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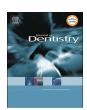
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# Adolescent perceptions of orthodontic treatment risks and risk information: A qualitative study

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#### ARTICLE INFO

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#### ABSTRACT

*Introduction:* For effective risk communication, clinicians must understand patients' values and beliefs in relation to the risks of treatment. This qualitative study aimed to explore adolescent perceptions of orthodontic treatment risks and risk information.

*Methods:* Five focus groups were carried out with 32 school/college pupils aged 12–18 in Wales, UK. Participants were purposively selected and had all experienced orthodontic treatment. A thematic approach was used for analysis and data collection was completed at the point of data saturation.

Results: Four themes emerged from the data; (a) day-to-day risks of orthodontic treatment, (b) important orthodontic risk information, (c) engaging with orthodontic risk information and (d) managing the risks of orthodontic treatment. Day-to-day risks of orthodontic treatment that were affecting participants "here and now" were of most concern. Information about preventing the risks of treatment was deemed to be important. Participants did not actively seek risk information but engaged passively with information from convenient sources. Perceptions of risk susceptibility influenced participants' management of the risks of orthodontic treatment.

Conclusions: This study demonstrates that adolescent patients can understand information about the nature and severity of orthodontic treatment risks. However, adolescent patients can have false perceptions if the risks are unfamiliar, perceived only to have a future impact or if seen as easy to control. Adolescent patients must be provided with timely and easily accessible risk information and with practical solutions to prevent the risks of treatment

Clinical significance: The views and experiences gathered in this study can assist clinicians to better understand their young patients' beliefs about treatment risks, facilitate effective risk communication and contribute to improved patient-centred care.

#### 1. Introduction

In healthcare settings, the concept of risk, has been described as a possibility of loss, injury, disease, or death [1]. A patient cannot make genuinely informed choices about their care without understanding the risks involved [2]. Risk communication is a collaborative process, whereby decisions about treatment are made through the open exchange of information and opinion about risk between two or more parties [3]. Effective communication of risk is a requisite for shared decision-making and the provision of person-centred care [4,5].

The risks of orthodontic treatment have been defined broadly as any of the deleterious or iatrogenic effects of orthodontic treatment, or any potential adverse outcomes or consequences [6–8]. Like many dental procedures, orthodontic treatment is often elective and takes place over

an extended period, requiring considerable investments of time and resources. Although some orthodontic patients commence treatment at a stage when they are not legally competent to consent [9], studies have shown that adolescent patients can understand risk information and participate meaningfully in treatment decisions [10,11]. In addition, adolescent orthodontic patients are normally responsible for their own oral hygiene and care of their appliances at home. For treatment success, the risks of orthodontic treatment must therefore be carefully articulated to adolescent patients.

Landmark court rulings in the United Kingdom [12], United States [13], Canada [14] and Australia [15] have shifted the way in which healthcare risks are communicated. When communicating risk, clinicians must now understand their patients' individual values, beliefs in relation to the risks of treatment and their risk information needs. However, the

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development of orthodontic risk communication tools, such as information leaflets [16–18], audio-visual information packages [19], decision aids [20,21] and messaging apps [22,23], have rarely been guided by the views of adolescent patients who may have different perceptions of risk information to professionals [24] and primary carers [11].

Qualitative studies suggest that adolescent orthodontic patients can experience many risks of treatment including pain and dietary impacts, dental aesthetic issues, problems with oral hygiene, appliances breaking and issues with retainers [20,25–29]. In addition, adolescent orthodontic patients appear to be concerned about demineralisation, gingival irritation, relapse and root shortening [20,30,31]. However, adolescent perceptions of orthodontic treatment risks have rarely been explored in detail and little is known about how patients' risk perceptions might change during treatment.

The literature suggests orthodontic patients have a desire for wide ranging information about the risks of treatment, including effects on diet and speech, treatment duration and procedures, preventative advice and the implications of retainers [16,20,25,32]. These studies however, have not identified the risk information that orthodontic patients most need or use when making choices about treatment and little is known about how young orthodontic patients perceive information about the risks involved in their care. As such, this study aims to understand adolescent perceptions of orthodontic treatment risks and risk information.

#### 2. Materials and methods

Ethical approval was granted by Cardiff University Dental School Research Ethics Committee (Ref 1527).

#### 2.1. Recruitment process

Participants were English speaking, secondary school/sixth form college pupils, 12–18 years of age, of mixed gender and ethnicity. Purposive sampling was used to select a range of year groups and schools/colleges in different geographical and socio-economic areas of Cardiff. To ensure meaningful insights, the sampling strategy was designed to include diverse perspectives and pupils with a range of orthodontic treatment experiences. This included pupils who had discussed treatment with a dentist/orthodontist but had not proceeded, pupils who were undergoing treatment at the time of the study and pupils who had completed treatment and were in different points of retention. Data collection and sampling were conducted in parallel and the preliminary findings informed participant selection. Recruitment continued until data saturation was achieved; this was the point at which no new themes or ideas were emerging [33].

#### 2.2. Conduct of focus groups

Focus groups were conducted at participants' schools/colleges between January and April 2016. Each focus group was conducted with pupils who belonged to the same year group to facilitate naturalistic discussions. The moderator (JP) was a male, white Caucasian clinician (postgraduate trainee in orthodontics) who had completed focus groups methods training over a six-month period with experienced researchers (IJ and PG). JP kept a reflective journal to help recognise the influence of personal biases and assumptions throughout the study. The assistant moderator (IJ) was a female, white Caucasian clinician, experienced in focus group studies.

The research team designed a questioning route informed by the existing risk communication literature and guidance on focus groups [34,35] (Appendix A). The questioning route was used consistently across groups and involved a number of approaches to explore participants' perceptions of orthodontic treatment risks and risk information; the first involved open questions, the second involved asking participants to write down ideas on sticky notes and the third involved a sorting exercise, using picture/word cards of orthodontic treatment risks identified by orthodontists as important risks during a Delphi

exercise [36] (Appendix B). Additional questions were asked in a flexible manner to explore emerging issues raised by participants.

Focus groups lasted 45–60 min and were digitally audio recorded. The assistant moderator took field notes including a record of contextual details and non-verbal communication. Participants were blinded to the professional expertise of the moderators.

Audio recordings were transcribed verbatim, by one author (JP) and imported into NVivo (version 10, QSR International, Victoria, Australia) to assist with data management. Transcripts were anonymised using pupil codes instead of names and were analysed in a timely fashion to inform future data collection.

#### 2.3. Data analysis

All data were reviewed and coded by JP and all coding was verified by IJ. Textual data and coding were discussed as a group to enrich interpretation. Themes were derived from the data using a thematic analysis approach [37]. Initially, each transcript was read to enable familiarity with the data and coding notes were recorded detailing thoughts, observations and early interpretations. Emergent themes were then developed by clustering related initial broad-based codes and searching for connections across them and finally, data were categorised and themes defined to capture their essence. Data contradicting emerging concepts and ideas were searched for and discussed to increase the depth of the analysis.

To encourage participant validation, pupils were given the opportunity to feedback on results; verbally during group debriefs and shortly after data analysis via feedback forms. Any feedback from the respondents was recorded and used to refine theme and theory development.

#### 3. Results

A total of five focus groups were conducted at five different schools/colleges, with 32 participants (Table 1). The gender ratio of participants was equal.

Four interconnected themes emerged from the data; (a) day-to-day risks of orthodontic treatment, (b) important orthodontic risk information, (c) engaging with orthodontic risk information and (d) managing the risks of orthodontic treatment. These four themes arose across all focus groups.

#### 3.1. Day-to-day risks of orthodontic treatment

Participants told stories about the risks of living with a *brace* and day-to-day problems. Issues such as pain, difficulty eating, "*braces* breaking", "cuts" and "ulcers" were an expected part of the orthodontic treatment process. Participants expected these issues due to previous experiences or information received from family, friends or dental professionals. However, issues such as pain and difficulty eating were still described as having a significant and emotional impact on participants' lives.

Pupil 45F: "I actually cried because I couldn't eat (group members laugh). I was sitting on my bed and I was crying (laughs). They were hurting and I couldn't eat, I was really hungry."

Participants described their resilience in dealing with everyday risks and many elected to "put up" with these day-to-day issues. The benefits of treatment were strong motivators for tolerating the negative aspects of orthodontic treatment and complying with healthcare recommendations. For example, participants tolerated problems with wearing retainers so that their "new smile" would be maintained.

#### 3.2. Important orthodontic risk information

Participants were familiar with common risks such as pain, ulceration or appliances breaking but knew less about specific clinical risks such as root resorption and demineralisation. However, the sticky notes and visual aids used during the sorting exercise helped participants to

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