Oral health of people with physical and intellectual disabilities

Training carers of people with physical and intellectual disabilities

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Commonly used acronyms

OHA	Oral Health Assessment
OHAT	Oral Health Assessment Tool
OHC	Oral Hygiene Care
OHCP	Oral Health Care Plan
OHIP	Oral Health Impact Profile
OHRQoL	Oral health-related quality of life

Background

Oral disease affects overall health, nutrition and wellbeing.[1] Poor oral health can lead to pain, difficulty eating, sleep disturbance, and decreased self-esteem, all of which can impact adversely on quality of life.[2] These impacts are more common among people with intellectual and physical disabilities (or 'special needs') than the general population.[3] This inequality is compounded by their poor access to health care. While public dental care is available to concession card holders for a capped co-payment, resource constraints mean there are significant waiting times for treatment, and less emphasis on preventive care.[4] Consequently, patients with special needs often require emergency treatment for oral disease and this involves hospital admissions and general anaesthesia.[5] Oral health knowledge among this group and their carers, where they require them, is also relatively poor.[6,7]

Australia's National Oral Health Plan 2004–2013 identified 'people with special needs' as a priority in 'Action Area Five', defining them broadly as 'people with physical and intellectual disability, or medical or psychiatric conditions that increase their risk of oral health problems or increase the complexity of oral health care'.[5] However, this group remains the only one identified in the Plan for which there is no Australian population data. This is probably due both to the heterogeneity of the group and difficulties with access to individuals, and their consent to research.

Ability to self-care varies widely for these people. Some depend on carers, either family or professionals, for help with everyday activities. Deinstitutionalisation of people with disabilities in Australia has meant that commonly four to five people with similar needs now live together in the community in group homes under 24-hour carer support.[8] Carers are therefore often ideally placed to detect problems and facilitate access to services. They are also responsible for providing daily personal care, healthy nutrition and regular visits to health services, including oral hygiene care and dental visits.[9-11] Those people with limited or no communication skills and unable to express pain and discomfort require additional input and vigilance from carers.[9] A South Australian study found that carers were unable to report oral health-related quality of life (OHRQoL) for many care recipients with limited communication.[6] Training of carers in oral care is therefore strongly recommended in the literature.[6,9,10,12,13]

Some studies have suggested that training in oral care should address the oral care behaviours of carers and psychosocial factors.[14,15] and two measures have been developed to evaluate the behaviours of carers[14]. One refers to self-efficacy in oral care behaviours. Self-efficacy is a construct of Social Cognitive Theory that refers to an individual's perceived ability to perform a specified behaviour/s, determining what individuals do with the knowledge and skills they have acquired.[16] Another refers to carers' knowledge, confidence and skills in providing oral health care for their care recipients. The psychometric properties of the measures are detailed elsewhere.[14]

Although there are few studies evaluating oral care training for carers of people with disabilities, most have demonstrated positive outcomes.[12,15,17,18] Outcomes in one study include improved knowledge among carers[12] and in another improved carer attitudes, behaviours and hygiene of care recipients.[17] A 'train-the-trainer' approach was used by an Irish study, which improved carer self-efficacy as well as attitudes and behaviours[18], although a study from the US failed to identify an impact on self-efficacy.[15] In Australia, training in oral care has been limited mostly to aged care settings. In a South Australian study, significant improvement in the oral health status of residents resulted from the training of general practitioners (GPs) and registered nurses (RNs) in aged care facilities.[13,19]

Other people with special needs who live independently have the capacity to self-care and may work in assisted employment. They can self-consent to research and self-report on their health status. Nonetheless, the oral health of these people where measured remains

relatively poor. One US study surveyed 433 adults enrolled in the Kansas Working Healthy project. Compared with the national population, they had greater prevalence of painful aching, uncomfortable eating, and difficulty working due to dental problems.[20] Dental treatment and direct oral health education may offer benefits to this group. A study in the UK found that the contribution of dental care was greatest in self-image and social interaction.[21] Workplace-based oral health education and/or referral has been shown to benefit oral health and reduce health expenditure in the general working population.[22,22] A group of 382 adult trainees in the UK with special needs had their oral hygiene and periodontal condition improved by an intervention of regular educational input from a dental hygienist.[24] As well as clinical and quality of life impacts, poor oral health is likely to inhibit work incentive projects aimed at increasing the independence of people with special needs. T our knowledge, there remains no published data in Australia on oral health-related interventions for employees with disabilities.

This study aimed to benefit the oral health and OHRQoL of two groups of people with special needs: 'care recipients' (directly and *via* their carers) and 'employees'. The study aims reflect the different approaches used.

For carers and care recipients,

- To provide a home-based intervention, training carers in providing improved oral care for adults with disabilities
- To evaluate the intervention by,
    - Assessing the change in carer psychosocial factors pre- to post-training
    - Benchmarking to a dentist the oral health assessment of carers post-training

For employees,

- To provide a workplace intervention combining oral health education and timely referral for treatment
    - To evaluate the intervention by assessing change in self-rated oral health, OHRQoL and oral health behaviours pre- and post-intervention

Methods

Challenges to data collection are often encountered when working with people with disabilities. To overcome these, two workshops were conducted by the Australian Research Centre for Population Oral Health (ARCPOH) and the South Australian (SA) Dental Service in July 2012. These involved managers and carers of disability organisations and dental professionals involved in care for adults with disabilities. Three organisations which provided care for dependent people with special needs and one organisation which provided employment for people with physical and/or intellectual disability agreed to be involved in the study.

Despite this engagement, the sample sizes that eventuated for both interventions were insufficient to support a control group. Thus the interventions were each treated as a pilot study with which to estimate effect size for a larger, controlled study at a future time.

INTERVENTION FOR CARERS AND CARE RECIPIENTS

Data collection

Participating organisations approached carers who would be available for the six-month period of the study, asked for their participation and invited them to attend one of 10 theory training sessions which were scheduled between April and August 2013. At the session, carers completed a pre-training questionnaire which included background questions and the measures of (1) self-efficacy of oral care behaviours, and (2) knowledge, confidence and skills in dental management of their care recipients.

The session was led by an experienced special needs dentist, and began with a one-hour oral presentation covering the importance of oral health, prevention of oral disease, how to note early changes in disease and strategies for managing care recipient behaviours. Carers were then shown a DVD entitled 'Dental Rescue: a guide for carers of the elderly'[25] and this was followed by an opportunity for discussion. At the end of the oral presentation, carers were given third-party consent forms to be completed by the person responsible (parent/manager) for their care recipient to allow their participation. A leaflet entitled 'Oral care for people with disabilities' was also given to the carers.

A clinical assessment of the care recipients was conducted once consents had been obtained for all care recipients living together in a group home. This occurred within two weeks of the theory training. Referrals were arranged as needed to the SA Dental Service clinic closest to the employee's residence or workplace. In most cases, employees were seen urgently, i.e. within one month, and were not waitlisted as they usually would have been.

The practical session for carers included completing oral health assessments (OHA), developing oral health care plans (OHCP), providing oral hygiene care (OHC) as per the OHCP and assessing the need for referral for treatment. The care recipients were assessed in their rooms either on their bed or in chairs using disposable mirrors. Gauze was used to remove food and debris when needed. Carers were demonstrated tooth brushing techniques and positions, and where needed, denture cleaning and care. These procedures took 5-20 minutes depending on the compliance and dentate state of the care recipients.

An Oral Health Assessment Tool (OHAT) was developed for this study, modified from the one used in aged care settings in the project 'Better Oral Health in Residential Care (BOHRC)'.[13] People with disabilities have drooling and swallowing problems rather than the dry mouth commonly seen in the aged. Thus, saliva assessment was replaced with examination of the roof of mouth, where food can be stuck due lack of self-cleansing ability. Oral health assessments (OHAs) thus comprised a qualitative categorical assessment of the lips, tongue, roof of mouth, gums, teeth, dentures, breath, cleanliness and dental pain. The

actions that were dependent on those assessments were summarised at the end of the OHAT. An individualised OHCP was then developed for daily oral care. OHCPs were to be completed and signed off daily by carers on duty. This was for accountability (requested by stakeholders) and to identify behavioural issues that impeded daily care provision. Ongoing support was provided by two dental hygienists who visited the trained carers and their care recipients one month and two months post-training. They reinforced appropriate oral care provided by carers as per the OHCP, and collected the completed OHCPs. A dentist visited the care recipients at three months post-training to collect data on gingival health. At six months, the dentist completed a full dental examination for the care recipients; and the carers also completed OHAs and post-training questionnaires. Post-training questionnaires which repeated the set of questions from pre-training also allowed for qualitative feedback on the training experience.

Data Analysis

Data were entered into SPSS Statistics (version 20, 2011). Descriptive statistics were used to summarise the background of carers. For the OHA, percent agreement was measured as the percent of assessments equivalent between the dentist and the carer, and reported with Cohen's kappa. Responses to items comprising self-efficacy, knowledge, skills and confidence measures were recorded on a 5-point Likert scale (strongly disagree= 1, disagree = 2, neutral= 3, agree = 4 and strongly agree = 5). Responses to each question were dichotomised (1-3 *vs* 4-5) and McNemar tests were used to compare the paired proportions. For the knowledge, skills and confidence measures, item responses were summed to produce a single score. Higher scores indicate greater knowledge, confidence and skills and overall. Change in mean scores of those measures among carers between pre- and post- training was evaluated with paired-samples t-tests ($\alpha = 0.05$). Effect sizes were calculated as the difference in mean scores between levels of each oral health variable divided by the standard deviation to supplement the standard statistical testing for a more complete and relevant understanding of the change.[26]

INTERVENTION FOR EMPLOYEES

Data collection

Employees over 18 years at two worksites in Adelaide were approached in 2013 *via* mail to participate. Managers followed up with them in person. A dentist and a dental recorder conducted face-to-face interviews at baseline, three and six months to collect information on pre- and post-test questionnaires about employees' age, sex, living arrangement, period since last dental visit, type of disability, tooth brushing frequency, consumption of sweetened food and drink, and self-rated oral health. OHRQoL was also assessed using 14 questions selected primarily from the Oral Health Impact Profile (OHIP-14).[27] OHIP items ask about the frequency of adverse impacts caused by oral conditions during the previous 12 months, e.g. 'How often during the past year have you had painful aching in your mouth because of problems with your teeth, mouth or dentures?' Responses were on a five-point ordinal scale ranging from 'very often' to 'never'. Only four questions were selected for the South Australian study on dependent adults with disabilities, as observable domains like function (problems with eating) or social issues (irritability) are more likely to be validly assessed by proxy carers.[5] As this study included independent adults with disabilities who could communicate, all the items of the OHIP-14 were used but with a few changes. Some items were combined ('has your diet been unsatisfactory' and 'have you found it uncomfortable to eat any foods'; 'have you been self-conscious' and 'a bit embarrassed') so that two items regarding stale breath and interrupted sleep could be added, retaining 14 questions in total. The added items were sourced from the long-form version of the scale (OHIP-49)[28] and reflected some oral impacts important to people with disabilities, e.g. bad breath. Comments provided by the employees on the dental intervention were also included in the evaluation.

One dentist clinically examined all consenting employees at baseline. Referrals were arranged as needed to the SA Dental Service clinic closest to the employee's residence or workplace. In most cases, employees were seen urgently, i.e. within one month, and were not waitlisted as they usually would have been. Clinic staff assisted the research team by actively following up referred employees by mail and phone call through to their appointment. At one month and two months a dental hygienist provided group oral health education to the employees. The dental hygienist had attended an oral health training program provided by the dentist to carers of people with disabilities.[6] The oral health education included topics such as demonstration of tooth brushing behaviours, reinforcement of healthy diet and the importance of regular dental visiting, in simple language that could be understood by the employees. At three months, the dentist re-examined the employees, reinforcing daily oral care and reminding employees of dental treatment needs. At six months, follow-up dental examinations were completed by the same dentist.

Data analysis

Data were entered into SPSS Statistics (version 20, 2011). Descriptive statistics were used to summarise the background of employees. Bivariate data analyses were conducted with t-test and chi-square tests. McNemar and paired t-tests were used to compare pre- and post-intervention results. Self-rated oral health responses were dichotomised into 'poor' ('fair' or 'poor') *vs* 'good' ('good', 'very good' or 'excellent'). Analysis of OHRQoL was conducted in two ways. Values for each of the 14 items were re-coded to 0 for a response of 'never' to 4 for a response of 'very often' and analysed individually. Three summary variables were also computed,[29]

- Prevalence: percent of people reporting one or more items 'fairly' or 'very often'
- Extent: the number of items reported 'fairly' or 'very often' (range 0 – 14)
- Severity: the sum of ordinal responses (range 0 - 56).

ETHICS CONSIDERATIONS

Ethics approval for both interventions was granted by the Human Research Ethics Committee of the University of Adelaide (H-2013-021). Employees were able to consent directly to the study. Participating carers sought permission from their managers to participate in the study, and all gave consent for their participation in the study prior to training. Third party consent was obtained for all care recipients either from their parents or the responsible managers. Third party consent is required "where the research involves a person under 18 years, the mentally ill or those in dependent relationships or comparable situations" in the Australian National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research, 2007.[30]

Results

INTERVENTION FOR CARERS AND CARE RECIPIENTS

Forty one carers (who provided care for 103 care recipients) attended an initial theory training session. Before the practical training 15 carers withdrew (most were asked to do so by their managers as they were involved in other research). 10 more carers were lost by the six-month follow-up due to moving house or jobs or being on leave. Retention of carers from baseline to six month follow-up was thus only 39%. Around half of the baseline sample were 35–54 years old and most (83%) were females. Almost 40% had no tertiary qualifications, and almost 75% had no training in oral care for people with disabilities (Table 1). Carers were lost to follow-up disproportionately from the youngest age group and non-English speaking group.

Table 1. Characteristics of carers at baseline and loss to follow-up.

Carer characteristics		**Initial n (%)**	**Lost to follow-up n (%)**
Age	**18-34**	10 (24%)	8 (32%)
	35-54	20 (49%)	13 (52%)
	55+	11 (27%)	4 (16%)
Sex	**Female**	34 (83%)	22 (88%)
	Male	7 (17%)	3 (12%)
Highest qualification	**High school or less**	16 (39%)	9 (36%)
	Technical	8 (20%)	6 (24%)
	College/University	17 (41%)	10 (40%)
Language spoken at home	**Non-English**	4 (10%)	4 (16%)
Previous oral care training	**No**	30 (73.2%)	19 (76%)

From the total of 103 care recipients, OHAs were completed for 58 of them by the dentist and the trained carers. The loss of carers by six month follow-up meant that OHAs were not completed for 32, and the remaining 13 were not completed due to behavioural issues. For assessment of the care recipients' tongue, roof of the mouth, dentures and dental pain the level of carer-dentist agreement was 100%. Agreement was also high on the assessment of the lips, gums, breath, cleanliness and actions needed, but moderate for teeth (carers tended to over-estimate problems). Moderate to high kappa (0.63 to 0.75) suggested that the carers' assessments were similar to the dentist (Table 2).

Table 2. Agreement on oral health assessments between dentist and carer post-training (n = 58 OHAs).

Category	Agreement (%)	Kappa
Lips	98.3%	0.661
Tongue	100.0%	1
Roof of mouth	100.0%	1
Gums	81.0%	0.625
Teeth*	73.5%	0.681
Denture	100.0%	1
Breath	88.0%	0.748
Cleanliness	81.0%	0.671
Dental pain	100.0%	1
Actions needed	84.5%	0.667

**n=49 (9 edentulous)*

Percent agreement with most self-efficacy items was high at baseline (Table 3). Even prior to training almost all carers agreed they ensured regular brushing and dental check-ups, gave a high priority for any dental problem and followed instructions from a dental professional. None of those proportions decreased post-training. Although the percent of carers who agreed they were able to control snacking between meals was lower than for other statements, this did not change significantly post-training (69% to 56%).

Table 3. Carer self-efficacy pre- and post-training (n=16)

Item	Percent Agree/ Strongly Agree		P-value (McNemar test)
	Pre	**Post**	
1. I ensure teeth are brushed at least once a day	100%	100%	NA
2. I ensure regular dental check-ups	94%	100%	>0.999
3. I give a high priority for any dental problem	100%	100%	NA
4. I am able to control snacking between meals	69%	56%	0.687
5. I carefully follow any instructions my dental professional gives me about home-care	88%	100%	>0.999

Post-training, there was an increase in the proportion of carers who agreed/strongly agreed to each item covering knowledge, confidence and skills (Table 4). The most marked (yet only significant) increase was in the proportion of carers who agreed to knowing what treatments were available. Pre-training, the lowest proportions of carers were found agreeing to be confident with solutions for new oral health problems, and managing behavioural issues.

Table 4. Carer knowledge, confidence and skills pre- and post- training (n=16)

Item	**% Agree/Strongly agree**		**P-value[a]**
	Pre	**Post**	
Knowledge			
1. I know how to assess oral health	69%	75%	>0.999
2. I understand their oral health problems and what causes them	75%	100%	0.125
3. I know what treatments are available for their oral health problems	56%	100%	0.016
4. I know how to prevent further oral health problems	69%	94%	0.219
Confidence			
5. I am confident I can tell whether they need to go to the dentist	75%	81%	0.500
6. I am confident I can tell a dentist about their possible dental concerns	81%	94%	>0.999
7. I am confident I can help prevent or reduce their oral health problems	81%	94%	0.625
8. I am confident I can maintain a healthy diet for them	94%	100%	>0.999
9. I am confident I can figure out solutions when new problems arise with their oral health condition	50%	75%	0.219
10. I am confident I can manage behavioural issues	63%	88%	0.219
Skills			
1. I carefully follow any instructions my dental professional gives me about home-care	88%	100%	>0.999
2. I take responsibility in caring for their oral health	94%	100%	>0.999
3. I take an active role in maintaining their oral health	100%	100%	NA

[a]McNemar test

There were significant increases from pre- to post-training in the mean scores of the overall measure, and the knowledge and confidence measures, with large effect sizes (Table 5). Although increase in the score for skills did not attain statistical significance, there was a measurable small change (effect size 0.29).

Table 5. Comparison of knowledge, confidence and skills measures (summative scores) pre- and post-training (n=16).

Scale	**Pre-test mean (SD)**	**Post-test mean (SD)**	**P value (paired *t*-test)**	**Effect size**
Overall	50.9 (6.1)	57.1 (5.7)	<0.001	1.22
Knowledge	14.2 (2.3)	17.4 (1.9)	<0.001	1.43
Confidence	23.4 (3.5)	26.1 (3.0)	0.003	0.89
Skills	13.1 (1.5)	13.6 (1.3)	0.261	0.29

A *post hoc* analysis of power and sample size was conducted on the three measures and overall measure only, to avoid multiple calculations. The power was high for the overall measure (0.99), and those for knowledge (0.912) and confidence (0.99), but was low for skills (0.18). Based on the observed effect sizes and assuming an alpha level of 0.05 and a power of 0.8, a sample of less than 16 would be sufficient to detect statistically significant differences as follows: overall (n=7), knowledge (n=12) and confidence (n=6), but n=94 would be required for the skills measure. This is consistent with the observed effect sizes which were large, except for the skills measure (Table 5).

Most carers (75%) rated the training as excellent or very good on post-training questionnaires, and qualitative feedback was supportive. The dental hygienists undertaking the study also reported carers' positivity about the training. Where there was continuity of care by the trained carers, OHC sheets were completed on a daily basis as instructed, giving reasons when actions could not be completed due to behavioural issues. However, some carers did not fill in the OHC sheets, stating they had not been directly trained and felt that the trained carer was not qualified to train them. OHC sheets were blank or missing from those who had changed roles, houses or were on leave within the six-month period of the intervention. Most care recipients were compliant and content with their clinical exams.

INTERVENTION FOR EMPLOYEES

Initially, only two responses were received from 200 employees at two worksites approached *via* mail to participate in the intervention. When managers approached participants at the worksites, responses increased to 26, and eventually *via* word-of-mouth reached 51. These employees underwent baseline dental examinations. After six months, seven employees had either left the job or were on leave due to ill health, leaving a follow-up sample of 44. Loss to follow-up tended to be from the youngest or oldest age groups, females and those living alone (Table 6). Of the 44 employees who completed the study, about 50% were 35–54 years old and 68% were male. Almost two thirds (64%) lived with family, the remainder alone. The main disabling condition was intellectual, with 34% of participants affected by both physical and intellectual disabilities. All employees but one could communicate verbally. Most were able to self-care, i.e. could brush their teeth and eat without assistance. Only 27% of employees had visited a dentist within the last year.

Table 6. Characteristics of employees at baseline and loss to follow-up

Employee characteristic		**Initial n (%)**	**Lost to follow-up n (%)**
Age	**18-34**	15 (34%)	3 (43%)
	35-54	24 (55%)	1 (15%)
	55+	5 (11%)	3 (43%)
Sex	**Female**	14 (32%)	5 (71%)
	Male	30 (68%)	2 (29%)
Living arrangement	**With family**	28 (64%)	3 (43%)
	Alone	16 (36%)	4 (57%)
Australian Indigenous origin		1 (2%)	0
Disabling condition	**Intellectual disability**	34 (77%)	5 (71%)
	Physical disability	25 (57%)	4 (57%)
Time since last dental visit	**Less than 12 months**	12 (27%)	2 (29%)
	1–2 years	8 (18%)	1 (15%)
	2– 5 years	8 (18%)	1 (15%)
	Never/don't know	16 (36%)	3 (43%)

The baseline dental examination revealed that 89% of the employees needed treatment and were referred. Despite extensive follow-up from clinic staff, only 72% of those referred completed the recommended treatment, which ranged from teeth cleaning to extraction of all existing teeth. Six employees claimed they were not notified of their dental appointments, and four did not attend due to dental fear or cost. One had a scheduled appointment but had not received care by the time of follow-up.

At baseline there was a low frequency of negative impacts on OHRQoL perceived often,

- about 11% had painful aching and unsatisfactory diet
- 9% had trouble sleeping
- 5% had bad breath and difficulty relaxing.

No employees reported trouble with interrupted meals or pronunciation, difficulty doing usual jobs or being totally unable to function often because of oral health problems. Thus although the prevalence of impacts on OHRQoL was 27%, the extent and severity of impact were relatively low at baseline. Nonetheless, the frequency of all impacts remained the same or decreased by follow-up, and all three summary measures – prevalence, extent and severity - improved (Table 7). The proportion of employees with poor self-rated oral health poor almost halved pre- to post-intervention, from 64% to 34%.

Table 7. Self-rated oral health and OHRQoL of employees pre- and post-intervention (n=44)

	Pre	Post	P-value
Self-rated oral health: % poor	64%	34%	<0.001[a]
OHRQoL			
Prevalence: %	27%	11%	0.008[a]
Extent: mean (SE)	1.3 (0.3)	0.6 (0.2)	0.013[b]
Severity: mean (SE)	3.6 (0.9)	1.8 (0.4)	0.008[b]

[a]McNemar test

[b]paired t-test

Further analysis stratified self-rated oral health and OHRQoL summary measures by three factors: age group, sex and whether the employee completed treatment. Consistent variation with age was seen in the extent of change of all variables: the older group improved more than the younger. For example, the percent of employees with poor self-rated oral health decreased from 55% to 21% for those 35 years and over, and from 80% to 60% for the younger group. The self-rated health of those who completed treatment also improved more post-intervention. For example, poor oral health decreased from 55% to 18% for those treated, and 75% to 63% for those who were not. There were no consistent differences between sexes in the measured change of variables.

Prior to education and treatment, only 34% of the employees brushed their teeth at the recommended frequency of twice a day (Table 8). At six months, this had only increased to 50%. The consumption of sweet drinks and sweet solids was relatively stable pre- to post-intervention, with acidic drink consumption decreasing the most, but not significantly, from 50% to 34%. However, qualitative feedback from employees and anecdotal evidence from managers indicated unmeasured behavioural changes; some employees quit smoking and others acknowledged financial and social gains. These employees shared their success with non-participating employees in the workplace and helped to promote healthy behaviours.

Table 8. Oral health behaviours of employees pre- and post-intervention (n=44).

Oral health behaviour		**Baseline n (%)**	**Follow-up n (%)**	**P-value (McNemar test)**
Tooth brushing	**Twice a day**	15 (34%)	22 (50%)	0.142
	Once a day or less	29 (66%)	22 (50%)	
Dietary consumption	**Sweet drinks (mod-high)**	34 (77%)	35 (80%)	> 0.999
	Sweet solids (mod-high)	11 (25%)	8 (18%)	0.453
	Acidic drinks (mod-high)	22 (50%)	15 (34%)	0.167

Discussion

INTERVENTION FOR CARERS AND CARE RECIPIENTS

This study showed preliminary evidence that carers of people with disabilities can be trained to closely assess their care recipients' oral health, note changes and assess the need for referral. Findings suggested that the training improved knowledge and confidence in oral care among carers. Oral health assessments showed high carer-dentist agreement in most categories, reflecting their capacity to assess oral health to the extent needed for referral to dental professionals. Where there was poorer agreement, this was from carers over-estimating problems, perhaps indicating their preference to err on the side of caution rather than ignoring change.

Study strengths

The tasks of completing and signing off the daily OHC sheet were initially not welcomed by carers as additional demands on their time. However, as the sheets were similar to existing medication charts, most accepted it within a month. This accountability served as a strength to the study. An additional strength was moving beyond the limitations of self-reported data by incorporating the analysis of carer-dentist agreement of clinical assessments.

Carer knowledge, confidence and skills

The moderate to high effects observed in the knowledge and confidence measures could have been due to the theoretical basis and multifaceted training (including ongoing support and accountability) of this intervention. The closest comparable published studies found that their training had varied impacts on carers.[15,18] Training methods from both of those comparable studies were adapted and integrated for use in this one, which may have increased its relative effectiveness. In particular, reinforcement of training by dental hygienists who visited carers and care recipients and ensured the OHCP was being actioned daily was deemed to be valuable.

Carer self-efficacy

High values at baseline for all but one of the self-efficacy items meant it was not possible to clearly evaluate the impact of the intervention on this construct. Notably, carer agreement was lowest with the ability to 'control snacking between meals', and remained so post-training. Choice and autonomy are intrinsic to client-focused care and people with special needs should not be deprived of choice. However, they can be supported in making healthy ones. Staff engagement in the process is vital so that behavioural change is not impeded.[31]

INTERVENTION FOR EMPLOYEES

This intervention delivered preliminary evidence that providing regular oral health education and enabling referral to treatment improves self-rated oral health and OHRQoL among employees with disabilities. Disentangling the effects of education and treatment in the intervention is problematic. However, stratifying the outcomes by treatment did indicate that it was the treatment component that was most responsible for the improved outcomes. Nonetheless, the group that undertook treatment were younger and reported worse oral health at baseline than the group who were not treated.

Oral health-related quality of life

The prevalence of impacts on OHRQoL measured at baseline in this study was not substantially higher than that measured for the general dentate population (18%), and the severity of impact was low.[29] This perhaps reflects the documented higher pain threshold of

people with disabilities, as many live with chronic pain.[34] Nonetheless, all summary measures of impact as well as self-rated oral health showed improvement following the intervention. Thus employees, especially those who completed the recommended treatment, benefitted from timely referral for treatment.

Referral for treatment

As reported for other patients with special health care needs, dental fear was a barrier to accessing services for some employees.[35] Given ample evidence about cost as a barrier to care for the general population, it is not surprising that this also emerged as a reason for non-attendance in this study.[36] Although participants were employed, their wages were low. Notably, only 27% of employees at baseline had visited a dentist within the last year, less than half of an Australian national estimate of 59%[36] and close to proportions for other disadvantaged populations such as the homeless.[37] The benefits suggested by timely referral to treatment in this study substantiate the importance of routine dental care, as found for the general population and older adults.[38-40]

Oral health behaviours

No significant change was observed in measured oral health behaviours, i.e. tooth brushing frequency and consumption of sweet food and drink. However, there was anecdotal evidence of improvement in unmeasured behaviours. Other studies have highlighted the challenges in changing oral health behaviours for this subpopulation.[6,15] It is likely that more intensive efforts than those employed in this study would be required to manifest change. Systematic reviews of the evidence for oral health promotion effectiveness in the general population have been inconclusive.[32,33] They have highlighted that gains in knowledge were more readily achieved than behavioural change, and there was little evidence for clinical impact. Moreover, one of those reviews[32] found that chairside health promotion was most effective, highlighting the importance of regular dental visiting already suggested by this study's findings.

Conclusions

POLICY OPTIONS

Recommendations for (1) improving carer knowledge, skills and confidence in oral care of care recipients, and (2) improving self-care, oral health and oral health-related quality of life of employees with disabilities include the following,

Recommendations

- Implementation of regular training in oral care and assessment for carers of people with disabilities. Encouragement and incentive should be provided to their employers to undertake training.
- Training in oral care for carers should be integrated with evaluation and conducted in coordination with public dental services and dental professionals specialised in care for people with disabilities.
- Encouragement and incentives for employers of people with disabilities to implement workplace programs for oral health education and referral for treatment.
- Expansion of opportunities within public dental care for people with disabilities to gain treatment. Patients need to be actively followed up to ensure that they attend appointments.
- Further research to identify barriers and enablers that facilitate the training of carers of people with disabilities. These findings could then inform the development of a coordinated approach to training that would benefit carers and their care recipients.

STRENGTHS AND LIMITATIONS OF THE STUDY

Valuable information was gained in this study that will assist planning for organisations involved with disabilities, the dental profession and service providers. The findings suggested that training improved knowledge and confidence in oral care among the carers. Carers had the capacity to assess oral health to the extent needed for referral to dental professionals. Regular oral health education combined with enabling referral to treatment is also suggested to have improved self-rated oral health and quality of life for employees.

In the intervention for carers and care recipients, high baseline values for several psychosocial measures indicated that those carers who were most engaged or capable self-selected to take part in the study. Thus a ceiling effect was introduced, although measureable improvements were still made by training in some measures. Training and assessments were conducted by the same dentist in this study, yet no reliability tests were conducted. These would have been difficult due to the availability of a single carer at any one time and short attention span of care recipients. Behavioural problems prevented even the simple OHAs from being completed for 13% of the care recipients.

Despite the effort expended to maximise sample size, slow response and low participation limited the size of both interventions and thus the power of analysis and generalisability of the findings. The resultant absence of control groups limited the capacity of either intervention to discern a causal effect. Outcomes could not be attributed unambiguously to the interventions but could be due to confounding factors. Another possibility is the Hawthorne effect,[41] i.e. carers and employees consciously consented to be involved in research and their awareness of such may have led to the observed improvements.

Given the limitations addressed above, it is evident that if funding permitted, a larger, broader sample in a controlled intervention would advance our understanding in this area. Further research is also needed to identify barriers and enablers that facilitate the training of

carers of people with disabilities. In conclusion, a stronger evidence base is needed to build on this contribution and improve the oral health of people with disabilities in Australia.

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