

Adults with intellectual disability: a mixed-methods investigation of their experiences of dental treatment under general anaesthetic

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ABSTRACT

Objectives: This study aimed to explore the experiences of dental care under general anaesthesia in adults with an intellectual disability.

Methods: The study used an explanatory mixed-methods design. In the initial quantitative phase of the study, a clinical audit of oral health services provided for adults with intellectual disabilities was carried out for individuals who underwent a general anaesthetic (GA) for dental treatment at Christchurch Hospital during a 5-year period.

In a qualitative second phase, fifteen semi-structured interviews were carried out for 13 individuals with an intellectual disability to investigate the experience and perceptions of individuals with an intellectual disability (and caregivers and guardians) relating to their oral health care.

Results: The majority of the treated patients lived in care, and many had severe medical problems. Most had both restorative treatment and tooth extractions carried out under GA. Their major concern was anxiety associated with the dental visits. Support people/guardians shared this concern, and played a vital role in helping to manage this anxiety. Many of the latter had difficulty identifying dental problems in their charges, and they often relied on detection of changes in the individual's behaviour or demeanour. The time spent waiting in waiting rooms for treatment was a frequently reported cause of stress.

Conclusions: As a group, these individuals present challenges for the provision of oral health care, given their severe disability and medical conditions, and many require a high level of support for daily activities. When dental treatment is required, a GA is often necessary in order to carry it out. The management of anxiety was a key issue for the patient group and support people play a vital role in helping to manage this anxiety, and achieve a successful visit. There is potential to improve the service with a multidisciplinary approach to coordinate other health services during treatment episodes, reduced time spent in waiting rooms, and improved waiting room layout.

INTRODUCTION

The 33,700 New Zealanders who were estimated in 2006 to have an intellectual disability comprise less than 1% of the total population. Of those, 94% lived at home, while the remaining 6% lived in residential care (Statistics New Zealand, 2006). Of those living in residential care in 2001, 98% were considered severely disabled¹ (Ministry of Health, 2005). People with physical, intellectual, behavioural, or cognitive disabilities, or who are medically compromised were identified as one of the priority groups in the 'Good oral health for all for life' policy document, which highlighted that little is known about the oral health of patients with special needs, or of their experiences of oral health services. The document states that reviewing the oral health services for this group is a priority for the Ministry of Health following the completion of child and adolescent work (Ministry of Health, 2006).

Individuals with an intellectual disability have poorer health than others, in terms of their prevalence of medical conditions, attention to care needs by support people, preventive care, health promotion, and access to health care (Krahn et al., 2006). These disparities exist in both general and oral health care. There is a wealth of data in the international literature showing that adults with intellectual disabilities experience poor oral health, with more untreated dental caries, worse oral hygiene, and more gingival inflammation and periodontal disease than the general population (Cumella et al., 2000; Gallagher and Fiske, 2007; Gizani et al., 1997; Anders and Davis, 2010). They have more missing teeth, and it has been suggested that they are more likely to have experienced extractions rather than restorations in response to dental caries (Cumella et al., 2000; Oliveira et al., 2013).

The severity of intellectual disability is an important factor in caries experience. A Swedish longitudinal study indicated that, despite receiving less preventive treatment, individuals with severe intellectual disability had a lower caries incidence and prevalence than those with milder disability. Individuals with poor cooperation had lost more teeth, and consequently had a lower number of remaining teeth than those who cooperated well (Gabre et al., 2001).

Internationally, there has been a trend away from the institution-based living of individuals with intellectual disabilities towards integrated community living (Scott et al., 1998). While such a policy aims to improve quality of life for individuals, it may also result in barriers to dental care (Pezzementi and Fisher, 2005), and may be associated with changes in dental attendance

¹ According to this definition, people with severe disability receive, or need, daily help with activities such as preparing meals, shopping, everyday housework, bathing or dressing; those with moderate disability use, or need, 'some type of assistive device, aid or equipment' and/or help with certain heavier or more difficult household tasks; and those with mild disability have a disability but do not require regular help from other people or technical aids (Ministry of Health, 2005).

and treatment patterns. Individuals living in institutions are more likely to receive regular dental examinations and operative dental treatment than those living in the community (Stanfield et al., 2003).

Data on the oral health of New Zealanders with intellectual disabilities are scarce. A New Zealand study of people with intellectual disability or psychiatric illness who were long-term hospital residents found that they had fewer filled teeth and more decayed or missing teeth than the general population. Oral hygiene was poor, with 84% requiring scaling and cleaning, and 18% requiring complex periodontal therapy. One-third of the sample required a general anaesthetic for most dental treatment (Whyman et al., 1995).

Given the policy changes towards integrated community-living arrangements for individuals with intellectual disabilities, and the apparent challenges these pose in oral health care, it is important that oral health services are adapted to cater for these changes. Qualitative studies can provide valuable insight into oral health care for individuals with intellectual disabilities, facilitating understanding of their opinions and attitudes towards their oral health and its care. While qualitative methods have been used successfully in studies with this group, the approach may not be useful for those who are severely disabled and may not be able to respond to open-ended questions (Cumella et al., 2000). Moreover, the influence of caregivers in the oral health of individuals with intellectual disabilities should not be underestimated. They play an important role in facilitating access to oral health care, but they may have difficulty identifying that a dental problem exists. This may contribute to dental problems being undetected and so going untreated. Issues of advocacy, autonomy, and the removal of barriers to care have been shown to be of primary concern for caregivers (Cumella et al., 2000; Grant et al., 2004; Voss Horrell et al., 2006).

The aim of this study was to investigate the experiences of dental care in a group of adults with an intellectual disability.

METHODS

The study used an explanatory mixed-methods design with two parts: an initial collection and analysis of quantitative data using a clinical audit approach; and a second qualitative phase. This design allows for qualitative data to help build on, add depth to, and explain the initial quantitative findings (Creswell and Plano Clark, 2007). Ethical approval for this study was obtained from the Upper South A Regional Ethics committee in July 2009.

The quantitative component

General anaesthetic lists for the period 1 January 2005 to 31 December 2009 were obtained from the dental department at Christchurch Hospital. Identified and included in the audit were individuals aged 18 or over, with an intellectual disability, who had had a general anaesthetic (GA) for dental treatment. Information collected included date of birth, ethnicity, living situation, medical diagnoses, and physical status according to the American Society of Anaesthesiologists' classification (ASA score), along with details on who provided consent for the surgery. Data were also collected on the provision of restorations, extractions, impressions, root fillings, scaling, and topical fluoride application.

Quantitative data were entered onto a database and analysed using SPSS version 17.0 (SPSS Inc, Chicago, USA). After the computation of descriptive statistics, bivariate associations

among categorical variables were tested for statistical significance using Chi-square tests.

The qualitative component

Fifteen semi-structured interviews were carried out for 13 randomly selected individuals with an intellectual disability (along with support persons where appropriate) who had had a GA for dental treatment at Christchurch Hospital during the most recent year within the 5-year period covered by the clinical audit. The project was explained to the individual, with the assistance of the caregiver/support person, and he/she was involved in the consent process.

Participants were interviewed to investigate their experience and perceptions of oral health care. Although there were communication difficulties with some of the individuals, they were given the opportunity to consent and participate in the interviews wherever possible (alongside their guardian/support person). Interviews were held in a location chosen by the participants, and were approximately 20 minutes in duration.

Participants were asked to describe their experiences in obtaining oral health care, and to identify what they thought were the strengths and weaknesses of the service. Caregivers and guardians were also asked what role they played in relation to oral health care for the individual, as well as their own (self-reported) oral health. Audio recordings were transcribed as soon as possible after the interview.

Interview transcripts were analysed by manual coding and labelling of the data in order to identify recurring themes. These were then grouped together to identify patterns and themes that were expressed by the participants. This process was repeated iteratively until no new themes were identified.

RESULTS

The clinical audit

A total of 168 adults with an intellectual disability underwent dental treatment under general anaesthetic during the 5-year period. Records for 1 patient were unable to be located. The remaining 167 patients underwent a total of 212 sessions over the five-year period, with each patient having between 1 and 3 episodes of treatment under GA during this time. There were 97 males (58.1% of the sample) and 70 females (41.9%). Ethnicity had been recorded in the clinical notes for 155 patients: 141 (91.0%) were of NZ European descent and 10 (6.5%) were Maori; there was 1 patient (0.6%) in each of the Samoan, Niuean, Chinese, and 'other' groups. The patients ranged in age from 18 to 69 years, with a mean age of 38.0 years (sd 11.6).

Most patients lived in care, with 126 (75.4%) in 24-hour residential care, 36 (21.6%) at home with family or a caregiver, and five (3.0%) living independently with some support. The most commonly recorded medical conditions were autism (29.3%), epilepsy (28.1%), physical disability (18.6%), asthma (13.8%), cerebral palsy (12.0%), mental illness (13.2%), and Down syndrome (10.8%).

Three-quarters of the group (125 patients) had had one episode of treatment within the 5-year period; 39 (23.4%) required two, and three (1.8%) required three. Patients who lived at home had a mean of 1.4 episodes; among those who lived in residential care or who lived independently, it was 1.2 and 1.0 respectively ($P = 0.03$). There were no differences in the number of GAs by patient ethnicity or sex.

Table 1. Experience of extractions and restorations placed under GA by patient sex, ethnicity, and living arrangement

	Mean number of extractions (sd) ^a	Number who had restorations (%) ^b	Mean number of all types of restoration placed (sd) ^b
Sex			
Male	4.1 (4.0)	72 (74.2)	3.2 (3.5)
Female	5.2 (5.4)	45 (64.3)	3.3 (4.0)
Ethnicity			
NZ European	4.5 (4.5)	96 (68.1)	3.2 (3.8)
Maori	7.6 (7.4)	8 (80.0)	4.5 (4.4)
Other	2.0 (1.0)	1 (25.0)	3.5 (3.0)
Living arrangement			
Residential care	4.4 (4.4)	81 (64.3) ^c	2.6 (3.2) ^c
At home	5.4 (5.5)	32 (88.9)	5.3 (4.5)
Independent	3.8 (1.8)	4 (80.0)	4.0 (4.2)

^a Of patients who had extractions under GA in the five-year period

^b Of patients who had restorations under GA in the five-year period

^c P<0.05

In total, 117 patients (70.1%) had had restorations, with between 1 and 18 restorations placed. Extractions were carried out under GA for 150 patients (89.8%), with patients having between 1 and 22 teeth extracted in a single GA procedure. In total, 102 patients (61.1%) had both restorative treatment and extractions under GA during the five-year period. Those who had only extractions accounted for 28.7% (48 patients), and just 17 patients (10.2%) had restorative treatment only. Table 1 presents data on the treatment provided, by patient sex, ethnicity, and living arrangement. Fewer of those in residential care had had restorations placed than those with other living arrangements (with fewer placed, on average).

Data on the treatment provided are presented in Table 2 by patient medical characteristics. A greater proportion of individuals with autism had restorations placed under GA during the five-year period; the converse held for those with cerebral palsy. Individuals with autism had fewer teeth extracted than those without autism.

One patient had teeth hand-scaled, 126 (75.5%) had their teeth ultrasonically scaled, and seven (4.2%) had teeth polished with a rubber prophylaxis cup. Some 38 patients (22.8%) had had topical fluoride varnish applied to their teeth at least once under GA. Ten patients had fissure sealants placed; two patients had a biopsy taken, one had sharp teeth smoothed, one had a temporary restoration placed, and one had a swelling incised and drained. Five patients had impressions taken during GA for denture work, and nine patients had a root filling. In some cases, there was coordination with clinicians in other specialties to enable the provision of non-dental treatment under general anaesthetic. Four patients had an ear-nose-throat (ENT) procedure, two had a gynaecological procedure, ten patients had blood taken for their general medical practitioner, and one patient had a non-dental radiograph taken during a dental GA.

At the most recent GA, only ten patients (6.1%) had capacity to consent for the operation themselves. Consent was sought from a guardian for 130 patients (79.3%), and, for 24 (14.6%) who did not have a legal guardian, Section 7.4 of the Code of Health and Disability Services Consumers' Rights (1996) was utilised.

Right 7.4 enables an individual to have non-urgent medical treatment when he/she does not have capacity to consent, and there is no legal guardian. In this case services can be provided when the treatment is in the best interests of the consumer, reasonable steps are taken to ascertain the views of the consumer, and either: where the consumers views have been ascertained and the provider has reasonable grounds to believe the service is consistent with the informed choice the consumer would make if he or she were competent; or where the views of the consumer have not been ascertained, the views of people actively involved and interested in the welfare of the consumer have been taken into account.

For patients' most recent GA, the ASA (American Society of Anaesthesiologists' classification) status had been recorded for 132 patients (79.0%). Of those, 75 (56.8%) were classified as ASA 2 (mild systemic disease), and 57 (43.2%) were classified as ASA 3 (severe systemic disease).

The qualitative interviews

For two of the individuals involved, separate interviews took place with both their support person, and their mother. Of the 13 individuals (7 females and 6 males) for whom interviews were carried out, 11 lived in residential care, and two lived at home with a parent. None of the interview participants lived independently. Where possible, the individuals with an intellectual disability attended the interviews, alongside their guardian/support person, and contributed to the interview. However, four individuals with an intellectual disability were not present during the interview because their support person/guardian deemed that they were not able to contribute; all four of those had severe autism. Nine individuals with an intellectual disability participated in the interviews. Of those, two participated non-verbally only, and four participated only to a limited extent (such as yes/no answers).

Although the responses of the individuals with an intellectual disability contributed only a small portion of the interview data, their views hold much importance because they were the primary consumers of the dental services. When interviewed alongside the patients, parents and support people were able

to act as additional informants to provide useful information on dental services for the group. Where it was not possible to obtain the information from the individuals themselves, parents and support people were an important source of information because they are instrumental in facilitating access to care for the individuals under their care, and they often accompany them to their dental appointments.

Anxiety

Overall, the most evident theme which came from analysis of the interview transcripts was anxiety about dental visits. The individuals with intellectual disability reported feeling generally nervous about dental visits but also spoke of specific fears such as the drill, needles, people in white coats, and the intimidating operating theatre lights. One participant described the fearful associations he had made with the operating lights in the theatre:

I have seen that on TV, those big circular lights, and people go under the knife under those lights. Because I have seen horror movies... where bad surgeries go wrong. That's what terrifies me. (Individual L)

Some participants described previous bad dental experiences which had left them with vivid negative dental memories. Some

of the support people also mentioned a bad childhood dental experience which the patient had had that may have contributed to their dental anxiety. They felt that where things had not gone well during a dental visit in the past, this had resulted in ongoing anxiety about dental visits.

Parents and support people were particularly concerned about managing the patient's dental anxiety, and employed a number of strategies during dental visits. These strategies included discussing the visit with the individual prior to going, coaxing them along, and ensuring they have a settled mood. Having the most appropriate support person attend on the day was instrumental to this, because it was reassuring for the patient.

Waiting time at hospital

Participants frequently reported that the time spent waiting at the hospital immediately prior to the GA had been problematic. They reported that even short waiting times seemed longer to individuals with intellectual disabilities and, because of this, were additionally stressful for caregivers. Some support people reported that the patients would be reluctant to sit down in a waiting room, and instead would need to walk around or pace to pass the time. A couple of support people mentioned the difficulty posed by a visible and available coffee cart when the individual needed to be fasting prior to surgery.

Table 2. Experience of extractions and restorations placed under GA, by medical condition

	Mean number of extractions (sd) ^a	Number who had restorations (%) ^b	Mean number of all types of restoration(sd) ^b
Autism			
Has condition	3.1 (2.1) ^c	40 (81.6) ^c	3.1 (3.4)
Does not	5.2 (5.2)	77 (65.3)	3.3 (3.9)
Epilepsy			
Has condition	4.2 (4.6)	33 (70.2)	3.1 (3.4)
Does not	4.7 (4.7)	84 (70.0)	3.3 (3.8)
Cerebral Palsy			
Has condition	5.2 (6.2)	10 (50.0) ^c	2.5 (3.5)
Does not	4.5 (4.4)	107 (72.8)	3.3 (3.8)
Down syndrome			
Has condition	4.7 (3.7)	13 (72.2)	4.2 (4.7)
Does not	4.6 (4.8)	104 (69.8)	3.1 (3.6)
Other syndrome			
Has condition	5.0 (4.5)	7 (53.8)	2.4 (3.3)
Does not	4.5 (4.7)	110 (71.4)	3.3 (3.8)
Physical disability			
Has condition	3.3 (3.2)	20 (64.5)	2.7 (3.3)
Does not	4.8 (4.9)	97 (71.3)	3.3 (3.8)
Mental illness			
Has condition	3.5 (3.3)	16 (72.7)	2.6 (2.4)
Does not	4.7 (4.8)	101 (69.7)	3.3 (3.9)

^a Of patients who had extractions under GA in the five-year period

^b Of patients who had restorations under GA in the five-year period

^c P<0.05

But when we arrive I think [she] expects to be seen, and waiting is a big issue. So you have to be really sort of, trying to entertain her or conning her into staying, because she wants to go. And she doesn't sit. She paces. So that makes it really hard... (Mother of individual M)

Oral hygiene at home

Where self-care was concerned, two patients reported that they were assisted with oral care. A few reported cleaning their teeth a couple of times a day, while another participant admitted that he was "a bit slack on it" and brushed once daily.

A number of support people reported that they had encountered resistance from their charge when assisting with oral care and some felt that they themselves could be hurt in the process. Another difficulty reported was that while some might have been able to brush their teeth themselves, the nature of the community house meant that free access to the bathroom was not possible. A few of the support people working in community homes expressed criticism of the oral care that the other staff provided for residents.

It was clear that support people employed a number of strategies for assisting with oral care, and that these were specific to each individual. These strategies included taking time with oral hygiene when the individual was reluctant, using an electric toothbrush, or using a specialised double-headed toothbrush, demonstrating what they wanted the individual to do, and singing songs to encourage brushing.

Another important issue was the difficulty some support people and parents faced when it came to identifying a dental problem and arranging a dental appointment. Many of their charges were not able to tell them about a dental problem, and support people had to rely on changes in the individual's behaviour or demeanour as a clue.

We noticed that when he was eating and drinking he made sounds. We went back to the dentist just in case. He needed 3 fillings at that stage. (Team leader for individual H)

Many support people felt that the individual they cared for had a poor long-term dental prognosis. They viewed the eventual loss of all teeth as being inevitable and were concerned about how he/she would cope with dentures. A number expressed what their wish would be if they were in that position but were not sure whether such a treatment could be successful for their charge. A few mentioned the effects of a good diet on oral health. There were a couple of support people who felt that the individual had good teeth and that the long-term prognosis was good, which was based on what the dentist had told them.

Some of the support people were able to identify how their own oral health may affect that of the individuals they assist with oral care.

If you are fussy about your teeth, you will be fussy with other people's teeth. And oral health, because I do get plaque so I am aware of it with other people. (House manager for individual F)

DISCUSSION

This study aimed to describe and explore the use of oral health services by a group of adults with an intellectual disability. It found that most of those with intellectual disability who had

dental treatment under GA at Christchurch Hospital in the 5-year period lived in care; many had severe medical issues, and few had capacity to consent for the most recent GA. Most had had both restorative treatment and tooth extractions carried out under GA and, in some cases, non-dental treatment was provided at the same time by clinicians in other specialties. The major concern for individuals with an intellectual disability was anxiety related to dental visits. Support people/guardians shared this concern, played a vital role in helping to manage it, and were instrumental to achieving a successful visit. Many support people/guardians have difficulty identifying dental problems in those with an intellectual disability, and often rely on detecting changes in the individual's behaviour or demeanour. The time spent waiting at the hospital for treatment was a frequently reported cause of stress. In addition, some problems were identified with the way in which waiting areas were set up for this vulnerable patient group.

Before considering how the study findings contribute to the understanding of the use of dental services by individuals with an intellectual disability, it is important to consider the choice of methodology and the strengths and weaknesses of the study design. An explanatory mixed-methods design was used to collect quantitative data on a sample of adults with an intellectual disability, and then follow up some of those individuals (and their caregivers /guardians) in order to explore the findings in more depth. The mixed-methods approach involves the collection, analysis, and mixture of both quantitative and qualitative data in order to gain a better understanding of a research question than can be achieved by the use of either approach in isolation (Creswell and Plano Clark, 2007). Although this approach has not been widely used in oral health research, it has been more commonly used in the social sciences. While clinical audit data can provide useful information on the volume and type of treatment received by a patient group, this type of data is insufficient for investigating the personal experiences of the patient group. In-depth interviews are useful when exploring an individual's experiences, beliefs, and motivations (Bower and Scambler 2007). The semi-structured interview allows the interviewees the freedom to identify issues that are important to them, and the interviewer to further explore topics as they arise.

The interviews highlighted issues that the patient group (and their support people/guardians) consider important, and that would not have been identified if only quantitative data had been used. Turning to the latter, the strength of clinical audit data depends on obtaining complete information. Of the 168 patients who fitted the criteria, clinical records could not be located for one patient (0.6%), so this is not likely to have affected the validity of the findings. The clinical records held in the dental department were compared and cross-referenced with general anaesthetic records kept on the Christchurch hospital computer system. While this is likely to have minimised the risk of inadvertent exclusion of eligible patients, it is still possible that some may have been missed, particularly if the diagnosis of intellectual disability had not been coded and entered on the hospital computer system.

The data collected in the quantitative phase of the study cannot be generalised to the population as a whole, or indeed the population of adults with intellectual disabilities. It is likely that those receiving dental treatment through the hospital dental service have more severe disabilities than those who receive care in the private sector. In addition, it is unknown

how many individuals with intellectual disabilities do not receive regular dental care. Because all of the patients included in the data-set had undergone a GA for dental treatment, it is likely that their characteristics differ from those who did not require a GA. Similarly, the data collected in the interviews during the qualitative phase of the study cannot be generalised to the population. While the selection of potential interview participants was random, generalisability was not the intent. The qualitative data collected was information-rich and allowed insight into the experiences and opinions of the participants. This was possible because interview participants included individuals with intellectual disability, caregivers/support people, parents, and team leaders in residential homes, thus enriching the data collected. By the time the 15 interviews had taken place, similar responses were being obtained, which was consistent with the concept of data saturation (Strauss and Corbin, 1998) and further interviews would not be required.

Potential interview participants were randomly selected from the most recent year within the 5-year period (2009), in order to improve the accuracy with which participants recalled events with respect to their dental GA. There is potential for error because the interviews relied on the memory of interview participants. In addition, it is possible that participants may have been reluctant to give negative feedback, and instead may have given socially desirable answers or an answer that they felt would please the interviewer (Blinkhorn et al., 1988). The role of the researcher as both a participant and observer in the interview process may have assisted participants in feeling at ease. The interview participants seemed to be comfortable sharing their honest thoughts and opinions during the interviews.

Of the 13 individuals for whom interviews were carried out, none lived independently, and nine individuals with an intellectual disability were able to participate in the interview. However, two of those participated non-verbally only and four participants were only able to participate verbally to a limited extent. This presents difficulties with a semi-structured interview and as a result, the support people or guardians acted as informants in many cases, and their opinions were instrumental in the collection of qualitative data. In essence, this meant that, in some cases, the experiences of an individual with an intellectual disability were collected vicariously. Other studies have reported difficulties in interviewing individuals with an intellectual disability, particularly where asked to give reasons or express opinions (Cumella et al., 2000).

There were more males than females in the sample. There are a number of reasons for this. Intellectual disability is more prevalent in males than females, with an approximate ratio of 1.6:1 (Bray, 2003). It is also possible that males were more likely than females to require a GA, perhaps due to higher anxiety levels, or more challenging behaviour. The most commonly reported medical condition was autism; of the 49 individuals with autism, 75.5% were male. Individuals with autism differed from those without autism in a number of respects. They were more likely to live in residential care, indicating that they required more daily support, and consequently were more likely to require a GA for dental treatment. In addition, a greater proportion of individuals with autism had restorations placed under GA than those without, and individuals with autism had fewer teeth extracted than those without. There are a number of reasons for this. Those with autism may experience a greater severity of

disability and be less likely to have even simple restorative work completed without a GA. In addition, early recognition of dental problems may be more likely in residential care settings due to the involvement of support people in daily oral hygiene routines, thus ensuring that treatment is sought earlier and extractions are less likely.

For a few individuals, there was coordination with clinicians in other specialties to provide non-dental treatment under GA. When a GA is necessary for a particular procedure, it can be beneficial to have other necessary procedures (particularly minor ones) completed under the same GA. While this may not always be practical (because it involves the coordination of multiple clinicians at one time and may increase the length of surgery), it has the benefit of reducing the number of GAs needed by an individual, or can allow procedures (such as the taking of blood samples) that would not have been possible otherwise.

The risks of GA for individuals with disabilities will vary with patient age, presence of systemic disease, physical limitations, and syndrome-related physiological or anatomical abnormalities (Messieha, 2009). A large proportion of individuals had a severe systemic disease (and was classified as ASA3). This indicates that the risks of GA were somewhat higher for this group. It is therefore necessary to consider the likely benefits of dental treatment against the potential risks of surgery when planning to undertake treatment under GA. This is another reason why the combination of other procedures in addition to dental treatment in the same GA may be useful. In addition, these risks mean that it is crucial that informed consent is obtained prior to dental treatment under GA. Consent was certainly an important issue for the patient group, because only a small number of the individuals (10) had capacity to consent for their own dental treatment. While most of the individuals did have a guardian to provide consent, for 24 individuals who did not have a legal guardian, the use of Section 7.4 of the Code of Health and Disability Services Consumers' Rights (1996) enabled non-urgent dental treatment to be provided. In this case steps need to be taken to ensure that the treatment is in the best interests of the individual, and that the views of people actively involved in their care and welfare are considered. Records of these discussions, and treatment decisions should be justified and fully documented in the patient's clinical record (Whyman and Rose, 2001).

There was much positive feedback from support people/guardians in respect of the dental and medical staff they had encountered during dental treatment and check-up visits. However, the time spent waiting in waiting rooms for treatment was a recurring cause of stress to the respondents. In some instances, there had been significant difficulty with managing the individual with an intellectual disability during those waiting times. In some cases, the clinical environment was not ideal for those individuals. For example, comments made relating to coffee carts visible to fasting patients, large communal waiting rooms, and the size of rooms for manoeuvring hoists, highlight small changes that could be made to ensure a successful dental visit for an individual with an intellectual disability.

CONCLUSION

In summary, those with intellectual disability present challenges in the provision of oral health care, given their severe disability and medical conditions, and many require a high level of support for daily activities. When dental treatment is required, a GA

is often necessary in order to carry it out. There is potential to improve the service with a multidisciplinary approach to coordinate other health services during treatment episodes. The management of anxiety was a key issue and the study identified that reduced time spent in waiting rooms, and improving waiting room layout could help to alleviate this anxiety. In addition, support people play a vital role in helping to manage this anxiety, and are instrumental to achieving a successful visit.

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REFERENCES

- Anders PL, Davis EL (2010). Oral health of patients with intellectual disabilities: a systematic review. *Spec Care Dentist* 30:110-117.
- Blinkhorn AS, Leather DS, Kay EJ (1988). An assessment of the value of quantitative and qualitative data collection techniques. *Community Dent Health* 6: 147-151.
- Bower E, Scambler S (2007). The contributions of qualitative research towards dental public health practice. *Community Dent Oral Epidemiol* 35: 161-169.
- Bray A (2003). *Demographics and characteristics of people with an intellectual disability. Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its project on services for adults with an intellectual disability.* Wellington: National Advisory Committee on Health and Disability
- Creswell JW, Plano Clark VL (2007). *Designing and conducting mixed methods research.* Sage Publications, Inc.: Thousand Oaks, California.
- Cumella S, Ransford N, Lyons J, Burnham H (2000). Needs for oral care among people with intellectual disability not in contact with Community Dental Services. *J Intell Disab Res* 44: 45-52.
- Gabre P, Martinsson T, Gahnberg L (2001). Longitudinal study of dental caries, tooth mortality and interproximal bone loss in adults with intellectual disability. *Eur J Oral Sci* 109: 20-26.
- Gallagher JE, Fiske J (2007). Special care dentistry: a professional challenge. *Br Dent J* 202: 619-629.
- Gizani S, Declerck D, Vinckier F, Martens L, Marks L, Goffin G (1997). Oral health condition of 12-year-old handicapped children in Flanders (Belgium). *Community Dent Oral Epidemiol* 25: 352-357.
- Grant E, Carlson G, Cullen-Erickson M (2004). Oral health for people with intellectual disability and high support needs: positive outcomes. *Spec Care Dentist* 24: 70-79.
- The Health and Disability Commissioner (Code of Health and Disability Services Consumers Rights) Regulations (1996.)
- Krahn GL, Hammond L, Turner A (2006). A cascade of disparities: Health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev* 12: 70-82.
- Messieha Z (2009). Risks of general anesthesia for the special needs dental patient. *Spec Care Dentist* 29: 21-25.
- Ministry of Health (2006). *Good oral health, for all, for life: The strategic vision for oral health in New Zealand.* Wellington: Ministry of Health.
- Ministry of Health (2005). *Living with intellectual disability in New Zealand: key results on intellectual disability from the 2001 household disability survey and the 2001 disability survey of residential facilities.* Wellington: Ministry of Health.
- Oliveira JS, Prado Jr RR, Lima KR, Amaral HO, Neto JMM, Mendes RF (2013). Intellectual disability and impact on oral health: a paired study. *Spec Care Dentist* 33: 262-268.
- Pezzementi ML, Fisher MA (2005). Oral health status of people with intellectual disabilities in the southeastern United States. *J Am Dent Assoc* 136: 903-912.
- Scott A, March L, Stokes M-L (1998). A survey of oral health in a population of adults with developmental disabilities: comparison with a national oral health survey of the general population. *Aust Dent J* 43: 257-261.
- Stanfield M, Scully C, Davison MF, Porter S (2003). Oral healthcare of clients with learning disability: changes following relocation from hospital to community. *Br Dent J* 194: 271-277.
- Statistics New Zealand (2006). Adults with disability, by disability type, age-group, sex and place of residence. Available online at: <http://wdmzpub01.stats.govt.nz/wds/TableViewer/tableView.aspx?ReportName=Disability/Adults with disability, by disability type, age-group, sex and place of residence, 2006>. Accessed 17 January 2011.
- Strauss A, Corbin J (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory.* 2 edn. Sage Publications Inc.: Thousand Oaks, California.
- Voss Horrell SC, MacLean WE, Conley VM (2006). Patient and parent/guardian perspectives on the health care of adults with mental retardation. *Ment Retard* 44: 239-248.
- Whyman RA, Rose, D (2001). Informed consent for people with diminished capacity to consent. *NZ Dent J* 97: 137-139.
- Whyman RA, Treasure ET, Brown RH, MacFadyen EE (1995). The oral health of long-term residents of a hospital for the intellectually handicapped and psychiatrically ill. *NZ Dent J* 91: 49-56.

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