

Total tooth loss and complete denture use in older adults with intellectual disabilities in Ireland

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Abstract

Objectives: The objectives of this study were to describe the reported dentate status and complete denture use of older people with intellectual disability (ID) and compare with those of older people in the general population in Ireland.

Methods: The first wave of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) study provides opportunity to measure edentulism and complete denture use in a nationally representative sample of older people with ID in Ireland. Data drawn from the first wave of IDS-TILDA were matched using propensity score matching with data from The Irish Longitudinal Study on Ageing (TILDA), a study among older adults in Ireland. All IDS-TILDA variables showing significant association ($P < 0.05$) with edentulism were entered into a regression model to identify predictors of edentulism.

Result: The proportion of the 478 IDS-TILDA participants with no teeth was higher (34.1 percent) than the proportion of participants with no teeth in the 478 matched TILDA participants (14.9 percent). Only age was predictive of edentulism among older adults with ID. Edentulism was prevalent earlier for those with ID. Notably, 61.3 percent of edentulous older people with ID were without dentures.

Conclusion: Older people with ID are more likely to be edentulous than those without ID in Ireland and when they lose their teeth, they are unlikely to use dentures. This suggests a need for targeted measures to maintain the teeth of this group and, in the short term, the provision of replacement teeth in this population, where indicated.

Introduction

People with intellectual disabilities (ID) are living longer (1). Life expectancy for adults with mild ID is now similar to that of the general population and people with moderate or severe ID now routinely reach their late 60s and late 50s, respectively (2). As the population with ID ages, they experience age-related chronic diseases in common with the general population. This aging among people with ID is said to present a challenge, by virtue of increasing numbers and heterogeneity in terms of health status and needs, to policy makers, educators, and clinicians alike (3).

Tooth loss increases with age in older adults with special needs (4). Longitudinal research suggests that periodontal

disease is a greater source of tooth loss for people with ID than caries (5). This is not surprising as periodontal disease is far commoner among people with ID than the general population (6–8). In addition, even though people with ID often have similar or even lower levels of caries than the general population, the treatment of dental caries usually leads to extraction rather than restoration (6,8–11).

While edentulism has decreased dramatically in developed countries over the last decades (12,13), it is accepted that people with ID have higher rates of edentulism than the general population (6,10,14,15), although this finding is not universal (16). In 2003, an oral health survey conducted with adults with ID in residential care settings in Ireland found high levels of edentulism among participants. Additionally,

many of these participants did not wear dentures to restore function or aesthetics. The authors concluded: “Lessons need to be learned to avoid perpetuating such an undesirable outcome for future generations of people with an intellectual disability” (6).

Ten years on, this study measures current levels of edentulism and complete denture wear in a nationally representative sample of older adults with an ID in Ireland. This study asks the following research question: What is the dentate status and complete denture use profile of older people with ID in Ireland in comparison with the general population?

Methods

Data were drawn from the first wave of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) (17), a study designed to explore aging among older adults with ID, their aging profile, physical and behavioral health, health services needs, psychological health, social networks, living situations, and community participation. These data were compared with data from The Irish Longitudinal Study on Ageing (TILDA). Data for both studies were collected in approximately the same time period and most data collection instruments were the same (17,18). The data regarding the general population have not previously been published, though further data on the TILDA study sample are available upon request through <http://www.ucd.ie/issda/data/tilda/>, and are not presented in detail here. Ethical approval was gained from the Faculty of Health Sciences Research Ethics Committee in Trinity College Dublin and all participating services.

Sample

The sample reported in this study was drawn from a representative sample of people with ID (IDS-TILDA), matched to a sample of people drawn from TILDA.

IDS-TILDA sample

The sample of older people with ID included in this study was taken from IDS-TILDA’s nationally representative sample of 753 people with ID over 40 years of age. The original sample was drawn from the population of people registered on the National Intellectual Disability Database (NIDD) (1), which includes persons at all levels of ID and the full range of residential circumstances. It is well established that the NIDD collates information on all people with ID in Ireland who are eligible for or receive services (1). A systematic approach guided sample selection: expecting a 50 percent response rate, staff at NIDD, consistent with inclusion/exclusion criteria, randomly selected 1,800 invitees based on personal identi-

cation numbers, provided by regional disability database administrators (RDDAs). RDDAs, acting as gatekeepers to maintain the anonymity and protect invitees from possible pressure to participate (as per ethical guidance), then mailed invitation packs explaining the project along with consent forms directed to the person with ID, their families, and support staff. The packets included easy-read versions of documents.

Where people could not self-consent, a family member/guardian was requested to review the materials and to sign a letter of agreement supporting participation in the study. Among the individuals who agreed to participate, 285 (38 percent) self-consented and a letter of agreement/consent to participate was received from a family member/guardian for 468 (62 percent) who were unable to self-consent.

Of the original 1,800 invitees, 753 participants fulfilled all inclusion criteria: a) age ≥ 40 years with ID; b) registered with NIDD; and c) written consent to participate and/or family/guardian written agreement, where required. Comparison with the published demographics of the 2008 NIDD cohort (1) (from which they were drawn) confirmed that the IDS-TILDA random sample was representative of the population (17).

Matched sample

For purposes of comparison with the general population, those within the IDS-TILDA sample aged 50 years and older were matched with a TILDA sample using propensity score matching. A dataset of 956 matched participants (478 in each study) was therefore generated. This paper uses this matched sample of 478 IDS-TILDA participants for noncomparative analysis and comparative analyses with 478 matched participants from TILDA.

Propensity score matching

This is a method of matching participants in one group in an observational study with participants in a second group (in this case, matching participants from IDS-TILDA and TILDA), based on observed covariates (19). The current study matched participants based on the covariates age, gender, and geographic location.

Given that the TILDA dataset is based on older adults in the general Irish population aged 50 years and over, IDS-TILDA participants aged under 50 years were excluded from analysis, resulting in 478 persons with ID in the current sample. Geographic location was included because the TILDA sample, drawn from the Irish Geodirectory, was stratified based on geographic location, whereas the IDS-TILDA sample was purposefully a random rather than a geographically stratified sample as it was known that geographic location clusters would reflect service provision

issues rather than characteristics of people with ID. Nevertheless, both samples were then compared with their sampling frames and in the case of TILDA, with census data to further confirm representativeness (17,18).

Data collection

The research team provided concurrent information seminars to raise awareness about the study and its purposes. Following rigorous training, data were collected by researchers who had experience of working with people with ID. We used a two-stage data collection technique. The first stage involved a postal preinterview questionnaire completed with or for each participant, which included the opportunity to draw data from existing records. This was then followed up with a face-to-face interview using a standard set of questions. Where necessary, a proxy who knew the participant well completed the interview jointly with or on behalf of the participant. IDS-TILDA required that proxy informants have known the person with ID for a minimum of 6 months and post-hoc analysis found that this was true for all proxies used.

Data relating to the general older population came from secondary analysis of TILDA study data, whose data collection methods are previously published (18).

Variables

Background variables included gender and age. Type of residence (independent/family or community group home or residential setting) and severity of ID (mild or moderate or severe/profound) are also presented for the IDS-TILDA-matched sample. Severity of ID (mild/moderate/severe or profound) was established in the preinterview and confirmed in the face-to-face interview. Respondents in this group received support in answering questions, where needed, by using proxy respondents. Based on whether the participant had support in responding or not, respondents were categorized as *respondent only*, *respondent and proxy*, or *proxy only*.

Self-reported dental status and denture use were recorded for both samples using five scoring options, as used in similar research (18,20). To enable comparison of dentate and edentulous respondents, the three options referring to dentate individuals (1. *I have all my own natural teeth – none missing*; 2. *I have my own teeth, no dentures – but some missing*; and 3. *I have dentures as well as some of my own teeth*) were coalesced into a single category considering all people reporting some teeth (referred to as *dentate*), and two variables considering all people reporting no teeth (1. *I have full dentures*; and 2. *I have no teeth or dentures*) were coalesced into another category (referred to as *edentulous*). The result was a dichotomous main outcome variable for analysis.

Analysis

Matching approach

Both datasets were first cleaned and variables recoded to ensure uniformity in the data. Extraneous variables (and for IDS-TILDA, cases) were deleted and the two datasets merged. Propensity score matching was then completed in SPSS 20 using the R plug-in and the “ps matching” custom dialog (19). Nearest neighborhood matching without replacement was used based on a greedy matching algorithm with a calliper of 0.15 of the standard deviation of the logit of the propensity score (to reduce potential imbalances among matches). Given that several covariates were represented, a single propensity score was generated, which can be viewed as the absolute difference between individuals in each group.

IDS-TILDA analyses

Data from the IDS-TILDA-matched sample were analyzed using SPSS 20. Summary statistics and counts with percentages are presented for demographic data. Pearson’s chi square was calculated to test for association between the dependent variable describing dentate/edentulous status and independent variables within the group with ID. Independent variables with a significant association ($P < 0.05$) were included in a binary logistic regression model.

Comparative analyses

Pearson’s chi square tested for any association between dentate/edentulous status and study allocation.

Results

Demographics and self-reported dentate status

There were more females than males in this study. Most participants were between 50 and 59 years of age. Demographic data for the matched IDS-TILDA and TILDA samples are summarized in Table 1.

Table 2 demonstrates that the majority of participants from the IDS-TILDA sample lived in either residential care or community group homes with only 14.6 percent living independently or with family. Half of participants (48.7 percent) had moderate ID. A minority of respondents ($n = 86$) replied to the interview without any support while almost half ($n = 219$) responded jointly with a person involved in their care (proxy). Responses were completed solely by a proxy family respondent or staff who worked regularly with the individual (that is, without any direct response from the participant) in about one-third ($n = 173$) of cases. Two-thirds of

Table 1 Demographics of IDS-TILDA- and TILDA-Matched Datasets (%)

	IDS-TILDA	TILDA
Total	478 (100)	478 (100)
Gender		
Male	203 (42.5)	190 (39.7)
Female	275 (57.5)	288 (60.3)
Age		
50-59	266 (55.6)	259 (54.2)
60-69	150 (31.6)	151 (31.6)
70+	61 (12.8)	68 (14.2)

IDS-TILDA, Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing; TILDA, The Irish Longitudinal Study on Ageing.

the sample ($n = 314$, 65.7 percent) had some teeth (Table 2). A complete lack of teeth showed initial association with being older, residential setting, and who responded on behalf of the participant ($P < 0.05$) but not with level of ID or gender ($P > 0.05$), using bivariate correlations.

Dentate status and denture use

Table 3 compares dentate status and denture use for IDS-TILDA- and TILDA-matched samples. Among adults over 50 years, 34.1 percent of those with ID were missing all teeth and

Table 3 Dentate Status and Denture Use of IDS-TILDA- and TILDA-Matched Datasets (%)

Which best describes the teeth you have?	IDS-TILDA		TILDA	
Total respondents	477	(99.8)	477	(99.8)
I have all my own natural teeth – none missing	45	(9.4)	51	(10.7)
I have my own teeth, no dentures – but some missing	217	(45.5)	192	(40.3)
I have dentures as well as some of my own teeth	52	(10.9)	163	(34.2)
Total dentate	314	(65.8)	406	(85.1)
I have full dentures	63	(13.2)	69	(14.5)
I have no teeth or dentures	100	(20.9)	2	(0.4)
Total edentulous	163	(34.1)	71	(14.9)

IDS-TILDA, Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing; TILDA, The Irish Longitudinal Study on Ageing.

there were 14.9 percent among the matched sample without ID. This association was highly statistically significant ($P < 0.0001$). This compares with 17.7 percent ($n = 1,502$) of the overall TILDA sample of older people in Ireland. Where participants had only some teeth missing, only 19.3 percent of the IDS-TILDA- and 45.9 percent of the TILDA-matched samples had partial dentures. Contrastingly, 61.3 percent of

Table 2 Association of IDS-TILDA Sample Variables with Dentate Status (%)

	Total	Dentate	Edentulous	P value¶
Total*	477 (99.8)	314(65.7)	163 (34.3)	
Gender				
Male	203 (42.5)	137 (67.8)	65 (32.2)	$P > 0.05$
Female	275 (57.5)	177 (64.4)	98 (35.6)	
Age				
50-59	266 (55.6)	201 (75.6)	65 (24.4)	$P < 0.001$
60-69	151 (31.6)	92 (61.3)	58 (38.7)	
70+	61 (12.8)	21 (34.4)	40 (65.6)	
Type of residence				
Independent/family	70 (14.7)	50 (71.4)	20 (28.6)	$P < 0.05$
Community†	169 (35.2)	119 (71.3)	48 (28.7)	
Residential‡	239 (50.1)	143 (60.1)	95 (39.9)	
Level of intellectual disability				
Mild	99 (22.8)	68 (68.7)	31 (31.3)	$P > 0.05$
Moderate	212 (48.7)	138 (65.1)	74 (34.9)	
Severe/profound	124 (28.5)	84 (67.7)	40 (32.3)	
Response type				
Respondent only	86 (18.0)	62 (72.1)	24 (27.9)	$P > 0.05$
Respondent and proxy	219 (45.7)	147 (67.4)	71 (32.6)	
Proxy only	173 (36.3)	105 (60.7)	68 (39.3)	

* One observation did not have a valid response for the dependent variable and was therefore excluded from this analysis.

† Community = community group home.

‡ Residential = residential care home.

¶ $P =$ Pearson's chi square test.

IDS-TILDA, Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing.

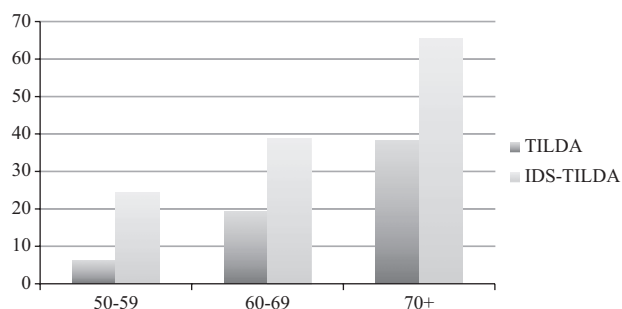


Figure 1 Percent of older people with ID (matched IDS-TILDA sample) and of the generic population (matched TILDA sample) who are edentulous in Ireland, banded by age. IDS-TILDA, Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing; TILDA, The Irish Longitudinal Study on Ageing.

edentulous older people with ID were without dentures compared with 5.2 percent of edentulous adults in the general population.

Figure 1 allows comparison of level of edentulism by banded age. The presence of edentulism increased stepwise with age. This was higher for the sample with ID, going from 24.4 percent ($n = 65$) of 50-59-year-olds through 38.7 percent ($n = 58$) of those 60-69 years old to 65.6 percent ($n = 40$) of those 70+. This compares with 6.2 percent ($n = 16$) of 50-59-year-olds through 19.3 percent ($n = 29$) of those 60-69 years and 38.2 percent ($n = 26$) of those 70+ in the TILDA sample.

When associations found through bivariate analysis were entered as predictor variables into a binomial logistic regression with dentate status as the outcome variable, only increasing age appeared to be predictive of having no teeth (Table 4).

Discussion

We found that a complete lack of natural teeth is common in older people with ID in Ireland. Over a third of this represen-

tative sample of people with ID over age 50 was without any teeth. Comparison with TILDA data suggests that being edentulous (14.9 percent of the matched sample and 17.7 percent of the TILDA sample as a whole) was more common for people over 50 years of age with ID than among those without ID in Ireland. As a further comparison, 19.4 percent of the general public over 60 years were reported to be edentulous in the United States (13).

The fact that edentulism is high among this group is disappointing, but not surprising. The current study mirrors the trend noted by Crowley and colleagues (6). In their study of adults with ID in residential services only, 14 percent of 35-54-year-olds (compared with 19.9 percent of those 50-54 years old in the IDS-TILDA sample) and 61 percent of those 55+ years old (compared with 38.6 percent of those 55+ years old in this study) had total loss of teeth. Differences in approach to selecting their samples notwithstanding, there was an important and unique opportunity for comparison given this is the only benchmark available in Ireland. With those limitations noted, the comparison does suggest that there are lower levels of edentulism among adults with ID in Ireland in 2013 than in the sample assessed in 2003 and confirms the need to further measure incidence and rates of edentulism on a longitudinal basis. Concerningly, the findings here confirm that all people with ID and not just those in residential settings are more likely to lose all their teeth than those without ID and that tooth loss starts earlier in life for the population as a whole.

Edentulism increases with age and is associated with features including race, literacy, sex, smoking, and social class (21,22). This study showed some initial association between lack of teeth and age, residential setting, and who responded on behalf of the participant. However, among the variables entered into the logistic regression model, only increasing age was found to be a predictor of edentulism. Age has been previously associated with tooth loss in a similar population (4).

The current study highlights the need to understand the impact of loss of teeth on older people with disabilities, regarding both their health and quality of life. This is important, as research has associated edentulism with many notable consequences such as reduced masticatory function, poor dietary selection, and psychosocial sequelae, as well as serious health conditions such as cardiovascular disease, and even death (12,23).

The second major finding of this study is that almost two-thirds of edentulous participants with ID did not have dentures. This compares with 5.2 percent of edentulous participants in the paired TILDA data and 8.8 percent of edentulous participants over 55 years in the SLAN (Survey of Lifestyle, Attitudes and Nutrition in Ireland) study (20). The contrast is stark and perhaps reflects a failure of dental services to provide a functional replacement of teeth and/or poor uptake of denture wear (6,14,24). The complete loss of teeth

Table 4 Predictors of Edentulous Status among People with ID

	B	OR	CI	P value
Age*				
50-59		1.00		
60-69	0.627	1.872	1.178-2.973	0.008
70+	1.951	7.037	3.639-13.606	0.000
Residential setting*				
Independent/home		1.00		
Community	-0.147	0.863	0.419-1.777	0.690
Residential	0.112	1.118	0.542-2.308	0.762

* Adjusted for gender and level of ID. This model shows that only age had a significant independent positive effect on edentulous status. This model accounted for only 9.2% of observed variance in dentate/edentulous status, using Nagelkerke R square. Sensitivity of the model = 90.6%, specificity of model = 30.7%. B, regression coefficient; CI, confidence interval; ID, intellectual disability; OR, odds ratio.

and a lack of functional replacement are a poor outcome for older people with ID in the current study. These findings strengthen the case for targeted, evidence-based programs for people with ID throughout life so as to avoid succedent complete tooth loss and lack of functional replacement. These programs should include a range of appropriate preventive, conservative, and rehabilitative primary and secondary services.

This study does not explain the reasons why dentures were not used by edentulous individuals. Findings here are of lower use of dentures among edentulous people with ID than people without ID (a *comparative* need). The assumption that a lack of teeth constitutes *need* for dentures is fraught, however, as there is a distinction between what a professional or expert might consider need (*normative need*) and what a patient/service user may consider need (*expressed need*) (25). Narby *et al.* stated that it is the interaction between clinician and individual that establishes need through a “communicative dialogue with mutual respect” (26). As such, we are unable to assume that a lack of dentures among edentulous individuals with ID means a failure to meet their need. Previous research found high levels of tolerance for prosthodontic treatment need among institutionalized elderly (27). Crowley’s research suggests that as many as two-thirds of edentulous people with ID not wearing dentures are unsuitable for denture wear (6) while others suggest that need may be reduced by at least a half, once propensity for treatment and other factors are considered in this group (28,29).

A further complication is that even if “suitable” and willing, edentulous people must undergo the extensive and often demanding denture fabrication process. Also once processed, it may be difficult to become accustomed to denture wear, even for people without cognitive issues, because of pain, discomfort, difficulty eating, and looseness (30,31). However, Crowley’s research found that few Irish adults with ID had dentures that they chose not to wear (6). Such issues then make it difficult to draw firm conclusion about the lack of dentures among edentulous people with ID.

Limitations

There are several limitations to note. The first relates to sampling and participation. Given that only 753 out of 1,800 original invitees (43 percent) were ultimately interviewed, there is a possibility that those who did not participate were somehow systematically different from those who did. There were a range of reasons for nonparticipation not under control of the researchers given the need for appropriate oversight by others to ensure adequate protections for an otherwise vulnerable population. Nevertheless, examination of key demographic variables found no significant dif-

ferences between the profile of the group interviewed and NIDD, the sampling frame from which it was drawn (17).

Use of propensity scoring to control for the effects of confounding variables is well established (32). Here, propensity scoring was used to address demographic variables such as age, gender, and geographic dispersal (which has implications for dental service access) that might otherwise explain differences in edentulism. Such an approach therefore increased the likelihood that any differences noted may instead be attributable to characteristics of having or not having an ID and/or to differential access to and use of dental services because of the presence or nonpresence of ID. The process benefitted from beginning with samples (TILDA and IDS-TILDA) that were previously demonstrated to be representative of the populations from which they were drawn (17,18), albeit that the initial sampling approaches used (stratified versus random sampling) were different. The IDS-TILDA sample (as the group to be matched to) remained representative of those in IDS-TILDA and NIDD over 50 years, but the TILDA sample, because they were matched to IDS-TILDA, became less representative (post-hoc analysis found some difference in geographic dispersal compared both to the larger TILDA sample and to Irish census data). The matched TILDA participants were also younger than the main TILDA dataset. Such differences do have implications for external validity.

Perhaps the major limitation of this study is the self-reported nature of the measure of dentate status. Using self-reported rather than clinical measures facilitated the inclusion of oral health-related measures without the need for training in specific indices among non-dental health data collectors who were collecting a large dataset. It was felt that ethical approval was also facilitated without the inclusion of clinical measures for the first wave of this study. Although the validity of the current results, based on self-reported measures, may be at risk of bias, they reflect those used in large-scale epidemiological research previously and currently undertaken in Ireland (18,20).

Partial or total reliance on proxy respondents is a common data collection approach among older people with cognitive issues, recognized to reduce missing responses but potentially increase misattribution bias (33). The proportion of self-only respondents who were edentulous was lower than for other groups, and while this showed initial borderline association ($P=0.05$), this was not predictive of edentulism in our regression model, which suggests these variables were not strongly correlated. We can assume from this that proxies did not misattribute either dentate or edentulous status consistently.

Future research

There is a need to further investigate the concept of need and demand for restoration of functional dentition, the tolerance

of such procedures, and the likelihood of desired outcomes among older people with ID. Additional studies where dentate status is clinically confirmed will help further understanding of the reliability of self and proxy responses in similar research. The IDS-TILDA protocol has been modified to consider these issues in future data collection waves.

Conclusions

Older people with ID across Ireland have higher levels of reported total tooth loss than the general population. A lack of teeth was predicted by increasing age and not level of disability or residential setting. Most concerning, when older people with ID lost all their teeth, there was little evidence that they were replaced with dentures. This suggests a need to study why dentures are not used by older adults with ID. There may be a need to offer targeted treatment services to address this identified need. The evidence suggests that prevention of tooth loss in people with ID is important throughout life so as to avoid this poor outcome when they become older. Therefore, service developments aiming to prevent edentulism among people with ID are also needed, before it is too late.

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