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Seen but not heard: a systematic review of the place of the child in 21st-century dental research

ZOE MARSHMAN[1], BARRY J. GIBSON[1], JANINE OWENS[1], HELEN D. RODD[1], HUW MAZEY[2], SARAH R. BAKER[1], PHILIP E. BENSON[1] & PETER G. ROBINSON[1]

[1]Department of Oral Health and Development, School of Clinical Dentistry, Claremont Crescent, Sheffield, and [2]Charles Clifford Dental Hospital, Sheffield, UK

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Background. The position of children in society has changed with increasing emphasis on children's rights and child-centred services. This study aimed to describe the extent to which contemporary oral health research has been conducted *with* or *on* children.
Design. A systematic review of the child dental literature from 2000–2005 was conducted. A purposive sample was used to develop categories describing the level of involvement of children in research. Four main categories were developed: 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. Electronic databases were searched and exclusion criteria applied. Each of the resulting papers was examined and categorised. The frequency distribution in each category and the distribution of these categories according to subject were calculated.
Results. The search revealed 3266 papers after application of the exclusion criteria. Of these, 87.1% were categorised as research where children were used as objects, 5.7% were found to involve proxies (parents or clinicians), 7.0% involved children to some extent and 0.3% involved children actively.
Conclusion. Most oral health research is conducted *on* children, in future research should strive to be conducted *with* children, involving them as fully as possible.

Introduction

'Children seen, but not heard' is a saying that originated from early Victorian times. During such times, children did not have a childhood as we know it today; they were seen as 'imperfect' adults, wearing smaller versions of adult's clothes and went to work rather than school[1]. The late nineteenth century was significant in the construction of the modern childhood and more recently, the past 30 years have seen the position of children in society change further, moving them to the forefront of personal, political, and academic agendas[2]. From a personal and family perspective, changes in developed countries have been due to a demographic shift; for example, in the UK, the proportion of the population aged under 16 has declined since the 1970s[3]. In addition, there has also been a change in family structure, with an increase in one-parent families[4]. Collectively, such changes have led to the idea of the child as a scarcity and thus more 'precious'[5].

Politically, legislation has changed children's rights both globally and locally. The United Nations Convention on the Rights of the Child was adopted in 1989 and is the most universally accepted human rights instrument in history, being ratified by nearly every country in the world[6]. This Convention confirms, amongst many other things, children's participation rights to express their views and to have them taken seriously and given due weight. In English law, the *Children Act 2004* requires welfare agencies to take account, not only of children's best interests, but also their wishes and desires[7]. The English government has also shown its commitment to ensuring health and other services are child centred[8,9]. The National Service Framework for Children, Young People and Maternity Services (Children's NSF) requires services to give children and their parents increased information, power, and choice over

Correspondence to:
Miss Zoe Marshman, Department of Oral Health and Development, School of Clinical Dentistry, Sheffield S10 2TA, UK. E-mail: z.marshman@sheffield.ac.uk

the treatment they receive and involve them in planning their care. Dental services are included in the Children's NSF[8].

There has also been a change in the field of childhood study and the level of involvement of children in research[2]. James and colleagues have described how most research until the 1990s viewed children as developmentally incomplete adults and gave little time to children themselves. Thus, there was a culture where research was conducted *on* children. Since then, as more weight has been given to the rights and views of the child, the voices of children have increasingly been recognized[10] with a change in emphasis to research *with* children. Social sciences have embraced this shift and moved away from research methods that view children as 'objects of concern', to methods that engage children as 'active participants'[11]. This research goes beyond just considering what is in the child's best interest to actually involving children in research to gain their perspectives and own experiences.

During dental care, the importance of seeking children's views is widely acknowledged. Paediatric dentistry texts on the subject outline the importance of understanding how children relate to the adult world, with dental students taught the importance of talking to children, listening to their answers, and giving children control over their dental care[12]. However, we have no knowledge of how far research in this field has been conducted *with* or *on* children.

This study therefore aimed to conduct a systematic review of the extent to which contemporary oral health research has been conducted *with* or *on* children. The review will enable any deficiencies in approaches to research in this field to be highlighted.

Materials and method

Developing the categories

The study was conducted in two stages, first to develop categories to classify research and then systematically reviewing the literature to place papers in these categories.

The categorization framework was developed using framework analysis, which classifies qualitative data by organization according to key themes and emerging categories[13]. This matrix-based method, which has been widely used in applied policy research, allows data to be synthesized quickly when specific information is needed. A purposive sample of child dental literature from the past 5 years was chosen to include a wide range of studies from both different subject areas (including paediatric dentistry, orthodontics, restorative dentistry, oral pathology/oral surgery/oral medicine, and dental public health) and epistemological stances. The two themes of *on* children and *with* children were explored and characterized, based on an initial sample of 20 papers. Four main categories were then identified and frameworks devised so the properties of these categories could be developed (Table 1).

The first category (category 1) included research where children were active participants being seen, listened to, and heard; this research attached a priority to fully involving children. Within this category two subcategories were derived based on the degree to which the children were involved. The first subcategory (category 1a) was research conducted with children as participants actively engaged throughout the research process (e.g. involving

Table 1. Frequency distribution of categories of papers.

Category	Properties	No. of papers (%)
1. *With* children – children seen as active participants	(a) Children involved in research process	2 (0.1)
	(b) Children's own accounts	6 (0.2)
2. *With* children – children seen as subjects	(a) Children completing measures designed by adults	220 (6.7)
	(b) Case report/series with child's input throughout case	10 (0.3)
3. Proxies for children used	(a) Parent/caregiver used appropriately as proxy	173 (5.3)
	(b) Clinician used appropriately as proxy	12 (0.4)
4. *On* children	Children seen as the objects of the research	2843 (87.1)

them in research design, in piloting, using participatory data collection methods, and getting their feedback on results). The second subcategory (category 1b) comprised research where children participated by giving accounts of their experiences in their own words using methods such as semistructured or in-depth interviews or focus groups.

The second category (category 2), also classed as research *with* children, included studies where children were seen and listened to as the subjects of research, although their own words were not heard. This category was subdivided into studies where children completed measures designed wholly by adults (category 2a) including self-complete questionnaires, structured interviews, and visual analogue scales. The second subcategory included clinical case studies showing evidence of the child's feelings being taken into account throughout the reporting of the case, such as reporting the presenting complaint in the child's own words and evidence of discussions with the child about the treatment (category 2b).

The third category included research that used either parents/caregivers (category 3a) or clinicians (category 3b) as appropriate proxies for children. It was felt appropriate to use proxies for young children (under 6 years) or those who lacked verbal articulacy, as research with the children themselves would not be a feasible option[14].

The final category (category 4) included research where children were simply objects to be studied. In this research, children were not listened to or heard but only seen. Included within this category was research that saw children as:

- a set of teeth or a mouth to be treated;
- a source of a sample of plaque, saliva, or hard/soft tissue;
- an age group of patients to be managed;
- a child patient with a medical condition;
- a population group to be surveyed clinically;
- a patient on whom a 'special investigation' was conducted; and
- a recipient of a oral health promotion intervention.

These four main categories with their subcategories were developed to classify papers identified in a systematic review.

Search strategy

The search strategy was based on published studies using child-related keywords (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).

The search strategy was performed on the databases MEDLINE (via Ovid) and EMBASE and limited to the English language. The resulting references were exported to an Endnote library[15] and all duplicates were removed. A list of dental journals was compiled based on the research team's knowledge and experience and any articles from nondental journals were excluded from the electronic library.

The so-called 'new social studies of children and childhood' were consolidated in 1998[2] with methods described for conducting such research published in 2000[11]. Consequently, the most appropriate time frame to explore how far dental research was conducted *on* or *with* children was from 2000 to 2005.

At the first pass through the library of references the following exclusion criteria were applied:

- reports before 2000;
- studies with participants over 16 years of age;
- studies with no primary data;
- articles reporting *in vitro* studies;
- conference proceedings; and
- articles that did not have children and aspects of their oral health as their main topic.

A team of researchers from different disciplines (paediatric dentistry, medical sociology, health psychology, dental public health, and orthodontics) was recruited to conduct the review. Two trained reviewers from the team independently applied the exclusion criteria based on the abstracts and where necessary the full-length papers. Agreements between the reviewers about application of exclusion criteria occurred for 77% of the papers and disagreements were resolved through discussion.

The initial search resulted in 18 249 papers although this represented 14 895 individual papers after duplicates were removed. After excluding articles from nondental journals the

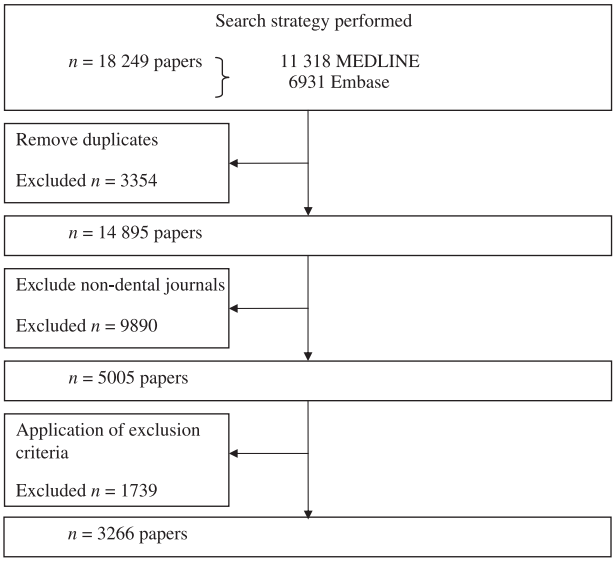

Fig. 1. Results of literature search.

number of papers reduced to 5005. Application of the exclusion criteria resulted in 3266 papers, of which 752 were case reports/series (Fig. 1).

Applying the categories

Before the papers were categorized the eight reviewers undertook training using 15 selected papers and then a calibration exercise on a further two sets of 15 papers. For the second set, agreement on the categorization of the individual papers ranged from 62.5% to 100%.

Two reviewers then categorized each paper independently, with four pairs of reviewers assessing approximately 817 papers per pair. When it was not possible to categorize 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 chosen. Inter-examiner agreement between the two reviewers was assessed. The agreement between the pairs of reviewers ranged from 88% to 92%. Disagreements about categorization were resolved through discussion and, if necessary, involvement of a third reviewer.

After the papers had been categorized, they were grouped according to the subject area covered by the journal in which they were published. Journals fell into six broad areas: general dentistry, orthodontics, oral surgery/oral medicine/oral pathology, restorative dentistry, dental public health, and paediatric dentistry.

Results

Of the 3266 papers that resulted from the literature search, only 238 (7.3%) were categorized as research *with* children (Table 1).

Research with *children*

Eight papers (0.3%) involved children as active participants, two (0.1%) with evidence of children being included throughout the research process (category 1a). These two papers both concerned developing questionnaires and involved children in the developing, compiling, and evaluating of the instruments[16,17]. These papers were published in 2002 and 2004 in two different journals. A further six (0.2%) papers reported qualitative studies using interviews or focus groups (category 1b). The first of these studies was published in 2002. These studies explored children's perspectives on oral health generally, dental services, habits (drinking carbonated drinks and smokeless tobacco use), oral health education messages, their oral symptoms, and compliance with orthodontic treatment. Most studies involved adolescents, although in one study children from 6 years of age were interviewed.

In the second category, where children were seen as subjects, 220 (6.7%) papers involved children completing measures wholly designed by adults (category 2a). Unlike papers in category one, these papers used measures developed without children's input into the topics they felt were relevant or in the format or wording of the measures.

Only 10 of 752 case reports/series had evidence of the child's involvement (category 2b). These 10 cases included the patient's presenting complaint in his or her own words, a description of the patient's input into decisions about the treatment options, and the patient's perspectives on the outcome of treatment.

Use of proxies

A total of 185 (5.7%) papers used proxies to gain the child's perspective of which 173

(5.3%) used parents/caregivers and 12 (0.4%) used clinicians. The children of interest in studies involving parents/carers (category 3a) were either less than 6 years of age or older children with communication difficulties. The papers reporting the use of clinicians as proxies (category 3b) investigated the impact of dental treatment or treatment services on young children or those unable to communicate themselves.

Research on *children*

Finally, the vast majority ($n = 2843$, 87.1%) of papers were categorized as research *on* children. Implicit in these papers was the idea of children as the objects of research, with no involvement of children or their parents to any extent. Within these were extreme examples that referred to the children studied as 'the material'.

Subject area

Papers were also grouped according to the subject area covered by the journals in which they were published. When expressed as a percentage of the total number of papers per area, 9.2% of papers in general dental journals involved research with children; 5.9% in orthodontic journals; 7.5% in oral surgery, oral medicine, oral pathology journals; 5.8% in restorative dentistry journals; 11.4% in dental public health journals; and 5.4% in paediatric dentistry journals (Table 2).

Discussion

The categories developed for this systematic review represented a hierarchy of involvement of children in child dental research ranging from full involvement in the research process to no involvement. When these categories were applied to child-related dental research over the past 5 years most research used children as objects with no other involvement. This study highlights the need for future research to be conducted *with* children to capture their own experiences of oral health and treatment.

While we acknowledge that research *on* children may be appropriate to answer certain questions, when research opportunities arise, the potential to capture the perspectives of children should be considered. From this review, research *on* children typically views them as objects: as a set of teeth to be treated or a source of a sample of plaque or saliva. It treats children as a homogenous age group rather than as individuals and makes generalizations to this effect. A more holistic approach to studying oral health is required that recognizes the interaction of these biological perspectives with the social and psychological perspectives of the individual[18]. For example, a study that reports the survival of re-implanted avulsed teeth from the normative view of the clinician will ignore the children's subjective experience of the trauma-related treatment and outcomes. Similarly, traditional epidemiological surveys of children have also usually relied on normative assessments of the prevalence of oral

Table 2. Frequency distribution of 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
With children:							
(1a) Children involved in process	1	0	0	1	0	0	2
(1b) Children's own accounts	5	0	0	0	1	6	6
(2a) Children completing measures designed by adults	68	37	13	27	47	28	220
(2b) Case reports with child's input	0	3	0	1	1	6	10
Proxies:							
(3a) Parent/carer used appropriately	44	7	17	41	13	51	173
(3b) Clinician used appropriately	1	1	0	1	5	4	12
On children:							
(4) Children as objects	689	634	193	184	590	553	2843

disease. In the UK, the authors of the national Child Dental Health Survey 2003 were keen to supplement these data, for the first time, with an assessment of the impact of oral health on children. However, a validated measure of child oral health-related quality of life was not available in the UK at that time[3]. Due to developments in child-centred research these measures are now available[19,20] and can be incorporated into future surveys of children's oral health. Only by conducting research *with* children will our understanding of children's oral health and their views of management be expanded.

Generally there has been an increasing emphasis placed on user involvement in research[21]. Research ethics committees and grant-awarding bodies require evidence of the level of involvement of participants throughout the research process, rather than merely assessing whether the research potentially puts participants at risk. Within health care the views of patients and the public on their experiences of health and health services have attained much higher significance in recent years[22]. Patient's rights to be listened to and have their needs acted upon have been clearly outlined[23]. This emphasis has been particularly strong in services for children with an explicit requirement for services to be child-centred. Given that it is the child who undergoes the treatment and who lives with the consequences, it is important to consider, not just what clinicians think is in their best interests, but their own perspective, desires, and expectations[24]. The Children's NSF suggests professionals should listen to children themselves, value their views, and take these into account in decisions about their care and the planning, delivery, and evaluation of services[8]. While communication with patients is stressed as a key feature of dentistry for children[12], this emphasis does not appear to be mirrored in research.

Within social science there has been an increasing recognition of the importance of listening to children to improve understanding of what is important to children, rather than research being defined by adult interests, biases, and agendas[2,10]. The child-centred nature of this kind of research is not just evident in the research methods used, but also through working with children to identify research questions that are meaningful to them and disseminating the findings back to them. This approach has led to social policy changes that reflect children's concerns more accurately[25]. We acknowledge that there is an overlap between the categories developed in this study and the research methods reported in the articles, but conducting dental research *with* children requires more than just using participatory methods, it demands that we strive to involve children more fully throughout the research process.

This systematic review did identify several studies that have successfully involved children as active participants, exploring their perspectives on oral health or involving them in questionnaire development[16,17]. Involving children in this way ensures that aspects pertinent to them are included, that language to which they can relate is used, and that questionnaires formats are appropriate[26]. Interestingly, only 5.4% of articles published in specific paediatric dentistry journals were categorized as involving research *with* children. This was the lowest percentage of the six subject areas suggesting considerable opportunity for publishing further research of this kind in the paediatric dentistry literature.

Qualitative research with children has also been attempted[27], which adds the advantage of capturing children's perspectives in their own words rather than imposing adult-generated frameworks that might distort their ideas[28]. Dentistry has been slow to adopt qualitative methodology with some initial resistance to its use[29]. If more qualitative research is to be conducted with children, paediatric dentists will require training to develop these skills or may choose to work collaboratively with other disciplines with this expertise. This systematic review should be repeated in 5 years' time to investigate whether an increasing emphasis on research *with* children can be observed.

About 6% of papers involved parents/carers or a clinician as a proxy for the child. The use of proxies has advantages in overcoming some of the practical problems of reading level and comprehension in young children[14]. However, when comparing data obtained from parents

as proxies with children's self-reports of quality of life, agreement is modest[30]. For this reason information from parents should be used to complement the views of children rather than as a substitute, although in some circumstances the use of a proxy is unavoidable.

It is acknowledged that the present study has some limitations. Notably, for practical reasons, the search was restricted to electronic databases, the English language and dental journals. The adoption of this strategy meant that some relevant studies may have been omitted. First, as child-centred research is at a relatively early stage in dentistry, such studies may not have reached the stage of publication yet. Inclusion of conference proceedings would have included some such studies, but would have resulted in an unmanageable number of articles. Second, studies reporting dental research *with* children may have been published out with the dental literature and therefore have been overlooked. Third, the reports of the research may not provide comprehensive details of the actual study. Children may have thus been more fully involved in some studies without this being documented as such in the text.

In summary, the findings of this systematic review demonstrate that in most child dental research, children are seen, but not listened to or heard. In future, researchers should attempt to involve children as far as possible in their studies to ensure that their perspectives are obtained.

What this paper adds

- An overview of the changing position of children in society
- An investigation of the extent to which child dental research is conducted *with* or *on* children
- Identifies opportunities for future research with children

Why this paper is important to paediatric dentists

- This paper challenges the way paediatric dentists involve children in research

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