identity and their ability and desire to connect with others. The theme encompassed the impact that poor oral health had on psychological constructs that are associated with mental health, such as self-esteem and sense of identity. Social relationships were also affected by dental deterioration. Participants conceptualised the interplay between oral health and mental health as a destructive cycle. Poor mental health led to a worsening state of oral health, which in turn further impacted on mental health.

'Well, they play with each other. Right, the teeth cause more problems with the mental health, the mental health causes more problem with the teeth so it's a catch 22 situation if you like.' P06

2.1 Oral health and self-identity

This sub-theme referred to the ways in which oral health affected peoples' sense of self and identity, in the context of psychosis. Participants believed that the appearance of their mouth, teeth, and gums was fundamental to their value as a person. Those who had experienced dental deterioration commonly described themselves as "dirty." Existing concerns about the appearance of the mouth, teeth and gums sometimes manifested as critical auditory hallucinations which had an impact on self-esteem.

'The voices might call you a tramp or things like that and you know, threaten to knock out you know the rest of your teeth and things like that.' P19

Overall, deterioration in oral health was an emotive topic for participants. The perceived loss of good oral health seemed to lead to a sense of loss in identity. It was as if the deterioration stripped away remaining positive attributes, such as their smile.

'I've always had a big smile, you know. People used to comment that I had a nice smile, so it was upsetting.' (P08)

2.2 Oral health and relationships with others

The cumulative impact of psychosis and poor oral health made social and romantic relationships challenging. People expressed feeling vulnerable and in danger from others, because of their paranoia, and this was further exacerbated by their poor oral health.

'It's like I say, when I'm going out and things like that as well because I'm paranoid anyway about going out just in case, I mean if I'm thinking of going out, you know, what if someone sees my teeth and wants to start trouble with me, they think I'm an easy target or something like that.' (P19)

Fears of negative judgement from others about their oral health seemed to perpetuate social avoidance. This related to the sub-theme oral health and self-identity (2.1), suggesting that people experienced a reduction in self-esteem because of deteriorating oral health, which affected the way they viewed themselves and how they expected others to perceive them.

To mitigate the impact of poor oral health in social situations, participants attempted to mask their oral health when smiling or talking to others to avoid embarrassment or shame. This affected their ability to have authentic connections with others. Masking included hiding their teeth when smiling and talking to people under their breath to disguise halitosis (bad breath). Poor oral health was also conceptualised as a strategy to keep people away in the context of experiences of early trauma, suggesting that this can sometimes be an active process to protect the self from further danger.

'I find it quite difficult to smile because I think me teeth are that bad, even though, no one can tell, erm, I know, you know, so, you know, I, sort of like maybe cover my mouth with my hand or, try and smile without actually opening my mouth.' (P13)

Theme 3: Systems for people with psychosis influences oral health

This theme related to the ways in which the presence of a psychotic disorder could influence how formal and informal systems interact with oral health. The lack of prioritisation of oral health in some mental health services was juxtaposed with the holistic care provided by others. Informal support from family and friends was a central factor in maintaining good oral health in this population.

3.1 The impact of system-level support

This subtheme related to the way in which the presence of a psychotic disorder could influence professional support systems. Participants talked about having support around them because of their psychosis, but that this support was designed to treat their mental health and that there was little consideration of wider physical health needs, including their oral health. In general, mental health professionals seldom asked about service users' oral health because their psychotic experiences were considered to be the priority. This passivity of healthcare professionals in relation to dental health mirrored service user perceptions that poor oral health was inevitable and may have contributed service users' lack of prioritisation of oral health behaviours.

'so I guess in that sense, like they (mental health professionals) never, I don't think they ever think of that as a, sort of, thing that they need to address, like the mental health team.'
(P10)

A neglect of oral health needs was not always the case. Practical support from mental health teams to access the dentist (e.g. making the appointment or providing transportation) sometimes positively impacted on dental visiting. More specialised psychological support to reduce dental fear also enabled access to the dentist by reducing psychological barriers. Support workers, nurses, and psychological therapy staff provided oral health support to people with psychosis, which was warmly received by service users. Participants who received tailored and holistic support spoke more positively of their care team.

'Me and [healthcare professional's name] done some work on it to like, to think about safe place when I'm in dentist chair and that's worked, that's been really helpful.' (P12)

3.2 Psychosis and informal support for oral health

Support from family and friends in people with psychosis was instrumental in maintaining oral health. The presence of a key family member or trusted friend made it easier to attend dental appointments and provided support following treatment. Informal support networks advocated for better dental treatment for people with psychosis.

'A friend, he's gone he's asked after my visit to do a better denture for me because they've done a bridge but they can't do it.' P02

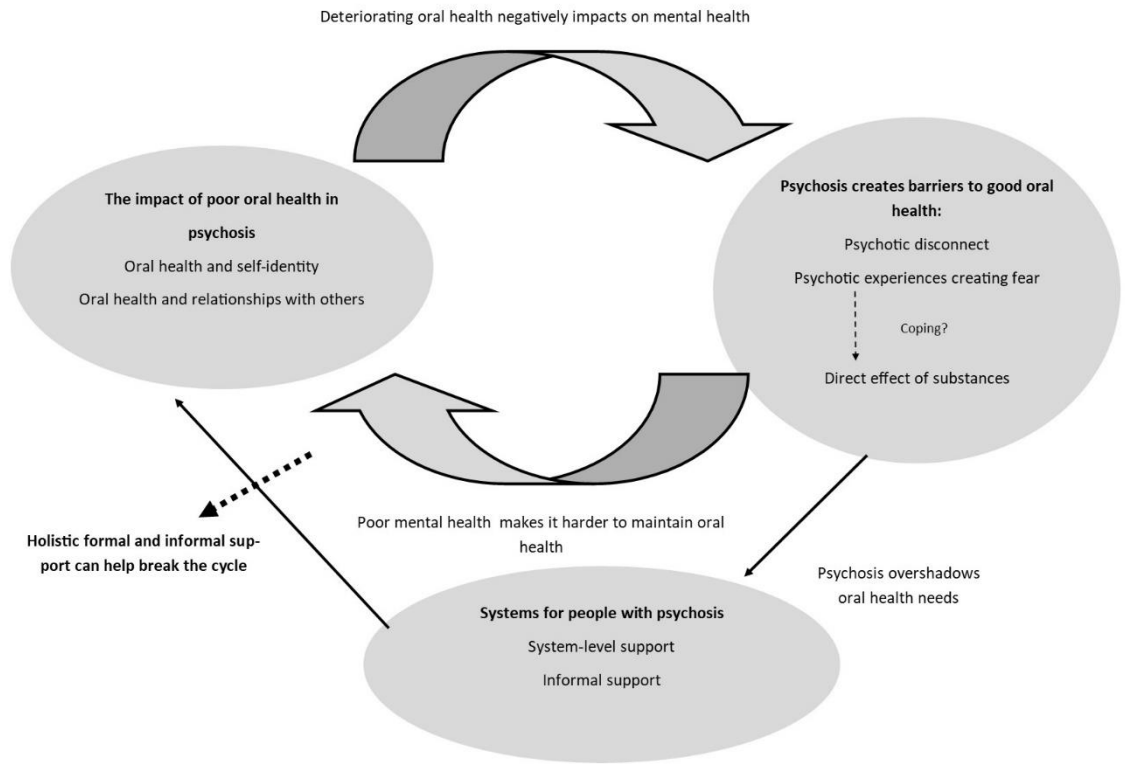
Participants recognised that sometimes intervention from close family or friends was needed, particularly in the form of reminders if self-care was low as a consequence of psychosis or associated difficulties (e.g. substance misuse). However, the heightened focus on tangible difficulties like oral health was sometimes perceived by participants as uncaring and neglectful of emotional needs.

'Yeah, cos sometimes I need it but sometimes I want her to say what's wrong with you? Are you okay? But sometimes she's just like, you've not brushed your teeth.' P18

Figure 4 is a thematic map of the themes and sub-themes (included for thesis version). The map illustrates how psychosis can impact on oral health through disconnection with the real world, interconnected psychotic experiences and the use of substances and prescribed medication. Participants perceived poor oral health to negatively impact on self-esteem, which had a detrimental effect on identity and the experience of voice hearing. Similarly, relationships with others were negatively affected by poor oral health through withdrawal and the use of masking strategies. Experiences of psychosis often overshadowed oral health needs, however when informal and formal support systems provided tailored support in this area service users with psychosis were more likely to attend to their oral health.

Figure 4.

Thematic map to illustrate themes and sub-themes.



Discussion

Summary of findings

This is the first qualitative study to explore service user perspectives of the perceived relationship between oral health and psychosis. Our analysis suggests that service users perceive a relationship between psychosis and oral health, whereby both factors affect each other. Symptoms and behaviours associated with psychosis were found to inhibit oral health self-care behaviours and cause direct damage to teeth and gums. Poor oral health can then disrupt self-identity and the ability to form relationships with others. The interplay between oral health and psychosis was conceptualised in this paper as a negative feedback loop, whereby poor mental health reduced oral health self-care behaviours leading to deteriorating oral health, which in turn negatively affected mental health. The presence of formal and informal support for dental needs increased access to the dentist and dental treatment. Informal networks provided everyday support which increased the likelihood of participants performing key oral health self-care behaviours.

Comparison to wider literature

The current study provides insight into potential mechanisms for the low uptake of oral health self-care behaviours in people with psychosis.¹⁶ This included a disconnection from reality, the role of positive symptoms, and the use of prescribed medication and illicit and non-illicit substances. Past research has suggested that feelings of detachment can negatively affect general functioning²⁵ and the present study indicates that this may extend to oral health care. Our analysis also suggested that fear and anxiety caused by hallucinations and delusions may prevent people from engaging in oral hygiene practices, adding to the burden of these disorders.

Participants perceived substances to be closely associated with psychosis and recognised that these were contributors to poor oral health, which is consistent with the wider literature.^{26, 13,14} A recent review suggested that antipsychotic medication can impact on functioning due to feelings of lethargy and reduced motivation,²⁷ directly referencing the effect this can have on self-care behaviours like toothbrushing. Present study results also highlighted the impact of fatigue alongside other key side effects such as xerostomia (dry mouth) and the increased desire for sugary foods. Like this study, other research has drawn parallels between use of substances (illicit and non-illicit) and antipsychotic medication and

its effect on oral health.²⁸ This paper similarly cited distress management as the reason for illegal substance misuse. However, additional drivers such as wanting to feel intoxicated have also been posited as a key motive for people with psychosis.²⁹ One possible explanation for this omission when talking about oral health is that participants felt uncomfortable disclosing the desire to be intoxicated whilst highlighting the damaging effect substances can have on oral health.

Recent research has explored whether appearance can be a focal point for auditory hallucinations in people with psychosis.^{30,31} Studies have found that many people experience appearance related voice content, particularly around weight gain which can negatively impact on self-esteem and can lead to social withdrawal.³⁰ This was reaffirmed by our data as participants disclosed appearance focused auditory hallucinations that were specific to the health of their mouth, teeth and gums. Similarly, these focused concerns about their appearance often led to social withdrawal.²⁶ The impact on low self-esteem and isolation may be particularly problematic given the role that these two factors can play in the development and maintenance of psychosis.^{32,33}

The current study found formal and informal support systems to be an integral factor in maintaining oral health. Previous findings have indicated that carers often bridge the gaps in support for service users with psychosis.³⁴ Similarly, the present study emphasised the value of informal support networks for people with psychosis and comorbid dental health needs. However, it is unclear how service users access oral health support in the absence of informal care as the analysis showed inconsistencies with the level of support provided by mental health teams. There was a sense that some services did not routinely prioritise needs outside of a mental health remit. A move towards more holistic care in mental health services has sometimes been endorsed^{2,35} and advances have been made to incorporate physical health needs into mental healthcare.³⁶

In comparison to a general population sample, participants experienced more difficulties in all oral health-related quality of life domains on the OHIP-14. Pain and psychological difficulties relating to oral health were key issues in the study population. These findings are consistent with past research (e.g. elevated rates of decay and periodontal disease)^{7,8} and the present results which highlighted the psychological problems associated with poor oral health. Risk factor knowledge was measured by the Oral Health Survey. Participants demonstrated a slightly better knowledge of risk factors pertaining to erosion and caries in

comparison to a general population sample.²⁰ However, risk factor knowledge of periodontal disease was greatly reduced. This type of knowledge related to preventative strategies and therefore could indicate that the sample have a poor understanding of the principles of brushing and flossing.⁷ See appendix D and E for further information on self-report data.

Strengths and limitations

This study has multiple strengths. The authors enabled trustworthiness and triangulation of the analysis by having a multi-disciplinary team that included psychologists, a dental expert, and a carer.³⁷ The research had strong PPI involvement resulting in a coproduced topic guide that was acceptable to participants and produced a wealth of relevant information. There were also limitations to the research, which included a lack of diversity in the sample. The study ran during the UK COVID-19 lockdown period, which restricted recruitment and made it difficult to adhere to the a priori sampling frame. A high proportion of participants were White-British and minority backgrounds were poorly represented in the sample. Furthermore, the majority were being treated by a community mental health team and there is a need to explore this relationship across a broader continuum of recovery. The study did, however, recruit from two NHS Trusts, which widened the geographical spread of participants.

Clinical implications

The findings from the study have key implications for mental health services. The analysis suggested that the maintenance of oral health care may be contingent on mental wellness. Therefore, support from services and informal systems around psychosis may enable people to access treatments and behaviours that improve oral health. There is a clear need for input from mental health services given the potential detrimental effects poor oral health has on mental health.

Our analysis suggests that consideration should be given to the iatrogenic effects of anti-psychotic medication, which have relevance to oral health. This could include informed and collaborative decision making about the potential impact of medication side effects on oral health (e.g. xerostomia – dry mouth). It may be pertinent for service users to discuss

prescribed medication with their dentist, to ensure that relevant advice and guidance is provided by dental professionals to mitigate possible side effects.

The findings suggest a negative feedback loop between oral and mental health. Interventions should target the avoidance of oral health self-care behaviours (e.g. dental visiting, toothbrushing, flossing) to break negative and perpetuating cycles of behaviour. A recent consensus statement³⁸ has advocated that poor oral health should not be an inevitable consequence of severe mental illness. Our data indicates that practical support from mental health teams and informal support networks can help facilitate access to dental care and treatment (e.g. support to book dental appointments / transportation). Therefore, such practical support must be encouraged to promote timely dental assessment and treatment. Based on the current findings, other specific interventions may include formulating the origins of avoidance, utilising motivational strategies to improve adherence to oral health routines, and cognitive behavioural strategies to reduce dental anxiety. There is a need for services to foster hope and promote optimism for change.

Conclusion

Findings indicated that psychosis and oral health might affect each other. Psychosis impacted on people's ability to attend to oral health needs and this led to a deterioration in dental health. Difficulties with oral health perpetuated worsening mental health. Mental health services and informal support networks play a key role in supporting oral health needs and facilitating access to dental treatment. Oral health difficulties are treatable with the right support and access to treatment.

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Paper Three:
Critical Reflection

Word count: 4319 (excluding references)

Introduction

This paper is a critical reflection of the large-scale research project undertaken in the form of a systematic review and a qualitative empirical study. The trainee will reflect on the process of planning and undertaking the research to illustrate the strengths, limitations and challenges.

The overall aim of the research was to better understand the health inequalities relating to oral health in people with psychosis. The trainee developed a good understanding of the oral health self-care behaviours in people with a serious mental illness by systematically reviewing and evaluating the literature. The trainee concurrently conducted a qualitative study which involved asking service users with experiences of psychosis about how they understand the relationship between oral health and psychosis. It is hoped that this research will result in meaningful change within mental health services and ensure that oral health becomes a priority for assessment and support.

Paper one:

Topic rationale

The aim of the systematic review was to explore oral health self-care behaviours in people with complex mental health problems (e.g., diagnosis of a bipolar disorder or psychotic disorder). Oral health outcomes are particularly poor in this population and the review topic aimed to gain insight into one facet of this problem. The trainee completed scoping searches into literature exploring the impact of psychological interventions in oral health behaviours in people with experiences of psychosis. However, the literature was sparse. From these scoping searches, the trainee recognised that no review paper had investigated whether people with psychosis are less likely to attend to oral health self-care behaviours (e.g. flossing, toothbrushing and visiting the dentist). This is an important area because oral health self-care behaviours are a key predictor of oral health and at present UK dental policies aim to protect limited National Health Service (NHS) resources. This is done by restricting patient's access to dental treatment if they do not comply with preventative strategies (e.g. regular flossing and toothbrushing). Treatment options for those with poor oral health is restricted to extractions and fillings.¹ Therefore, if the uptake of oral health

behaviours is low in people with complex mental health problems, then this group is likely to be disadvantaged by such conditional policies. A member of the research team highlighted an unpublished thesis that explored the rate of oral health behaviours in people categorised as having a serious mental illness.² However, the review search was completed in 2012 and it had not been published. Furthermore, serious mental illness was poorly defined in the review and it was difficult to distinguish what samples would be eligible for inclusion. The review did however stipulate that samples with high rates of dementia or learning disability would be excluded. The trainee decided to undertake a review investigating the rate of oral health behaviours in people with a serious mental illness. Serious mental illness was well defined based on National Institute for Health and Care Excellence (NICE) guidance.³ The findings suggested that oral health behaviours were low and reduced in comparison to non-clinical controls. These findings provided a target for prevention and intervention strategies. However, further understanding into why behaviours are low was needed and it was hoped that the empirical study would provide some insight into this.

Search strategy

The search process is a key stage in the review. Search terms were based on past reviews²⁻⁴ and the research team's expertise in dentistry and mental health. They were piloted and revised multiple times to ensure they included relevant literature. Search databases were chosen to reflect articles from key and relevant disciplines (e.g. nursing, psychology and psychiatry). The number of articles identified through the final search was great (7,691), however increasing precision could have increased the probability of overlooking relevant articles.⁵ See appendix F for details of the search strategy. Once search terms were finalised the trainee registered the review with PROSPERO (see appendix G) to ensure transparency and reduce the risk of bias.⁶

Inclusion criteria

The author excluded grey literature from the scope of the review. Grey literature relates to a broad spectrum of sources which has benefits (e.g., reduces publication bias) and challenges (e.g., heterogenous, not peer-reviewed).⁷ Other exclusions included limiting to studies published after 1980 (to coincide with the release of DSM III) and only reviewing those published in English. Such decisions may have introduced bias.⁸ Furthermore, only studies which included a sample of at least 75% of people with a diagnosis of a bipolar, psychotic disorder or first-episode psychosis were included. However, this excluded many

studies due to the broad definition of SMI often including neurodevelopmental and neurocognitive conditions like autism, dementia and learning disabilities. Following screening, the trainee contacted 28 corresponding authors to provide further information about the sample to maximise the inclusion of studies. Multiple emails were sent, initially to corresponding authors and then to other authors who had contributed to the paper. Seven authors provided additional data, which led to more relevant articles being included in the review. If additional information was not provided, then the studies were not included. The inclusion criterion was thorough, and the trainee followed a rigorous screening procedure to ensure all relevant articles were included. Ratings were completed independently and reliability was checked throughout the process.

Quality appraisal

The quality assessment is an important part of the review process as it evaluates methodological rigour and evidences the strength of the study.⁵ The Effective Public Health Practice Project (EPHPP)⁹ was chosen given its public health focus. Research has shown it has good construct and content validity and inter-rater reliability.¹⁰ However, in practice this was a complicated tool to use. To resolve this, the trainee and independent rater piloted the tool and the scoring dictionary was carefully adapted and refined, following discussions in supervision about uncertainties regarding ratings (appendix H). The tool was adapted for the observational design of studies and only included relevant domains. The tool has been adapted in previous reviews to ensure the quality domains were consistent with methodological characteristics of included studies.^{11,12} The quality of the papers was mixed. The trainee reflected that oral health behaviour data was often an adjunct and consequently analyses tended to be basic. Questionnaires were often a single question opposed to a validated questionnaire and information collected was seldom objective. Furthermore, key confounders like socioeconomic status (SES) were rarely accounted for in analyses. This posed as a limitation as confounders such as SES are known to impact on oral health.¹³ Given the association between psychosis and SES,¹⁴ the omission of such analyses makes it difficult to tease apart what factors contributed to the rate of oral health behaviours.

Analysis

The trainee used meta-analysis to quantitatively synthesise outcomes relating to toothbrushing and dental visiting behaviour. This method was considered appropriate when studies provided sufficient data and the measurement of outcomes was

comparable.¹⁵ A random effects model was employed to allow for variability (e.g. across setting, measure, population)¹⁶ and data was computed into Odds Ratios (ORs) using Comprehensive Meta-analysis Software Version 3. The measures were relatively comparable and could be computed into ORs. However, the research team did seek statistical advice regarding whether Risk Ratios (RRs) would be more appropriate and further analyses were undertaken to explore the effect if RRs were computed. However, based on advice ORs were considered as preferable as the aim of the synthesis was to summarise the magnitude of the association for the two outcomes (toothbrushing and dental visiting).¹⁷ Using ORs also allowed the trainee to retain the maximum number of studies for the analysis.

The analysis suggested that people diagnosed with a serious mental illness were significantly less likely to visit the dentist and brush their teeth in comparison to non-clinical comparators. Only a limited number of studies could be entered into the meta-analysis and therefore post-hoc analyses were not recommended.¹⁸ This is a limitation of the review. However, meta-analysis was still considered to be an appropriate method and research suggests as few as two studies can be meta-analysed.¹⁹ The Q test and I^2 statistic were used to determine the presence and level of heterogeneity. High levels of heterogeneity indicated that the strength of the relationships between population and outcomes was variable.²⁰ The small number of studies, variable quality and presence of heterogeneity meant that results from the meta-analysis were interpreted with caution.

Narrative synthesis

The synthesis without meta-analysis guidelines²¹ were used to narratively synthesise the wider literature. Narrative synthesis was valuable as it highlighted gaps in the research (e.g. minimal data on other oral health behaviours) and differences between samples (e.g. tentative evidence that people with a diagnosis of bipolar disorder or people categorised as first episode reported a higher rate of oral health behaviours). The trainee noted that definitions of oral health self-care behaviours tended to be poor, which made it hard to compare the literature. Furthermore, the lack of definition around behaviours like dental visiting might have inflated the figure as research suggests that this population are more likely to utilise emergency dental care opposed to routine appointments.²²

Summary

The results from this systematic review highlighted that oral health behaviours are likely to be lower in people who experience psychosis. It was unclear whether this remained the

case for people with a diagnosis of bipolar disorder due to the number of studies that investigated this population. Low rates of oral health self-care behaviours are likely to contribute to the health inequalities as preventative behaviours such as toothbrushing and flossing are a prerequisite for access to some dental treatments. The overall aims of the review were met and this information provided key understanding into the complex relationship between oral health and psychosis.

Dissemination

This systematic review was accepted for publication in April 2021 in *Acta Scandinavica Psychiatrica* (appendix I). Its findings have been included in the Right to Smile Consensus Statement.²³ The consensus statement is a document created by mental health practitioners, dental professionals, researchers and people with lived or carer experience of psychosis. The statement aims to reduce health inequities and sets five-year targets to improve oral health in people with psychosis. An online blog “The Dental Elf” written by dental academics wrote a summary of the review.²⁴ This was particularly helpful as it meant that people who did not have paid access to journals could read about the findings. Furthermore, the blog targeted dental professionals who are another key audience for this review.

Paper two:

Topic rationale

The trainee has a keen research interest in reducing health inequalities, particularly those concerning people with mental health problems. This interest developed whilst working as a research assistant on a research trial which explored the effectiveness of a lifestyle intervention in people prescribed anti-psychotic medication. Following this role, the author completed a MSc in Health Psychology and gained further understanding into the social gradient of health. Such experiences illustrated the cumulative disadvantage people with psychosis face and led to a strong desire to promote change. The author was familiar with the stark statistics relating to physical health in this population. For example, people with a diagnosis of schizophrenia have a reduced life expectancy of around ten to twenty years in comparison to the general public.^{25,26} This gap is only growing wider.²⁷ Furthermore, 75% of deaths are caused by physical ill health (e.g., cardiovascular problems). However, the author was less familiar with the research literature on oral health disparities that present in people with psychosis and the widespread subsequent difficulties.

There was a gap in the literature pertaining to the relationship between oral health and psychosis. Some of the qualitative literature more broadly explored the barriers and facilitators of oral health in this population²⁸⁻³⁰ and the experiences of oral health in people with first-episode psychosis only.³¹ However, no studies had sufficiently captured the perceived interaction between oral health and psychosis from a service user point of view. In addition to this, much of the literature is not UK based and the author felt that there were specific systemic issues within the UK dental system that contribute to this relationship.

Methodology

Reflexive thematic analysis was chosen as the most appropriate method to provide a flexible framework to structure a large body of data and generate a rich narrative of the dataset.³² This type of methodology fits well with health research as it promotes seeking the perspectives of a wider research team, whilst valuing researcher subjectivity³³ which was favourable given that the trainee had the benefit of a multi-disciplinary research team comprising of a dental expert, psychologists and a carer representative. This way of working also reduced the potential bias of personal judgements and preconceptions, which can be considered a limitation of reflexive thematic analysis.

Other methodologies were considered however, were not thought to fit the research question as well as thematic analysis. For example, interpretative phenomenological analysis (IPA) studies often recruit smaller samples with greater emphasis on individual experience.³⁴ This method would have provided rich and important data. However, people with psychosis are a diverse population, with unique experiences. It felt important to capture a broader range of perspectives to get a rich understanding of the complex relationship between oral health and psychosis. The authors similarly considered codebook reliability thematic analysis, as a possible limitation of reflexive thematic analysis is that coding reliability is not assessed (e.g. interrater reliability). However, within the qualitative paradigm, such reliability was not considered necessary when interpreting the data from a position of placing value on the researcher's subjectivity.

Furthermore, it is hoped that this study will inform future policies and service delivery therefore the results need to be accessible to professionals outside of the clinical psychology profession and research suggests that thematic analysis is a useful method informing policy development.³²

The trainee adopted a pragmatist approach. This approach is pluralistic and action-focused and therefore useful in research that focuses on inequity.³⁵ This approach allowed the researcher to apply the most appropriate methods to answer the research question and promote change. Pragmatism utilises and values multiple perspectives, recognising that knowledge is based on both unique and socially shared experiences with the aim to translate research into action and change.³⁶

Patient and Public Involvement

The author sought patient and public involvement (PPI) to develop and refine the topic guide. This included a member of the University of Manchester Community Liaison Group (CLG), two service user researchers and a carer representative. The feedback suggested that this was a worthwhile topic to pursue, and each person recalled experiences of oral health difficulties. A member of the CLG wondered whether service users might feel stigmatised by questions focused on routine, particularly if rates of oral health behaviours were low. This was discussed as a research team and consensus was that these difficult questions needed to be asked to better understand the relationship between oral health and psychosis. The author reflected that the routine nature of oral health behaviours could lead to interviewer's asking questions in a practical manner, disregarding the potential emotional impact. In response to these discussions, sample questions were added to the Participant Information Sheet (PIS) (appendix J) to prepare participants for the types of questions to be asked. Feedback from a carer representative helped the trainee consider wider support systems that typically help people with psychosis (e.g., family and friends) rather than restricting the questions to support from healthcare professionals. Finally, the trainee piloted the interview with a service user researcher. Discussions after the interview indicated that oral health could be a sensitive topic for service users. The research team problem-solved this issue and it was decided that interviews would end with debrief questions (e.g. how did you find the questions? Have any concerns been raised by the questions I've asked?) to ensure that any distress was shared and managed.

The author attended the NHS Research Ethics Committee (REC) and received positive feedback on the premise of the study and found the experience to be supportive and helpful. Some minor changes were made to the documentation on the basis on this discussion (e.g., language revisions in the participant information sheet) and there was a decision to document consent for gathering risk information. The favourable outcome letter can be found in appendix K.

Recruitment

Participant recruitment officially began in February 2020. The author contacted team managers of mental health teams and units within the two participating trusts and presented the study in team meetings. The author recruited three participants through this method, these interviews were conducted face-to-face. A copy of the consent form can be found in appendix L. In March 2020, the UK went into national lockdown due to the COVID-19 pandemic and all face-to-face research was stopped to prevent the spread of the virus. This resulted in ethics amendments to allow remote consent procedures and interviews. All further interviews were conducted over the telephone. The author wondered if not being visible to the interviewer made it easier to talk about this topic, given that teeth are so visible in face-to-face conversation. A previous decision to include a picture of the researcher on the PIS was helpful as it hopefully made the experience of speaking to the researcher less impersonal. The trainee did note that one participant found it hard to engage with the interview over the telephone, despite attempts to overcome this by offering frequent breaks and conducting the interview over several sessions, the interview remained superficial.

Recruiting during the COVID19 pandemic was an unprecedented challenge and consequently the trainee found it difficult to adhere to the purposive sampling frame because access to services was reduced to teams that the trainee had already established contact with. Despite some recruitment issues due to remote working, the trainee was able to recruit nineteen service users. Some participants spoke of reduced contact from mental health teams because of the pandemic and voiced benefitting from additional contact from researchers, like the trainee. Sometimes, this meant that the initial conversations about research naturally moved towards the difficulties the individual was facing with the pandemic (e.g. loss and fear). There were also additional practical barriers to oral health care such as not being able to access a dentist which were unique to the period the study was conducted in.

The author had limited prior qualitative research experience and consequently sought supervisor feedback on early interviews (appendix M). Feedback related to giving the participant more opportunity to share their experiences and suggestions included longer pauses between questions and more follow-up questions to get richer responses from participants. The author noticed a change in interviewing style as the project progressed. Overtime, interviews became more flexible and guided by the participants, which led to a

more in-depth understanding of difficulties and better rapport. To illustrate this change, the trainee noted that a participant from one of the later interviews had shared that she liked how the questions followed on from what she had said as it felt like the interviewer was “*really listening.*”

Analysis

The author did not use saturation as a guide for sample size. Evidence suggests that saturation is often based on surface level understanding due to this decision being made prior to the formal analysis.³⁷ Furthermore, saturation is more consistent with coding-reliability thematic analysis opposed to reflexive thematic analysis.³⁷ The sample size recruited was similar with past qualitative papers in similar populations³⁸ and is considered a large enough sample to get a rich understanding of the problem.³⁹

Following the guidance set out by Braun and Clarke,³² the author immersed herself in the data through transcription and taking the time to actively read and reflect on transcripts (appendix N). The author used Nvivo version 12⁴⁰ to complete line by line coding (appendix O). A hybrid approach to coding was taken which allowed the researcher to code in a way that was both driven by the data and relevant literature. Relevant literature included past qualitative research exploring oral health and psychosis, knowledge of dental policies and more generally existing knowledge of psychosis. This systematic approach provided some structure to a process that could feel overwhelming with a large dataset. Once the data had been initially coded, the author sorted the codes to map out preliminary themes and shared these with the wider research team. Please see appendix P for an example of bringing together the data. At this point, the author took a year out of the clinical psychology doctorate course for maternity leave. Great effort was taken to leave a clear audit trail of decisions made regarding coding and NVivo provided a good framework to do this.

Upon returning from maternity leave, the author familiarised herself with the data through re-reading transcripts and revisiting the coding process and moving codes to an Excel spreadsheet for ease (appendix Q). Time away from the project meant that the trainee felt more detached from the data and this time allowed ideas to percolate. This helped the trainee gain a clearer perspective of the data. Effort had been made to publish paper one before returning to study, which helped as it allowed the trainee to focus solely on paper two. This was helpful given the different style of writing and thinking required for the two papers. Knowledge from others was sought through two supervisors coding a subsection

of the interviews and more generally through wider team discussions about themes and sub-themes in supervision. The coding process remained iterative throughout analysis and write-up as suggested by Braun and Clarke.³² At times, this felt frustrating. However, the trainee noted that it was easy to become fused with concepts or try to use themes as a “catch all” whereas Braun and Clarke stipulate that it is impossible to capture all the intricacies of the data.³² Feedback from supervisors enabled the trainee to have a helicopter view of the dataset and provided the much-needed reminder to ensure the results answered the research question and were grounded in the data.

Reflexivity

Reflexive thematic analysis recognises that researchers remain central to the process of thematic analysis.^{41,42} Experiences prior to and during training have informed the trainee’s views on topics relevant to the research. For example, the trainee had previously worked as a support worker and supported a service user to dental visits. The trainee recalled dental staff directing questions towards her rather than to the service user. When the question was redirected, the service user was able to provide lots of information about past treatment and current needs. From this the trainee had predetermined ideas about interactions with dental staff and service users. The trainee also held pre-existing views about anti-psychotic medication, its side effects (e.g. weight gain) and service user decision making about taking such medication.⁴³ These experiences and beliefs may have shaped the ways in which questions were asked and how participant answers were responded to. For example providing more space for discussions about side effects rather than benefits.

Societal views impact on everyone and sociocultural beliefs held by the trainee may have impacted on her interview style. The trainee received feedback on an interview from a research supervisor (appendix M) regarding her questioning style when responding to a good oral health routine. The supervisor suggested that her response may have communicated approval which may have made it more difficult for the participant to disclose difficulties with their oral hygiene. With consideration to the concerns about stigma shared by the CLG member, the trainee began to introduce the study with further emphasis on looking at this from a mental health perspective, highlighting that she was not a dental professional and would not pass judgement on routines and habits. Despite his,

the trainee noticed a trend in participants commenting that they intended to brush their teeth more once the interview had completed. It is possible that the interview gave participants the space to reflect on their current routine and make plans for better oral health. However, it is also possible that the content of the interview resulted in some internal conflict and perceived judgement about current routines and habits.

Summary

The results from paper two indicate that oral health has clear implications for emotional health in this population. Clinical implications were targeted at mental health services to ensure regular assessment and support for oral health needs are routinely provided. The trainee reflected on her experience of sharing the aims of her research with colleagues. That sense of inevitability or presumed poor oral health seemed to permeate across disciplines. These experiences made the trainee more passionate about advocating for oral health whilst on her specialist placement at a medium secure unit. These difficulties unsurprisingly emerge time and time again. It was felt that the aims of paper two were met as the trainee was able to develop a rich understanding of the perceived relationship between oral health and psychosis and develop clear service-focused recommendations to promote change.

Dissemination plan

The trainee plans to submit paper two to the British Journal of Psychiatry as it was agreed that this journal would have the biggest impact on the field of mental health. The trainee will also disseminate on Twitter to broaden the audience to other key professions (e.g. dental) and service users. The trainee plans to develop an infographic to disseminate findings to local mental health services.

Relevance to clinical psychology

A key finding was that poor oral health negatively affects emotional health by its impact on self-identity, psychosis and relationships. The perceived relationship between oral health and psychosis resulted in the trainee proposing clinical implications to target the avoidance of oral health self-care behaviours to break the cycle between oral health and psychosis. Clinical psychologists are well placed to provide or oversee (e.g. supervising professionals from other disciplines) psychological interventions pertaining to oral health. Such interventions would likely include increasing motivation to improve adherence to oral health self-care behaviours and reducing emotional barriers by utilising cognitive

behavioural strategies to target dental anxiety and unusual beliefs or experiences. Other psychological support may be indicated such as supporting the development of coping skills to manage distress at the dentist (e.g. safe place imagery, grounding skills, relaxation techniques). In addition to this, clinical psychologists are often in leadership roles within multi-disciplinary teams to promote optimism and change. A whole team approach is needed to adequately assess, care plan and provide practical and psychological interventions for oral health needs.

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Author Guidelines

Your main document file should include:

- A short informative title containing the major key words. The title should not contain abbreviations
- The full names of the authors with institutional affiliations where the work was conducted, with a footnote for the author's present address if different from where the work was conducted;
- Acknowledgments;
- Abstract structured (intro/methods/results/conclusion)
- Up to seven keywords;
- Main body: formatted as introduction, materials & methods, results, discussion, conclusion
- References;
- Tables (each table complete with title and footnotes);
- Figure legends: Legends should be supplied as a complete list in the text. Figures should be uploaded as separate files (see below).

Reference Style

This journal uses AMA reference style; as the journal offers Free Format submission, however, this is for information only and you do not need to format the references in your article. This will instead be taken care of by the typesetter.

Figures and Supporting Information

Figures, supporting information, and appendices should be supplied as separate files. You should review the [basic figure requirements](#) for manuscripts for peer review, as well as the more detailed post-acceptance figure requirements. View [Wiley's FAQs](#) on supporting information.

Systematic Reviews

Summations: Provide up to three significant Summations encapsulating the 'take-home messages' of the manuscript, The Summations should be presented succinctly (ideally only 1 sentence and max 2 sentences each), in tabulated form and should derive from the conclusions of the manuscript, without merely restating the conclusion, raising new issues, posing further questions or being dogmatic.

Limitations: Provide up to three noteworthy Limitations. The Limitations must reflect any caveats or limitations related to the review process or the meta-analysis. The Limitations are to be presented succinctly (ideally only 1 sentence and max 2 sentences each) in tabulated form.

In the manuscript, the *Summations* and *Limitations* must be placed immediately below the Abstract/Keywords.

Appendix B: Author guidelines for British Journal of Psychiatry

Title – The title should be brief and relevant. Titles should not announce the results

Ethics Statement – All authors are required to follow the [ICMJE guidelines](#) on the protection of research participants. Reports on research involving human participants must include the following statement in the Methods section: *The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by [name of the relevant local, regional or national review body and approval number].* For further assistance in writing an ethics statement please visit [Ethics Statement Generator](#).

1. **References** – References should be numbered in the order that they appear in the text and listed at the end of the manuscript using the [Vancouver](#) style.

Unpublished doctoral theses may be cited but no other citation of unpublished work, including unpublished conference presentations, is permissible. Authors are responsible for checking all references for accuracy and relevance before submission. Read our guide to Vancouver referencing [here](#).

1. **Tables** - Tables should be numbered (e.g. Table 1, Table 2...) and referenced in the text of the manuscript. Authors must indicate the desired position of the

table in the manuscript. Authors must obtain permission from the original publisher if they intend to use tables from other sources, and due acknowledgement should be made in a footnote to the table as follows: *Permission to replicate this table has been given to the authors by XXX*. Please ensure tables are a reasonable size. Tables over two typeset pages (around 1,400 words) will be moved to supplementary material.

2. **Figures** - Figures should be numbered (e.g. Fig 1, Fig 2, Fig 3...) and referenced in the text of the manuscript. Authors must indicate the desired position of the figure in the manuscript. Please consult the [journal artwork guide](#) for a detailed specification on accepted file formats. Authors must obtain permission from the original publisher if they intend to use figures from other sources, and due acknowledgement should be made in the legend as follows: *Permission to replicate this figure has been given to the authors by XXX*.

Paper

- The word count should be between 3,000 and 4,000 words (excluding references, tables and figure legends) and may include up to 25 essential references beyond those describing statistical procedures, psychometric instruments and diagnostic guidelines used in the study.
- Structured abstract of up to 250 words with the headings: **Background; Aims; Method; Results; Conclusions (Trial Registration Number and Data Set Information** where appropriate). Please find further guidance on writing an effective abstract [here](#).
 - Conclusions, in isolation, are likely to be used by others citing or promoting the work and must therefore be an accurate reflection of the study's main findings.
- Main text should include the following sections: **Introduction, Method, Results and Discussion**.
 - Introductions should be no more than one paragraph. Longer introductions may be permissible but should be split with subheadings if they exceed two paragraphs.
 - Discussion section should always include limitations of the paper to ensure balance, use of subheadings is encouraged in this section.
 - A Conclusions section is not required in the main text.

- In total, up to four tables and figures may be included in the print version of each paper (e.g. three tables and one figure). Additional tables and figures may be included as online only supplementary material. All large tables (exceeding one journal page) will be published as online only supplementary material. Authors are encouraged to present key data within smaller tables for print publication.

Qualitative research

The Editorial team recognises that the term 'qualitative research' encompasses diverse methods, manuscripts will be evaluated based on the appropriateness of the selected framework, the coherence of the report and its adherence to quality criteria consistent with the methodology and method as follows:

Epistemological and/or theoretical frameworks

- The epistemological underpinnings and/or theoretical framework are made explicit and applied consistently

Study design and method

- The research goal is clear, justified and in context regarding the literature
- The approach matches the purpose of research and is justified
- Methods of sampling, data collection, data management and analysis are made explicit and consistent with the methodology
- Analytical and interpretative processes are described in full

Findings, discussion and implications

- Findings represent the depth and breadth of data
- Findings and interpretations are supported by the data
- Direct quotations, exemplars or other data presentations are used judiciously to illustrate the findings
- Findings are presented in a way that is consistent with the methodology, method and study aims
- Authors are appropriately cautious about knowledge claims
- Findings are explored theoretically and applications discussed

Process issues

- The report provides an account of reflexive practice in keeping with the methodology

The Mouth and Mind Study- Draft Topic Guide

Primary aim: What are service users' experiences of oral health and psychosis?

Opening sentence: *"We're interested in hearing about your mouth and teeth. There are no right or wrong answers. Please be as honest and as open as you feel comfortable. Some of the questions may apply to you and some may not, this is absolutely fine. You can stop the interview or take a break at any time."*

Section 1. Dental self-care

- **Please tell me about the health of your mouth, teeth and gums.**
 - Prompt: What does looking after your mouth, teeth and gums mean to you?
 - Prompt: How important is it to you to keep your mouth and teeth healthy?
 - Prompt: How do you feel about the health of your mouth and teeth?

- **How do you look after your mouth and teeth?**
 - What would you do on a day to day basis to look after your mouth and teeth?
 - Prompt: What helps you to do this? What stops you from doing this?
 - Prompt: Are there other things that affect how you look after your mouth and teeth?
 - Prompt: Can you tell me about the things that you do that might not keep your mouth and teeth healthy?

- **Tell me about any difficulties that you have had with your mouth, teeth or gums.**
 - Prompt: What did you do about these difficulties?
 - Prompt: What were these difficulties like? What do you think caused them?
 - Prompt: What helped or made them worse?

Section 2. Dental issues and your day-to-day life.

- **Tell me about any times when dental problems have affected your day-to-day life.**
 - Prompt: How do they affect your activities?
 - Prompt: How do they affect your ability to do things?
 - Prompt: How do they affect how you are around others?
 - Prompt: How do they affect your social life?

Section 3: Visiting the dentist

- **Tell me about your experiences of visiting the dentist.**
 - Prompt: Tell me about the last time that you visited the dentist. What was it like?
 - Prompt: What was your experience of attending the dentist on other occasions?
 - Prompt: For what reasons do you usually visit the dentist?
 - Prompt: What do you think / how do you feel about visiting the dentist?
 - Prompt: What makes it easier or harder for you to go to the dentist?
 - Prompt: Tell me about any times where you have not attended the dentist. Why was this?

Section 4. Mental health and dental care

- **How does your mental health affect your mouth and teeth?**
 - Prompt: Tell me about a time when your mental health was particularly bad.
 - Prompt: What impact did this have on your mouth and teeth?
 - Prompt: How do your mood or thoughts affect your mouth or teeth?
 - Prompt: How do your experiences affect your mouth and teeth?
 - Prompt: How does psychosis affect your dental hygiene?
 - Prompt: How does psychosis affect your mouth and teeth?

Section 5. Support and dental care

- **What conversations have you had with other people around your mouth, teeth and gums?**
 - Prompt: Who supports you?
 - Prompt: What support have you been given?
 - Prompt: What was it like trying to get support for these difficulties?
 - Prompt: What support would you have liked?

- Prompt: What was helpful or unhelpful in these situations?
- Prompt: How do you get information about looking after your mouth, teeth or gums?

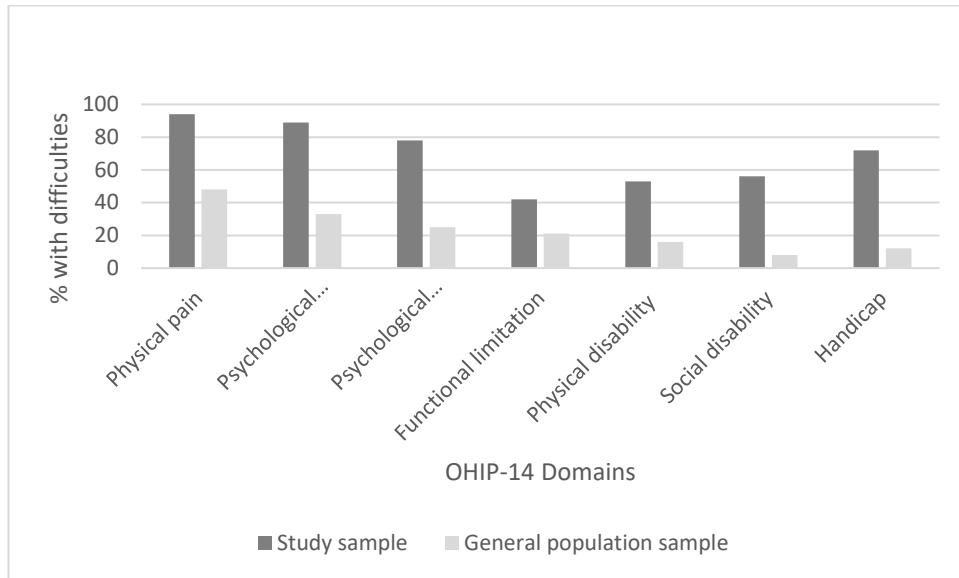
Section 6. Medication

- **(if taking) How does the treatment that you receive for your mental health affect your mouth, teeth or gums?**
 - Prompt: Tell me about any times where psychosis or medication has affected the food you eat or things you drink.
- **Summary**
- Is there anything else you would like share with me?
- Do you have any questions about the interview?
- Thanks for taking part in the study, has anything been raised by the questions I've asked?

Interview additional prompts

- **Set Prompts:**
- Can you tell me more about that?
- I'd be interested to hear more about that....
- Can you think of a time when that has happened?

Appendix D. Results from Oral Health Impact Profile-14



Appendix E. Results from Oral Health Survey

Risk factor knowledge domain	Correct response rate study sample (%)	Correct response rate general population sample (%)
Caries	51	47
Periodontal disease	30	77
Erosion	47	31

Appendix F: Search strategy

Total hits= 10, 739

Duplicates removed= 8522 (further duplicates removed during screening)

CINAHL (4446)

("severe mental" or "serious mental" or "chronic mental" or schizo* or psychoti* or psychos* or hallucinat* or paranoi* or bipolar or mania or manic).

("oral health" or "oral hygiene" or tooth* or teeth* or dent*)

S1 AND S2

Limit to English Language

Limit to peer reviewed

Limit to Human

Limit year 1980-current

Medline (2104 hits) (1st MEDLINE OPTION -

(severe mental or serious mental or chronic mental or schizo* or psychoti* or psychos* or hallucinat* or paranoi* or bipolar or mania or manic).mp.

(oral health or oral hygiene or tooth* or teeth* or dent*).mp.

1 and 2

limit 3 to English language

limit 4 to yr="1980 -Current"

limit 5 to human

PsycINFO (572 hits)

(severe mental or serious mental or chronic mental or schizo* or psychoti* or psychos* or hallucinat* or paranoi* or bipolar or mania or manic).mp.

(oral health or oral hygiene or tooth* or teeth* or dent*).mp.

1 and 2

limit 3 to English language

limit 4 to yr="1980 -Current"

Limit 5 to human

Limit 6 to "0110 peer-reviewed journal"

Embase (3618 hits)

(severe mental or serious mental or chronic mental or schizo\$ or psychotic\$ or psychos* or hallucinate\$ or paranoi\$ or bipolar or mania or manic).mp.

(oral health or oral hygiene or tooth\$ or teeth\$ or dent\$).mp.

1 and 2

limit 3 to English language

limit 4 to yr="1980 -Current"

limit 5 to human

Citation

Elizabeth Turner, Katherine Berry, Jasper Palmier-Claus, Vishal Aggarwal, Leah Quinlivan, Timothy Villanueva. Oral self-care behaviours in serious mental illness: a systematic review. PROSPERO 2020 CRD42020176779 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020176779

Review question

This aim of this paper is to systematically review the rates of oral self-care behaviours in people with a serious mental illness. In the presence of a control group (people without a diagnosis of a serious mental illness), we aim to statistically synthesise the size and consistency of the differences in oral health self-care behaviours using random-effects meta-analysis. We will also evaluate the quality of the available studies using the adapted Effective Public Health Practice Project (EPHPP) and establish future directions for research.

Searches

Separate systematic searches will be conducted on MEDLINE, PsycINFO, CINAHL and EMBASE.

Group one search terms pertain to serious mental illness and include the following: (severe mental or serious mental or chronic mental or schizo* or psychoti* or psychos* or hallucinat* or paranoi* or bipolar or mania or manic).

Group two search terms relate to oral health and include the following: (oral health or oral hygiene or tooth* or teeth* or dent*).

Searches will be restricted to the English Language and human studies. Searches will be restricted to 1980 - current publication period.

Search terms were developed on the basis of the research team's clinical experience and past systematic reviews (Kisley et al., 2011; Kisley et al., 2015; Yang et al., 2018). We will screen the reference lists and conduct forward/ backward searches of citing papers in eligible articles.

Articles will be accessed in hard copy and electronic format from the libraries at the University of Manchester, Lancaster University and the University of Leeds. If a copy cannot be accessed from the above institutions, the first authors will be contacted for a copy of the manuscript.

Types of study to be included [1 change]

Eligibility criteria

- Case control, cohort design, longitudinal and epidemiological studies.
- A Quantitative measure of oral self-care behaviours.
- Studies will include a sample of people formally diagnosed with a SMI. Diagnoses will include schizophrenia, schizophreniform, schizoaffective disorder, delusional disorder, and bipolar disorder. Participants eligible for an EIS will also be included.
- At least 75% of the sample must have one of the predefined diagnoses and diagnoses must have been reached in accordance with the Diagnostic and Statistical Manual (DSM-III or later) or International Classification of Diseases (ICD-9 or ICD-10).
- Articles published before 1980 will be excluded in line with the introduction of the modern classification system for mental health disorders.

- Peer reviewed articles to ensure the inclusion of high-quality studies.
- Written in the English language.
- Restricted to humans.
- For the meta-analyses all studies will include a non-clinical comparator. Studies will not share participants.

Condition or domain being studied [1 change]

Diagnosed serious mental illness. This is defined as a schizophrenia or bipolar spectrum disorder, diagnosed in accordance with the DSM (DSM III or later) or ICD (ICD-9/ICD-10). Diagnoses will include schizophrenia, schizophreniform, schizoaffective disorder, delusional disorder bipolar I, bipolar II and cyclothymic disorder. In addition to this, participants who meet the operational criteria for an early intervention in psychosis service (EIS) will be eligible for inclusion.

Participants/population [1 change]

Eligible studies will include a sample of people diagnosed with a serious mental illness (SMI). This is the collective term used for people with severe and enduring mental health problems. Eligible diagnoses will include schizophrenia, schizophreniform, schizoaffective disorder, delusional disorder, bipolar I, bipolar II and cyclothymic disorder providing that they were formally diagnosed in accordance with the DSM (DSM III or later) or ICD (ICD-9/ICD-10). In addition to this, participants who meet the operational criteria for an early intervention in psychosis service (EIS) will be eligible for inclusion. Studies will only be included if at least 75% of the sample have one of these predefined diagnoses.

Intervention(s), exposure(s)

Variables associated with oral self-care behaviours e.g. ownership of a toothbrush, dental attendance (routine and emergency) and frequency of brushing, flossing and use of inter-dental sticks.

Comparator(s)/control

Control samples will include people without a diagnosis of a serious mental illness. For epidemiological studies, the control will be the general population free of the exposure of interest.

Main outcome(s)

Quantitative assessment of oral self-care behaviours including: ownership of a toothbrush, dental attendance (routine and emergency) and frequency of brushing, flossing and use of inter-dental sticks.

Measures of effect

This outcome will be defined/measured based on the statistical procedures authors have used to report this. This will include, where available, estimates of effect size (i.e. correlations, mean difference, odds ratio, standardised mean difference) alongside indicators of statistical significance (confidence intervals will be preferred over p values).

Additional outcome(s)

None.

Measures of effect

Not applicable.

Data extraction (selection and coding)

Selection

A systematic search will be conducted using the following databases: MEDLINE, EMBASE, CINAHL and PsycINFO. Scoping searches have been conducted to ensure that the identified search terms generated a sufficient amount of literature pertaining to oral self-care behaviours and serious mental illness. Furthermore, following the screening process, the author ET will review the reference lists and citing articles of eligible

papers and existing reviews to identify any further articles for inclusion.

Screening

Author ET will screen articles at the title, abstract and full article level. Reliability will be ensured as an additional researcher will independently screen a % of the identified articles at the title and abstract level. All remaining included articles will be screened at full text level by at least two members of the research group. Any discrepancies will be discussed with the full research team until a consensus is achieved.

Covidence or ENDNOTE referencing software programme will be used to export citations and screen articles.

Meta-analysis Data extraction

Two authors (ET and JPC) will independently extract information for the meta-analysis onto a proforma. Relevant study information (e.g. study design, setting, sample and matched control criteria) will be extracted from the studies and relevant outcome measure data will be coded (e.g. type of oral health self-care behaviour, measure of behaviour and statistical information). In cases whereby relevant information is not available, the authors of the paper will be contacted. If key data is missing then the study will be excluded from the analyses. Any discrepancies will be resolved through a discussion with the research team.

Risk of bias (quality) assessment

Quality Assessment

Two authors will independently extract information for the quality assessment onto a proforma. Information will be extracted relating to the study design, criteria for participant selection, matched control criteria, outcome measure, data collection methods, missing data (e.g. withdrawals and drop-outs) and type of analysis used. This information will be used to assess the quality of individual studies using an adapted version of the EPHPPP.

Strategy for data synthesis [1 change]

Meta-analysis

Studies with a non-clinical comparator sample will be meta-analysed to explore the size and consistency of the observed effects using Comprehensive Meta-Analysis or Stata. Data will be extracted to compute effect sizes in the form of Odds Ratios (OR) or standardised mean differences. The meta-analysis will be computed using a random effects model. This method is considered to be appropriate when statistical heterogeneity is expected across analyses. The random effects model will lead to more conservative findings in comparison to the fixed effect model. Funnel plots will be visually examined for publication and selection bias. Statistical heterogeneity will be assessed using the Q test and I^2 statistic. One study removed sensitivity analysis will be conducted throughout the process to establish whether any included studies are considered to be an outlier.

Narrative synthesis

We will calculate a weighted average across the available literature irrespective of a non-clinical comparator. We expect that the majority of studies will be meta-analysed. A minimum of three studies will be required to conduct the synthesis. A narrative description of studies/ primary findings using the PICOS format will be provided. Outcomes will be grouped according to oral self-care behaviours. Outcome data will include quantitative measure of oral self-care behaviours. The most basic unit of measurement will be extracted from outcome data (means/ SDs or ORs). The odds ratios for individual studies will be calculated to explore the effects of different outcomes for individual studies using a random effects meta-analysis. If there are multiple data points, then the most basic unit of measurement will be extracted. If confounders are included as covariates, then we will conduct an unadjusted analysis to ensure a consistent analysis across studies. A sensitivity analysis will be including the adjusted effect sizes to assess the impact.

Analysis of subgroups or subsets

None.

Contact details for further information

Elizabeth Turner
elizabeth.turner-4@postgrad.manchester.ac.uk

Organisational affiliation of the review

The University of Manchester
<https://www.manchester.ac.uk/>

Review team members and their organisational affiliations

Mrs Elizabeth Turner. The University of Manchester, Greater Manchester Mental Health Trust
Professor Katherine Berry. The University of Manchester
Dr Jasper Palmier-Claus. Lancaster University
Dr Vishal Aggarwal. The University of Leeds
Dr Leah Quinlivan. The University of Manchester
Mr Timothy Villanueva. Mersey Care NHS Foundation

Type and method of review

Systematic review

Anticipated or actual start date

27 March 2020

Anticipated completion date

29 January 2021

Funding sources/sponsors

None.

Conflicts of interest

Language

English

Country

England

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Humans; Mental Disorders; Self Care

Date of registration in PROSPERO

26 June 2020

Date of first submission

30 March 2020

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions
26 June 2020

Review Title: Oral self-care behaviours in serious mental illness: A systematic review

Author: Elizabeth Turner

Effective Public Health Practice Project (EPHPP)

**QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES
(ADAPTED*) DICTIONARY**

The purpose of this dictionary is to describe items in the tool thereby assisting raters to score study quality. Due to under-reporting or lack of clarity in the primary study, raters will need to make judgements about the extent that bias may be present. When making judgements about each component, raters should form their opinion based upon information contained in the study rather than making inferences about what the authors intended.

DICTIONARY: SELECTION BIAS

(Q1) Participants are more likely to be representative of the target population if they are randomly selected from a comprehensive list of individuals in the target population (score very likely). They may not be representative if they are referred from a source (e.g. clinic) in a systematic manner (score somewhat likely) or self-referred (score not likely).

(Q2) Refers to the % of subjects in the control and intervention groups that agreed to participate in the study before they were assigned to intervention or control groups.

STUDY SPECIFIC NOTES: SELECTION BIAS

(Q1) They may not be representative if they are referred from a source (e.g. clinic) in a non-systematic manner (e.g. convenience sample approached based on service such as Early Intervention Services) or subsample selected from an earlier study (score not likely). If there are two groups (e.g. clinical and control) then answer question with relevance to both.

*(Q2) This includes declines only and does not include those who were approached but do not meet inclusion criteria.*When papers did not give details of selection procedures, but*

direct you to another paper/provide reference for further details then rate based on this info but do make a note for discussion

STUDY SPECIFIC NOTES: CONFOUNDERS

The following are examples of confounders:

Ethnic group; Gender; Age; Education/employment; Marital status; Socioeconomic factors; Healthcare/ dental plan; Income

Diagnosis; Service (inpatient/outpatient, acute/rehab, CMHT); Medication; Substance misuse; Duration/severity of mental health problem

General psychopathology factors (e.g. depression, anxiety); Positive/ negative symptoms, functioning,

Similar number of participants in each group

DICTIONARY: CONFOUNDERS

By definition, a confounder is a variable that is associated with both the independent variable and the dependent variable. The authors should indicate if confounders were controlled in the design [by stratification or matching] or in the analysis. There should be no obvious dissimilarities between groups that may account for differences in outcomes.

****Please note question 1 includes analysis but we have changed this to also include research design***

Examples of controlling for confounders in design include restriction (e.g. control for gender and age by including all males over 60 years) and matching (e.g. for age and gender – also have to control for this in analysis as use different stats to unmatched studies) and randomisation (i.e. equal chance of being in each group, so likely similar distribution of confounding factors – success can be examined via statistical comparison of baseline characteristics)

Examples of controlling for confounders in analysis include comparing groups (e.g. t-test) to check for differences if one group not included in analysis; partial correlation; controlling for variables in regression; covariates in ANCOVAs

**Focus on analyses relevant to the review question only.*

(Q1) If some attempt to control for confounders in either analysis or design rate as 'yes'

(Q2). Where there are two or more relevant analyses, the rating for percentage of confounders will be analysed across all relevant analyses (e.g. if there are two relevant analyses and a number of confounds are adjusted for but only in one out of the two analyses, then rate across both and reduce the final percentage rating – cannot score higher than '60-79%')

- Rating of 80-100% (most) = 2+ confounders controlled for in analysis or design (where applicable)*
- Rating 60-79% (some) = 1+ confounders controlled for in analysis or design (where applicable)*
- Rating less than 60% (few or none) = No attempt to control for confounders in analysis or design (where applicable)*

**If you rate Q1 as "no" then Q2 should be rated "not applicable".*

DICTIONARY: DATA COLLECTION METHODS

Only assess outcome of interest e.g. toothbrushing, dental visiting, flossing etc.

Tools for primary outcome measures must be described as reliable and valid. If 'face' validity or 'content' validity has been demonstrated, this is acceptable. Some sources from which data may be collected are described below:

Self-reported data includes data that is collected from participants in the study (e.g. completing a questionnaire, survey, answering questions during an interview, etc.).

Assessment/Screening includes objective data that is retrieved by the researchers. (e.g. observations by investigators).

Medical Records/Vital Statistics refers to the types of formal records used for the extraction of the data.

Reliability and validity can be reported in the study or in a separate study. For example, some standard assessment tools have known reliability and validity.

STUDY SPECIFIC NOTES: DATA COLLECTION METHODS

**If there is more than one measure and one is valid/ reliable and the other is not valid/ reliable, rate 'no'. All measures have to have some indication of validity/reliability to rate 'yes'.*

Guidance for rating validity and reliability of dental service usage:

- 1) Gold standard reliability: Data obtained from database (e.g. insurance/ national health database). Rate strong.*
- 2) Validated questionnaire/ item. Rate moderate.*
- 3) Questionnaire not validated. Rate weak.*

STUDY SPECIFIC NOTES: ANALYSES

** Consider this rating in terms of whether the analysis was appropriate and reported in a way that it is clear how it illuminates the research question.*


**Rate yes if some level of clarity. If score yes, can then score strong or moderate depending on extent to which appropriate and reported in such a way that it is clear how answers aims/ research questions (see scoring).*

**When assessing whether the analysis was appropriate for the question asked, consider sample size, power analyses and type of statistical test.*

Things to consider

**Consider whether the authors report analysis clearly – Is the analysis clearly reported? (I.e. is there an analysis section in the methods or is the analysis sufficiently described in the results?) Are relevant statistics presented? Do the authors report and justify decisions (e.g. power analysis for sample size and p values)? Do the authors report the distribution of data and skewness statistics? Do the authors report missing data?*

Oral health self-care behaviours in serious mental illness: A systematic review and meta-analysis

Elizabeth Turner^{1,2} | Katherine Berry^{1,2} | Vishal R. Aggarwal³ | Leah Quinlivan^{1,2,4} | Timothy Villanueva⁵ | Jasper Palmier-Claus^{6,7} 

¹Division of Psychology & Mental Health, The University of Manchester, Manchester, UK

²Greater Manchester Mental Health NHS Foundation Trust, Manchester, UK

³School of Dentistry, Faculty of Medicine and Health, The University of Leeds, Leeds, UK

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⁵Mersey Care NHS Foundation Trust, Liverpool, UK

⁶The Spectrum Centre for Mental Health Research, Faculty of Health & Medicine, Lancaster University, Lancaster, UK

⁷Lancashire & South Cumbria NHS Foundation Trust, Lancashire, UK

Correspondence

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Email: J.palmier-claus@lancaster.ac.uk

Abstract

Aim: To understand the relationship between serious mental illness and oral health self-care behaviours using meta-analytic methods and a narrative synthesis of available literature.

Method: The review followed the Preferred Reporting Items for Systematic Reviews and Meta-analyses guidelines [PROSPERO reference: CRD42020176779]. Search terms pertaining to serious mental illness and oral health were entered into EMBASE, PsycINFO, Medline and CINAHL. Eligible studies included a sample of people with a serious mental illness and a quantitative measure of an oral health self-care behaviour (eg dental visits, toothbrushing). The Effective Public Health Practice Project tool was utilised to appraise the quality of the literature. Studies in the meta-analysis contained a non-clinical or general population comparator sample.

Results: People with a serious mental illness were significantly less likely to visit the dentist (OR 0.46, 95% CI 0.32–0.66, $p > 0.001$) or brush their teeth (OR 0.19, 95% CI 0.08–0.42, $p < 0.001$) when compared to non-clinical comparator samples. Few studies explored other oral health self-care behaviours (eg flossing and mouth washing), but uptake was generally low in people with a serious mental illness. The study quality of included studies was variable.

Conclusions: The research showed a reduced uptake of oral health self-care behaviours in people with a serious mental illness. Suboptimal oral health can negatively impact on physical, social and psychological functioning. Further research is needed to understand the reasons for low rates of oral health self-care behaviours in this population.

KEY WORDS

bipolar disorders, dental care, oral health, psychotic disorders

Summations

- People with a serious mental illness were less likely to visit the dentist.
- They were also less likely to brush their teeth.
- There was limited evidence around the use of dental floss and mouthwash

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The Mouth and Mind Study - Participant Information Sheet

Understanding the perceived relationship between oral health and psychosis

You are being invited to take part in a research study that will explore your views about the relationship between the health of the mouth, teeth and gums and psychosis. This study is being carried out as part of a doctoral thesis in Clinical Psychology.

Before you decide whether to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully before deciding whether to take part and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

Thank you for taking the time to read this.

About the research



Who will conduct the research?

Elizabeth Turner (Trainee Clinical Psychologist) will conduct this research on behalf of the Division of Psychology and Mental Health, School of Health Sciences, Faculty of Biology, Medicine and Health at The University of Manchester.

The research team is made up of Professor Katherine Berry (Senior Lecturer, University of Manchester), Dr Leah Quinlivan (Research Associate, The University of Manchester), Dr Jasper Palmier-Claus (Senior Lecturer, Lancaster University) and Dr Vishal Aggarwal (Associate Clinical Professor, The University of Leeds).

What is the purpose of the research?

We are inviting people to take part in the study if they have experienced psychosis and are under the care of an outpatient or inpatient mental health team.

People with psychosis often experience problems with their mouth, teeth and gums. They are more likely to have decayed or missing teeth. The reasons for this are not fully known. Problems with the mouth, teeth and gums can cause pain and impact on a person's self-esteem and people's lives.

This study hopes to explore service user's experiences of dental care, problems and treatment to better understand the relationship between psychosis and dental health. We hope that this research will inform future policies and guidance so that better support can be provided to people experiencing psychosis and dental problems.

What would I be asked to do if I took part?

You will be invited to meet with Liz Turner at a location that is convenient to you (e.g. your own home, NHS setting or community venue). When arranging the interview over the phone, Liz Turner will ask for your consent to speak to a member of your care team to gather risk information (to yourself, others or the environment). This is to make sure that the interview can take place safely. You will have the opportunity to discuss the study and ask any questions. If you decide to take part, you will be asked to sign a consent form. The researcher will then invite you to share information about yourself such as your age and gender.

The main part of the study involves an interview, where the researcher will ask you questions about your mouth, teeth and gums and psychosis. This interview will be recorded on a password-protected encrypted audio recorder. After this, the researcher will invite you to complete two brief questionnaires about your teeth and gums.

In total, the session should take no longer than 1.5 hours. At the end of the session, the researcher will ask if you have any questions or want to discuss any concerns. You will be given the opportunity to take breaks or you can complete the interview and questionnaires over two sessions if you prefer. After the interview has taken place, the interview will be transcribed (by Liz Turner or an approved member of the Clinical Psychology Department at the University of Manchester, who will have signed a confidentiality agreement). Once the identifying data has been removed, the research team will then identify common themes from all of the data collected from all participants combined.

To help you decide whether you want to take part in our study, we have included some of the questions you will be asked.

Sample Questions

- *How do you look after your mouth and teeth?*

Tell me about any difficulties that you have had with your mouth, teeth or gums.

How does your mental health affect your mouth and teeth?

With your permission, once you have taken part in the study, we will send a letter to your care coordinator / care team to let them know you took part in the Mouth and Mind Study.

What are the advantages and disadvantages of taking part?

The information that we gather from this study may help us better understand the relationship between the health of people's teeth, mouth and gums and their psychosis. This could help to inform future research and guide policies and guidance to ensure that people who experience dental problems and psychosis are offered the right level of support and have access to information about oral health.

There are no expected disadvantages to taking part. However, it is possible that talking about your mouth, teeth and gums and experiences of psychosis could be upsetting. You will have the opportunity to share any concerns with the researcher and can end your involvement at any time without it affecting the care that you receive.

Will I be compensated for taking part?

As a token of appreciation, you will be reimbursed £12 for taking part in the study. There will not be any travel expenses for you from taking part in the research, as Liz will arrange to meet you at a location that is convenient to you (e.g. your home, NHS setting or community setting).

Do I have to take part?

Participation in this study is completely voluntary. If you decide not to take part, this will not affect any of the treatment or the standard of care that you usually receive, now or in the future.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself. However, it will not be possible to remove your data from the project once it has been anonymised as we will not be able to identify your specific data. This does not affect your data protection rights. If you decide not to take part you do not need to do anything further.

It is important that all interviews are audio-recorded to ensure that the information is transcribed correctly. However, we want to ensure that you are comfortable with the recording process at all times and you will be free to stop recording at any point in the interview.

Will the outcomes of the research be published?

Findings from the study will be written up for publication in academic journals and will be presented at national and international conferences. All data will be pseudonymised. This means that the researchers will assign a unique code (e.g. SO1) to your name so that your data cannot be identified. Any identifiable information (e.g. names/ places/ services) will be removed from the data. Any direct quotes from the interviews will not include identifying data.

If you wish to find out the outcome of our research, the findings will be on our website www.rightfromthestartmatters.com.

Disclosure and Barring Service (DBS) Check

All members of the research team have undergone the appropriate level of DBS check as determined by their School and obtained via The University of Manchester, The University of Leeds or Lancaster University.

Who has reviewed the research project?

North West - Greater Manchester East Research Ethics Committee.

Reference number: 19/NW/0723

Data Protection and Confidentiality

What information will you collect about me?

In order to participate in this research project, we will need to collect information that could identify you, called “personal identifiable information”. Specifically, we will need to collect:

Demographic information including age, gender, medication, diagnosis, ethnicity, information about any other psychiatric diagnoses (e.g. anxiety/ depression), clinical services involved, number of inpatient admissions, whether registered with a dentist, date of most recent visit to a dentist, and any physical health difficulties

Your name and signature on the consent form

Voice only audio-recordings of the interview

Under what legal basis are you collecting this information?

We are collecting and storing this personal identifiable information in accordance with data protection law which protect your rights. These state that we must have a legal basis (specific reason) for collecting your data. For this study, the specific reason is that it is “a public interest task” and “a process necessary for research purposes”.

What are my rights in relation to the information you will collect about me?

You have a number of rights under data protection law regarding your personal information. For example, you can request a copy of the information we hold about you, including audio recordings.

If you would like to know more about your different rights or the way we use your personal information to ensure we follow the law, please consult our [Privacy Notice](#) for [Research](#):

<http://documents.manchester.ac.uk/display.aspx?DocID=37095>

Will my participation in the study be confidential and my personal identifiable information be protected?

In accordance with data protection law, The University of Manchester is the Data Controller for this project. This means that we are responsible for making sure your personal information is kept secure, confidential and used only in the way you have been told it will be used. All researchers are trained with this in mind, and your data will be looked after in the following way:

Electronic data will be stored on the University server. Access will be restricted to the research team and documents will be password protected. Identifiable data will be stored on a separate database to all other data. All other data will be pseudonymised. This means that the link between identifiable and associated data is obscured through the use of a unique ID number. Only University of Manchester members of the research team will be able to access the database which contains identifiable data. Physical data will be stored in locked cabinets, in locked offices at the University of Manchester. Any identifiable data (e.g. consent forms,) will be stored securely and separately from all associated data. We will destroy your contact information once the interview has been completed. Audio recordings will be stored securely and separately from all other study data including participant consent forms and all other study data. Pseudonyms (unique ID numbers) will be used for all other data to protect anonymity. The database linking your pseudonym (unique ID number) to your name will be stored in a secure location, separate from all other study data. The database that will link your name to a pseudonymisation ID number will be retained until all transcriptions have been completed and the data has been analysed. Once this database has been destroyed the data will be completely anonymous, therefore the link between the participant and study data cannot be made. Audio recordings will be recorded on a University of Manchester approved device. Data will be transferred to the University server as soon as possible and deleted securely. All recordings will be deleted once transcription is complete. Once your unique ID code has been assigned and all identifiable information has been removed, it will be shared with members of the research team who are affiliated with other institutions to aid the analysis process. This information will be password protected and sent via email or post. Furthermore, this data will be destroyed using confidential waste facilities when no longer required.

Five years after the last publication (or 10 years whichever is greater) all research data will be destroyed. Physical data will be shredded and incinerated. Electronic data will be shredded using an electronic shredding programme.

Potential disclosures:

If, during the study, we have concerns about your safety or the safety of others we will need to inform your clinical care team. If at any point we have significant concerns about your safety or the safety of others we may have to exceptionally contact emergency services without your consent. This is something that we would discuss with you first, if possible.

Individuals from the University, the site where the research is taking place and regulatory authorities may need to review the study information for auditing and monitoring purposes or in the event of an incident.

Use of audio recordings

Audio-recordings are essential to the study. The devices used for audio-recording will be University of Manchester approved, encrypted and exclusively for research use. A member of the research team or an approved University of Manchester employee who has signed a confidentiality agreement will transcribe interview data. These interviews will be pseudonymised. This means that the researchers will assign a unique code (e.g. SO1) to your name so that your data cannot be identified. No personal identifiable information will be included in the final transcript and the direct quotations used for publication will not be identifiable. Audio-recordings will be deleted as soon as transcription has been completed.

Please also note that individuals from The University of Manchester or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data. All individuals involved in auditing and monitoring the study will have a strict duty of confidentiality to you as a research participant.

What if I have a complaint?

Minor complaints

If you have a minor complaint then you need to contact the supervisor of the researcher(s) in the first instance.

Dr Katherine Berry

School of Health Sciences

University of Manchester

Zochonis Building, 2nd Floor

Brunswick street

Manchester

M13 9PL

Email: katherine.berry@manchester.ac.uk

0161 2758485

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact the **Research Governance**

and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning **0161 275 2674** or **275 2046**.

If you wish to contact us about your data protection rights, please email dataprotection@manchester.ac.uk or write to The Information Governance Office, Christie Building, The University of Manchester, Oxford Road, M13 9PL at the University and we will guide you through the process of exercising your rights.

You also have a right to complain to the [Information Commissioners Office about complaints relating to your personal identifiable information](#) Tel 0303 123 1113

<https://ico.org.uk/make-a-complaint/>

Independent Advice

[If you would like to seek independent advice regarding this project, please contact your local Patient Advice and Liaison Service \(PALS\):](#)

Greater Manchester Mental Health NHS Foundation Trust (GMMH)

[Telephone: 0800 587 4793](tel:08005874793)

[Email: Customercare@gmmh.nhs.uk](mailto:Customercare@gmmh.nhs.uk)

Pennine Care NHS Foundation Trust

[Telephone: 0161 716 3178](tel:01617163178)

North West Boroughs Healthcare NHS Foundation Trust

Telephone: 01925 664450

Lancashire Care NHS Foundation Trust

Telephone :01772 695315 Email: Hearing.Feedback@lancashirecare.nhs.uk

Harm

In the event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against the University of Manchester or Greater Manchester West Trust, North West Boroughs Trust, Lancashire Care Trust or Pennine Care Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you

Contact Details

If you have any queries about the study or if you are interested in taking part then please contact the researcher(s)

Elizabeth Turner, Trainee Clinical Psychologist, The University of Manchester

Email: Elizabeth.turner-4@postgrad.manchester.ac.uk

Mobile: 07384659138



**Health Research
Authority**

North West - Greater Manchester East Research Ethics Committee

3rd Floor, Barlow House
4 Minshull Street
Manchester
M1 3DZ

Please note: This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 December 2019

Mrs Elizabeth Turner
Trainee Clinical Psychologist
Greater Manchester Mental Health Trust
Division of Psychology and Mental Health, School of Health Sciences, The University of Manchester
Zochonis Building
Manchester
M13 9GB

Dear Mrs Turner

Study title: Understanding the perceived relationship between oral health and psychosis
REC reference: 19/NW/0723
Protocol number: 1
IRAS project ID: 270350

Thank you for your response of 29 November 2019. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 November 2019.

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Other [Information for HRA and REC]		
Participant information sheet (PIS) [2. PIS Oral Health V2]	2	29 November 2019
Research protocol or project proposal [1. Protocol Oral Health V2]	2	29 November 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

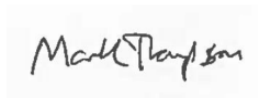
<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Manchester Insurance]	1	30 October 2019
GP/consultant information sheets or letters [9. Letter to clinical team oral health V1]	1	30 September 2019
Initial Assessment for REC		
Interview schedules or topic guides for participants [13. Draft Topic Guide]	1	30 October 2019
IRAS Application Form [IRAS_Form_04112019]		04 November 2019
Letter from sponsor [Sponsor Letter]	1	30 October 2019
Non-validated questionnaire [Oral Health Survey]	1	30 October 2019
Other [4. Consent to Contact Oral Health V1]	1	30 October 2019
Other [4.1 Consent to Contact Oral Health V1]	1	30 October 2019
Other [6. Information for Professionals Oral Health V1]	1	30 October 2019
Other [14. Demographics Data Collection Sheet]	1	30 October 2019
Other [15. Crisis Card]	1	30 October 2019
Other [16. Right from the Start Resource]	1	30 October 2019
Other [17. Risk assessment Oral Health]	1	30 October 2019
Other [18. Email to services]	1	30 October 2019
Other [Employers Liability Insurance]	1	30 October 2019
Other [Insurance Confirmation]	1	30 October 2019
Other [Insurance for research project]	1	30 October 2019
Other [Leah Quinlivan CV]	1	30 October 2019
Other [Vishal Aggarwal CV]	1	30 October 2019
Other [Jasper Palmier-Claus CV]	1	31 October 2019
Other [5. Distress Protocol Oral Health V1]	1	30 October 2019
Other [Information for HRA and REC]		
Participant consent form [3. Consent Oral Health V1]	1	30 September 2019
Participant information sheet (PIS) [2. PIS Oral Health V2]	2	29 November 2019
Referee's report or other scientific critique report [The University of Manchester Research Subcommittee Approval]	1	30 October 2019
Research protocol or project proposal [1. Protocol Oral Health V2]	2	29 November 2019

Response to Additional Conditions Met		29 November 2019
Summary CV for Chief Investigator (CI) [Elizabeth Turner CV]	1	30 October 2019
Summary CV for student [ET CV]	1	30 October 2019
Summary CV for supervisor (student research) [KB CV]	1	30 October 2019
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Insurance document]	1	30 October 2019
Validated questionnaire [Oral Health Impact Profile-14]	1	30 October 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

19/NW/0723	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Mark Thompson
Approvals Officer

E-mail: nrescommittee.northwest-gmeast@nhs.net

Copy to: *Mrs Elizabeth Turner, Greater Manchester Mental Health Trust*
Ms Sarah Leo, Greater Manchester Mental Health Trust

The Mouth and Mind Study- Participant Consent Form

Understanding the perceived relationship between psychosis and oral health

If you are happy to participate please complete and sign the consent form below

		Please initial box
1	I confirm that I have read and understood the attached information sheet (Version 2, Date 29/11/2019) for the above study. I have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2	I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to myself or the standard of care I receive. I understand that it will not be possible to remove my data from the project once it has been anonymised and forms part of the data set. I agree to take part on this basis.	
3	I agree to the interviews being audio recorded.	

4	I agree that anonymised direct quotes from the interview can be used in the write-up of the research	
5	I understand that data collected during the study may be looked at by individuals from The University of Manchester, the Trust or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
6	I agree that pseudonymised data may be shared with members of the research team who are at different institutions.	
7	I agree for my clinical care team be informed about my involvement in this study.	
8	I understand that there may be instances where during the course of the interview information is revealed (e.g. concerns about your safety or the safety of others) which means that the researchers will be obliged to break confidentiality and this has been explained in more detail in the information sheet.	
9	I agree to take part in this study.	

Data Protection

The personal information we collect and use to conduct this research will be processed in accordance with data protection law as explained in the Participant Information Sheet and the [Privacy Notice for Research Participants](#).

<http://documents.manchester.ac.uk/display.aspx?DocID=37095>

Please see the sheet overleaf for further details.

Name of Participant

Signature

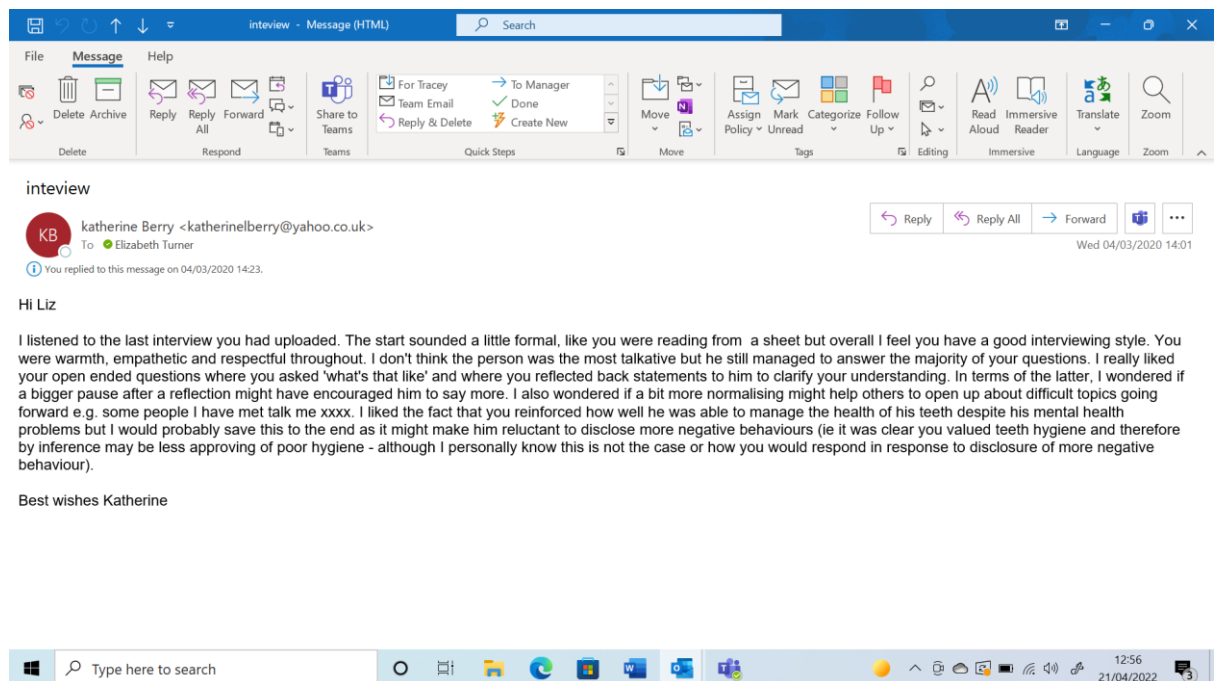
Date

Name of the person taking consent Signature

Date

[1 copy for the participant, 1 copy for the research team (original)]

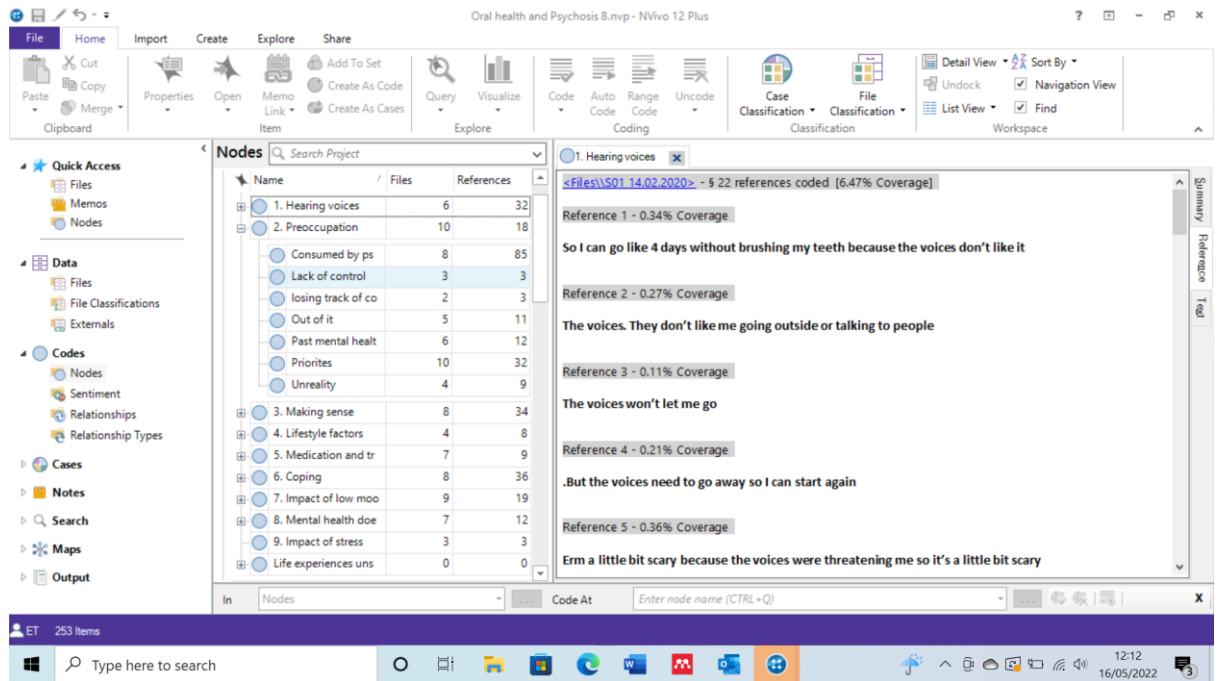
Appendix M: Feedback from interview



Appendix N: Active reading example

S13	Thoughts
Appearance	Gender differences in how men / women worry about appearance of teeth- unable to smile,
Deterioration	inevitability of teeth getting worse and emotional impact – upset/ embarrassed, Progressively gets worse Over time Losing teeth “before your time” Age as a factor Acceptance
Psychosis	Specific experience? Psychosis? Preoccupied, stops me from doing it
Dentist continuity	
Emotional impact	reflecting on difficult times, bigger emotional impact
Fluctuating ability	“2 sides to it” – obsessed about or in psychotic episode hours pass less attentive
Causal factors? Blame?	Smoking/ drug use in the past

Appendix O: Nvivo Coding



Appendix P: Early theme development

Transcript no.	Key aspects	Example	Notes
S01	<p>Dental/ Dentist Fear</p> <p>Capability/ Confidence</p> <p>Trying my best/ I'm doing the best I can</p> <p>Forgetfulness responsibility</p> <p>Psychosis impact on oral health</p> <p>Voices stopping self-care/ dental visits, increasing in intensity/ steal my teeth</p> <p>Dental problems</p> <p>Pain/ needle</p>	"It's not my fault"	

	Poor routine and poor oral health		
S02	<p>Dentures- more comfortable going out, wouldn't go out with gap- don't want people to see</p> <p>Seeking approval for answers</p> <p>Worry about impact on eating</p> <p>Eating difficulties – hard to chew</p> <p>Keeping a routine</p> <p>Support from friend- better at putting things across</p> <p>Feel better after oral hygiene routine</p>	<p>S13 – wouldn't go out without denture</p> <p>S16 – feel good vibes</p>	
S04	<p>Unusual beliefs – fluoride, learnt from childhood – being poisoned/ trusting mouthwash over toothpaste</p> <p>No current difficulties</p> <p>Poor routine – calls self lazy / can't be bothered</p> <p>Impact of drug taking</p> <p>Relationships – reason for good OH</p> <p>Shame / embarrassment – stigma?</p> <p>Fear of negative judgement</p> <p>Trying to make sense – cavemen</p> <p>Experiences when mentally unwell – ate full tube of toothpaste “alkaline”</p>	<p>S13 Relationships</p> <p>S06 Flouride</p> <p>S14 S10 straighter teeth</p>	

	Desire for straighter teeth		
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Appendix Q: Excel Developing themes

Theme 1: Barriers to good oral health	Theme 2: Oral health erodes mental health	Theme 3: Support systems influence oral health
1.1 A psychotic disconnect	2.1 Self identity	3.1 Professional support systems
Preoccupation	Self-loathing	Didn't seek help
Consumed by psychosis	Self-esteem (unsure about code name?) Appearance	Good environment
Past mental health	Self-esteem – stigma of wearing dentures	Informative support
Unreality	Unclean	Lack of choice
Lack of control	Impact on mental health	Lack of support
Losing track of conversation	Impact on wellbeing	Mental health support
Out of it	Impact on confidence	Mental health treatment
Priorities	Emotional impact	Need for collaborative care
Inevitability	Upset	Need for holistic care
Being thorough	Regret	Not needed support
Obsessive overbrushing	Process over time	Not wanting help
worries about overbrushing	Worries about deterioration	Reassurance
Trying my best		Specialist support
1.2 Psychotic experiences creating fear	Emotional impact	Staff support
Hearing voices	Deterioration	Stigma of asking for support
Derogatory voices	Accept deterioration	3.2 Informal support
Paranoia	Deterioration of oral health	Support from friends
Unusual beliefs	2.2 Avoiding people	Family support
Positive unusual beliefs	Impact on relationships	Family support with dental problems
Suspicious about fluoride	Impact on smiling	
1.3 Chemical inevitability	Impact on socialising	

Lifestyle factors	Negative judgements from others
Drugs and alcohol	Impact on talking
Lifestyle factors - Food and drink	
Lifestyle factors - Smoking	
Medication and Treatment	
Absence of side effects	
Anti-medication	
Lack of choice	
Benefits of medication	
Managing side effects	
Medication side effects	
Changes to appearance	
Desire to lose weight	
Coping	