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Development of a condition-specific measure to assess quality of life in patients with hypodontia

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Structured Abstract

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Objectives – To develop a measure to assess quality of life in patients with hypodontia.

Setting and Sample Population – Royal Devon and Exeter NHS Foundation Trust.

Materials and Methods – The study was divided into two parts. The first phase involved developing a patient-specific questionnaire using 22 patients with hypodontia in five focus groups. The transcripts from these groups were analysed thematically, and emerging themes used to direct the remaining focus groups. When no new themes were identified, it was assumed that data saturation was reached and no further focus groups were organised. In the second phase of the study, a health-related quality of life questionnaire was developed.

Results – Analysis of transcripts revealed four themes: treatment, effect on daily activities, appearance and other peoples' reactions. These themes were incorporated into a questionnaire. The readability, ease of administration, face and content validity of the questionnaire were tested.

Conclusions – A new measure for assessment of quality of life in patients with hypodontia is presented.

Key words: hypodontia; impact; quality of life; questionnaire

Introduction

Hypodontia is defined as the developmental absence of one or more teeth, excluding the third molars (1).It is one of the most common craniofacial malformations (2, 3), and its prevalence varies across different ethnic backgrounds. A meta-analysis of the prevalence of dental agenesis of permanent teeth showed the prevalence rate to be 5.3–5.6% in European (White) population, 3.7–4.1 and 3.1–4.6% in North American White and African American populations, respectively (4). Hypodontia can be classified by the number of teeth missing. Mild hypodontia is classified as up to two teeth missing, moderate hypodontia is classified as between 3–5 teeth missing and severe hypodontia as greater than six teeth missing (5). Other authors have reported on the patterns of hypodontia by assigning numeric codes called Tooth Agenesis Codes (TAC) (3) to allow individual patterning of absent teeth per quadrant. Creton et al. (6) used

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the TAC in a group of 116 patients with six or more teeth missing. They reported that in the maxilla the most common pattern was absence of upper lateral incisors, first and second pre-molars. The other common pattern in the maxilla was the presence of the central incisor and first molar only with absence of all other maxillary teeth. In the mandible, the most common pattern was the absence of second pre-molars.

Quality of life (QOL) is defined as 'a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important for him/-her (7), and the importance of health-related quality of life (HRQoL) is widely accepted in medicine. However, until recently interest in oral health-related quality of life (OHRQoL) has been limited. Oral health is a standard of health of the oral and related tissues which enables an individual to eat, speak and socialise without active disease, discomfort or embarrassment and which contributes to general well-being (8). The developmental absence of teeth can seriously disable a young person both physically and emotionally, especially during adolescence (2). Indeed, research has shown that missing anterior teeth are considered the most unattractive of occlusal traits (9). The dental management of severe hypodontia can also place a considerable burden on the family as treatment is often protracted.

In orthodontics, quality of life changes have previously been studied more in relation to orthognathic than orthodontic treatment (10, 11). However, like orthognathic treatment, the management of hypodontia is a complex process and differs from other medical interventions in that patients are generally young and fit. For this reason, there is a need to develop a condition-specific quality of life instrument. Unlike their peers, patients with hypodontia undergo complex and usually lengthier multidisciplinary treatment and commencing at a very young age. The issues of importance for such patients can therefore be very different from those that are undergoing routine orthodontic treatment. There is currently no specific measure designed to assess the quality of life in patients with hypodontia. Whilst the literature evaluates the importance of an increased overjet on psychosocial well-being, there is little understanding of how hypodontia affects the patients' quality of life: symptoms experienced, oral function or any social or emotional impacts.

There is clearly a need to be able to sensitively assess the impact of hypodontia on the quality of life through a condition-specific scale. Therefore, this study aimed to:

- employ qualitative research methods to identify issues of importance for patients with hypodontia,
- develop a questionnaire based on the issues identified which can then be used to assess the impact of hypodontia on quality of life.

Materials and methods

The development of a measure of patient perceptions involves three stages (12). First, items for investigation are generated. A questionnaire is then designed using these items and finally the questionnaire is tested.

Ethical approval was obtained from the Devon and Torbay Research and Ethics Committee (REC 09/H02 02/24). Research and Development approval was obtained from the Royal Devon and Exeter NHS Foundation Trust, Musgrove Park and University of Bristol Dental Hospital.

Item generation

Study sample

A series of focus groups were used to identify issues of importance for patients with hypodontia. Patients were recruited from joint orthodontic-restorative clinics, orthodontic treatment clinics and new patient orthodontic clinics. To provide an overall view of the impact of hypodontia, the sample was not just limited to those patients who were currently undergoing orthodontic treatment, but included those before, during and after completion of their active treatment, but still in retention. It was anticipated that the sample would include patients with a range of severity of hypodontia. All patients were aged between 11 and 18 years.

The following exclusion criteria were applied:

- Patients with cleft lip and palate
- Patients with hypodontia as part of a syndrome

Five focus groups were run with 22 patients over a 6-month period. The ideal number of participants in each focus group was thought to be between four and ten (13). The total number of participants contacted was much higher to allow for a low response rate. Figure 1 shows the flow of participants in this stage of the study.

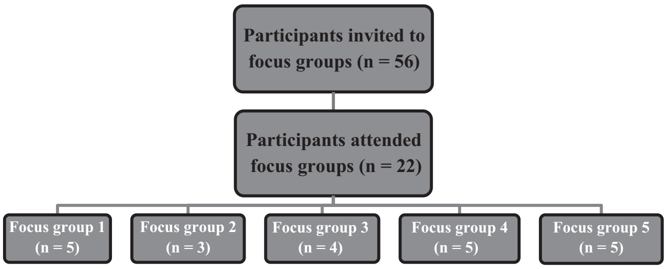


Fig. 1. Flow diagram for participants in the focus groups.

Patients with hypodontia were identified from the departmental patient database. All subjects and parents/guardians for those under the age of 16 were given an information sheet regarding the purpose of the study. They were also provided with an invitation letter for the focus groups and a reply slip which they were asked to return in postage paid envelopes. Participants were assured of confidentiality and that failure to participate or withdrawal from the study at any time would not affect their present or future care.

Focus groups

Written consent was obtained from both the patients and the parents/guardians (if required) before commencing the focus group. Each was held in a non-clinical environment and arranged after school hours, and all travel expenses were reimbursed.

Each focus group was lead by the researcher (AA) and a trained facilitator, and written as well as tape-recorded transcripts obtained. A topic guide, previously developed through informal interviews with clinicians, was used and a semi-structured approach was followed by using flip charts with mind maps. Accompanying parents were not involved and were seated in a separate room. However, as part of the protocol it was agreed that if it was noted that any participant was being bullied excessively as a result of their condition in everyday life, their parents would be informed and local support organised.

Data analysis

At the beginning of each meeting, participants were asked to introduce themselves and talk briefly about their hobbies. This dialogue was used, together with the field notes, to help the transcribers identify when each participant was talking. The tape recordings were transcribed by two independent transcribers into a Word document (Microsoft Word©). Names were changed to preserve anonymity. Thematic analysis of the data was performed using qualitative analysis software (N Vivo 8©) to code the key areas to be included in the questionnaire (14). Tree nodes and sub-nodes were created to identify themes and sub-themes. Data analysis identified the issues to expand on during the next focus group.

The transcripts were analysed and triangulated by three researchers working independently to reduce bias. After analysing the transcripts of each focus group, the researchers compared their results and a common set of themes was created. When no new themes were identified, no further meetings were organised. To give an indication of the relative importance of each issue, the frequency of occurrence of each theme was noted.

Questionnaire development

Questionnaire content

The issues identified were used to create the questionnaire. Once the questionnaire had been designed, it was returned to the Research and Ethics committee for approval. The themes and issues identified from the focus group meetings dictated the sections of the questionnaire, and the question wording reflected the words used by participants in the focus groups.

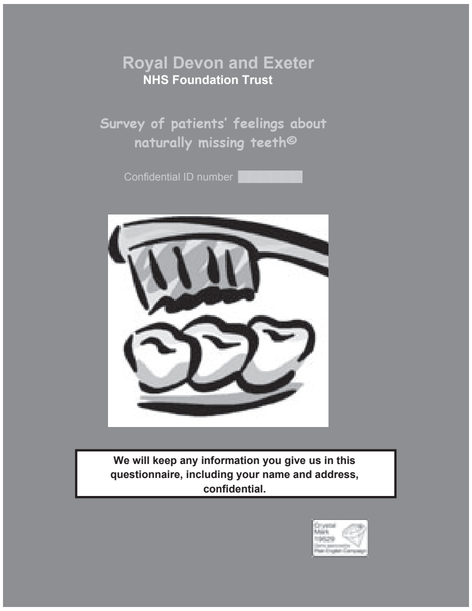
An initial introductory section about age, gender and stage of treatment was included in the questionnaire to enable associations between patient characteristics, stage of treatment and the severity of hypodontia.

Questionnaire layout

The questionnaire was professionally printed on A4 size paper and bound in a folder. The front cover was designed with a colourful logo to look distinctive (Fig. 2) and be inviting to the respondent (15), and instructions were provided on the next page. The questionnaire itself comprised 16 pages with individual sections demarcated by bold headings. All the response boxes were positioned on the right-hand side of each page. The completed questionnaire was granted a 'Crystal Mark' seal of approval by the Plain English Campaign for clarity.

Format of questionnaire

As the data used to construct the questionnaire was obtained from a saturated thematic analysis, it was felt



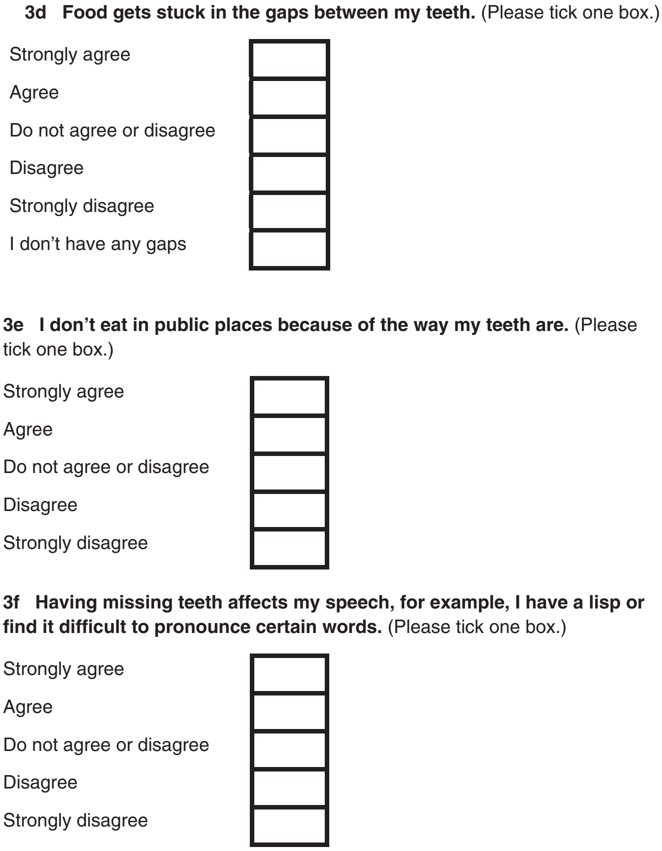
Royal Devon and Exeter
NHS Foundation Trust

Survey of patients' feelings about naturally missing teeth©

Confidential ID number

We will keep any information you give us in this questionnaire, including your name and address, confidential.

Fig. 2. Front cover of questionnaire.



3d Food gets stuck in the gaps between my teeth. (Please tick one box.)

Strongly agree ☐
Agree ☐
Do not agree or disagree ☐
Disagree ☐
Strongly disagree ☐
I don't have any gaps ☐

3e I don't eat in public places because of the way my teeth are. (Please tick one box.)

Strongly agree ☐
Agree ☐
Do not agree or disagree ☐
Disagree ☐
Strongly disagree ☐

3f Having missing teeth affects my speech, for example, I have a lisp or find it difficult to pronounce certain words. (Please tick one box.)

Strongly agree ☐
Agree ☐
Do not agree or disagree ☐
Disagree ☐
Strongly disagree ☐

Fig. 3. Example of closed questions in the questionnaire.

that a closed answer format should be used. However, because of the patient age group, a scale answer format, with verbal markers rather than numbers, was included (Fig. 3).

Testing of questionnaire

Once the questionnaire was developed, the readability was tested using Word. It was then given to patients with hypodontia to test ease of administration, face and content validity. Purposive sampling was used to identify patients for this stage of the study, thereby including patients with differing degrees of severity and at different stages of treatment (16). Information sheets about the questionnaire were provided to the patients and parents/guardians, and written informed consent obtained before the questionnaire was completed.

The inclusion and exclusion criteria were the same as the first stage of the study. Patients were asked to complete the questionnaire by themselves in the waiting room to ensure a high response rate

Results

Results of the focus groups

Five focus groups were held over a six-month period. Table 1 shows the characteristics of the patients that took part in the focus groups. The average number of participants per focus group was four, and the mean age of the participants was 12.6 years (range 11–16 years). Each focus lasted for approximately 1 h. No new themes were identified after the fourth focus group. An additional focus group was organised to confirm that saturation had been reached. As a result of the focus group meetings, it emerged that two subjects were currently being bullied. As per the protocol, their

Table 1. **Characteristics of focus group participants**

Focus group participants	*n* = 22
Stage of treatment	
Pre treatment	6
Mid treatment	14
Post-treatment	2
Severity of hypodontia	
Mild	5
Moderate	13
Severe	4
Site of hypodontia	
Anterior	8
Posterior	2
Anterior and Posterior	12

parents were informed and support organisation information provided.

Themes emerged under four main headings (nodes): 1) treatment, 2) effect on daily activities, 3) thoughts on appearance, and 4) the reaction of other people, including friends and family (Fig. 4). These headings were further divided into sub-headings (tree nodes). These themes are considered later.

Treatment

Several sub-themes emerged in this section. Most frequently, participants felt their treatment was more complex and lengthy compared with their friends. Although most were optimistic about the end result, some worried about the eventual loss of retained baby teeth and how the resultant gap would be dealt with. Participants who were yet to start treatment were anxious about how painful it would be. The following is an example of participant's transcript:

> I am kind of worried as I am having more treatment then my friends and I don't know anyone in my class or in my population or anything who is also having the same treatment as me. So, I feel kind of different sometimes when I think about it
>
> Participant in focus group 5
> Coded 1.3 Complexity of treatment

Activities

This category included sub-themes that related to the impact of missing teeth on activities such as tooth brushing, speech, eating, playing musical instruments and sports. An excerpt of a transcript on this theme was:

> Well it was like when I was little the missing teeth down the bottom used to affect my speech when I learnt to speak when I was one it was hard to pronounce stuff like every day words and it was like hard to say like mum and dad and I found it particularly hard to say stuff with 'S' in them
>
> Participant in focus group 3
> Coded 2.3 difficulty speaking

Appearance

This was one of the more sensitive topics of discussion. Participants were unhappy about the presence of gaps and the size of their teeth. There were worries about what the false teeth would like and if they would match the colour of natural teeth. An excerpt of a transcript on this theme was:

> I would like to keep my own teeth then have false teeth because with false teeth when you are at school and you run and trip and they fall out everyone will take the mick out of you and I would rather have my own teeth as long as possible
>
> Participant in focus group 5
> Coded 3.5 worries about false teeth

Other peoples' reactions

In this section, issues such as bullying and support from family members with regard to the process of treatment were discussed. It was clear that some participants were suffering from extensive teasing and name calling because of the appearance of their teeth. An excerpt of a transcript on this theme was:

> I told them that I have never had any teeth at the bottom and they just like laugh about it and call me names and there is a boy called Harry and he calls me six teeth, but I actually have 22 teeth but people thing I hardly have any and it upsets me
>
> Participant in focus group 5
> Coded 4.5 would not want peers to know about missing teeth

Hypodontia coding tree

Treatment	Activities
Anxiety about the treatment process	Difficulty eating certain foods
Lengthy treatment	Mouth guards not fitting well due to gaps
More complicated treatment compared to peers	Effects of gaps on speech
Worries about baby teeth falling out	Tooth brushing difficult due to gaps
Not keen on having false teeth	Musical Intruments

Appearance	Other people
Dislike gaps	Bullied at school
Small teeth	Family members overprotective
Peers have better teeth	Family supportive
Conscious about smiling	Odd ones out
Worried about size and colour of false teeth	Would not want peers to know about missing teeth
Dislike dentures and plates	

Fig. 4. Themes and sub-themes identified from focus groups.

There was a variation in the frequency of themes across the five focus groups. However, the themes remained essentially consistent. Overall, artificial teeth, bullying, anxiety and gaps had high frequencies of occurrence.

As a result of the themes identified from the focus groups, the questionnaire was divided into four sections:

- Treatment
- Activities
- Appearance
- Other peoples' reactions

Readability results

The Flesch reading ease and Flesch Kincaid grade level were tested by using a facility available in Microsoft Word©. The Gunning Fog Index (FI) was also calculated. Results are shown in Table 2.

The questionnaire had to reworded once during the ease of administration testing. The final questionnaire showed good levels of readability being scored at a US grade (5- or a 10-year-old reading ability). Similarly, for the Flesch Reading Ease scores, the questionnaire exceeded the desired score of 60–70 of the population. The FI of the final questionnaire was 7.7, which indicates easy readability.

Ease of administration results

Ease of administration comprises several aspects of questionnaire design, such as time taken for participants to complete the questionnaire and assessment of how many questions were misunderstood or left unanswered. Ten patients took part in this stage of the study. Two were boys and eight were girls; the mean age was 12.9 (range 11–15). Table 3 details the characteristics of patients that took part in this stage of the study.

As the researcher was present throughout the completion of the questionnaire, they were able to direct the participants if they needed help. The researchers made a note of any questions that seemed difficult to answer, were left out, or were unanswered and the time taken by each participant to complete the questionnaire. Questions that were misunderstood, unanswered or incorrectly answered were reworded and repiloted. The readability of the reworded questions was retested.

Table 2. **Readability results for questionnaire**

Flesch reading ease	Flesch-kincaid grade level	FI
81	5.1	7.7

The time taken to complete the questionnaire ranged from 5 min 45 s to 12 min. The mean time to complete the questionnaire was 7 min 9 s. One question and response was reworded following this stage of the study.

Results face and content validity testing

Face and content validity were tested by giving the questionnaire to specialist orthodontists and a restorative dentist for assessment. It was also tested on the ten patients that took part in the ease of administration testing where no objections were raised. Both the face and the content validity were considered good as the questionnaire was based on data obtained from focus groups.

Discussion

This study presents the development of a condition-specific questionnaire for assessing quality of life in patients with hypodontia. The advantages of using questionnaires are that they are relatively inexpensive, are familiar and acceptable to most people (17) and can

Table 3. **Characteristics of participants in the questionnaire study**

Questionnaire study	n = 10
Stage of treatment	
Pre treatment	2
Mid treatment	6
Post-treatment	2
Severity of hypodontia	
Mild	2
Moderate	4
Severe	4
Site of hypodontia	
Anterior	2
Posterior	2
Anterior and Posterior	6

be used in further studies and in other populations to compare results. Questionnaires can also be used at different stages in treatment to assess the response to treatment. Condition-specific measures reduce patient burden and increase acceptability by including only relevant dimensions (18). Their rationale lies in the potential for providing greater insights into the consequences of a specific oral condition rather than assessing quality of life in relation to overall oral health (19).

There are some disadvantages to using self-report questionnaires, the most frequent being that they can be intrinsically manipulative. This drawback can be overcome in the early design stage by using qualitative research methods to generate the items for the questionnaire. This ensures that the questionnaire represents the views of the population being studied and reduces researcher bias. In this study, the focus groups were used for item generation. Focus groups lead to the generation of rich data as a result of the interactions of group members (20). The number of participants in our focus groups was on average four per group. This small size ensured that all view points were expressed. No objections were raised from patients or clinicians about the content of the questionnaire during the testing stage, suggesting good face and content validity.

The focus groups revealed some interesting themes. In general, arch spacing was a significant issue for most participants and unfortunately also a key target for teasing and bullying. There were concerns about the size and colour of false teeth and a dislike of removable dentures because of their association with elderly people. A few participants did comment on the size of their teeth and problems with getting a sports gum shield to fit well. There were also worries about the eventual loss of deciduous teeth where permanent predecessors were missing. The themes remained essentially the same across the groups, but there were wide variations in the frequency of occurrence of themes and their relative importance. To reduce selection bias, patients who fulfilled the inclusion criteria for the study were invited to the focus groups regardless of the site or severity of hypodontia or the stage of treatment. The variation in the frequency of themes can be explained by the heterogeneous sample. Patients with anterior teeth missing may well have greater concerns about appearance than patients with missing pre-molars. Similarly, patients for whom prosthetic replacement is planned may have different issues compared with patients for whom space closure is planned.

Previous studies have used generic measures such as Oral Health Impact Profile (OHIP) to assess quality of life in patients with hypodontia (21). Patients in this study felt that some of the questions in the OHIP were irrelevant to their condition. The researchers found that the total OHIP score was inferior in rehabilitated patients with tooth agenesis as compared to the control group of patients without tooth agenesis. They also reported a better aesthetic outcome in patients rehabilitated with implant supported prosthesis as compared with patients treated with tooth supported fixed dental prosthesis. Goshima et al. (22) using the OHIP, also found an improvement in oral health-related quality of life on provision of implant supported crowns in patients with tooth agenesis. Two other studies have investigated the impact of hypodontia using the Child Perception Questionnaire (CPQ) (23, 24). Although the results for both studies showed the oral health impact on quality of life was immense, the CPQ is a generic measure and there are concerns about its face and content validity (25). Laing et al. (26) also used the CPQ to assess the psychosocial impact of hypodontia and compared this with the results from a routine orthodontic treatment group who also completed the CPQ. Their results contrast with other studies as they did not report a significantly larger psychosocial impact of hypodontia compared with routine orthodontic treatment groups. However, patients with hypodontia in this study did report greater difficulty in chewing.

To date, the impact of hypodontia on quality of life is a relatively unexplored area. The results of this study show that the issues of importance for patients with hypodontia can be very different from those undergoing routine orthodontic treatment. It is important to be able to assess the impact of developmentally absent teeth on a patient's quality of life. While it is important that the outcomes of orthodontic treatment are assessed using objective measures such as the Peer Assessment Rating (PAR), there is no doubt that these should be supplemented with patient-based outcome measures. It is hoped that the quality of life of patients with hypodontia improves as treatment progresses and is eventually completed. A condition-specific measure as has been developed in this study can be utilised before during or after treatment to assess the impact of both the condition and its treatment from a patients' perspective.

Conclusion

This study presents the development a new questionnaire to assess quality of life in patients with hypodontia. It is based on issues of importance for patients with hypodontia, has good readability, ease of administration, face and content validity and is now ready to be piloted on patients with hypodontia to test its internal consistency reliability, test–retest reliability, construct validity and criterion validity.

Clinical relevance

It is widely accepted that the developmental absence of teeth can impact significantly on a person's quality of life. However, there is currently a lack of robust scientific evidence to support this view and also how orthodontic treatment might improve the quality of life. It is for this reason a health-related quality of life questionnaire was developed for patients with hypodontia.

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