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The impact of dental caries on children and young people: what they have to say.

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Summary

Background: Dental caries affects 60-90% of children across the world and is associated with a variety of negative impacts. Despite its ubiquity, there has been surprisingly little exploration of these impacts from the child's perspective.

Aim: The aim was to allow children to describe the impact of dental caries on their daily lives and to describe the terminology they used.

Design: Children, aged 5-14 years, with caries experience were purposively sampled from primary and secondary care dental clinics. Focus groups (n=5) and in-depth interviews (n=15) were recorded and transcribed verbatim. Data analysis took a narrative approach and themes were derived from the data using framework analysis.

Results: Pain was the main theme which emerged. Within this, three sub-themes were identified: impacts related to pain; strategies adopted to reduce pain and emotional aspects resulting from pain. A second theme was also identified relating to the aesthetic aspects of caries.

Conclusion: Children as young as five years of age were able to competently discuss their experiences of dental caries. Participants reported a number of impacts affecting various aspects of their lives. These will be incorporated into the future development of a caries-specific measure of oral health-related quality of life.

Introduction

Dental caries is a ubiquitous disease of childhood, affecting 60-90% of children and young people across the world¹. From both a societal and health care perspective, a number of negative impacts have been ascribed to this largely preventable condition². There is now a growing interest in how caries impacts on the affected individual and its relevance to the provision and evaluation of dental interventions for caries reduction and management.

To date, the most popular line of enquiry into caries-related impacts has been through the use of oral health-related quality of life (OHRQoL) measures. These questionnaires seek self-reported quantitative data relating to oral symptoms, functional limitations, social and emotional wellbeing. The most commonly employed child measures include:

- Child Oral Impacts on Daily Performances (C-OIDP)³
- Child Oral Health Impact Profile (COHIP)⁴
- Child Perceptions Questionnaire (CPQ)⁵⁻⁷
- Scale of Oral Health Outcomes (SOHO-5)⁸

In the main, these have provided compelling evidence that children and young people with caries have more frequent negative impacts than those without the disease^{9-11, 8, 12-14}.

However, there are acknowledged limitations in relying on such measures as a sole means of understanding the range and extent of caries-related impacts in children. It is clear that these instruments perform poorly in paediatric populations with relatively low levels of disease and there may be other factors which mediate impacts, such as socioeconomic status, cultural differences and general health¹⁵⁻¹⁹. Furthermore, existing child measures of OHRQoL are generic and were not designed for exclusive use in populations with dental caries. It is speculated, therefore, that a disease-specific measure would be more sensitive in identifying impacts which are associated with dental caries and related treatments²⁰. However, no such patient-reported measure currently exists.

Other investigators have elected to employ parents as proxies to determine the impact of caries on children. This approach has been adopted mostly in relation to pre-school aged children, or those with learning difficulties, as both groups have been traditionally viewed as unreliable historians^{21,22}. Caution must be exercised when interpreting data obtained from a proxy as it has been shown that some parents have limited knowledge about their child's OHRQoL, particularly in relation to social and emotional impacts²³.

It is no surprise that previous studies have focused on pain as the main impact associated with dental caries. An American survey of 7.5 million children found that almost one third of those with dental caries had also experienced dental pain²⁴. This figure aligns with data cited in the 2003 children's dental health survey in the United Kingdom, where dental pain was reportedly experienced by 26% of 8-year-olds, 30% of 12-year-olds and 24% of 15-year-olds with dental caries²⁵. A national oral health survey in Thailand found that 39% of 12-year-olds and 34% of 15-year-olds with poor OHRQoL attributed this to dental pain²⁶. In Brazil, a life course study involving 339 children found that between 36% and 71% of children with caries experience had suffered dental pain by the age of 6-years and that this increased to 65-85% by the age of 12-years²⁷. Although these studies were performed in a variety of settings, it would appear that at least half of all children with caries have experienced concomitant dental pain. Due to the recall periods and methods employed, this may actually be an underestimation of the true prevalence of pain symptoms in children with caries.

Other caries-related impacts have also been reported by children and these have included: loss of sleep; time of school; difficulty eating, cleaning teeth and speaking, and interference with normal social activities^{28-30, 27, 26}. Indeed, Krisdapong and co-workers found that 5% of 12-years-olds and 4% of 15-year-olds in Thailand had missed an average of 1.4 school days due to of having toothache³¹.

Despite the substantial body of work that has been undertaken in relation to dental caries experience in children, there is a paucity of qualitative data from the child's own perspective. Thus there is considerable scope to actively engage children in order to elucidate how dental caries impacts on their everyday lives, thereby gaining greater understanding of the wider psychosocial aspects of this common disease.

Increasingly, it is recognised that children have their own unique views and that they should have the right to express these³². Contemporary sociological theories of childhood focus on "children's own perspectives, rather than learning about their lives through the eyes of others"³³. In keeping with this construct, researchers are encouraged to regard children as experts on their own lives. Several qualitative studies in the medical field have taken this approach to investigate children's experiences of various illnesses. Children in these studies have been able to discuss their knowledge and understanding of their condition, the limitations their illness places on their lives, their emotions and their role in self-care³⁴⁻³⁸. Children have also been found to be able to describe their pain experiences, however, the language children used was different to that used by adults³⁹⁻⁴¹. Thus, the overall aim of this study was to give children the opportunity to describe the impact of dental caries on their daily lives. Specific objectives were to explore impacts according to age and caries experience and to capture the vocabulary and terminologies used by young patients in their narratives about dental caries.

Method

Ethical approval for the conduct of this study was first obtained from South Yorkshire Research Ethics Committee (Reference number: 11/H1310/3). Written consent was obtained from parents/guardians as well as assent from the child participants themselves. No ethical concerns arose during this project which was part of a wider programme of research which sought to develop the first caries-specific OHRQoL measure.

Study design

Interviews and focus group discussions were held with children and young people with active dental caries or who had past experience of dental caries. The use of focus groups is common practice within the social sciences as a means of stimulating conversation between participants in order to generate a breadth of information^{42, 43}. Where children are involved, it is advisable to have small groups to give everyone an opportunity to participate. It is also

preferable that focus groups comprise similarly-aged children. In contrast, individual interviews allow participants to talk freely and in private. This approach can generate richer information and allow younger, quieter children to have a voice. A combination of these two approaches to data collection was therefore used in the present study. Both children and their parents were informed that a parent could be present during the focus group or interview if the participant desired this.

Participants

Participants were purposively sampled from both primary (salaried dental service clinic) and secondary care (dental hospital clinic) dental settings within a city in the North of England over a 25-month period (June 2011-July 2013). Recruitment continued until saturation was achieved and there was wide representation from children of different ages, caries levels and treatment experiences⁴⁴. Potential participants and their parents were first identified by their clinician, in accordance with the following inclusion and exclusion criteria:

Inclusion criteria

- Children and young people aged 5-16 years of age at recruitment
- Children with active caries or who had previous experience of caries
- English speaking.

Exclusion criteria

- Children with a significant pre-existing medical condition (American Society of Anesthesiologists' Physical Status Classification System of Grade 3 or greater⁴⁵)
- Children with a dental or oral condition other than caries
- Children with severe learning difficulties who would be unable to participate with the intended activities even with support

A member of the research team (FG), who was not involved in the child's clinical care, explained the nature of the study to the potential participants and provided age-appropriate information sheets. The following clinical data were collected for each participant: dmft/DMFT; presence of anterior caries; any pulpal involvement; any reported pain symptoms and, where appropriate, the nature or any previous dental treatment.

Focus groups

Following recruitment, children were allocated to an age-appropriate group. The focus groups were facilitated by two dentally-qualified researchers (FG and ZM) and took place in a non-clinical room with a separate waiting area for accompanying parents. All

children were asked to provide a pseudonym. Conversations were recorded (Olympus Digital Voice Recorder WS-812) after explaining why this was necessary. Recordings were transcribed verbatim and data collection and analysis occurred concurrently. Some of the younger children did not express themselves in sentences but would nod or shake their head in response to questions or provide “yes” or “no” answers. Gestures, where noted, were included in the transcripts. Refreshments were provided for participants and parents.

Interviews

The interviews were conducted by one researcher (FG) and were recorded as described above. The venue and time of the interview were selected by the participant and their family.

Data analysis

Analysis of qualitative data should result in a detailed description that identifies patterns and develops explanations, while remaining faithful to the data in its original form⁴⁴,⁴³. In order to prioritise the child’s voice, the analysis took a narrative approach, so that rather than trying to “verify” what participants said, the focus was on how they described their experiences and what they meant to them⁴⁶. The most appropriate method to meet the aim of this study was framework analysis, which is concerned with classifying data by organisation according to themes and categories that emerged from the data. This methodology has developed from social policy research to facilitate handling a large volume of data including data from focus groups and interviews⁴⁷. The transcripts were analysed independently by two researchers (FG and ZM). Initially notes were made on the general themes and these were then discussed to further refine the themes. Once developed, the themes were grouped into main and sub-themes.

The analytical approach involved several stages with data from both focus groups and interviews analysed together⁴⁸. First, transcripts were read to gain a broad understanding of the areas covered and notes made on the general themes. Recurring themes were identified and then further developed. The themes were then grouped into a number of main and sub-themes. Each section of the transcripts was then labelled with an index number to represent the theme to which the data related. Data with the same index number were then brought together. Finally, thematic charts were created for the main themes retaining the context and as much of the children’s language as possible.

Results

Participants

Six children were invited to take part in a focus group. Five of these, together with their parents, agreed to participate (a response rate of 83%). Two focus groups were convened to ensure that participating children were of a similar age in each group. The accompanying parents of the younger children (n=3) were included in the forum as this facilitated discussions. The focus groups comprised one boy and one girl in Focus Group 1, both aged 12 years. Two girls (both aged 8 years) and one boy (aged 9 years) contributed to Focus Group 2. All participants were white British. Focus groups were between 12 and 14 minutes in length. The information provided by these children formed the basis of the topic guide (Figure 1) for the interviews. These were supplemented with themes which were identified from other OHRQoL measures to ensure all aspects of OHRQoL were explored.

Forty-one children and young people satisfied the inclusion criteria and were approached to take part in an interview. The families were initially given packs and asked to return a reply slip if they were willing to have an interview. However, only five reply slips were actually returned. It was therefore decided that, where a family had expressed interest at the first contact, a follow-up telephone call would be made with their permission. This approach was found to increase recruitment. Fifteen children were recruited to have this interview.

The interview participants ranged in age from 5-13 years with equal representation from boys and girls. The majority of participants were white British (n=12). Participants exhibited a wide spectrum of caries levels and treatment experiences. Their clinical and socio-demographic profiles are detailed in Table 1. Fourteen interviews were held at the child's home and one was held in a quiet non-clinical room within a dental hospital. Most children wished to have their parent present, although parents were generally not directly involved in the conversations. The interviews varied in length from 6 minutes to 16 minutes, with a mean duration of 7 minutes. Data saturation was reached after 15 interviews and two focus groups.

Caries-related impacts

Pain was the main theme to arise from children about their experiences of having caries. Participants were able to give detailed descriptions about the nature of the pain symptoms they had experienced. Within the overall theme of pain, three subthemes emerged, which were:

- impacts related to pain
- strategies adopted to reduce pain
- emotional aspects resulting from pain

A second theme was identified which related to the aesthetics of dental caries. These themes will now be explored using quotes from the children to illustrate the impacts experienced and how the children described them.

Descriptions of pain experienced

Children reported pain as the impact that most bothered them. They used the words “*hurt*” or “*toothache*” to describe the pain from their carious teeth, although the actual term “*toothache*” was often interjected by their parents.

“Well, I wouldn’t call it toothache, but if that’s the name then, that’s what I would call it” (Mark, aged 8 years)

Others described the pain as “*earache*”, suggesting that the tooth-related pain was referred to another anatomical site.

“It were mainly earache” (Leah, aged 6 years)

Children described the dental pain that they had experienced in a variety of ways and were articulate in illustrating the nature of the pain in terms of its severity, nature and location.

“It’s where your tooth aches and hurts quite a lot” (Brodie, aged 9 years)

“It felt like you wanted to itch it and pull it out” (Mark, aged 8 years)

“It was like sharp” (Liam, aged 13 years)

“It’s the tooth, and then, my gum bit below.....like its prodding”(Lily, aged 12 years)

Children were probed about the nature of pain, in order to elucidate whether it was the frequency of the pain that bothered them most or whether it was the severity. Generally, participants reported that it was the severity of pain at any one time that affected them the most.

“Would it be how much it bothered you or would it be how often it hurt would it be the main thing for you do you think?” (FG, interviewer)

“Erm, probably the how much it hurt” (Jack, aged 11 years)

“Erm, how bad” Elizabeth, aged (7 years)

However, some children did describe the frequency as bothering them.

“Does it matter how often something hurts or is it how bad it hurts?” (FG, interviewer)

“It’s how often” (Isabelle, aged 7 years)

The severity of pain was described as hurting “*a lot*” or “*so much*”. However, the phrase “*a lot*” was also used to describe the frequency of pain.

“I keep getting toothache a lot” (Lily, aged 12 years)

Impacts related to pain

A number of impacts relating to dental pain were reported by participants, which largely focused on eating and sleeping. School and social activities were also adversely affected as a result of toothache.

In terms of eating, children encountered a number of problems such as not being able to bite with their sore teeth and not being able to eat some foods or finish their meals. In addition, they reported that food often got stuck in their teeth which then caused them pain.

“It did stop me eating on my teeth” (Wayne, aged 9 years)

“Yeah, like, I can’t eat some food...” (Lily, aged 12 years)

“I couldn’t eat apples ‘cos that, ‘cos skin kept going in” (Brodie, aged 9 years)

Disturbed sleep was another pain-related impact experienced by some children.

“Yeah, I couldn’t get to sleep” (Jack, aged 11 years)

*“I had like half an hours sleep then I kept waking up and it started hurting again”
(Lily, aged 12 years)*

Children who had experienced pain both during the day and night felt that it was worse at night. Furthermore, a lack of sleep led some participants to feel tired at school the following day, and some felt it interfered with their schoolwork.

“Yeah, I get tired at school” (Lily, aged 12 years)

As a consequence of their dental pain, some children reported that they had not been able to participate in planned social activities such as going out with friends or family. Others said that they had experienced difficulty in talking or brushing their teeth.

“When it’s that bad, I just sit there and go, like that, and I don’t eat and talk” (Lily, aged 12 years)

Strategies adopted to reduce pain

Children used a variety of methods to alleviate or prevent pain. Children who experienced pain whilst eating, discussed methods they had used to prevent pain or food getting stuck in their teeth. These behaviours included changing the way they ate or, as mentioned previously, avoiding foods which were likely to cause pain.

“Just, er, tried to eat carefully” (Jack, aged 11 years)

“I just had to eat on the other side of my mouth” (Precious, aged 11 years)

Participants also discussed eating more slowly, but the predominant strategy was to eat on one side of their mouth, thus avoiding the painful tooth. Where there was bilateral pain, this was not possible so soft foods like soup or sandwiches would be consumed.

“Medicine” was also seen as an option to alter the pain. However some remarked that having “medicine” didn’t always relieve the pain, whilst others found it difficult to swallow tablets.

“Well, cos it was hurting, I, I had some medicine” (Annie, aged 8 years)

“Yeah, I don’t like taking tablets” (Liam, aged 13 years)

“Medicine” was also seen as something that could reduce the other impacts associated with pain, such as disturbed sleep.

“Well, before I went to bed my mum gave me some medicine” (Precious, aged 11 years)

Both children and accompanying parents reported incidents where children had required analgesia during school hours. This created logistical difficulties for parents as schools required consent to administer analgesics or parents themselves had to take time off work to bring the required analgesics to the school.

“Does it stop you doing your schoolwork quite as well?” (FG, interviewer)

“Yeah so I go erm, medical tutor” (Lily, aged 12 years)

“And do they give you some medicine?” (FG, interviewer)

“No, they ring my mum” (Lily, aged 12 years)

Emotional aspects resulting from pain

Children used a variety of descriptors when explaining how their dental pain made them feel. “Annoyed” was the typical term used by participants to describe both how they felt about having a pain in their tooth/teeth the pain in their teeth and the impact the pain was having on their lives.

“Yeah, annoyed ‘cos it’s annoying me that I can’t do much things ‘cos of pain, like I can’t eat and sleep and stuff” (Lily, aged 12 years)

Children also reported feeling “sad” or “grumpy” and stated that the pain had caused them to cry on occasions. There was a sense that some children felt that it was unfair that they were suffering and that they were “worse than most people”. This sense of injustice was reiterated by parents who mentioned that their children often said things like “why does it have to be me?” when they were suffering pain.

Aesthetics

Although some participants had caries involving their anterior teeth, the appearance of these teeth did not seem to evoke any real concerns. Older children did comment on the appearance of their teeth, stating that they had noticed “holes” in their front teeth before they had been filled, but that they had not been worried about this. Others commented that their teeth “looked better” following treatment.

“Well after it’s done, it looked better” (Brodie, aged 9 years)

Relationship between impact and clinical status or age

There was no apparent relationship between the level of caries (dmft/DMFT) experienced by participants and the reported impacts. For instance, some children with a single carious tooth reported greater impact on their lives than children who actually had multiple carious teeth. Furthermore, no data emerged to suggest that caries-related impacts were fundamentally different between younger and older children. Clearly, some of the older participants were more eloquent and detailed in describing the impacts whereas younger children would gesture or use single word descriptions.

Discussion

This study sought to give children a voice to describe the impact of dental caries in their own words and has provided some rich data. Not surprisingly, the main impact was pain and its consequences. However, the way in which children described these impacts has important relevance for clinical practice and future research.

Reflection on main findings

Firstly, children’s choice of words and descriptions for pain-related symptoms deserves further consideration. Previous studies which have explored children’s perceptions of other diseases or health conditions have found them to be competent in discussing how they are affected⁴⁹⁻⁵¹. In the present study, most participants used the term “hurts”. This was also found to be one of the most common words used by children in North America to describe pain^{52, 53}. The word “hurt” was also found to be frequently used in a UK study where parents were asked about their child’s use of pain words⁵⁴. Older children were able to expand on their pain description by comparing it to another sensation: “It felt like you wanted to itch it” “It was like sharp” “Like prodding”. There was however, a lack of temporal terms, such as pulsing or throbbing, which concurs with findings from previous studies⁵⁵.

An important caveat to the use of language in this present study is that the participants were from only one UK city. Thus, although English-speaking, some terms may be specific to that region, such as the colloquialism “*dint*” for describing a hole (cavity). This highlights the need for caution when using oral health measures developed in other countries, even when the same language is adopted.

The use of the word “*earache*” to describe caries-induced pain was interesting as previous investigations have revealed the tendency for children to loosely use terms like “*tummy ache*” or “*headache*” when describing pain in other parts of their bodies⁵⁶. There is little understanding as to how children learn the names for diseases/conditions in different parts of their body, although it is thought to be learnt from their family context⁵⁷. This finding has clinical relevance as children may not give anatomically-accurate descriptions of the pain experienced from a carious tooth, leading to potential misdiagnosis by parents or clinicians.

Another important finding was that children generally discussed caries-related symptoms in terms of severity (how much it hurts) rather than frequency (how often it hurts). This observation has also been made in a previous studies investigating general health, the effects of treatment for amblyopia and the impacts of malocclusion on young people⁵⁸⁻⁶⁰ and has clear implications for the design of the response formats in child OHRQoL measures. It is worth noting that two of the most frequently used existing measures, the CPQ and the COHIP, both require a response in terms of the frequency of impacts experienced: the questions ask about the frequency of events in the previous three months in relation to the child's dental status^{5,9}. In light of the present study's findings, it would be more appropriate for a future caries-specific OHRQoL measure to incorporate a response format relating to the severity of the impact rather than the frequency.

Some of the other reported impacts namely disturbed eating and sleeping are common complaints at any ‘emergency’ dental presentation. However, it was evident that some children live with dietary restrictions for prolonged periods of time, unable to eat hard food or getting food stuck in their teeth. Interestingly, children who described these impacts appeared to adopt different eating habits, such as chewing only on one side, in order to avoid any potential pain. This adaptive behavior may have masked the true impact of caries in some of these children. The ability of children to cope with discomfort, in conjunction with the episodic nature of dental pain, and the different language used by children, does call into

question the validity of data from studies which have reported on the prevalence of caries-related dental pain. Studies which have relied on retrospective data, documented by general dentists, may have underestimated the true prevalence of caries-related pain and the wider impacts of this common disease.

Study design

Recruitment was challenging and yielded a relatively low response rate (27%) for interview participants. The initial approach was to give the family an information pack to take home with a reply slip and prepaid envelope for its return. Non-return of reply slips is a common occurrence in health and dental surveys even when reminders are sent out by schools^{61, 62}. However, the response rate did improve slightly with a follow-up telephone call. As the parents were acting a “gatekeepers” it is difficult to know whether it was the child’s decision not to participate or that of their parents. Reasons for non-participation offered by the parents included: the child was not interested; they would find it difficult to organise a convenient time due to work or their children’s extracurricular activities, or that they had an illness in the family. It was clear that families are busy and have many competing demands on their time. A more acceptable approach may be to coincide research interviews with a scheduled dental appointment. However, it would be important to use a non-clinical space so that the environment was comfortable and non-intimidating. Another acknowledged limitation of this study was that, although participants came from a variety of socioeconomic backgrounds and age groups, there was limited representation from children of different ethnic minority groups. The suggestion of a home interview, conducted by a white female researcher, may have been a barrier to participation for some ethnic minority families. More culturally acceptable approaches need to be developed to ensure that there is wider participation in future studies in this area of enquiry.

As FG had approached the children and their families in the clinical environment, they were aware that they were being interviewed by a dentist. However, FG was not involved in their care and wasn’t actively involved in clinical activities when they were invited to participate, this perhaps made FG’s clinical role less apparent. In addition, although the participant’s were purposively sampled to have a range of presentations, FG did not look at their clinical notes until after the transcripts had been analysed to minimise any preconceptions about their experiences. The children did not seem to be inhibited by the fact that FG was a dentist and were happy to discuss their experiences of dental caries and the treatment they had received to manage it. In fact, although comments about the dental profession and the treatment they

received were generally positive, both children and their parents were openly critical at times, indicating that they did not feel inhibited by FG's status as a dentist.

The focus groups involved a small number of children as is advised when conducting focus groups with young children⁶³. This may limit the range of views which are expressed, but may aid the inclusion of younger, quieter children. In this study, the data from the focus groups were used, in part, to inform the topic guide and therefore acted as a guide to important themes which could be explored in the interviews.

On a more positive note, a particular strength of this study was the inclusion of children as young as five years. Young children, given the appropriate forum in which to communicate, have opinions and experiences which are equally valid. Furthermore, the high prevalence of early childhood caries remains the area of greatest concern in many developed and developing countries⁶².

Further research

Further qualitative and inclusive research is indicated *with* children outside the UK to identify similarities and differences in the way that dental caries impacts on the lives of children in other countries with differing severities of caries, languages and cultures. Robust evidence for the impact of dental caries in childhood is essential to justify the allocation of adequate resources to prevent and treat this disease.

It is becoming increasingly important for health care providers to utilise valid patient-reported and clinical outcome measures to demonstrate the quality and benefits of treatment interventions. Future clinical trials, relating to caries management in young patients, would also benefit from the use of a sensitive patient-reported caries-specific OHRQoL measure. Insights gained from this study will therefore be invaluable in informing the content of a future caries-specific OHRQoL measure for use amongst children and young people as such a measure does not currently exist.

Why this paper is important to paediatric dentists

- This paper describes the impacts of dental caries from the child's perspective, describing the terminology and vocabulary used.
- The main impact was pain, with the related effects on sleeping, eating schooling and socialising.

- Children reported a sense of unfairness that they had caries and pain.

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