

Research

Impact of Oral Health Education on the Knowledge, Behaviors, Attitudes, and Self-Efficacy of Caregivers for Individuals with Intellectual and Developmental Disabilities

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Abstract

Purpose: Individuals with intellectual and developmental disabilities (IDD) have a higher risk of oral disease and require assistance in performing oral self-care. The purpose of this study was to measure the impact of an oral health education program in improving caregivers' oral health knowledge, attitudes, behavior, and self-efficacy in providing oral health care to clients with IDD, residing in intermediate care facilities.

Methods: A non-probability sample of new hire caregivers (n=47) for clients with IDD residing in an intermediate care facility was used for this quasi-experimental study. A one-group repeated measures design was used to explore the effectiveness of an oral health education program. All variables were examined using summary statistics and evaluated for normality and statistical assumptions.

Results: Forty-seven participants attended the oral health education program intervention and completed the pre- and post-intervention questionnaire. Seventy percent (n=33) completed the four-week post-questionnaire. A statistically significant ($p=0.004$) improvement in knowledge between the baseline questionnaire and four-week questionnaire was identified. Findings demonstrated slight increases in knowledge for caregivers with <1year experience, and in those with previous medical training. No significant differences were found in behaviors or attitudes from baseline to the four-week follow up, however, there was a trend toward positive behavior changes.

Conclusion: Increased knowledge alone is not adequate to bring about and maintain positive oral health behavior change. Longer-term caregiver interventions, in addition to on-site support for oral care, are warranted to evaluate outcomes for individuals with IDD with the goal of reducing the burden of oral disease.

Key words: caregivers, oral health, oral health education, developmental disabilities, intellectual disabilities, intermediate care facility, oral care

This manuscript supports the NDHRA priority area, **Population level: Access to care** (interventions).

Submitted for publication: 1/13/20; accepted: 8/15/20

Introduction

Sixty-one million adults (25.7%) in the United States (US) are defined as having a disability under the Americans with Disabilities Act.^{1,2} Developmental disabilities (DD) are defined as mental or physical impairments that limit or prevent normal development, whereas intellectual disabilities (ID) limit intellectual functioning and adaptive behavior that may impair routine social skills and activities of daily living.^{2,3} In young adults, cognitive disabilities are the most prevalent disability.¹ Examples of cognitive disabilities include autism, mental retardation, anoxic brain damage, stroke, and

post-traumatic injury resulting in learning disabilities.^{2,3} The prevalence of developmental disabilities in children in the US (2009-2017) between the ages of 3 to 17 years, was shown to be one out of six children, an increase over previous years.³

Intellectual and developmental disabilities (IDD) are disorders that negatively impact the individual's physical, intellectual, and emotional development.⁴ These disabilities can occur *in utero* in all racial, ethnic, and socioeconomic groups; they may also occur after birth due to injury, infection, or be due to other environmental factors.^{2,5} Intellectual and

developmental disabilities affect multiple body systems and can impair a person's ability to learn, reason, problem solve, and perform social and life skills.⁵

Individuals with IDD have a higher risk of oral disease due to their limited understanding of oral health, their inability to perform physical tasks independently, sensory impairment, dysphagia, and poor access to dental care.^{4,6} A systematic review of 27 studies that included individuals with ID from 12 countries in a variety of living situations, including community dwelling and institutions, identified poorer oral hygiene, higher prevalence and severity of periodontal disease, and higher levels of untreated caries.⁷ Petrovic et al. found individuals with IDD had 1.6 times greater odds of experiencing dental caries than the general population, and those living in institutions had 2.4 greater odds of having untreated caries.⁸ Morgan et al. found that almost 90% of the individuals with IDD had some degree of periodontal disease, and the average numbers of decayed, missing, and filled teeth (DMFT) was 13.9 compared to the general population average of 7.7 DMFT.⁶

In addition to the previously noted factors affecting oral health, individuals with IDD frequently have complex oral health needs related to congenital and developmental anomalies that may be further compromised by behavior patterns and communication issues.^{7,9} Treating individuals with ID demands more time, patience, oral health knowledge, home care education, and greater overall caregiver skills than patients without an ID.⁹ Previous research suggests uncooperative behavior during oral care activities, combined with a caregivers' lack of oral health knowledge, are the largest obstacles in providing daily oral homecare to individuals with IDD.^{4,9}

In addition to a lack of fundamental oral health knowledge and inadequate training, caregivers also report additional barriers to providing oral hygiene care to individuals with IDD including lack of time and uncooperative clients.^{10,11} Research has also suggested that caregivers' comfort in providing oral home care to individuals with IDD was linked to training experience, job experience, and length of time working with individuals with IDD.¹¹

A study by Gonzalez et al. found that an educational program was more effective than exclusively discussing oral care procedures with caregivers of individuals with IDD, and that hands-on training, combined with a lecture, had an even larger impact on increasing caregiver oral care knowledge.¹² Research by Binkley et al. evaluated the outcomes of caregiver oral health training and found increases in caregiver supervision of residents (77% to 94%), dental flossing behaviors (66%), and praise used to support compliance (63%).¹³ The increase

in the level of caregiver supervision, use of dental aids, calm atmosphere, and monitoring of residents' oral hygiene care were all positive changes as a result of the oral health program implemented in eleven group homes.¹³

Despite these positive outcomes, research has been inconsistent and further study is warranted regarding oral health outcomes resulting from oral health education and training provided to caregivers working in intermediate care facilities (ICF) and group homes.^{4,13} Research has indicated a need to further investigate the most effective methods to increase oral health knowledge of caregivers that will lead to behavior changes in oral care activities and ultimately reduce the burden of oral disease in the individuals they care for with IDD.¹¹ The purpose of this study was to measure the impact of an oral health education program on caregivers' oral health knowledge, attitudes, behavior, and self-efficacy in providing oral healthcare to clients with IDD living in an intermediate care facility.

Methods

The MCPHS University Institutional Review Board (IRB) gave this study exempt status, protocol number IRB072018B.

This quasi-experimental, one-group repeated measures design used a non-probability sample to assess the outcome of an oral health education program for caregivers. Participants completed a baseline questionnaire prior to the program, a post-questionnaire immediately after the program, and a four-week follow-up questionnaire to measure retention and changes in oral health knowledge, behaviors, attitudes, and self-efficacy.

Sample selection

The study setting was Southern Wisconsin Center, a state-operated intermediate care facility for individuals with IDD, in Union Grove, WI. The Southern Wisconsin Center (SWC) opened in 1919 and is one of three sites managed by the Department of Health and Treatment Services for individuals with IDD offering a wide range of programs and care to their clients.¹⁴ Southern Wisconsin Center provides their caretakers with training on activities of daily living care for their clients; however, the training does not include a oral health component. The non-probability sample consisted of caregivers newly hired through SWC (n=47). Caregivers were invited to participate in the oral health program during the SWC new hire training sessions. Inclusion criteria were SWC new hires who were 18 years of age and older, who spoke English. No specific previous oral health training was required for participation. A power analysis for this study recommended a minimum of 40 and a maximum of 60 participants.

Survey instrument

The questionnaire contained demographics (8 items) and 25 oral health-related questions regarding the following four subscales: knowledge (10 items), attitudes (6 items), reported behavior (4 items), and self-efficacy (5 items). The validated and reliable instrument ($\alpha=0.60$) was created by Mac Giolla Phadraig et al.¹⁵ The only modification to the original instrument was one additional question in the attitude section (item 20).

Oral health education program.

The oral health program was based on “Train the Trainer, An Oral Health Training Toolkit” and permission was granted by Mac Giolla Phadraig et al. for use in this study.¹⁵ The program trainer was a registered dental hygienist with 13 years of working experience and the principal investigator (PI) for the study. The education program was two hours in length and consisted of an overview of oral health care, prevention of oral disease, causes of poor oral health, consequences of oral disease, oral-systemic links, adapting a toothbrush for special needs use, and patient positioning for brushing. The face-to-face delivery was through lecture, slides and live demonstrations. Participants were broken into small groups for demonstrations of brushing, flossing, and use of other oral hygiene aids on tooth models. The final component consisted of role playing with a partner. Participants demonstrated the brushing and flossing procedures on their partner and practiced adapting the toothbrush or patient positioning as needed while being observed by the PI. The program concluded with a question-and-answer session.

Procedure

Caregivers were invited to participate in the oral health training program as part of the training session for new hires. An email introducing the program and PI was sent by the SWC director prior to the start of the new hire training. Prior to the start of the oral health program, participants were provided with an informed consent form. The baseline questionnaire (T0) and demographic questions were completed prior to the attending the oral health education program using a web-based survey software program (SurveyMonkey®, San Mateo, CA). A post-questionnaire (T1) was distributed to measure the impact of the education session on four domains of oral health directly following the completion of the program. A follow-up questionnaire was distributed four weeks (T2) after completion of the program to assess retention and changes in behavior practices.

Statistical analysis

Statistical analysis was carried out with SPSS® version 23 (IBM, Armonk, NY). All variables were examined using summary statistics and evaluated for normality and statistical assumptions. For each subscale, the responses to items in that subscale were averaged to create a subscale value for each participant’s response.

Correlations were performed using the distribution appropriate test to determine relationships between all variables. Repeated measures one-way ANOVA was used to determine if knowledge improved after the intervention. Matched-pairs t-tests were used to identify statistically significant mean differences between each data collection time point. The independent Mann-Whitney U was employed to test the difference in knowledge scores between different demographic groups. The Friedman K-sample test was used to determine whether attitude improved after the intervention. The Mann-Whitney U was calculated to test statistically significant differences in median attitude scores between demographic categories. The Friedman and Mann-Whitney U were also used to test whether positive behaviors increased after the intervention. A Bonferroni adjustment for Type II error was used for all matched pairs t-tests. For all inferential statistics, the alpha level, 95% Confidence Interval, and all relevant effect size data were calculated and reported.

Results

A total of 47 participants participated in the intervention and completed the pre- and post-intervention questionnaire (n=47). Seventy percent (n=33) of the sample completed the four-week follow up questionnaire. The sample included 38 females (81%) with a mean age 31.7 years and 4.7 years of experience. Sample demographic data are shown in Table I.

Knowledge

The average number of correctly answered questions for each time point are shown in Table II. To test the effect of training on knowledge, a one-way repeated measures ANOVA was conducted to compare the percentage of correctly answered items (DV) across time for each participant. There was a significant effect of time, Wilks’ Lambda=.69, $F(2, 25)=5.58$, $p=0.01$. Three paired samples t-tests were used to make post hoc comparisons between conditions. Results indicated there was not a difference between the mean number of correctly answered questions ($p=0.054$) between pre- (M=7.5, SD=1.6) and post- (M=8.1, SD=1.2) intervention questionnaires. However, there was an improvement between pre-intervention and four-week follow up questionnaires

Table I. Demographics (n=47)

Category	Mean	SD*
Age	31.7	10.8
Experience, years	4.7	7.1
Hours worked, weekly	38.6	4.5
	n	%
Gender		
Male	9	19.1
Female	38	80.9
Education		
High school	12	25.5
Some college no degree	19	40.4
Associate or bachelor	14	29.8
Master or doctorate	2	4.3
Training Type		
During training	9	19.1
CBRF	9	19.1
RN	4	8.5
CNA	22	46.8
Missing	3	6.4
Previous oral care training		
Yes	15	31.9
No	32	68.1

*SD=standard deviation of the mean

Table II. Measures of central tendency for dependent variables* (n=47)

	Pre (SD)	Post (SD)	Four Weeks** (SD)
Knowledge	7.5(1.6)	8.1(1.1)	8.9(1.1)
Behavior	3.0(1.0)	4.0(1.0)	3.0(.81)
Attitude	8.0(1.3)	7.0(1.2)	7.0(1.2)

*Knowledge scale was normally distributed and the mean plus SD=standard deviation reported. Attitude and behavior were skewed thus the median is reported.

** n=33

(M=8.9, SD=1.1, $p=0.004$). There was also an improvement between mean number of correctly answered questions post intervention and at the four-week follow up ($p=0.01$) as shown in Table III.

Table III. Correct responses for knowledge and self-reported positive behavior questions* (n=47)

	Pre n (%)	Post n (%)	Four-Weeks** n (%)
Knowledge Items			
Gum disease often occurs even when the mouth is properly cleaned	25(53.2)	37(78.7)	20(74.1)
Gum disease may cause serious problems like heart disease	37(78.7)	47(100.0)	25(92.6)
Gum disease is inevitable in people with IDD	30(63.8)	27(57.4)	22(81.5)
If a client has a lot of sugary food and drink, their teeth are more likely to decay	45(95.7)	46(97.9)	25(92.6)
Clients are often on medications that increase their risk of decay	36(76.6)	39(83.0)	24(88.9)
When people with ID get decay, they usually have teeth extracted rather than filled	28(59.6)	26(55.3)	21(77.8)
Ideally, dentures should be carefully placed in the mouth at night	42(89.4)	45(95.7)	26(96.3)
Dentures can cause infection if not cleaned regularly	45(95.7)	45(95.7)	27(100.0)
Gloves worn while brushing the clients' teeth should be rinsed thoroughly between uses	20(42.6)	23(48.9)	22(81.5)
If gums bleed during brushing, they should be brushed less often	45(95.7)	46(97.9)	27(100)
Self-Reported Positive Behaviors			
I always ensure that the client's teeth are brushed at least once a day	46(97.9)	45(95.7)	27(100)
I actively discourage client's from eating sweets	29(61.7)	37(78.7)	22(81.5)
The client's that I care for allow me to do a good job of brushing their teeth	38(80.9)	38(80.9)	14(51.9)
I make sure that the clients' who I care for get a dental check at least once a year	41(87.2)	43(91.5)	25(92.6)

* Knowledge question were coded as either correct=1 or incorrect=0. Behavior question were coded as positive response=1 and negative response=0.

** n=33

Independent sample Mann-Whitney U tests were used to investigate mean differences between the demographic variables *years of experience, education, training, and previous oral care training* and the mean number of correct responses at each time point. Years of experience was dichotomized into caregivers with one year or less (n=19) or more than one year (n=28); education was dichotomized into caregivers with a college degree (n=16) and those without (n=31). Training Type/Certifications were dichotomized into caregivers with a CNA or RN license (n=26) and those without (n=18). After accounting for familywise error using a Bonferroni adjustment, there were no significant differences between demographic variables years of experience, education, training, or previous oral care training for the mean number of correctly answered items at each time point ($p>0.05$).

Behavior

The behavior scale was scored by summing the number of positive oral health behaviors (yes=1 and no=0) at each time point. The median number of positive oral health behaviors for each time point is shown in Table II and frequency of self-reported positive behaviors is shown in Table III. To examine the effect of the intervention on the positive oral health behaviors, a Friedman test was conducted with the independent variable time of questionnaire completion and the dependent variable median number of oral health behaviors implemented. There was a statistically significant difference in median number of positive oral health behaviors, depending on time of survey completion, $\chi^2(2)=6.6, p=0.04$.

Post-hoc analysis with Wilcoxon signed-rank tests was conducted with a Bonferroni correction applied, resulting in a significance level set at $p<0.017$. Median (IQR) positive oral health behaviors pre-, post- and at the four-week follow up were 3 (3 to 4), 4 (3 to 4) and 3 (3 to 4), respectively. Despite a significant Friedman test, there were no significant differences between pre- and post- intervention ($Z=-1.7, p=0.1$) or between pre-intervention and four-week follow up ($Z=-0.2, p=0.8$), or between post intervention and four-week follow up ($Z=-2.1, p=0.04$) after adjusting for familywise error.

Attitude

The attitude scale was computed by summing the total number of positive responses for oral health behaviors towards all attitude and self-efficacy questions (Agree or Strongly Agree=1, Neither Agree nor Disagree, Disagree, and Strongly Disagree=0) at each time point. The median number of positive responses for attitudes towards oral health behaviors for each time point are shown in Table II. To examine the effect of intervention on positive attitudes towards oral care behaviors, a Friedman test was conducted with the independent variable *time of questionnaire completion* and

the dependent variable *median number of positive oral health behaviors*. There was not a statistically significant difference in median number of positive oral health attitudes depending on time of survey completion, $\chi^2(2)=0.5, p=0.8$. Frequency of responses for attitudes is shown in Table IV.

Table IV. Frequency of self-reported positive attitudes and self-efficacy*

	Pre (n=47) n (%)	Post (n=47) n (%)	Four-Weeks** n (%)
I see it as my responsibility to keep client's teeth clean	44(93.6)	45(6.4)	27(100)
In my opinion, it is better to wait until there is a problem before seeking a dental appointment for a client	45(97.8)	44(93.6)	27(100)
Since most people with a learning disability who have some teeth will eventually lose them, regular tooth brushing is not important for them	47(100)	45(95.7)	26(96.3)
Brushing teeth is a very personal thing that you should not be expected to do for somebody else	47(100)	44(93.6)	27(100)
If a client, who needs assistance brushing their teeth, shows any sign of resistance while their teeth are brushed, brushing should be stopped immediately	13(27.7)	10(21.3)	11(23.4)
If a client, who needs assistance brushing their teeth, shows any sign of resistance, an alternative method is attempted.	41(87.2)	45(95.7)	26(96.3)
Self-efficacy			
When I brush a client's teeth I do a very good job	43(91.5)	44(93.6)	23(92.0)
I believe I can help in preventing client's teeth from becoming decayed	42(89.4)	45(95.7)	23(92.0)
I believe I can help in preventing client's teeth from getting gum disease	43(91.5)	44(93.6)	24(92.3)
When I brush a client's teeth I am unsure if I am doing it right	37(78.7)	37(78.7)	25(96.2)
I spend as much time brushing client's teeth as I would like	20(42.6)	22(46.8)	11(42.3)

* Attitude and self-efficacy questions were recoded as agree and strongly agree=positive response and neutral, disagree, and strongly agree as negative response. Positive=1 and negative=0.

**n=33

Independent sample Mann-Whitney U tests were used to investigate median differences between the independent variables *years of experience, education, training type, and previous oral care training* for median number of positive responses for attitudes towards oral health behaviors. After accounting for familywise error using a Bonferroni adjustment, there were no significant differences between any groups for median number of positive responses for attitudes towards oral health behaviors ($p > .05$).

Discussion

The purpose of this study was to measure the impact of an oral health education program on caregivers' oral health knowledge, attitudes, behavior, and self-efficacy in providing oral healthcare to clients with IDD residing in an intermediate care facility. Statistically significant improvements in caregiver knowledge at baseline and at the four-week follow-up were demonstrated. This improvement in knowledge could be have been a result of both the oral health care education intervention and caregiver work experiences between questionnaires. The results also demonstrated slight increases in knowledge for caregivers with less than one-year experience and training, and in those with previous medical training. However, the study participants did not demonstrate any significant changes in their oral health behaviors in regard to actually carrying out oral health care practices with their clients. The oral health behaviors of the participants only increased slightly following the education program and these behavior changes were not sustained as indicated by the four-week follow-up responses. These findings are similar to those of other studies that have identified the need for an ongoing support network following an oral health education intervention to maintain the implementation of positive oral health care behaviors.¹¹⁻¹³

There is clearly a need for a continuous support network to maintain positive intervention changes. Results from this study and previous research suggest that these supportive intervention measures could include activities of daily living care check off sheets that identify the OHC services provided for each patient each day. These daily forms could be reviewed and signed off by the supervising staff, which would improve compliance as well as indicate support for oral health practices from the supervisory staff. Another intervention could include OHC review during staff meetings either quarterly or as needed. Annual or random assessments of caregiver performance in providing daily living care services, including oral health care services could be another avenue for increased compliance.^{11-13,15-16}

Another option to improve the quality of oral care for the population with IDD would be to include oral

health care training into the community-based residential facility (CBRF) certification training programs and other similar programs throughout the country. Currently CBRF training focuses on fire safety, first aid, choking, medication administration, and standard precautions.¹⁸ This program, along with other activities of daily living skill programs could be a point of access to training caregivers on providing daily oral health care services and added into operational protocol for intermediate care facilities. Currently, SWC has a dentist on staff who provides patient restorative care; however, the role is limited to the provision of dental care and the needed education for proper oral health care services is unattainable. One solution would be to add a supervising direct access dental hygienist on staff to address gaps in oral health care education, provide preventive services, and case management of individuals needing restorative dental care. This addition of a dental professional would be the ideal standard of care for this patient population.¹⁶

Limitations to this study included the convenience sample from a single institution located in Wisconsin, and possible bias due to self-reporting of questionnaire responses. The low response rate to the four-week follow-up questionnaire also limited the evaluation of the longer-term effects of the intervention. Future research is needed to investigate the best methods to implement oral health education support systems for residents of intermediate care facilities and to enhance access to care. The dental therapist and advanced dental hygiene practitioner are models being explored in dentistry to increase the access to care for under-served populations, including intellectually and developmentally disabled individuals.¹⁷ These mid-level oral health care providers could be a part of the staff, offer regular educational support, and oversee caregiver oral home care services, while increasing access to dental care services.¹⁷

Conclusion

Results from this study suggest the need for further investigation on the impact of oral health education for caregivers of clients with IDD, as well as the most effective interventions to maintain on-going, quality oral health care provided by caregivers. Programs, such as community-based residential facility certification training, and the utilization of direct access dental hygienists, dental therapists and advanced dental hygiene practitioners on-site, would be opportunities to ensure continuous competence of caregivers in supporting the comprehensive oral health needs of clients with IDD..

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