

The Sheldon Friel Memorial Lecture 2020:
It's not just about the teeth: Patient-centred Orthodontics

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Summary

The provision of high quality healthcare involves many different aspects, including safety, effectiveness, efficiency, and patient centredness. In order for care to be truly patient centred requires patients' views being sought and considered, and this may be achieved through patient centred research. Patient centred research is fundamentally important in contemporary health care and has many benefits; for example, it ensures that research is relevant, identifies those aspects of care which are important to patients, provides information which is important to current and future patients, and allows integration of patients' views regarding how services may be enhanced in the future.

This paper provides an overview of how we currently involve patients in orthodontic research, what this means to the specialty and how we can enhance patient involvement in the future.

Patient centred research

The term “patient centred research” is becoming increasingly important in healthcare and is likely to be even more so in the future. Patient centred research examines the beliefs, preferences, needs, and values of patients (1) and focuses on the questions and outcomes which matter most to the patient. Crucially it provides information for us, as clinicians, so that we have a better understanding of our patients’ experiences, preferences and outcomes. As such, patient centred research provides information which is important to current and future patients, to clinicians and to funders of treatment.

Research in medicine and dentistry has traditionally been clinician-centred and has focused on measurable clinical outcomes, for example in orthodontics many studies have focussed on cephalometric outcomes or clinical measurements, such as changes in overjet. Such studies undoubtedly remain important but, equally important in healthcare, is the patient perspective and this is where patient centred research becomes a key area of contemporary practice. Patient centred research is an evolving area and it is not just about including patients as participants in research, it is also about involving patients in the design and conduct of research (2) and allowing patients to “have a voice” which is heard and acted upon; it is only by including patients in this way that we can provide the highest quality patient centred care.

Patient involvement in orthodontic research

It is therefore important to consider how well we currently involve patients in orthodontic research. A systematic review by Tsihlaki and O’Brien looked at how well research in orthodontics reflects the values of adolescent patients (3). The review included 133 papers reporting randomised controlled trials in orthodontics and found that the majority (63%) measured morphological features of malocclusion but only 9% considered quality of life and social outcomes, aspects which are clearly of importance to the patients themselves. The authors highlighted the importance of developing a core set of outcomes for use in orthodontic trials which could allow this limited patient focus in research to be addressed. There has undoubtedly been an increased focus on patient centred research since this paper was published in 2014 and this reflects many aspects of clinical care, including changing patient expectations. It is therefore incumbent on the profession to reflect on this and continue developing these areas of research.

The primary goal in healthcare is to provide the highest possible quality of care for our patients and high quality care means looking at the safety and outcomes of our treatment and also considering the patient experience (4). As clinicians, we can certainly comment on these but

only our patients can give us their own perspective. This paper will therefore focus on three areas, look at the patient centred research evidence and consider how it may help in clinical practice:

1. Patient experience
2. Patient reported outcomes
3. Patient satisfaction

1. Patient experience

The patient experience incorporates many different elements of care and this is one area of orthodontic research where there has been significant interest in the last 10-15 years. The fundamental aim in providing a good patient experience is to deliver care where patients' values, preferences and needs are considered and to ensure that the patient is at the centre of decision making (5).

The introduction of qualitative research in orthodontics has undoubtedly contributed to our understanding of how patients want their treatment to be delivered and how they perceive that treatment; it is vital that we understand these concepts if we want to enhance delivery of care. A qualitative study by McNair *et al.* explored patients' perceptions of orthodontic care within the UK National Health Service setting and found that the aspects of care which were most important to patients were: being treated with respect, being included in discussions and having kind, supportive clinicians and nurses (6). Similar themes were also highlighted in more recent qualitative research looking at hypodontia care (7) and adult orthodontic treatment (8). Patient quotes from both studies highlight how much patients value being treated with respect and being involved in decision making about their own care.

"I felt that I was looked after. I felt that every part of the treatment was explained to me so I knew exactly what was going to happen."

"All the dentists I had were really nice and friendly."

(7)

"It made the whole process feel a bit more collaborative. It was kind of a shared process."

".....They ask for your opinion, they show you things and I felt that I'd come to the right place."

However, involving patients in decision making about their treatment goes far beyond the informed consent process. Shared-decision making (SDM) is about the patient and clinician working together to select treatment, based on clinical evidence but also based on the patient's own preferences and values (9). There is limited research in this area in orthodontics, but there is evidence that we do not practice shared-decision making as well as we perhaps should (10,11). Motamedi-Azari *et al.* used the Control Preference Scale to investigate how well a cohort of 100 adult orthodontic patients felt they had been involved in decision making about their own treatment. There was a disparity between how much the patients wanted to be involved in their own care and how well they felt they had actually been involved, with patients generally wanting to be more actively involved in decision making about their own treatment (10). Interestingly these findings were similar to other studies in dentistry in both the UK and Germany (12,13). This highlights the importance of encouraging patients to have a more active role in their care, with the intent of ultimately improving patient satisfaction. It also highlights the importance of ensuring that clinicians are appropriately trained in shared-decision making at all stages of their career in order to achieve optimal patient involvement (14).

One way that the SDM process can be enhanced is through the use of patient decision aids (PDAs) which help patients make informed choices about their care, taking into account their own personal values and preferences (15). Patient decision aids can take various formats including leaflets, internet-based programmes and decision boards and they go a step beyond our usual information resources in that they require patients to consider how they really feel about the options being offered. There are several examples in dentistry, including two in orthodontics and, importantly, both PDAs were developed with patient input and were then tested by adolescent orthodontic patients (16,17). The primary outcome in both studies was decisional conflict regarding whether or not to proceed with fixed appliances. Whilst the Parker *et al.* randomised controlled study did not find a significant difference in decisional conflict between the PDA and the control group (16), the Marshman *et al.* study found that decisional conflict was reduced after having access to the PDA and, additionally, both patients and parents also had more realistic expectations of treatment (17). Research focussing on the effectiveness of such PDAs in orthodontics is important for the future and may prove useful in areas such as orthognathic treatment where there are several potential treatment options to consider, all with distinct advantages and disadvantages.

Another crucial aspect of the patient experience is the provision of clear, comprehensive information, delivered in a way in which patients can readily access it. Research in this field has evolved over the years from the relatively early publications looking at, for example,

comparison of verbal information, information leaflets and videos/DVDs (18-22) to more recent research looking at the internet, social media and Apps to provide high quality information (23-25). The evolution of research in this area has undoubtedly been led by patients' wishes to utilise the internet and social media for information seeking in all aspects of healthcare. With more than 4.5 billion people using the internet and 3.8 billion social media users at the start of 2020 (26), there is no doubt that patient demand will continue to drive information development further along this route.

The findings from some studies investigating the use of social media in orthodontics are undoubtedly encouraging. For example, Al Silwadi *et al.* undertook a randomised controlled trial to investigate the effect of a YouTube video for patients having fixed appliance treatment and found significantly better knowledge in those patients who had access to the video compared with a control group who received only the routine information provided (23). However other studies in this area give cause for concern, especially where the accuracy of information has been investigated (27). The obvious question which therefore remains is how we ensure that information is accurate, high quality and truly patient centred. The key to this is involving patients in the development and provision of the information and also asking patients to assess those information resources which have been developed. This is an important area where researchers and patients can work together and is illustrated in two examples of information resources developed by our national society, the British Orthodontic Society (BOS). *Your Jaw Surgery* (<https://www.bos.org.uk/Your-Jaw-Surgery>) is an online resource for patients considering orthognathic treatment; this resource has been developed and refined based on research studies in which patients were asked to discuss how useful they found the resource and what changes they would suggest for future versions. Flett and colleagues worked with patients to evaluate the initial version of this resource and found that patients valued a trusted source of information and were able to highlight those elements which helped them in decision making and those elements which caused confusion (28). This patient feedback was then utilised in the most recent version of the resource and this has again been evaluated in a patient centred study in order to allow effective continuous development of the resource (29).

A further national resource, the BOS "*Hold that Smile*" retainer campaign, involved the creation of two videos to highlight the importance of wearing retainers. This resource was evaluated in a multi-centre audit in which 278 patients were asked to rate the quality of various aspects of the resource and also asked to reflect on whether it would affect their own decision regarding whether or not to wear their retainers long term (30). Prior to watching the videos, 77.0% of the patients felt they knew about long-term retainer wear and, of those patients, 74.3%

intended to wear their retainers long-term. After watching the videos, 96.4% of all of the patients thought they would now wear their retainers long-term and the authors recommended the routine use of these videos for patients at all stages of treatment.

Without involving patients in research studies of this type and asking for feedback, the quality of the information provided will not progress and new methods of providing information will not be considered. This is a key area of research where we need to work alongside our patients to develop reliable information resources delivered in a way in which the patients really want to utilise them.

The other important aspect for future research is the development and testing of robust measures of patient experience which fully incorporate patient views, by undertaking research in this area will allow a much better understanding of patients' perceptions of the orthodontic treatment experience.

2. Patient reported outcomes

Alongside investigating how patients feel about their experiences of orthodontic care, we also need to consider their perceptions of the outcomes of treatment. Outcomes of treatment are important to all stakeholders, patients, parents, clinicians and funders of care, but these stakeholders all have different aspects which they consider in reaching a decision about the quality of a treatment outcome. There are always risks and costs (direct and indirect) associated with treatment and we need to be sure that the benefits of treatment outweigh those risks and costs.

Qualitative research has also played an important part in looking at patient reported outcomes of treatment. Al Quraini *et al.* and Shah *et al.* undertook in-depth interviews with adolescent patients and their parents to explore perceptions of outcomes of orthodontic treatment and identified three main themes: (i) health related behavioural changes, for example the perceived ability to maintain good oral hygiene and the focus on a better diet (ii) dental health, including enhanced aesthetics and function and (iii) psychosocial influences, including improved confidence, self-esteem and better social interactions (31,32). The authors concluded that these themes support quality of life benefits associated with treatment. By undertaking research of this type where patients play a key role, there is an increased understanding of what patients believe they gain from treatment and this, alongside other forms of research, allows us to provide appropriate information for future patients.

One outcome which has seen an increasing interest in orthodontics is quality of life or, more accurately oral health-related quality of life (OHQoL). These terms are often used interchangeably although quality of life is a broad concept including many aspects of life, whereas health-related quality of life and oral health-related quality of life relate to those health and oral health conditions which might impact on daily life. Many definitions of OHQoL have been published, including that by Locker and colleagues (33) who defined it as *‘the extent to which oral disorders affect functioning and psychosocial well-being’*. The concepts associated with OHQoL and our understanding of exactly what is being measured are complex (34), however much of the orthodontic treatment that is undertaken is sought, and justified, on the basis of improving oral health-related quality of life. Only the patients themselves are able to assess these aspects so research in this area clearly relies on patient involvement.

Whilst there is good evidence for the relationship between malocclusion and poorer OHQoL, especially in terms of emotional and social well-being (35-37), the relationship between orthodontic treatment and improved OHQoL has been more difficult to quantify for routine orthodontic care. In recent years there have been a number of longitudinal OHQoL studies published in the orthodontic literature (38-40) which have shown positive associations between orthodontic intervention and OHQoL, but longitudinal studies of this type remain difficult and expensive to undertake. There are also many factors which complicate research in this area including the complexities of undertaking longitudinal research in an adolescent population where there are psychosocial changes associated with maturation anyway. Changes in the way we live may also cause a paradigm shift in this area of research in the longer term. Recruitment of comparable control groups is difficult and there is an added complication due to the variation in the questionnaires being utilised in research of this type which contributes to heterogeneity of data and makes meta-analysis of data extremely difficult to undertake. An important systematic review and meta-analysis published by Javidi *et al.* showed evidence that oral health related quality of life does improve after orthodontic treatment, again mainly in the emotional and social well-being domains (41). However, in their discussion the authors highlighted the problems associated with research of this type and also the problems associated with the questionnaires available, and called for the development of malocclusion specific quality of life questionnaires designed for use with young people.

Two publications in 2016 described the development of such a quality of life questionnaire to measure oral health-related quality of life in young people with malocclusions, with the aim of using it in future longitudinal studies to investigate OHQoL outcomes in orthodontics (42,43). One of the major benefits of this Malocclusion Impact Questionnaire (MIQ) questionnaire is that it was developed based on in-depth interviews with young people and the subsequent

validation and reliability testing of the questionnaire also involved patients. This is an important example of patient involvement in research; in this case to develop a quality of life measure which is truly patient centred and which it is hoped can ultimately be used in longitudinal studies to provide robust high quality evidence of the effects of orthodontic intervention. Undertaking research in this way ensures that the patient perspective remains central to oral health-related quality of life assessment.

More than 30 years ago, O'Young and McPeck noted that "...*unless quality of life effects are quantified and reported in trials, they will be ignored or undervalued in health policy decisions*" (44). In orthodontics, as in many other specialties, we need to ensure that we are doing this and it is fundamentally important that we focus on measuring OHQoL in clinical trials and routinely include it as an outcome measure.

Research in this area relies on patients playing an important role in development of robust psychometrically tested measures to assess OHQoL, as well as in rating their own oral health-related quality of life. This area of research in orthodontics does however depend on large sample sizes followed up over significant time periods and this highlights the importance of multicentre studies, also with international collaborations which will allow cross-cultural comparisons. With an ever increasing focus in this area of healthcare, this again gives exciting prospects for future work.

3. Patient satisfaction

It is tempting to think that if we obtain a good technical result from treatment, with a well aligned dentition and a good occlusion, then the patient will be happy; however we know from experience that this is not necessarily the case and there are many complex and inter-related factors which contribute to satisfaction. Only by including patients in research in this area do we enhance our understanding of some of those factors which play a part. However, patient satisfaction measures are frequently developed with no patient involvement which limits the conclusions which can be drawn (45) and such measures are frequently said to have low discriminatory value (46).

Patient expectations of treatment are often said to be a key determinant in satisfaction (47-49), therefore studies exploring patients' expectations are an important focus in allowing us to fully understand why patients may, or may not, be satisfied with their treatment. A recent qualitative study by Sayers et al. identified typologies related to patients' expectations of orthodontic treatment and this information may guide clinicians when discussing expectations

at the start of treatment, and hopefully thereby enhance post-treatment satisfaction (50). Sayers et al. (51) also explored whether it is possible to identify those patients with “high expectations” and whether, in doing so, it is feasible to reduce patient dissatisfaction.

The clinical team undoubtedly contributes to patients’ views about their treatment. As highlighted earlier in this article, the clinical team, together with information provided through other routes (including social media), influence decisions which patients make but also affect how patients judge outcomes. Patients have highlighted the importance of the dentist-patient relationship and the quality of care received in determining their satisfaction with treatment (8,52,53). Keles and Bos distributed questionnaires to patients who were completing orthodontic treatment at the Academic Centre for Dentistry Amsterdam in the Netherlands and found that the doctor-patient relationship was the most important factor contributing to patient satisfaction (52). Feldmann studied satisfaction in 110 patients and found significant correlations between satisfaction with outcome and the patients' perception of how well they had been informed and cared for during treatment (53). By obtaining patients views, orthodontic practices and departments are able to focus on these important areas during staff/ team development.

Pacheco-Pereira et al. undertook a systematic review of factors associated with patient and parent satisfaction with orthodontic treatment (54). Their review included 18 papers and, whilst acknowledging the moderate risk of bias associated with the evidence, the authors concluded that satisfaction appeared to be associated with perceived aesthetic and psychological benefits, and also quality of care. Under “quality of care”, the dentist-staff-patient interactions were particularly important and this is consistent with the first section of this paper regarding experience of treatment, where patients discussed the importance of how they were treated by their orthodontist:

“It comes down to the whole [dentist-nurse-patient] relationship, remembering names of my kids, how things are going; just made me feel warm and welcomed.”

(8)

These research findings highlight the importance of ensuring patients and parents have realistic expectations about treatment and also the key role which good patient-staff interactions play. However, there are undoubtedly many other aspects which contribute to satisfaction and this is an exciting area for future research where patients can play a crucial

part in both the development of, and participation in, research. Involving patients in the development of high quality patient satisfaction questionnaires would also ensure that we fully include patients' views in research to determine those factors which play a part in satisfaction with orthodontic treatment.

Where do we go in the future?

There is no doubt that there is considerable interest in patient centred research in orthodontics and many teams are now working in this area. Importantly, there is also a real commitment to undertake multi-centre studies which have the capacity to provide high quality, robust data. Crucial to this though is to keep a clear focus on patient centred research alongside more conventional research.

One area which has been talked about for a number of years is the development of a core outcome set for clinical trials in orthodontics so that we have a real understanding of how patients perceive their treatment and the outcomes; this ongoing research in orthodontics also offers an opportunity for the future (55). A core outcome set would have the real benefit of allowing data from different studies to be combined, thereby increasing the certainty and generalisability of research findings in orthodontics.

Finally, one of the key factors for success in undertaking high quality patient centred research is for patients to contribute to the design and conduct of research looking at all aspects of health services and interventions; this means patients playing a central role in planning research and not just as research participants. This is becoming a focus in orthodontics, with many grant funding bodies now asking for patient involvement in the development of research protocols.

Conclusions

In order to provide high quality care for patients, it is increasingly important to assess their perceptions of the experience and outcomes. To do this well, involves the orthodontic team interacting with, and listening to, patients in order to ascertain what they want and need from the patient journey and, as ever, good communication is central to this.

Patient centred research has a crucial role to play, with patients involved not only as research participants but also in the design and planning of research. Only by interacting with patients in this way will we be able to address those questions which are most important to them.

We still have a great deal of work ahead of us, but the interest and the expertise exist within our specialty; I think the future for this aspect of research is really exciting and I look forward to seeing how the next 10 years develop.

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Conflict of Interest Statement

The author does not have any conflicts of interest

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