Patient involvement to explore research prioritisation and self-care management in people with periodontitis and diabetes

Running title: PPI in periodontology

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Acknowledgements

Abstract

Aim:

To investigate, firstly, research priorities for people with periodontitis and periodontitis and diabetes. Secondary aims were to explore disease self-management barriers, difficulties and enhancers for people with periodontitis and/or diabetes, mutual learning in patient groups regarding self-care and views of academic researchers on patient-derived research prioritisation.

Materials and Methods:

Research prioritisation and self-care management was based on the James Lind Alliance workshop methodology. Participants generated and ranked research priorities and enhancers and barriers to self-care management. Semi-structured interviews were undertaken to explore the views of academic staff about patient and public involvement (PPI) and the findings from this research.

Results:

Periodontitis patients ranked preventive educational interventions highest whereas the top priority for those with both periodontitis and diabetes was increasing public awareness about periodontitis and systemic health links. Regarding self-care, both periodontitis and diabetes groups highly ranked the importance of being able to self-assess their condition and efficacy of management. Important barriers for the diabetes patients were psychological issues while for periodontitis patients the main barrier was receiving conflicting or lacking information. Both groups reported shared learning helped to develop a better understanding of their conditions and improved management. Academics believed it was essential to involve patients in developing research and most felt the findings would influence their institutions research priorities; however, they would not change their own research only based on patient's perspectives.

Conclusions:

The workshops led to new insights for research priorities and approaches for health self-management. PPI should be further investigated across oral health applications.

Abstract 243 words

Keywords

Clinical relevance

Scientific rationale for study

Patients' views and priorities are rarely considered in designing periodontal research despite patients being at the receiving end of all our therapeutic efforts. Research funders are increasingly insisting on the need to involve patients when designing research studies to ensure that investigations remain relevant and meaningful for the ones ultimately receiving care. In our field, it is of the utmost importance to understand what aspects of research and self-care are considered as more important by patients and the public. This ranking and prioritisation may be useful for the individual researcher, research organisations and funding bodies; given limited funding and resources, allocation should be guided in some instances by what is relevant to those receiving care.

Principal findings

Patient involvement can identify novel concepts for research and key aspects of methodology that patients consider important. Patient priorities may differ from academic researchers potentially undermining the relevance of the research.

Practical implications

Patient involvement in periodontal research should be considered a priority. Methods to best achieve this need to be investigated based on the body of research that already exists on involvement within healthcare.

Introduction

Diagnosis, prevention and treatment in healthcare is generally driven by research aiming to improve the health and wellbeing of patients[1]. This research is usually carried out _on_ but rarely _with_ patients as part of the research team. Currently however, there is a strong

emphasis to change this culture as part of an agenda to improve both quality and relevance of research. The UK National Institute for Health Research (NIHR) will only fund studies which incorporate patient and public involvement (PPI)[2]. The potential opportunities for PPI range from identifying research questions to interpreting and analysing results and sharing or disseminating findings more effectively to people for whom the research is intended to benefit[3,4]. Involvement, engagement and participation of the public are connected but are distinct. The NIHR advisory group on patient involvement in research, INVOLVE, classifies public involvement in research as 'research being carried out with or by members of the public'. Whilst public engagement to raise awareness of research and create a dialogue with the public are important, this is considered separate to PPI[5].

Involving patients can develop new insights into what patients believe is important[6]. One recent example explored experiences of adults with intellectual disabilities and highlighted the need for better access to chronic disease management in primary care[7]. PPI can lead to improved quality of research and relevance due to the unique perspective that people with lived experience of a condition (or carers) can bring to studies[8, 9].

Marked differences have been shown between existing research strategies and patient priorities in osteoarthritis. Existing research focused heavily on drug therapies. In contrast, patients wanted to know more about knee replacement surgery and educational interventions[10]. The James Lind Alliance (JLA) was developed to facilitate PPI in research prioritisation[11]. The methodology employs Priority Setting Partnerships (PSPs), where patients, carers and clinicians focus on single conditions and discuss aspects of research that they feel are important[12 13].

To date, there have been few published studies investigating PPI in oral health. One priority setting exercise involving PPI for oral health was undertaken in collaboration between the NIHR Clinical Research Network Oral and Dental Health Specialty Group, Dental Schools Council and Public Health England and supported by the JLA[14]. From a list of 1100 questions in 38 themes generated from a UK survey of the public, patients, carers and dental health professionals, 25 questions were ranked in a priority setting workshop. The top priority was

prevention of tooth decay and reduction of oral health inequalities. Periodontal health was one of the top ten priorities focussing on the best way to prevent gum disease.

Another study of PPI in oral health explored possible research methods using co-production to investigate patients with complex needs in special care dentistry[15]. Co-production embodies researchers, practitioners and the public working together, sharing power and responsibility from the start to the end of a research project, including the generation of knowledge[16]. Other studies have attempted to provide a framework for good practice when carrying out priority setting partnerships, building consensus amongst knowledge users (patients, carers and clinicians) and knowledge producers (researchers)[17].

To date, there have been no PPI or co-production studies reported within periodontology. We recognised that PPI might be particularly important for health conditions such as periodontal health and diabetes, where patient engagement and adherence to care may be decisive in both improving health and wellbeing and reducing the risk of complications. Periodontitis and diabetes are common chronic inflamamtory conditions which require an element of self-care for their management. With the strength of the established bi-directional link between type II diabetes and periodontitis it was an important topic to explore with patients for future research and providing some insight into ways in which patients can be empowered to control their disease. Empowerment and control for diabetic patients is crucial in disease management and is recognised by the National Health Service which offers courses known as Desmond (Diabetes education and self-management for ongoing and newly diagnosed, for type II diabetes) or DAFNE (Dose adjustment for normal eating, for type I diabetes)with the aim of helping patients to achieve this. Even though we did not explore this further in this research project, advice on periodontitis self-care could potentially be incorporated into these educational courses. The primary aim of this project was to investigate the research priorities of people with periodontitis and those with periodontitis and diabetes. In addition, the study sought to report

- how people with these long-term conditions self-manage their health in relation to barriers, difficulties and enhancers.
- mutual learning in the patient groups in relation to self-care

- views of academic researchers on patient-derived research prioritisation and their own research priorities

Materials and methods

Study design

Ethical approval was obtained from University College London, Research Ethics Committee ethics ID number 13405/001. Verbal and written consent was obtained. We based the study design on the methodology proposed by the JLA[2]. We used participant workshops, semi-structured interviews and group discussions. Twelve participants were invited to each of the two workshops. Each workshop was three hours and was moderated by the researchers. The participant numbers were determined by the recommendation from the JLA[2]. Workshop one involved research prioritisation aiming to generate and rank research priorities of participants with periodontitis or those with periodontitis and diabetes. The second workshop investigated self-care management in relation to barriers, difficulties, and enhancers for people with periodontitis, diabetes or both conditions concurrently. We also aimed to explore whether participating in the workshops led to new learning that might benefit self-management. Finally, we looked at eight academic researchers' views on PPI-derived research prioritisation from the workshop. We examined these perspectives through semi-structured interviews with academics within the field of periodontology at the Eastman Dental Institute, University College London and Kings College London.

Participant recruitment and study population

Participants were recruited from the Eastman Dental Hospital, University College London Hospital NHS Foundation Trust, Diabetes UK (by liaising with their patient and public involvement research team) and the UCL/UCLH Biomedical Research Centre Oral Health Patient Forum. The participants had all agreed to participate in PPI research and were either enrolled with the organisations or were recruited from the hospital through personal contact by one of the study researchers (PR). Participants with type I or type II diabetes were recruited to this study as both types require self-management. The diabetes diagnosis was confirmed either through the UCLH endocrinology department or through diabetes UK. No threshold for HbA1c or the stage and grade of periodontal disease was used or tested prior to recruitment of participants to this project. Academic researchers were interviewed face to face.

Inclusion criteria

Patient workshops:

1. People with periodontitis, diabetes (type I or type II) or both concurrently

2. Informed consent

3. Aged 18 years or over

4. Able to understand the consent process

5. Consent for audio recording and photography

6. English speaking

7. Willing to contribute to discussion in the workshop

Academic researchers:

1. Currently or previously involved in periodontal research

2. Not affiliated with this study

Research prioritisation workshop

Participants were divided in to two groups: those with periodontitis or those with both periodontitis and diabetes. In total there was seven participants with periodontitis and five with periodontitis and diabetes. The groups each nominated an individual to collate and present their findings. A 15-minute introductory presentation was delivered to the groups by one of the researchers (PR) summarising concepts of periodontitis and current research in periodontology and diabetes.

Workshop structure:

1. Individual participants identified their own research topics. A list of example research topics (generated through literature review) was provided as a guide if needed. However, participants were encouraged to identify their own research priorities.

2. Synthesis of the topics into themes within workshop groups.

3. Discuss and agree ranking of the topics for research within groups where possible. Groups were asked to include reasons for selecting and ranking the topics.

4. Presentation by each group of topics and rankings followed by a general discussion between participants. After the discussion, each group had the opportunity to amend and agree final rankings.

Self-care management workshop

The self-care workshop followed a similar structure with the same presentation and presenter (PR) as the first workshop. The two participant groups were people living with periodontitis or diabetes only. Participants with both conditions were allocated to the periodontitis group. In total there were five participants in the periodontitis group and three in the diabetes group.

Workshop structure:
1. Individual participants were asked to identify factors that enhanced or acted as barriers to their self-care.
2. Ranking of importance of self-care factors by discussion and agreement amongst participants.
3. Presentation by each group to plenary and finalisation of items and rankings, achieved by discussion between groups.
4. Identification of new learning arising from the workshop.

Semi-structured interviews

Semi-structured interviews were undertaken with academic researchers in periodontology at the two universities in London. Nine questions were included in the interview and the questions were developed from the results produced from the research prioritisation workshop. The interview sought responses to:
1. What were the academics research priorities in the field of periodontitis and diabetes?
2. What were the researchers' views about the patients' priorities?

A table summary of the PPI workshop research priorities results was shown to the academics and questions asked in relation to these results. The responses were recorded verbatim and tabulated. Analysis of the academic responses was undertaken by examining the recurrent themes and interpretation of the qualitative responses. The data and results were collated and tabulated for all eight academic interviews.

Results

The workshop participants were from different parts of the UK and ranged in age from 18-74 years old. In total nine males and 11 females attended for both workshops. Overall, 10 participants had periodontitis, three had diabetes (two had type II diabetes and one had type I diabetes) and seven had both conditions (periodontitis and type II diabetes). We had four participants who did not attend.

Research priorities (Table 1)

Periodontitis group: Eight research priorities were ranked (all statements, words and ideas are verbatim). The top three research priorities for this group included educational interventions, holistic approach to treat periodontitis and the contribution of genetics to periodontitis.

Periodontitis and diabetes group: This group ranked five research priorities. The top three included improving public awareness, targeted check-ups for people with periodontitis and diabetes and the development of medications to treat both periodontitis and diabetes simultaneously.

Comparison between groups: In both groups, education, intervention, prevention and public awareness were identified as the top categories. The second ranking differed between groups; for the periodontitis group this related to holistic approaches to treat periodontitis and for those with periodontitis and diabetes, development of targeted check-ups for people with both periodontitis and diabetes.

Results from the self-care management workshop (Table 2)

The data generated from this workshop was in the form of statements or paragraphs. An item was only ranked if its inclusion was agreed by all members of the group.

Ranking of enhancers and barriers (periodontitis group)

In total, six enhancers and seven barriers were ranked. The top three enhancers included: an organised daily regime, ample availability of oral hygiene products and being able to carry the products with you. The barriers consisted of conflicting information from healthcare

professionals, alternative agendas of the dentist (such as having their own targets to reach) and the cost of the products.

Ranking of enhancers and barriers (diabetes group)

In total, nine enhancers and six barriers were ranked. The top three enhancers included: a blood glucose meter app enabling monitoring of own blood sugar levels, relevant educational materials and easy contact with doctors and nurses across the country. The top three barriers identified were: psychological barriers, stress/lack of control and costs related to self-care management such as buying tools like glucose monitors.

Identification of new learning from workshop participation (Table 3)

New learning was reported from both groups. A key insight from the periodontitis group was learning about the potential effect of gum health on systemic health and the importance of developing a routine for plaque control. The diabetes groups reported improved learning about their own condition through the presentations and from sharing experiences with other participants. Crucially, both groups felt that the new and shared learning helped them to understand and better manage their conditions. Post-workshop formal evaluation indicated that 75% of the research prioritisation workshop participants and 100% of the self-care workshop participants reported new learning.

Academic research priorities (Table 4)

In total, eight interviews were undertaken, involving four academics from each university. The participants included ranged from junior to senior researchers. In terms of the research priorities reported by the academics, these could be categorised into three areas:

1. Periodontitis-diabetes: two researchers, including link mechanisms and best management
2. Periodontitis-other systemic health: four researchers, including management of complex risk factors, cardiovascular disease and neurological disease
3. Periodontitis alone: two researchers, including treatment in primary care and patient reported outcomes

Following presentation of the patient workshop-generated results, the most popular topic for research (selected by three academics) was the development of a single medication that could treat both periodontitis and diabetes.

Academic researcher's views on patient priorities (Table 4)

The patients' views had a measurable initial impact on the academic researchers. All reported that the workshop findings generated ideas that they had not previously considered such as a medication to simultaneously treat both periodontitis and diabetes, and most (6/8) thought it is essential to involve patients in research. The majority (7/8) felt that the results might have at least some influence on their intuitional research priorities. In contrast, none of the academic staff thought that the results from the research prioritisation workshop would make them change their own current research priorities.

Discussion

We believe that this is the first study specifically in periodontology to investigate PPI for research prioritisation and the findings offer important insights both for research design and for healthcare. In this research project, we explored related health conditions of patients and investigated aspects which previous research had not considered such as the development of medications to treat related but different chronic inflammatory conditions. In addition, this project demonstrated how patient groups can benefit and help one another in terms of mutual learning and dissemination of knowledge relating to disease management. Not surprisingly, participants' health status appeared to influence their research priorities. In addition, bringing patients together with different but related health conditions led to mutual learning about their health which also influenced the outcome of the prioritisation. For example, as shown by the concept of developing a single medication to treat both periodontitis and diabetes, both being inflammatory conditions

Perhaps surprisingly, the highest priority research topics for the periodontitis and periodontitis and diabetes groups were educational interventions for prevention of periodontitis and increasing public awareness regarding the periodontal and systemic health links. This priority suggests that they viewed prevention and self-management as most important to future health.

Participants' health status strongly influenced research priorities as might be expected. For example, those with both conditions gave a higher priority to research that investigated the links between the conditions whereas people with periodontitis alone were more focused on oral health alone despite presentations and discussion regarding the links between periodontitis and systemic health conditions. The periodontitis group ranked the side effects of periodontal treatment as a research priority. This is important as a lack of assessment or reporting of adverse effects is a frequent finding in oral health research[18, 19].

Top ranking enhancers of self-management for people with periodontitis included having appropriate oral hygiene aids, utilising technology and knowing how to manage periodontal inflammation. These enhancers are also related to proposed research priorities such as education and prevention. Therefore, factors which help participants self-manage their condition are also areas of priority for further research. The barriers to self-care management of the periodontitis group involved costs and the conflicting information about different types of oral hygiene products (such as the use of floss versus interdental brushes) even though there is evidence for greater efficacy of interproximal brushes for prevention of periodontitis compared with other devices[20]. Therefore, there appears to be a gap between best evidence and awareness or practice; this is well recognised in many healthcare applications[21]. In view of the fundamental importance of effective plaque removal for periodontal health[21], methods to improve knowledge transfer would seem a priority for research[22].

The diabetes group prioritised a more holistic approach to care highlighting the need for materials for self-education to enhance their self-management and easy contact with healthcare professionals to help with their glycaemic control. Similar to the participants living with periodontitis, barriers to self-care were factors resulting in loss of control over their health, such as the lack of understanding and education about their condition. Therefore, a major commonality for patients with either or both chronic diseases (periodontitis and diabetes) is being empowered with knowledge and materials (and their availability) to support self-management. Both from a research and healthcare perspective, being empowered and having this material improves self-management and therefore warrants greater emphasis.

The immediate impact of the workshop findings on the academic researchers was striking in terms of generation of new ideas and potential influence on institutional research priorities. However, the academics reported that none planned to change their own research priorities based on the patient's perspectives. This might be a consequence of existing similarities between the researcher's areas of interest and those prioritised by the workshop participants. For instance, six of the eight researchers already prioritised periodontal health and general health research themes. The potential lack of direct influence of PPI on the researchers might also be related to the methods of the study, particularly the researchers lack of participation in the PPI workshops as is standard for the JLA methodology. Further research should investigate the effect of involving academic researchers together with patients on the dynamics of research formulation[15].

There were several limitations to this study. Firstly, ideas were often voiced in the workshops that were not research questions but policy issues. E.g. "GP's/nurses to target patients who are at increased risk of developing diabetes and/or periodontitis". There was also an imbalance in the participant numbers in the workshop. For example, in the self-management workshop the diabetes group only consisted of three participants, as opposed to five participants who had periodontitis or both conditions, this was in-part due to the non-attenders on the day. No assessment was made regarding the extent and severity of the participants disease (periodontitis, diabetes or both) and whether some participants needed to exercise more control on their condition compared to others. The time available in the workshops (three hours) was limited to manage these issues. Specifying more clearly the requirements of a research question might have been helpful although it might also have constrained discussion. Another option would be to allow for a further separate session for development of research questions. A further limitation was the difficulty of ensuring equitable contribution from all the different participants to the discussions. The nominal group technique has been suggested as one approach to capture all views[2]. Nevertheless, formal evaluation of the workshops found that all participants felt able to participate (data not shown). Clearly, the findings from the workshops might not represent the views of UK patients more broadly; however, participants were recruited from diverse ethnic and sociodemographic backgrounds to try and ensure a representative sample. Conducting

additional workshops in different settings would be helpful to determine the 'stability' of the findings.

Comparison with previous studies

We found no previous studies on periodontal health with PPI through literature search other than the oral health project described previously (Oral and Dental Health Priority Setting Partnership 2018).

Conclusions

Patients' research priorities are influenced by their health status and may differ markedly from those of academic researchers. The workshops engaged participants and led to new insights for both research prioritisation and the approaches for health self-management. PPI can produce important new information both for research and patient management and should be further investigated across oral health applications. We recommend more development of PPI for oral health research to explore its potential to improve research and to evaluate its impact on improving healthcare outcomes, research quality and relevance and benefits to participants and patients.

Declaration of interests

The authors declare no conflicts of interest. Ian Needleman is an advisory group member of the UCL Centre for Co-Production in Health Research and leads the British Society of Periodontology Patient Forum.

We used the SRQR checklist for reporting studies of qualitative research.

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