

Parent perceptions—oral health for rural children with intellectual disability

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Linda Slack-Smith is a tenured Professor of Oral Epidemiology (Teaching and Research), Chair of Research Committee and Graduate Research Coordinator in the School of Dentistry at the University of Western Australia. With her research collaborators, she has undertaken a substantial research program investigating social public health issues, child and reproductive health, oral health issues (including oral cancer) in disadvantaged groups and Indigenous health. This work has resulted in a significant number of reports and peer-reviewed publications. She has been a chief investigator on over \$2.8 million dollars of competitive grants and has over 122 citations in Scopus. Importantly, she has had a substantial focus in supporting new researchers (colleagues and students). She was a lead applicant for a \$2.5 million NHMRC Indigenous Capacity Building Grant, which is now completed. The major outcome from this project and greatest contribution to the future is the significant professional development of 10 Indigenous child health researchers. An important focus of her work has been consultation with stakeholders and she has actively developed the use of qualitative research methods alongside epidemiology. Her work includes a significant focus on dental services and oral health in rural groups such as the aged, Indigenous and children with intellectual disability.

Introduction

Dental services account for in excess of \$5.3 billion or over 10% of our health system expenditure in Australia,¹ yet most dental disease is entirely preventable.^{2,3} The major dental disease, dental caries, is a significant cause of morbidity across the lifespan and can be an aggressive disease, particularly for the very young and very old.^{2,3} A number of groups have been identified as being at increased risk of poor oral health including the disabled, those living in rural and remote locations, migrants, Indigenous and the aged.⁴⁻⁶

Children identified as having an intellectual disability are important group in terms of oral health,⁷ partly because of their dependence on others for the management of self care. However, there can be considerable variation in dependency according to the type and severity of the disorder.⁸ There are challenges in maintaining adequate oral health in this group and in access to appropriate dental services. The children may be more difficult to treat and it may be difficult to find providers willing to treat them.⁹

This study reflects our commitment to including consumers in the research process and the contribution of these parents is invaluable, particularly given the burdens they face. Consideration of care and services for these children raises many issues crucial in planning dental services – multidisciplinary care, consideration of prevention versus treatment, population approaches compared to individual approaches. In terms of dental caries, Richard Watt recently noted, "Failure to change our preventive approach is a dereliction of ethical and scientific integrity ..."¹⁰

We have previously investigated parent perceptions of oral health and dental care for children with an intellectual disability in the Perth Metropolitan Area.¹¹ In the study of interest today, we focused on children identified with intellectual disability living in rural areas.

Aim

The aim of this study was to identify oral health concerns and issues for parents of children identified with an intellectual disability living in rural Western Australia.

Methods

This study used a qualitative research approach, with data collected via the telephone using a semi-structured interview schedule. Qualitative research is used in the attempt to capture people's meanings and interpretation.¹²

The sample comprised 15 adults who were related to and who cared for children with an intellectual disability and who live outside (or on the outer rim) of the Perth Metropolitan Area. Almost all of the children had

autism (n = 13) (including Asperger's Syndrome) except for one child with chromosomal abnormality and another child with possible microcephaly. Both parents of one child with autism were interviewed on separate occasions while one mother had two children with autism.

A variety of avenues were pursued to recruit parents of children with intellectual disability. Parents were contacted through community support groups and schools for disabled children. "Invitation to participate in research" flyers were sent to the groups with project reply paid envelopes used to encourage responses. Due to the long distances between country settlements, telephone interviews were considered more appropriate than focus groups or face-to-face interviews.

Ethics approval was obtained from the Human Research Ethics Committee of the University of Western Australia.

Results

Demographic characteristics and service use of participants

Fifteen adults who cared for children with a disability participated in the study (mothers = 13; father = 1; grandmother = 1). Eleven participants resided in the south-west region of WA. Four participants resided in the semi-rural outer suburbs of the Perth Metropolitan Area. Overall, there were 16 children with a disability being cared for by the participants (males = 11; females = 5). Children's ages ranged from four years (n = 3) to 17 years (n = 2).

Participant ages ranged from 33 years to 63 years. Approximately 90% of the participants are from an English speaking background (about 60% were born in Australia). With regard to participant education, four participants (40%) had completed studies equivalent to Year 10, one had completed studies equivalent to Year 12 and three had university degrees. Seventy per cent of the participants were not in paid employment. Three held a pension card, four held a health care card. Seven participants received a child disability allowance. Nine participants stated that their child was a client of Disability Services Commission (a state government department).

Dental visits and service use

Half of the participants visited a dentist for emergencies only. Three visited every two years or less while two visited a dentist annually. Most (60%) visited a private dentist. Two visited both private and government-subsidised dental professionals. Ninety per cent of the participants had private health insurance, including private dental cover. The furthest dental service in terms of kilometre distance from home was 20kms (one participant), the closest was 3 kilometres from home (two participants). Others travelled four, five and 10 kilometres from home to the dental service.

Most participants took advantage of a locally based school dental service, perhaps due to the convenience of the service, that is, the location and regular check-ups. Three parents (two parents of one child) commented that even though their child went along to the service, the child would not allow any of the professionals to look into his or her mouth or to perform any treatment.

For those who utilise a private dentist, reasons include the importance of continuity of care for their child in addition to the inefficiency of or dissatisfaction with the school dental system. For those who used both the school system and private or government-based services, the reasons were primarily because the school service had referred the carers to a service which could provide more specialised treatment. In the case of the two mothers who utilised solely the government services, this was due to the need for a specialist service and the need for a general anaesthetic or sedation for the child. The two mothers who commented that they will use school services have children under primary school age.

Details from interviews

The following key themes arose from the interviews: managing oral care at home; diet and oral health; access to dental care and dentist behaviour.

Managing oral care at home

Most participants (n = 12) reported the child in their care underwent some form of tooth brushing. Many children (n = 8) performed some form of regular brushing daily (once or twice a day) on their own, however participants felt that they needed to assist their child. This included supervision which meant that the participant either cleaned the child's teeth for them or checked that their teeth were clean and sometimes told the child to repeat the brushing. Supervision generally occurred two-three times per week (sometimes every day). Two children refused any form of touching of or contact with their mouths, so that no or very little tooth brushing had occurred at any stage.

It's been really hard with the teeth brushing because he is very sensitive in that area, the same with his fingernails and getting his hair cut. He doesn't like getting any of those sorts of things, we've had to adopt strategies for that. But usually its done by modelling - showing him how he should brush. (Mother of 10 year old son with autism).

... oral de-sensitising ... was a lot of hard work and a lot of heartache. Started on a scooter board doing different exercises and having a toothbrush wrapped up in a face washer ... 'Ooh what's in here? Surprise! What's this? What do we do with this?' and then just started with laying the toothbrush on the cheek, tracing the toothbrush around the jaw ... little bit more whizzing on the scooter board, scooting around, wrap the toothbrush back up again in the face washer ... (Mother of son 6 years of age with autism).

Diet and oral health

One mother of a boy aged 17 years, commented that her son ate anything he wanted, which consisted of generally, "unhealthy" foods. She found this difficult to control. This practice has made the boy overweight. The mother understands that a healthy diet is important and believes that the boy will change his eating habits as he gets older.

Another mother noted of her daughter:

... understanding autism, moderation is not a word she comprehends and if you put down ... a chocolate cake in front of her, she will eat until she could not possibly fit in anymore, because you put it in front of her, therefore it is for her to eat ... (Mother of autistic daughter 9 years of age).

Three mothers expressed concern with the use of lollies and sweets as a reward system in school, intervention and therapy programs. Another mother occasionally used lollies or savoury snack foods as part of her own "training program". She felt that this facilitated to make certain activities easier to undertake (such as administering medicine or surviving long car travel periods).

Access to dental care

Most participants took advantage of a locally based school dental service, perhaps due to the convenience of the service. Three parents (two parents of one child) commented that even though their child went along to the service, the child would not allow any of the professionals to look into his or her mouth or to perform any treatment.

For those who utilised a private dentist, reasons included the importance of continuity of care for their child in addition to the inefficiency of or dissatisfaction with the school dental system. For those who used both the school system and private or government-based services, the reasons were primarily because the school service had referred the carers to a service which could provide more specialised treatment. In the case of the two mothers who only attended the government services, this was due to the need for a specialist service and the need for a general anaesthetic or sedation for the child. The two mothers who commented that they would use school services in the future had children under primary school age

We don't get PATS [Patient Assistance Travel Scheme] when we go to Perth. You can't get that for going to see a dentist. It is a real pain, they'll say come in for your check up and you get a week's notice and it's an expensive trip - a \$70 or \$80 trip and he won't even let you look in his mouth anyway. So I have missed quite a few check-ups. I have just weighed it up, I just can't put myself through it. (Mother of 11 year old son with autism).

Dentist behaviour

Five mothers of autistic children commented about the suitability of dental professionals to the task of giving their children regular checkups. They reported that the professionals were generally unaware of the child's needs in terms of the disability and appeared impatient and intolerant. In essence, a dental professional who had experience communicating and caring for autistic children was difficult to find.

I think just trying to find like a dentist who would be appropriate for kids with a disability was hard.
(Mother of 5 year old son with autism).

Discussion

Input of consumers such as these parents in research on dental services is extremely valuable. These parent interviews informed us of the challenges they face in maintaining oral health and accessing dental services for children with an intellectual disability. The themes arising in these discussions were similar to those with Perth Metropolitan Area counterparts but with the added complexity of being further from the city and often far from services.

The use of a qualitative approach to explore concerns and issues for carers provided insight into important issues and perceptions of oral health care for disabled children. Some vital issues for carers have been highlighted and include the following:

- The many difficulties associated with caring for children with a disability;
- The importance of an appropriate environment and appropriate and highly developed skills in addition to a sound rapport between dental health professionals and the child;
- The desire for good information and communication;
- The need for appropriate and easily accessible dental services in rural areas; and
- A desire to prevent and minimise major dental treatment particularly that which requires general anaesthetic.

Conclusion

Family carers of children with a disability faced extreme demands on their time and resources (both physical and emotional) in terms of providing care for their children, including that for oral health. Many encountered difficulties with keeping their children's teeth clean and expressed concern about dental health and services including; caries, bad breath (halitosis), teeth grinding (bruxism), increased susceptibility to infection because of immune status and the lack of availability and flexibility of dental appointments.

Prevention or control of dental caries cannot be achieved by reliance only on current methods and models of dental care. We need to consider the integrated roles of dental, medical, and other health-care providers and assess effective public health interventions and the introduction of oral health promotion activity linked to general health promotion.²

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Acknowledgment

This study was supported by the Department of Health, Western Australia.