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Seen and heard: towards child participation in dental research

Abstract

Background. There has been an increasing emphasis in many countries worldwide to capture the views of children on health services and research. A previous systematic review found that most oral health research from 2000-2005 was conducted *on* children and highlighted the need for greater research *with* children.

Aim. To describe the extent to which oral health research between 2006-2014 has been conducted *with* or *on* children.

Design. Systematic review. Electronic databases were searched for literature on child dental health. Each identified paper was examined by two researchers and categorised based on the extent to which children were involved in the research, the type of study (evaluative or otherwise), the country of origin and the clinical discipline.

Results. The search included 2950 papers after application of the exclusion criteria. Of these 17.4% were *with* children, 18.3% involved the use of proxies (parents or clinician) and 64.2% were *on* children.

Conclusions. The proportion of studies from 2006-2014 involving research *with* children has increased from 7.3% in 2000-2005. This systematic review provides evidence for movement towards children's involvement in dental research over the last ten years. Future dental research must focus on incorporating children's perspectives into the evaluation of dental treatments in order to improve outcomes for children

Introduction

Twenty five years ago the United Nations Convention on the Rights of the Child (UNCRC) provided a mandate for the rights of children globally and nationally. The UNCRC recognises children as active members of families, communities and societies with rights to express their views and to have their views taken seriously ‘to all matters affecting the child’, including health, healthcare and research (1). It states children should have opportunities and facilities to ‘develop in a healthy manner’ with the right to adequate medical services.

The convention has since been reflected in international and national policies. For example, the Council of Europe’s ‘Guidelines on Child-Friendly Health’ advocates children’s rights *to* healthcare, but also stresses the need to respect and protect children’s rights *in* healthcare. The core principles being: the rights of all to have their best interests treated as a primary consideration in all actions concerning them and to have their views taken into account in all decisions affecting them (2). The UK Department of Health has placed increasing emphasis on giving children and their parents more information, power and choice over the treatment they receive and involving them more actively in planning their care (3, 4). The recent Children and Young People’s Health Outcomes forum report sets a compelling case and recommends that all health organisations must demonstrate the ways in which they have listened to the voices of children and young people, and how this will improve their health outcomes (5). Furthermore, it suggests that, where appropriate, health outcomes important to children, young people and their families should be included in relation to research and improving health services (5). These policies place the onus on dental services and researchers to ensure that children and young people’s perspectives about the treatments they are offered and their views on the outcomes of their treatments are heard and acted upon.

The UNCRC has also brought children and their rights to the forefront of the research agenda (6). Academics in childhood studies recognise children as active participants rather than objects in research, viewing children as experts on their own lives (7, 8) who can contribute valuable knowledge and unique insights (9). However, a previous systematic review found that dental research is mostly conducted *on* children rather than *with* children (10). This comprehensive review of the child dental literature published from 2000–2005 considered papers in four main categories: children as the objects of research; proxies used on behalf of children; children as the subjects of research with some involvement, and children

as active participants with their perspectives explored. Of the 3266 included papers, only 0.3% involved children actively, 7% involved children to some extent, and 5.7% involved proxies (parents or clinicians). However, the vast majority (87%) of research used children as objects. The authors suggested that future researchers should strive to work with children, involving them as fully as possible throughout the research process. The increasing political and academic recommendations in many countries worldwide advocate the inclusion of the views of children and young people within health services and research. This study aimed to describe the extent to which contemporary oral health research has been conducted *with* or *on* children.

Objectives

1. To perform an updated search of electronic databases on recently published child dental literature (2006-2014).
2. To categorise the identified literature based on the extent to which children were involved in the research, the type of studies involving children, the country of origin and the subject area.

Methods

Search strategy

The same search strategy was employed as for the previous systematic review (10). Child-related (child* or young person or young) and dental-related keywords (erosion and dent* or trauma and dent* or fluorosis and dent* or periodont* or malocclusion or orofacial or oral or periodont* or orthodont* or caries) were used as search terms. The databases searched included MEDLINE (via Ovid) as previously, but also Web of Science (core collections) and Scopus. Articles were limited to the English language and those published in dental journals. The resulting references were exported to an Endnote library and all duplicates removed. The previous review (10) considered dental research *on* or *with* children until 2005. Hence, an updated search was undertaken to identify all studies published in the child dental literature from 2006 to 2014.

At the first pass (titles and abstract screening) the following exclusion criteria were applied:

- studies with participants over 16 years of age
- reports with no primary data
- conference proceedings

- articles not having children and aspects of their oral health as their main topic, including laboratory based studies and studies of craniofacial morphology and injury
- case reports or case series

Data were extracted by eight trained reviewers from different specialities (paediatric dentistry, medical sociology, health psychology, dental public health, and orthodontics). Two reviewers independently screened each title and abstract for their relevance. Agreements between the reviewers about application of exclusion criteria occurred for 95% of the papers and disagreements were resolved through discussion.

The initial search resulted in 27,417 papers although this represented 18,457 individual papers, after duplicates were removed. Application of the exclusion criteria and categories resulted in the inclusion of 2950 papers (Figure 1).

Applying the categories

The four main categories, together with their subcategories, which were used to classify papers *with* children and *on* children within this review are described in Table 1. The process of developing these categories has been described elsewhere (10). In addition, data were extracted on the country where the study was conducted and the type of study involved. Studies were categorised as descriptive (concerned with and designed only to describe the distribution of variables e.g. cross-sectional studies) or evaluative (where changes in variables were measured or explained e.g. longitudinal studies). After the papers had been categorised, they were grouped according to the subject area of the journal in which they were published (general dentistry, orthodontics, oral surgery/oral medicine/oral pathology, restorative dentistry, dental public health, and paediatric dentistry).

All eight reviewers categorised five papers together as a training exercise and a further five papers for calibration purposes. Two reviewers then categorised each paper independently, with the four pairs of reviewers assessing approximately 1000 papers per pair. When it was not possible to categorise the papers from the abstract, the full article was reviewed. Where a paper appeared to fit into more than one category, the category that presumed the greater involvement of children was selected. Inter-examiner agreement between the two reviewers was assessed. The agreement between the pairs of reviewers

ranged from 75% to 90%. Disagreements about categorisation were resolved through discussion and, if necessary, the involvement of a third reviewer.

[INSERT **Figure 1**. Results of literature search]

Results

Of the 2950 included studies, 514 (17.4%) were categorised as research *with* children (Table 1).

[INSERT **Table 1** Frequency distribution of the categories of papers]

Research *with* children

Research *with* children was divided into two sub-categories. The first category (category 1), which included research where children were seen, listened to, and heard, contained 18 (0.7%) papers. Six papers (0.2%) involved children as participants actively engaged throughout the research process (category 1a) (11-16). Examples of active engagement included involvement of children in the development and piloting of paper and video diaries, informing the content of topic guides for interviews or in the development of child-centred questionnaires such as measures of patient's expectations or patient's information-seeking behaviours. A further 12 papers (0.4%) reported qualitative studies describing accounts of children's experiences in their own words (category 1b) on the impact of oral diseases, evaluation of treatment or services, perceptions of need for oral healthcare, oral health promotion initiatives or involvement in evaluation of the content and face validity of questionnaires. These studies used methods such as semi-structured or in-depth interviews or focus groups, solicited diaries and drawings.

The second category (category 2), also classed as research *with* children, but where children were seen and listened to as the subjects of research, included 496 papers (16.8%). In these studies, children completed measures designed by adults such as self-completed questionnaires or structured interviews, including oral health-related quality of life measures

When children's involvement was considered according to the dental speciality, it was found that: 26% of papers in dental public health involved research *with* children; 19.5% in general dental journals; 14.7% in paediatric dentistry journals; 14.7% in orthodontic journals; 13% in restorative dentistry journals, and 10.5 % in oral surgery, oral pathology, oral medicine journals (Table 2).

[INSERT **Table 2** Frequency distribution of 2950 papers by journal area]

Most research *with* children (86%) was descriptive in that it was concerned with and designed only to describe the existing distribution of variables e.g. observational or cross-sectional studies of the impact of diseases or conditions on children's daily lives. Only 14% of research *with* children was involved with measuring and evaluating change e.g. randomised controlled trials evaluating treatments using patient-reported outcome measures.

Use of proxies

A total of 542 (18.3%) papers used proxies to gain the child's perspective. Most (18.1%) used parent/caregivers as proxies (category 3a), often for children below the age of six years. The papers reporting the use of clinicians as a proxy (category 3b) investigated the impact of dental treatment on young children by observing physiological signs, rating details of the child's behavioural response or pain through instruments such as the Face, Legs, Activity, Cry and Consolability (FLACC) scale.

Research on children

The vast majority of papers (n=1894, 64.2%) involved research where children were not listened to or heard, but only seen (category 4).

Countries

Publications could be grouped according to the countries where the research had been conducted (Table 3). While, the largest number of papers (n=537) reporting child dental research were from Brazil, USA and India, only 17.8%, 9.7% and 18.1% were *with* children respectively. Over one-third (34.4%) of papers from the UK involved research *with* children. All six papers where children were involved throughout the research process (category 1a) were from the UK.

[INSERT **Table 3** Frequency distribution of papers according to country and involvement of children]

Discussion

This review suggests that children have become increasingly involved in dental research over the past decade, with an increase from 7.3% in 2000-2005 to 17.4% in 2006-2014. An increase in the number of studies using parents/caregivers as proxies was also seen (5.2% to 18.3%). Correspondingly, the number of papers viewing children as objects of research had decreased from 87.1% to 64.2%. While it is not possible to involve children in all studies, it is clear that there were some missed opportunities to involve children, for example in trials of new or existing restorative techniques or orthodontic treatments. Thus, it is evident that the predominant emphasis of evaluative dental research remains solely on clinical outcomes (e.g. evaluation of the clinical success of different restorative or orthodontic treatments) rather than the use of child-centred patient reported outcome or experience measures or the exploration of children's acceptance of these different treatments.

Research *with* children

Several reports identified within this review successfully involved children as active participants throughout the research process (category 1a), involving them in the development of diaries, topic guides and questionnaires and exploring their perspectives on oral healthcare and seeking feedback on treatments (11-16). Other studies provided accounts of children's experiences in their own words (category 1b), using methods such as qualitative interviews, solicited diaries and drawings (17, 18). All the papers classed as category 1 were qualitative in nature. The involvement of children and young people through qualitative research provides their unique perspective on oral health to address issues which adults may not anticipate.

The second category (category 2), also classed as research *with* children, where children were seen and listened to as the subjects of research included studies where children completed measures designed by adults such as oral health-related quality of life (OHRQoL) measures including the Child Perceptions Questionnaire and Child-Oral Impacts on Daily Performances index. While the use of OHRQoL measures with children is increasing (19) their use remains principally in descriptive, rather than evaluative studies. More recently in

other fields, child-centred measures of health-related quality of life or health utility have been developed involving children throughout the development process and these have been successfully incorporated into clinical trials (20-23). A recent systematic review of the outcomes used in 133 trials of orthodontic treatments found that most were concerned with clinical changes, with few patient outcomes included (24). In future, dental research *with* children should strive to be of high quality and provide answers to questions about which treatments provide the best outcomes for patients.

Use of proxies

A total of 18.3% papers used proxies to gain the child's perspective, an increase of 12.6 % since the last review, suggesting that researchers are increasingly trying to gain insights into children's experiences of their oral health. However, this increase in the use of proxies suggests that dental researchers might still assume that children are unreliable participants. Eiser and Morse's (25) systematic review concluded that there are inevitable differences between adults and children in their understanding and experiences of illness and health. They further classify the use of proxies as either being a substitute for the child's perspective (e.g. child is too young or too ill) or as a complementary perspective (e.g. as providers of additional information). An example of a proxy, used as a substitute, is seen in a study which sought to assess parental satisfaction and plaque-removal efficacy of a novel infant tooth wipe in high caries-risk babies. Parents of the infants scored their satisfaction and baby-perceived acceptance of the cleaning method (26). This demonstrates an appropriate use of the parent proxy as the substitute in a very young child. However, many identified studies used parents/caregivers as proxies for older children, where research with children was possible and proxies should only have been used to provide a complementary perspective rather than a substitute (27).

This systematic review found one paper where focus groups were conducted with five-year olds with the aid of a puppet to elicit children's views on the visual and intra-oral photographic assessment examination method for detecting caries in epidemiological studies (28). This study demonstrates that very young children can be involved in research through the use of appropriate research methods and therefore the use of proxies in such instances might be avoided. It has been suggested that the use of material and visual prompts is an effective and easy way to communicate with very young children (29).

Research on children

The vast majority of studies included in this review presented research where children were not listened to or heard, but only seen. However, the number of papers viewing children as objects of research had decreased by 23% over the past decade. While it is not possible to involve children in all studies some missed opportunities to involve children were observed, for example in trials of new or existing restorative techniques or orthodontic treatments.

Societal and academic trends

It is fascinating to look at the volume of studies relating to children's oral health that are emanating from different countries across the world. Brazil published by far the greatest proportion of the total child dental literature, consistent with its reputation for a high overall contribution to the wider dental literature. This may simply reflect the high number of dental institutes and active researchers within the country. However, there may be other facilitators to this research output such as funding availability and lack of overly bureaucratic ethical and governance processes. There were also marked inter-country differences according to what proportion of the published studies had engaged children. Standing out from the other countries was the UK, where around one third of all studies had involved children. This finding may reflect the increasing emphasis within government health, social and educational policies to involve children and young people in matters which relate to them. In addition, many funding bodies stipulate that user involvement must be demonstrated in grant applications, thereby ensuring that patients are actively involved throughout the research process. Interestingly, Iranian studies were the second most likely to involve children, accounting for 18.6% of all papers. Clearly there is great scope for worldwide collaborative research within the field of child oral health.

Limitations

For reasons of feasibility, the search was restricted to dental journals. It may be that extending the search beyond these limits would have yielded more papers involving children in research about oral health, particularly in journals from disciplines such as sociology or psychology.

Conclusions

In conclusion, this systematic review provides evidence for movement towards children's involvement in dental research over the last ten years. While it may not be possible to involve children in all types of research, where possible, appropriate research methods should be used as children themselves can act as the best co-constructors of knowledge related to their daily lives and oral health experiences (30). In future, dental research needs to focus more on incorporating children's perspectives into the evaluation of dental treatments in order to improve outcomes for children (31).

Why this paper is important to paediatric dentists

- This paper provides a comprehensive overview of the movement of dental research towards conducting research *with* children
- This review highlights the need for paediatric dentists to encourage greater involvement of children in high quality research.

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Figure legends

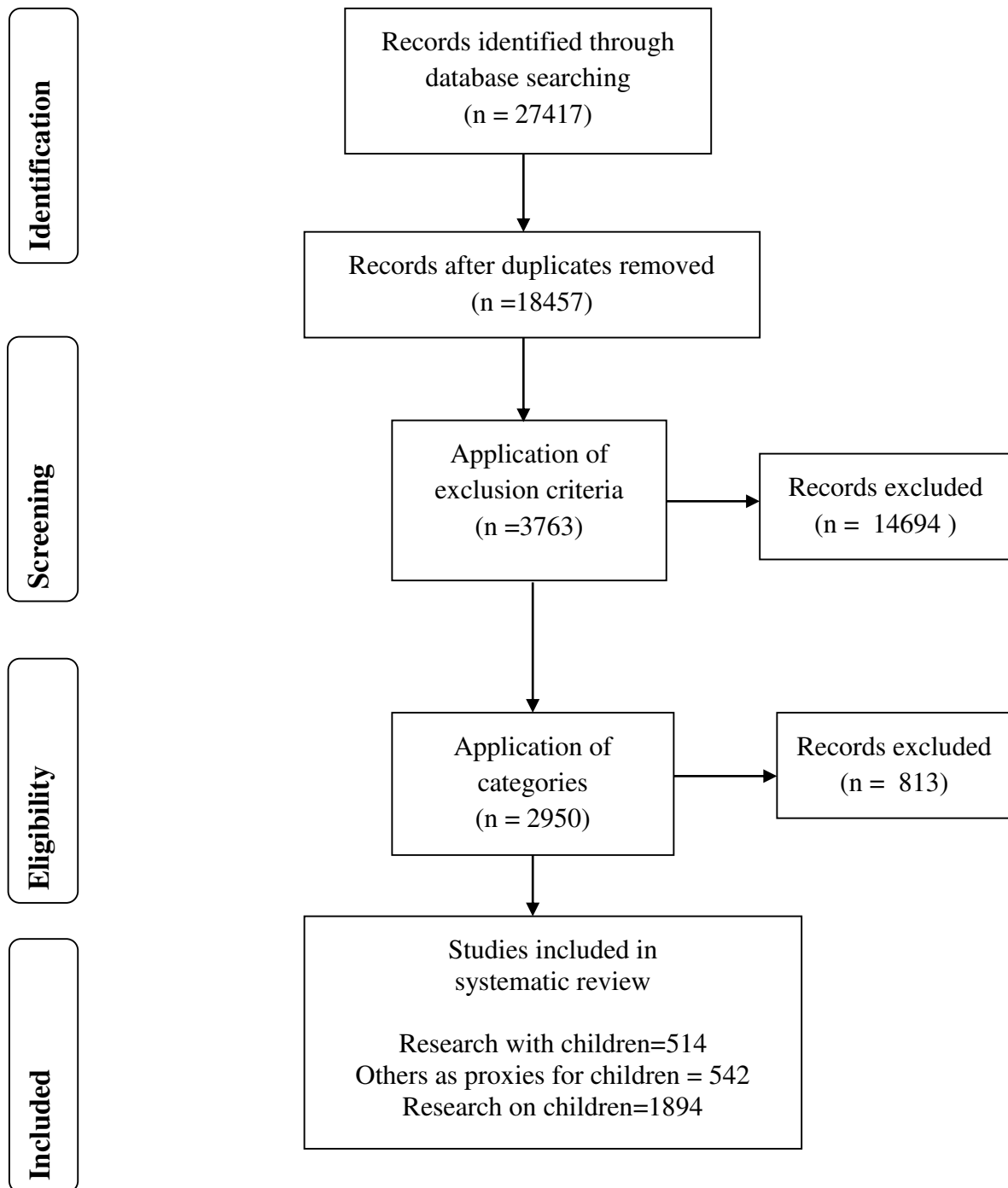
Figure 1. Results of literature search

Table 1 Frequency distribution of the categories of papers

Table 2 Frequency distribution of 2950 papers by journal area

Table 3 Frequency distribution of papers according to country and involvement of children

Figure 1. Results of literature search



Category	Properties	No. of papers (%)
1. <i>With</i> children – children seen as active participants	a) including children in the research process	6 (0.2)
	b) in their own words e.g. qualitative interviews, in-depth, unstructured, semi-structured	12 (0.4)
2. <i>With</i> children – children seen as subjects	children completing measures designed by adults e.g. structured interviews, questionnaires, other scales	496 (16.8)
3. Others as proxies for children - another person reporting on their oral health	a) Parent/caregiver used appropriately as a proxy e.g. child too young/sick	535 (18.1)
	b) clinician used as a proxy	7 (0.2)
4. <i>On</i> children	Children ‘seen’ as the objects of the report	1894 (64.2)

Table 1 Frequency distribution of the categories of papers

Table 2 Frequency distribution of 2950 papers by journal area

Properties	General dentistry	Orthodontics	Restorative dentistry	Dental public health	Oral surgery, oral pathology, oral medicine	Paediatric dentistry	Total no. of papers
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
<i>With children</i>							
(1a) Children involved in process	0 (0.0)	3 (0.5)	0 (0.0)	1 (0.2)	0 (0.0)	2 (0.2)	6 (0.2)
(1b) Children's own accounts	4 (0.4)	2 (0.4)	0 (0.0)	2 (0.4)	0 (0.0)	4 (0.5)	12 (0.4)
(2) Children completing measures designed by adults	156 (19.1)	73 (13.8)	21 (13.0)	116 (25.2)	26 (10.5)	104 (14.0)	496 (16.8)
<i>Proxies</i>							
(3a) Parent/carer used appropriately	171 (20.9)	16 (3.0)	36 (22.3)	140 (30.5)	28 (11.3)	144 (19.4)	535 (18.1)
(3b) Clinician used appropriately	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	7 (0.9)	7 (0.2)
<i>On children</i>							
(4) Children as objects	486 (59.4)	434 (82.2)	104 (66.6)	200 (43.5)	192 (78.0)	478 (64.6)	1894 (64.2)
<i>Total</i>	817	528	161	459	246	739	2950

Table 3 Frequency distribution of papers according to country and involvement of children

	Total papers N (%)	With children N (%)
Brazil	537(18.2)	96 (17.8)
USA	319 (10.8)	31 (9.7)
India	231 (7.8)	42 (18.1)
UK	174 (5.9)	60 (34.4)
Turkey	151 (5.1)	11 (7.2)
Italy	143 (4.8)	7 (4.8)
Sweden	97 (3.3)	16 (16.5)
Germany	97 (3.3)	13 (13.4)
China	88 (3.0)	11 (12.5)
Iran	75 (2.5)	14 (18.6)