Oral health and children with an intellectual disability: a focus group study of parent issues and perceptions.

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Abstract

Aim: Children with intellectual disability are at risk of poor oral health outcomes and it is important to understand the parental perspective to design appropriate services and resources. The aim of this study was to investigate parental issues and perceptions regarding the provision of dental care (both services and home care) for children with an intellectual disability.

Design of the study: Parents who care for children with an intellectual disability participated in focus groups and interviews. Thematic content analysis underpinned the coding and interpretation of data.

Subjects: Seven focus groups and two interviews were conducted (44 female, 3 male) with participants who were contacted through community support groups and special schools.

Results: Many parents reported difficulties (mostly related to behaviour) in providing oral care for their children. Parents related a variety of problems using dental services and obtaining relevant information for a range of reasons relating to parent, child and the service, even when specialist services were available to them. Many parents were concerned about the use of general anaesthetics for simple dental procedures. Some parents shared positive experiences.

Conclusions: The use of focus groups provided valuable insights into parent issues and perceptions. These insights are important to inform policy-makers and those health professionals involved in the care of children with intellectual disability. Discussions gave participants an opportunity to share their experiences, which will be useful for service planning for families and training of dental professionals. Many of the parents’ perceived needs should be simple and relatively inexpensive to implement.

Key words: Intellectual disability, focus group, oral health, oral health issues for parents of disabled children

Introduction

Children with an intellectual disability (ID) have been recognised to be at risk of receiving inadequate dental care and having poor oral health, partly because of substantial dependence on others for the management of their oral care (Brown and Treasure, 1992: Desai et al., 2001). However, there can be considerable variation in dependency according to the type of disorder and degree of impairment (Leonard et al., 2001). Although for a sizeable proportion the cause still remains unknown, ID has multiple aetiologies with individual causes often only accounting for small numbers of subjects (Bower et al., 2000). Some of these disorders are known to have specific dental problems or have poorer oral health outcomes (Swallow, 1964; Vigild, 1985; Barnett et al., 1986; Nunn, 1987, Collado and Collado, 2008). Depending on the nature and degree of disability, it may be very difficult to manage appropriate oral examinations and treatments. Thus, children with ID more frequently require these to be performed under a general anaesthetic (Holloway and Swallow, 1982; Leonard et al., 1999; Slack-Smith et al., 2009; Williams et al., 2005), a procedure which involves some risk (Blayney et al., 1999). In Western Australia free basic dental care by dental professionals is available for most school children through the School Dental Service (Riordan, 1995). At the time of these interviews, specialist services in Western Australia were provided through a government department specialising in disability. A dental
Clinical and specialist paediatric dentists provide care on a fee-for-service basis. This can be subsidised by private health insurance.

This project investigated the oral health related issues and concerns for parents of children with an ID living in a metropolitan centre with a total population of 1.6 million (Australian Bureau of Statistics, 2009). A previous study identified four primary areas of concern for mothers of children with disabilities, these were: medical and legal concerns, concerns for the child, concerns for the family and concerns for the self (Noojin and Wallander, 1996). The conceptual model provided in the Noojin and Wallander study provided an extremely useful framework for the overall areas of concern in mothers of children with disabilities, which informed this study, without being prescriptive (Noojin and Wallander, 1996). Qualitative methods provide a powerful research tool to elucidate deeper understanding of these issues in the context of the details of the disability and family structure and process (Gift, 1996; Pine, 1997). However, the use of a qualitative approach to gain an understanding of oral health needs remains limited (Stewart et al., 2008). The parental perspective is an important part of an assessment of the oral health and dental services requirements for this group of children.

The aim of this study was to describe parent issues and perceptions regarding the provision of dental care (both dental services and home care) for children with an intellectual disability.

Method

Selecting the participants

The sample was obtained using purposeful sampling. This is a common form of sampling for qualitative research where appropriate participants, who have knowledge and experience of the issue under investigation and who are likely to give rich and relevant information, are targeted (Patton, 1990). Parents of children with a disability were contacted through community support groups and schools in the Perth Metropolitan Area for children with disabilities. Fliers describing the project were distributed through these organisations and reply paid envelopes were used to encourage responses. Parents were invited to attend a focus group to discuss their concerns and issues related to oral health. Parents of children with an intellectual disability were targeted but parents of children with other disabilities were not excluded (on reviewing information, we consider that only one of the children discussed was unlikely to have an intellectual disability). Recruiting these parents was challenging but we attempted to recruit a range of parents (from different socioeconomic residential areas) with children having different forms of intellectual disability. Ethics approval was obtained from the Human Research Ethics Committee of The University of Western Australia.

Conducting the groups and interviews

Focus groups were conducted by an experienced moderator at a location where participants felt comfortable (for example support group meeting locations or the child’s school). Focus groups are generally highly dynamic and require skill in their moderation (Berg, 1998). Introductions were followed by asking specific research questions, with the opportunity to discuss other issues as they arose. Audio tapes were used in addition to a non-participant note-taker to record the discussion. This assisted in the analysis of the transcripts and in particular in identifying the speakers. Participants were asked simple demographic details about themselves and their child in a brief written questionnaire. Focus groups and interviews were held with successive groups until major themes were recurrent.

Focus group questions included: oral health care of their child, factors affecting dental visits, any problems with access to services, availability of information about oral health for their child, positive and negative aspects about current services and what would improve dental services for their child. Initial questions were supported by further probing questions. Data collection was continued until saturation of the data was considered to have occurred with similar themes repeated.

Analysis

Transcripts were produced by combining written notes with transcription from audio tapes. Thematic content analysis underpinned the coding, sieving, grouping and interpretation of data with elucidated themes often supported by appropriate quotes (Boyatzis, 1998; Stewart et al., 2008). Two of the investigators explored themes independently and then combined these results and discussed them with the third investigator. Major themes were those that generated discussion between several participants within the group or were raised in several groups.

Results

Despite substantial support from co-ordinators of support groups and special school principals, considerable effort was required to recruit participants in focus groups, which is not surprising given the demands on these parents.

In total seven focus groups and two interviews were conducted. A total of 47 parents (one female was a grandmother) participated in this study (44 female, 3 male). The origin of contact for each group is noted in Table 1. Medical records and diagnostic details of disorders were not requested but of 45 children considered in the study, parental reports indicated that eight had autism (including Asperger’s Syndrome), seven had Down syndrome (or related disorders), 22 had another form of intellectual disability, seven had possible intellectual disability and one was unlikely to have an intellectual disability. Mothers and a grandmother comprised 96% of the participants; 70% of participants were born in
Australia or New Zealand and 19% in Europe. Almost half, (49%) had completed a post-school qualification. One third (32%) worked outside the home 80% had partners, of whom 79% were employed; 59% of participants had private health insurance with dental cover and 32% received a pension.

Once parents attended a group, they were very keen to participate and smaller focus groups than used in previous research projects were considered preferable to allow all participants to have adequate input. No participants reported any negative feedback and most noted participating as a positive experience.

A predominant theme in the discussions was the overall burden of caring for a disabled child. Many parents recounted daily events in great detail, showing evidence of how much they planned ahead to reduce the likelihood of difficulties. Their discussion mostly pertained to their own personal experiences with occasional reference to the experience of their friends. The focus group and interview results are considered here under the appropriate interview question.

**How do you assist your child in their oral health care?**

Parents described their personal experiences with cleaning children’s teeth. In the process of answering this question they also related some of their concerns in relation to dental health and services. These included caries, bad breath (halitosis), teeth grinding (bruxism), overcrowding of teeth, the possibility of choking when baby teeth fall out, increased susceptibility to infection because of immune status and the lack of availability and flexibility of dental appointments. Parents considered that the appearance of their child’s teeth may also have an important impact on their overall quality of life.

“Clean teeth make an obvious difference. Important for oral health, bad breath etc … prevents trauma associated with future dental work. I’ve always had an obsession about clean teeth.”

The issue of dependency of the child for oral care was usually raised early in the discussions. Only a few parents spoke of children cleaning their own teeth and children with physical disability e.g. cerebral palsy may not be able to hold the toothbrush.

“…only ensuring she brushed twice a day. Ensure not too much toothpaste, help her with flushing it out. Bad for her to swallow too much toothpaste.”

Self cleaning of the child’s mouth was sometimes a problem. Some children were fed through a gastrostomy tube and had minimal oral intake.

“Daughter does not self clean her mouth, so food can just sit there until her teeth are cleaned.”

Some children enjoy having their teeth brushed while others dislike it intensely. Some parents had established effective routines and had few problems with tooth brushing. However, children with autistic or other behavioural problems could be unpredictable in terms of their cooperation. There was often difficulty in encouraging the child to open their mouth for teeth cleaning and sometimes the risk of the parent being bitten. Sometimes fathers assisted in physical interventions and teamwork was evident for some couples. Several parents noted the difficulty in finding a toothpaste the child liked.

“Wait until he is asleep and then sneak in and brush his teeth. We set our alarm for 2am to make sure he is really asleep.”

Parents discussed different options to assist with cleaning teeth such as specially designed curved toothbrushes or electric toothbrushes. However, not all parents knew about these options and several mentioned the cost. Parents played a major role in oral health care and were keen to make the task easier and more effective.

“Just started using electric toothbrush six weeks ago. She hates it, have to hold her down to brush her teeth. It is a nightmare, we dread it...”

**Table 1 Focus group and interview participants**

<table>
<thead>
<tr>
<th>Groups</th>
<th>Participant contact</th>
<th>Number of Participants</th>
<th>Mean Age In Years (Range) (Adults)</th>
<th>(Child)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Groups</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>A</td>
<td>Support group</td>
<td>10</td>
<td>39 (27-49)</td>
<td>8 (3-14)</td>
</tr>
<tr>
<td>B</td>
<td>School group</td>
<td>7</td>
<td>40 (35-44)</td>
<td>7 (5-11)</td>
</tr>
<tr>
<td>C</td>
<td>School group</td>
<td>7</td>
<td>42 (30-59)</td>
<td>6 (4-9)</td>
</tr>
<tr>
<td>D</td>
<td>Support group</td>
<td>4</td>
<td>32 (27-36)*</td>
<td>5 (3-5)</td>
</tr>
<tr>
<td>E</td>
<td>School group</td>
<td>5</td>
<td>37 (27-42)*</td>
<td>7 (4-12)</td>
</tr>
<tr>
<td>F</td>
<td>School group</td>
<td>6</td>
<td>44 (40-48)</td>
<td>10 (5-16)</td>
</tr>
<tr>
<td>G</td>
<td>School group</td>
<td>5</td>
<td>47 (38-54)</td>
<td>10 (6-14)</td>
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<td>Interviews</td>
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<tr>
<td>H</td>
<td>Support group</td>
<td>2</td>
<td>46 (34-59)</td>
<td>17 (5-29)</td>
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<tr>
<td>I</td>
<td>Support group</td>
<td>1</td>
<td>37</td>
<td>5</td>
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<tr>
<td>Total</td>
<td></td>
<td></td>
<td>47</td>
<td>41 (27-59)</td>
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</table>

*One participant in these groups did not provide age
What is important about maintaining the dental health of the person you care for?

Parents generally spoke about maintaining oral health to prevent the need for dental treatment and associated pain. Many parents spoke of the long term effects of good oral hygiene. They were keen to avoid caries and toothache and to prevent the need for any extra dental care, particularly when this treatment often required a general anaesthetic. Some parents mentioned that it could be difficult to differentiate between toothache and behavioural symptoms when their child was unable to communicate that he or she was in pain.

Issues for individual parents included specific dental anomalies or enamel problems associated with their child’s condition; gingival hypertrophy associated with anticonvulsant medication; and the antibiotic cover required because of their child’s heart condition. Parents wanted more information on what was normal for teeth for their child’s condition and the effects of medications.

“He has weird teeth, like sharks teeth, pointy”

How easy is it to provide a healthy diet - particularly in terms of reducing refined sugar?

Parents had different opinions and knowledge regarding appropriate diets for their children. Food and feeding were strong themes in the discussions. Parents noted that they often used food as a reward. However, many children had a healthy diet with limited access to ‘lollies’. Some parents felt as if they were in control of the diet they provided their children (including those with gastrostomy feeding), whereas others felt that they were controlled by their children in this process. Two parents mentioned specifically serious nutritional issues where children were not consuming a balanced diet because of their insistence on sweet foods at the expense of more healthy foods. Another mentioned the development of cavities associated with prolonged bottle feeding. The problems associated with pica were also raised.

“Conscious about food. Child holds out. Chocolate and biscuits. Refuses milk, meat, vegetables. We want counselling about eating problems.”

“He is fussy. Spaghetti only and sweet food, and peanut paste. This is all he will eat. Use diabetic versions of food to cut out sugar. He refuses water, so we use watered down sugarless juice.”

“...because of his developmental delay and head banging we have given him bottles of milk for comfort and bottles of milk are causing cavities”

Do they have regular dental check ups? (What have been the barriers to your child getting regular check ups? If you have attended the dentist what has made it easier?)

Most children were reported to have regular check-ups on a six or 12 monthly basis. Many children required a general anaesthetic for even simple dental treatments such as scaling and cleaning. Several parents had the perception that other parents did not take their children to the dentist, although those attending the groups generally did attend.

In terms of services provided, some parents mentioned that there is a need for more availability of appointments and identified various problems with service provision while others were content with the standard of service. There were varying opinions on the strengths and weaknesses of the individual service providers. These were often based on the administrative process and the individual skills and personality of the dentists and their support staff. Each experience could alter parent perceptions and lead to anxiety during and prior to future visits.

Dental services had been provided by a variety of sources, which included the state government service for children with an intellectual disability, the children’s hospital, private paediatric dentists and a private dentist who appears to have developed specialised experience in this area. A small number of children attended the school dental service. Parents commented on the early medical demands of their disabled children, several of whom were given a poor prognosis. Hence regular dental care was not established until the children were older.

“Medical problems overshadow dental problems, don’t think about dental. Realise dental health is important later. Then you are already in the system and not having regular check-ups. My son did not see a dentist until he was six years old.”

Many parents used the state service but often had concerns about access for urgent treatment. Parents were satisfied with private specialist dentists who appeared to provide a good service but at a cost. Some parents elected to go directly to a private hospital. Many parents would rather pay for private care than wait for appointments or surgery. Other parents would have liked the financial situation to choose to pay for private services. Parents commented that general dental practitioners tended not to be able to treat disabled children and to refer on to a specialised service. Parents felt that many dentists needed more training and experience in managing children with disabilities. One suggestion was the development of a register of dentists with experience in this area.

Several parents suggested that a system should be in place for disabled children when they start school similar to the regular school dental service for non-disabled children. They saw advantages in the provision of routine dental services in familiar surroundings with nurses and staff the child knew nearby and then the child could be referred on if necessary.

The distance required to travel was a concern in relation to attendance at central facilities such as the children’s hospital and the state facility for disability. Parking at both facilities could be difficult. Some parents had to travel by
taxi and this option was difficult when length of wait was uncertain or special taxis were not available. The physical effort of lifting her daughter in and out of her wheelchair was a barrier for one mother while another mother could not close their disabled van herself.

Parents wanted reminder notes and flexible appointment times to suit their routine and school hours of both disabled children and siblings. Many had concerns regarding the time required to obtain an appointment and then delays in waiting rooms when the child was likely to become disruptive and totally uncooperative, sometimes disrupting the child’s medication and feeding schedule.

“...children’s quality of life is, well, not very good. Son spent the first three years of his life going in and out of the car at appointments. Also affects his brother.”

One parent emphasised how important it was to work with children and build their trust from a very early age. This meant that they were less frightened and much more cooperative in the dental chair. This worked best with continuous care from the same dentist. Some dentists had very helpful attitudes. Showing the child the instruments prior to using them was helpful in some cases. One parent commented that her daughter was particularly frightened of the dental chair at the state facility.

“Daughter is terrified of the chair. She freaks out when it moves. She can’t handle it.”

Parents commented that it was better for children if they can stay in their wheelchair rather than being transferred into the dental chair.

One parent expressed general dissatisfaction with the system and chose the option to pay for private treatment. However, she stated that she still used the school system for check ups but resorted to private services when treatment was needed. In general comments one parent said that the cost may put parents off accessing private services because the fees can be very high.

“There is a general lack of understanding of dentists regarding children with special needs. School dentist tried to take an impression and the child threw up and dentist got impatient....”

**What about your access to information on dentists/oral health to assist your caring role? (How are you informed about oral health care for your child - and do you have sufficient information?)**

Parents’ responses to this question were varied. One parent felt that she did not require information about caring for her child’s teeth as it was intuitive. However a number felt that in general there was a lack of information and some that other parents were the best source. One parent felt that her experience with her previous child was her best source of information. It was reported that speech therapists tended not to volunteer information about oral health. One parent felt that staff at a dental services facility provided good information but only to assertive parents who asked appropriate questions.

One parent felt that although information on tooth brushing was provided, she also needed information on diet. This is especially relevant since inappropriate food snacks were often used to combat behavioural problems. Another parent felt similarly that there was a lack of information on preventative measures. Two parents wanted information in relation to tooth-grinding. One parent raised the issue of managing such children when they are unable to express that they have toothache. The mother of a girl with Down syndrome would have liked information in any format regarding any specific dental problems associated with the syndrome.

“We need reassurance about what is normal for our kids.... It is hard to tell when they are in pain.”

“For the long term, I would love to have better information. I would like to know more about what might happen, are teeth more vulnerable? Braces?”

Several parents mentioned that in the context of all the problems with which they have to deal, oral health is not always a priority. Many parents felt they needed more information regarding available services, payment options and oral care. Parents suggested information should be available through a range of sources including schools, dental facilities and other health professionals or via the internet. Parents also wanted to know eligibility requirements for particular dental services and being able to plan these in an integrated way. It was also clear that parents were often stressed during dental appointments and may not retain information given to them at these times.

**What services do you consider would be useful for improving dental health for the person you care for?**

Many issues of relevance to this question had already been raised in previous questions. Parents wanted reduced waiting times for an appointment, more flexibility in times and less waiting when they arrived. Parents also wanted access to basic dental care at schools. Parents considered that dentists need to be trained appropriately and there needs to be better communication and coordination between different services.

**Comments from questionnaire**

The following comment was made in response to an open question in the demographic questionnaire.

“Let’s educate dentists and assistants particularly on disabled needs, patience and sensory difficulties.”

Parents were also pleased that their issues were being heard.

“Also good to know there is interest in this much neglected and apparently poorly funded area of need.”
Discussion

Qualitative research offers an important perspective in investigating perceptions of oral health, particularly in such a diverse and complex group. There has been limited qualitative research in dentistry and even more limited qualitative research with parents of a child with ID regarding dental care (Stewart et al., 2008), with one study investigating parents of adult children with Down syndrome (Kaye, 2005). One previous study used a content analysis approach to identify four primary areas of concern for mothers of disabled children. These were medical and legal concerns, concerns for the child, concerns for the family and concerns for the self (Noojin and Wallander, 1996). The first two of these were most evident in this study. There are some important themes arising from our results: the burden on these parents, the importance of the environment and skills of staff when child was attending dental treatment, the desire for good information and communication, a desire to prevent and minimise major dental treatment particularly that requiring general anaesthetic and also the desire to reduce pain.

Many of the issues raised are similar to those for all dental patients; access, cost, information and relationship with provider (Land, 2000), but more problematic in this group. It is recognised that families of disabled children often report more stress and need more support, with many facing extreme demands on their time and resources (Boyce et al., 1991, Heiman and Berger, 2008). Many of the parents reported planning an event such as a dental visit in great detail to try and avoid the stress for them and their child. Many of these parents could benefit from advice such as how other parents had made this easier and what other mechanisms could facilitate these visits. The ability of the dental staff to deal with the disabled child was crucial.

Parents wanted more information about access to services and appropriate oral care for their child. Only some parents demonstrated evidence of a partnership approach with the practitioner. Cost was not an issue for all parents due to the government services available to these parents. However, for some parents cost considerations were about not having to wait for treatment (and electing to have private treatment).

Parents attending groups were likely to be more representative of those with a support network, i.e. the school or support group. The effort required to set up groups would limit our recommendation for extending this approach in this group of parents to researchers with previous experience and understanding of such community networks. It is also known that support groups are often poorly attended and parents that attend support groups do not represent all parents (Smith et al., 1994). The co-ordinator of one support group told us they had virtually no attendance at meetings and when offered funding for a day of respite and indulgence (massage etc), not one parent responded to their invitation. However we found the groups were a valuable source of information and participants.

The group discussion and interviews clearly represent the varied experiences of parents with children for each of whom the disability is different. It can be seen that perceptions and attitudes are also extremely important in accessing services. This concurs with the findings of Maizels and Sheiham (Maizels et al., 1993), who found that beliefs about dentistry, satisfaction with dental services and fear of the dentist predicted quality of dental care.

Similar issues were found in a questionnaire based study of families of adults with Down syndrome (Kaye et al., 2005). Provision of dental services for disabled children can be challenging and not all dentists may wish to undertake such work (Willard and Nowak, 1981). Clearly some parents are much more assertive than others and this sometimes resulted in very different experience in the care of their child and the use of health services. Parents who chose to participate were more likely to have issues regarding oral health care for their children. Reasons for not attending included the problems involved in getting to a group, the fact that parents had not thought about dental visits yet and the feeling that they had little to contribute. Mothers were the major participants in the study and results indicated they played the major role in the oral care and use of dental services for their children.

This study offered an important insight into the issues and needs for these parents in providing oral health care for their intellectually disabled children.

These results must be considered in terms of current trends and contexts in oral health. Individuals are increasingly responsible for their own oral health (and health in general) with the use of fluoride toothpastes and dietary advice. For children with substantial intellectual disability, their oral care and dental treatment requires significant support by parents and dental professionals. Care of these children would benefit from the increasing acceptance in health that oral health is integral to overall health.

There are limitations to this study. It was difficult to recruit these parents and, given that similar approaches had been successful with other groups, this difficulty is likely to result from the overall burden on these parents. As with most qualitative studies, we do not know the representativeness of the parents interviewed although we tried to recruit from multiple community groups in different socio-economic areas. Although we were getting consistent themes about overall issues, it was not possible to get representative groups of parents for each major form of intellectual disability.

This research improves our knowledge of the dental health needs, and to an extent demands, of children with an intellectual disability and importantly gives us the parent perspective. As Newsome and Wright (1999) have
noted, perceptions of dental care is a complex area. It is also important that we investigate perceptions of the dental professionals and associated health professionals (Hallberg and Klingberg, 2005). From parent comments, it appears many dental professionals were struggling to deal with these children and may need training or even other models of service provision where they work more closely with other health professionals. Further research with dental professionals is needed to understand their issues and perceptions.

The results are useful for those working in service provision for such children, the wider dental profession, those involved in dental education and all of those involved in providing care and services for children with a disability.

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