Check for updates

Received: 1 November 2022 | Revised: 30 October 2023 | Accepted: 23 January 2024

DOI: 10.1111/jar.13209

ORIGINAL ARTICLE

JARID Journal of Applied Research in Intellectual Disabilities bild WILEY

Prevalence of swallowing difficulties and associated factors in older people with intellectual disabilities

Kim J. V. Sanders[1,2] | Roy G. Elbers[1] | Luc P. Bastiaanse[1] | Michael A. Echteld[3,4] | Heleen M. Evenhuis[1] | Dederieke A. M. Festen[1,2]

[1]Department of General Practice, Intellectual Disability Medicine, Erasmus MC, University Medical Center Rotterdam, Rotterdam, The Netherlands

[2]Ipse de Bruggen, Zoetermeer, The Netherlands

[3]Prisma Foundation, Waalwijk, The Netherlands

[4]End of Life Care Research Group, Avans University of Applied Sciences, Tilburg, The Netherlands

Correspondence
Kim J. V. Sanders, Department of General Practice, Intellectual Disability Medicine, Erasmus MC, University Medical Center Rotterdam, P.O. Box 2040, 3000 CA Rotterdam, The Netherlands.
Email: k.sanders@erasmusmc.nl

Funding information
ZonMw, Grant/Award Number: 57000003

Abstract

Background: We investigated the prevalence of swallowing difficulties and associated factors in people with intellectual disability.

Methods: We included people aged 50+ receiving care for people with intellectual disabilities. The Dysphagia Disorder Survey (DDS) was used to assess swallowing difficulties. We determined the agreement between the DDS and swallowing difficulties in medical records. We used logistic regression analyses to explore associated factors.

Results: One thousand and fifty people were included. The prevalence of swallowing difficulties was 43.8%. Swallowing difficulties were not reported in the medical records of 83.3% of these cases. Frailty (odds ratio (OR) = 4.22, 95% CI = 2.05–8.71), mobility impairment (OR = 2.50, 95% CI = 1.01–6.19), and mealtime dependency (OR = 3.05, 95% CI = 1.10–8.47) were independently associated with swallowing difficulties.

Conclusion: Swallowing difficulties are prevalent in older people with intellectual disability but may be under-recognised. Frailty may be a good indicator for population-based screening for swallowing difficulties.

KEYWORDS
association, dysphagia disorder survey, intellectual disability, older people, prevalence, swallowing difficulties

1 | INTRODUCTION

Swallowing difficulties can cause severe health problems, such as recurrent lower respiratory tract infections, chronic lung diseases (Calis et al., 2008), choking, poor nutritional status, dehydration, and in some cases death (Chadwick & Jolliffe, 2009). Swallowing difficulties can lead to dietary restrictions and the need of support when eating or drinking, this may negatively impact quality of life (Robertson et al., 2017). Early recognition of swallowing difficulties is important and may reduce the risk of adverse health outcomes and improve the management of swallowing difficulties. Unfortunately, signs of swallowing difficulties are often labelled as part of normal ageing (Nawaz & Tulunay-Ugur, 2018), and swallowing difficulties remain undetected until people get admitted to the hospital with swallowing related complications (Madhavan et al., 2016). The recognition of swallowing difficulties in people with an intellectual disability may be even more complicated, as people with an intellectual disability may not identify symptoms promptly or may have difficulties articulating what the difficulty is (Heslop et al., 2013).

This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.
© 2024 The Authors. *Journal of Applied Research in Intellectual Disabilities* published by John Wiley & Sons Ltd.

Accurate estimates for the prevalence of swallowing difficulties are important, allowing services and policy makers to be better informed when planning health and social care resources (Robertson et al., 2017). A systematic review (Robertson et al., 2017) found that the prevalence of swallowing difficulties in people with intellectual disability varied considerably across studies. Two of the studies included in that systematic review, investigated a representative sample of adults with an intellectual disability and reported prevalence estimates from 8.1% to 11.5%. Other studies found percentages up to 69.7% in institutionalised children and adults (Robertson et al., 2017). The review authors suggest that this wide range may be explained by the different characteristics of the investigated samples, but also by the used definition of swallowing difficulties and the method of assessment (Robertson et al., 2017). For example, in one of the included studies a speech and language therapist assessed the oral, pharyngeal and oesophageal stage of the swallowing process (Chadwick & Jolliffe, 2009), whereas others reviewed medical files and used a reference to the ICD-9 code (787.2) to estimate the prevalence of swallowing difficulties (Henderson et al., 2009).

Although no studies investigated factors associated with swallowing difficulties in older people with intellectual disability, it has been suggested that swallowing difficulties are more likely to occur in people with more severe levels of intellectual disability (Robertson et al., 2017; Robertson et al., 2018), people who use neuroleptic medication (Robertson et al., 2018), and people who receive mealtime support (Robertson et al., 2018). Other studies reported a high prevalence of swallowing difficulties specifically in people with Down syndrome (Blake et al., 2021) and in people with cerebral palsy (Henderson et al., 2009). Factors known for their association with swallowing difficulties in the general population, such as higher age (Baijens et al., 2016; Madhavan et al., 2016), more dependent functional status (Baijens et al., 2016; Eglseer et al., 2018), sarcopenia (Cha et al., 2019), frailty (Bahat et al., 2019; Baijens et al., 2016), stroke (Takizawa et al., 2016), and dementia (Michel et al., 2018), are often present in people with intellectual disability.

In people with intellectual disability the DDS (Sheppard et al., 2014) is a commonly used instrument for the classification of swallowing difficulties. In 2014 we used the DDS to investigate the prevalence of swallowing difficulties in older people with an intellectual disability, and estimated that 77.4% of the participants had swallowing difficulties (Bastiaanse, 2014). The results of that study have been published in a doctoral dissertation (Bastiaanse, 2014). However, since then, different well-accepted cut-off values have been developed for the DDS (Sheppard et al., 2014). Therefore, in the present paper, we aimed to re-estimate the prevalence of swallowing difficulties, using these new cut-off values, in the same underlying cohort as in 2014. Also, we investigated the association of age, severity of intellectual disability, Down syndrome, mobility, spasticity, centrally acting medication (antipsychotics, anticonvulsant drugs, and benzodiazepines with a long half-life time), mealtime dependency, frailty, sarcopenia, stroke, and dementia with swallowing difficulties. We also estimated the agreement between the classification of swallowing difficulties by the DDS and reporting of the diagnosis of swallowing difficulties in medical files.

2 | METHODS

2.1 | Study design and participants

This retrospective cohort study was part of the "Healthy Ageing in Intellectual Disability (HA-ID) study" (Hilgenkamp et al., 2011). We obtained ethical approval from the Medical Ethics Review Committee of the Erasmus University Medical Center, Rotterdam, the Netherlands (METC 2008-234). We aimed to include all people aged 50 years and over, who received care of one of the following care providers specialised in care for people with an intellectual disability: Abrona (Huis ter Heide), Amarant (Tilburg), and Ipse de Bruggen (Zoetermeer). No exclusion criteria were applied. The care providers are located in rural and urban areas and provide care to people with varying levels of intellectual disability, mobility, and living arrangements. People received care in a centralised setting, community-based setting, or were living independently. We classified the level of intellectual disability as mild (IQ > 55), moderate (IQ 35–55), and severe (IQ <35).

The study population was nearly representative for the total Dutch client population aged 50 years and over, with a slight overrepresentation of women, and a slight underrepresentation of individuals living independently, and individuals aged 80 years and over (Hilgenkamp et al., 2011). More detailed information about recruitment and design of the HA-ID study, and details about the representativeness of the cohort have been published elsewhere (Hilgenkamp et al., 2011). We included people with complete DDS forms in the analyses presented in this study.

2.2 | Assessment and classification of swallowing difficulties by the DDS

Trained speech and language therapists, dieticians, and an occupational therapist, used the DDS (Sheppard et al., 2014) to observe swallowing function. The assessor observed three food consistencies: solid, non-chewable, and liquid during a typical mealtime situation in the participant's natural environment or during a sample meal that included food types that are in the participant's typical diet. The DDS is a standardised mealtime observation developed for people with intellectual disability and has been validated in children and adults with an intellectual disability (Sheppard et al., 2014). The DDS has shown a high rate of agreement between speech and language therapists (97%) and good internal consistency (Cronbach's Alpha 0.93) (Sheppard et al., 2014). Also, the DDS scores correlate strongly with the clinical judgement of speech and language therapists (Sheppard et al., 2014).

The DDS consists of 15 items and is divided in two parts. Part One (items 1–7) consists of seven items that evaluate factors related to feeding and swallowing: body mass index, diet, independence, adaptive utensils used, positioning, postural control and feeding

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

techniques Scores for each of these items are weighted differently, with higher scores indicating higher severity of swallowing difficulties. Part Two (item 8–15) consists of eight items that assess feeding and swallowing competency: orienting, reception, containment, oral transport, chewing, oral-pharyngeal swallow, post swallow and gastro-oesophageal function. For these items, a binary scoring system is used (0 for competent, and 1 for deficient) (Sheppard et al., 2014). As suggested by the developers of the instrument, we used the validated version that excludes item 1 (body mass index) and item 15 (gastro-oesophageal function) because these items lowered reliability and validity of the DDS (Sheppard et al., 2014). The total score of this version is 34 points.

We classified participants with scores higher than 3 as having swallowing difficulties (Sheppard et al., 2014). The people who were classified as having swallowing difficulties were further categorised into mild, moderate, severe, or profound swallowing difficulties using the Dysphagia Management Staging Scale (DMSS). The DMSS has been developed for rating the severity of swallowing difficulties using the DDS raw scores (Sheppard et al., 2014).

2.3 | Reporting of swallowing difficulties in medical records

We asked general practitioners and physicians specialised in the care for people with intellectual disability to review their medical records of the participants for a diagnosis of swallowing difficulties (yes/no). The general practitioners and physicians were blinded for the outcome of the DDS assessment.

2.4 | Associated factors

We collected information on age and level of intellectual disability (borderline or mild, moderate, and severe) from the records of the care providers. General practitioners and specialised physicians recorded the presence of Down syndrome (yes/no), lifetime occurrence of stroke (yes/no), and spasticity (yes/no). The current use of antipsychotics (yes/no), anticonvulsant drugs (yes/no), and benzodiazepines with a long half-life time (>12 h) (yes/no) were recorded. The diagnosis of dementia (yes/no) was obtained by the participants' physician and behavioural scientist and was only included in the analysis in case of consensus between these professionals.

Professional caregivers categorised mobility as walking independently, walking with aids, or mobility in a wheelchair. We used the Barthel Index (Mahoney & Barthel, 1965) to assess if participants were independent, needed some help, or were fully dependent on a caregiver when having a meal.

We used the frailty index (FI) to calculate a frailty score between 0 and 1 (Schoufour et al., 2013). The FI consists of 51 deficits, including social, physical, and psychological aspects of health. Participants were categorised as non-frail (<0.2), pre-frail (0.2–0.35), or frail (>0.35) (Schoufour et al., 2017). We defined sarcopenia (yes/no) as having low muscle mass (calf circumference less than 31 cm) combined with low muscle strength (grip strength lower than 30 kg for men, and 20 kg for women) or low muscle performance (comfortable walking speed lower than 0.8 m/s) (Bastiaanse et al., 2012).

2.5 | Statistical analysis

Statistical analyses were performed using the Statistical Package for Social Sciences for Windows version 25 (SPSS Inc., Chicago, Il, USA). We calculated the prevalence with a 95% confidence interval (95% CI) for swallowing difficulties as classified by the DDS (yes/no), and for mild, moderate, severe, and profound swallowing difficulties. We used Cohen's Kappa (ƙ) to determine the agreement between the classification of swallowing difficulties obtained with the DDS and the diagnosis of swallowing difficulties retrieved from the medical record. We categorised the strength of agreement as poor (<0.20), fair (0.21–0.40), moderate (0.41–0.60), good (0.61–0.80) or very good (0.81–1.00) (Altman, 1999).

2.5.1 | Univariable and multivariable logistic regression

We performed univariable logistic regression analyses with swallowing difficulties (yes/no) as dependent variable, and age, level of intellectual disability, Down syndrome, spasticity, stroke, use of anticonvulsant drugs, use of benzodiazepines, use of antipsychotic drugs, dementia, mobility, mealtime dependency, frailty, and sarcopenia as independent variables. Second, we performed a multivariable logistic regression analysis with the independent variables that were associated (p-value ≤.10) (Field, 2009) with swallowing difficulties in the univariable model. We entered the independent variables simultaneously in the multivariable model.

2.5.2 | Multicollinearity analyses

To investigate multicollinearity, we constructed a Spearman's rank correlation matrix including all independent variables that were associated with swallowing difficulties in the univariable model. In addition, we checked the variance inflation factor of the multivariable model. We considered a Spearman's rank correlation above 0.80 (Field, 2009), or a variance inflation factor value above 5 (Kim, 2019) as possible multicollinearity.

2.5.3 | Post-hoc multivariable analysis excluding frailty

Because the frailty index includes items related to mobility, history of stroke, sarcopenia, and medication use, we investigated the impact of the frailty score on the association between the other independent

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 1 Characteristics of participants ($n = 931$).

	n (%)
Gender	
Male	473 (50.8)
Female	458 (49.2)
Age, mean (range; SD)	61.6 years (50–93; 8.1)
Level of intellectual disability	
Mild (IQ >55)	229 (24.6)
Moderate (IQ 35–55)	447 (48.0)
Severe (IQ <35)	235 (25.2)
Unknown	20 (2.1)
Residential status	
Centralised setting	495 (53.2)
Community based setting	388 (41.7)
Living independently	48 (5.2)
Swallowing difficulties	
No (score ≤3)	523 (56.2)
Yes (score >3)	408 (43.8)
Mild	271 (29.1)
Moderate	109 (11.7)
Severe	26 (2.8)
Profound	2 (0.2)
Down syndrome	
No	690 (74.1)
Yes	134 (14.4)
Unknown	107 (11.5)
Stroke	
No	762 (81.8)
Yes	45 (4.8)
Unknown	124 (13.3)
Mobility	
Independent	663 (71.2)
Walking aid	135 (14.5)
Wheelchair	96 (10.3)
Unknown	37 (4.0)
Spasticity	
No	710 (76.3)
Yes	92 (9.9)
Unknown	129 (13.9)
Mealtime dependency	
Independent	76 (8.2)
Partial dependent	281 (30.2)
Dependent	537 (57.7)
Unknown	37 (4.0)
Dementia	
No	838 (90.0)
Yes	75 (8.1)
Unknown	18 (1.9)
Frailty	
Non-frail (<0.2)	280 (30.1)
Pre-frail (0.2–0.35)	381 (40.9)
Frail (>0.35)	230 (24.7)
Unknown	40 (4.3)
Sarcopenia	
No	709 (76.2)
Yes	121 (13.0)
Unknown	101 (10.8)
Anticonvulsant drugs	
No	651 (69.9)
Yes	173 (18.6)
Unknown	107 (11.5)
Antipsychotic drugs	
No	524 (56.3)
Yes	300 (32.2)
Unknown	107 (11.5)
Benzodiazepines with a long half-life time (>12 h)	
No	776 (83.4)
Yes	48 (5.2)
Unknown	107 (11.5)

Abbreviations: IQ, intelligence quotient; *n*, number of participants; SD, standard deviation.

variables and swallowing difficulties. Post-hoc, we excluded frailty from the multivariable logistic regression analysis as described in Section 2.5.1.

3 | RESULTS

In total, 2150 people with intellectual disability aged 50 years and over were invited to participate in the XXX-study. The final number of people with informed consent was 1050. A detailed description of the inclusion process is published elsewhere (Hilgenkamp et al., 2011).

We obtained a complete DDS form for 931 out of the 1050 participants (88.7%) of the HA-ID study. Reasons for missing forms were informed consent limited to medical record information ($n = 12$), illness ($n = 7$), refusal for mealtime observation ($n = 57$), an incomplete observation form ($n = 6$), deceased ($n = 1$), and other ($n = 24$) or unknown reasons ($n = 12$). Table 1 summarises the characteristics of the participants with a complete DDS form. The mean age of the participants was 61.6 years (range 50–93; standard deviation (SD) = 8.1).

3.1 | Prevalence of swallowing difficulties

Swallowing difficulties were present in 408 out of 931 participants (43.8%, 95% CI = 40.6%–47.1%). Of the 931 participants,

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

271 participants (29.1%, 95% CI = 26.2%–31%) had mild swallowing difficulties, 109 participants (11.7%, 95% CI = 9.7%–13.9%) had moderate swallowing difficulties, 26 participants (2.8%, 95% CI = 1.8%–4.1%) had severe swallowing difficulties, and 2 participants (0.2%, 95% CI = 0.0%–0.8%) had profound swallowing difficulties.

3.2 | Agreement between swallowing difficulties classified by the DDS and registration in medical records

Medical records were available for 824 participants. In 83.3% of the participants who were classified as having swallowing difficulties according to the DDS, swallowing problems were not registered in their medical record. There was poor agreement between the classification of swallowing difficulties and the reported diagnosis in medical records ($k = 0.17$, 95% CI = 0.12–0.21). More detailed results for participants who were classified as having mild, moderate, severe, or profound swallowing difficulties are presented in Table 2.

3.3 | Factors associated with swallowing difficulties

Table 3 presents the results of the univariable logistic regression analyses. All independent variables, except age, had missing values. The missing values were equally distributed over the participants who were classified as having swallowing difficulties or not having swallowing difficulties. Because of these missing values, univariable analyses were performed with different numbers. Age, level of intellectual disability, Down syndrome, history of stroke, mobility, spasticity, mealtime dependency, dementia, use of anticonvulsant drugs, use of antipsychotic drugs, use of benzodiazepines, frailty, and sarcopenia were all associated with swallowing difficulties (p-value ≤0.10) and entered in the multivariable logistic regression model.

The multivariable logistic regression model (Table 4) shows that frail people had increased odds (odds ratio (OR) = 4.22, 95% CI = 2.05–8.71) of exhibiting swallowing difficulties compared to non-frail people. People in a wheelchair had increased odds (OR = 2.50, 95% CI = 1.01–6.19) of swallowing difficulties compared to people walking independently. Mealtime dependency was associated with increased odds of exhibiting swallowing difficulties (OR = 3.05, 95% CI = 1.10–8.47) compared to people who independently have a meal. The multivariable model explained 34% of the variance (Nagelkerke $R^2 = 0.34$). All values in the Spearman's rank correlation matrix were below 0.80 and variance inflation factor values were below the threshold for multicollinearity.

3.3.1 | Post-hoc multivariable analysis excluding frailty

Table 5 presents the results of the post-hoc analysis excluding frailty from multivariable logistic regression model. Sarcopenia (OR = 2.04, 95% CI = 1.15–3.59), age (OR = 1.03, 95% CI = 1.01–1.06), severe to profound intellectual disability (OR = 1.83, 95% CI = 1.05–3.21), mobility impairment (OR = 3.47, 95% CI = 1.43–8.40), spasticity (OR = 2.13, 95% CI = 1.07–4.24), antipsychotics (OR = 1.52, 95% CI = 1.02–2.27), and mealtime dependency (OR = 3.81, 95% CI = 1.43–10.14), were independently associated with swallowing difficulties. The multivariable model explained 32% of the variance (Nagelkerke $R^2 = 0.34$). All values in the Spearman correlation matrix were below 0.80 and variance inflation factor values were below the threshold for multicollinearity.

4 | DISCUSSION

In this study we used a validated mealtime observation and well-accepted cut-off values to investigate the prevalence of swallowing difficulties in a large population of ageing people with intellectual

TABLE 2 Recognition of swallowing difficulties ($n = 824$).

	Classified according to the DDS (*n*)	Swallowing difficulties reported in medical record (*n*)		Percentage misclassification in medical record
		Yes	No	
No swallowing difficulties (score ≤3)	458	7	451	1.5%
Swallowing difficulties (score >3)	366	61	305	83.3%
Severity of swallowing difficulties				
Mild	242	18	224	92.6%
Moderate	98	28	70	71.4%
Severe	24	13	11	45.8%
Profound	2	2	0	0.0%

Abbreviations: DDS, swallowing difficulties disorder survey; *n*, number of participants.

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 3 Univariable associations with swallowing difficulties.

Independent variable	Odds ratio (95% CI)	*p*-Value
Age	1.02 (1.00–1.04)	0.02
Level of intellectual disability		
Borderline/mild[a]		<.01
Moderate	1.71 (1.21–2.41)	<.01
Severe/profound	5.56 (3.69–8.19)	<.01
Down syndrome	1.46 (1.01–2.11)	.05
Stroke	1.90 (1.03–3.51)	.04
Mobility		
Walks independently[a]		<.01
Walks with support	1.69 (1.16–2.45)	.01
Wheelchair	9.74 (5.41–17.54)	<.01
Spasticity	6.70 (3.87–11.58)	<.01
Mealtime dependency		
Independent[a]		<.01
Partial dependent	4.13 (3.04–5.61)	<.01
Dependent	20.95 (9.84–44.61)	<.01
Dementia	2.58 (1.57–4.23)	<.01
Frailty		
Non-frail (<0.2)[a]		<.01
Pre-frail (0.2–0.35)	3.46 (2.41–4.97)	<.01
Frail (>0.35)	14.29 (9.31–21.94)	<.01
Sarcopenia	4.28 (2.80–6.56)	<.01
Anticonvulsant drugs	2.78 (1.96–3.94)	<.01
Antipsychotic drugs	1.49 (1.12–1.98)	<.01
Benzodiazepines with a long half-life time	3.62 (1.89–6.95)	<.01

Abbreviation: CI, confidence interval.
[a]Reference category.

disability. Over 40% of all participants were classified as having swallowing difficulties. For most of these participants, we found no reference to swallowing problems in their medical record. We found that frailty, impaired mobility, and mealtime dependency, were independently and positively associated with swallowing difficulties.

The prevalence of swallowing difficulties found in our study falls within the range of previously published estimates in people with intellectual disability (Robertson et al., 2017). However, given the differences in clinical characteristics and the methods used to assess swallowing difficulties in people with intellectual disability (Robertson et al., 2017), it is difficult to directly compare results between studies. Compared to the prevalence we reported in 2014 (77.4%), we think the current prevalence estimate is more valid because it is based on the cut-off values of the complete DDS. The diagnosis of swallowing difficulties used in 2014 was only based on Part 2 of the DDS. Part 1, related factors, had not been included in the diagnosis. Comparing our findings to the general older population is challenging as well because our study sample consisted of people who can be compared to community dwelling elderly, but also included people who can best be compared to nursing home residents. In a systematic review, the prevalence of swallowing difficulties in community dwelling elderly ranged from 5% to 34% (Madhavan et al., 2016). The studies included in that systematic review used different tools to assess swallowing difficulties, varying from questions regarding swallowing difficulty, to instrumental assessment via fiberoptic endoscopic evaluation of swallowing (FEES). One study performed in nursing home residents, reported a prevalence of 12.8% based on a clinical dysphagia evaluation by a speech and language therapist (Jukic Peladic et al., 2019). Another study that used the Eating Assessment Tool (EAT-10) estimated the prevalence of swallowing difficulties at 31.1% in nursing home residents (Chen et al., 2020).

Almost 30% of the participants in our study were classified as having mild swallowing difficulties. Only 7.4% of these participants had a diagnosis of swallowing difficulties reported in their medical record. Even of the participants with more severe forms, only 54.2% had a diagnosis of swallowing difficulties in their medical record. These findings support our clinical observation that symptoms of swallowing difficulties are difficult to recognise for caregivers, and swallowing difficulties and associated health risks may be unnoticed. This stresses the need for a structural screening of swallowing difficulties in people with intellectual disability.

As far as we know, this is the first time that frailty, measured with a validated instrument suitable for this population, is found as a factor associated with swallowing difficulties in older people with intellectual disability. We found that impaired mobility and mealtime dependency were independently associated with swallowing difficulties. These results are in line with two literature reviews that summarised factors associated with swallowing difficulties in people with intellectual disability. The review authors suggested that swallowing difficulties were associated with motor impairment (Robertson et al., 2017), and were more likely in people who received mealtime support (Robertson et al., 2018).

Our main analysis did not show associations between swallowing difficulties and age, the use of centrally acting medication, spasticity, and the level of intellectual disability. These findings may be surprising because the physiology of swallowing changes with advanced age, and older people are at higher risk of swallowing difficulties (Sura et al., 2012). In people with intellectual disability, Sheppard (2002) described a relationship between deterioration in swallowing function and advanced age. We found an univariable association between age and swallowing difficulties, but this association disappeared in the multivariable model where we adjusted for other variables. Furthermore, previous studies found associations between swallowing difficulties and centrally acting drugs such as benzodiazepines (Baijens et al., 2016), and severe intellectual disability (Robertson et al., 2017). We decided to include frailty as a variable in our main analysis because associations between frailty and swallowing difficulties have been described in community dwelling elderly (Bahat et al., 2019), frailty is strongly associated with adverse health outcomes, and age-related health deficiencies seem to start earlier in life in people with intellectual disability (Coppus, 2013; Schoufour et al., 2016).

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 4 Multivariable, independent, associations with swallowing difficulties.

	B	Wald	Odds ratio (95% CI)	*p*-Value
Age	0.01	0.66	1.01 (0.99–1.04)	.42
Level of intellectual disability				
Borderline/mild[a]		2.62		.27
Moderate	−0.02	0.01	0.98 (0.62–1.56)	.94
Severe/profound	0.36	1.51	1.44 (0.81–2.57)	.22
Down syndrome	0.29	1.03	1.34 (0.76–2.35)	.31
Stroke	0.07	0.03	1.07 (0.46–2.49)	.87
Mobility				
Walks independently[a]		6.18		.05
Walks with support	−0.27	0.92	0.77 (0.45–1.32)	.34
Wheelchair	0.92	3.90	2.50 (1.01–6.19)	.05
Spasticity	0.65	3.31	1.91 (0.95–3.82)	.07
Mealtime dependency				
Independent[a]		12.07		.00
Partial dependent	0.72	9.90	2.05 (1.31–3.20)	.00
Dependent	1.11	4.57	3.05 (1.10–8.47)	.03
Dementia	0.08	0.03	1.08 (0.48–2.41)	.86
Frailty				
Non-frail[a]		15.78		.00
Pre-frail	0.75	9.39	2.12 (1.31–3.43)	.00
Frail	1.44	15.17	4.22 (2.05–8.71)	.00
Sarcopenia	0.51	3.00	1.67 (0.94–2.99)	.08
Anticonvulsant drugs	0.28	1.24	1.32 (0.81–2.17)	.27
Antipsychotic drugs	0.31	2.10	1.36 (0.90–2.05)	.15
Benzodiazepines with a long half-life time	0.49	1.07	1.63 (0.65–4.14)	.30

Note: Proportion of variance explained by the model (Nagelkerke R^2) = 0.34.
Abbreviation: CI, confidence interval.
[a]Reference category.

However, the post-hoc analysis shows that frailty weakened the association between swallowing difficulties and all other clinical characteristics included in the multivariable model. This implicates that frailty may be a good indicator for population-based screening, but for a more detailed—individual—recognition of swallowing difficulties, clinical characteristics such as sarcopenia, impaired mobility, spasticity, use of antipsychotics, and mealtime dependency may be more useful.

The explained variance of the multivariable models is modest (R^2 = 34% and R^2 = 32%). An explanation may be that swallowing difficulties are a multifactorial phenomenon and that we were not able to include all aspects related to swallowing difficulties in the multivariable models. For example, it is likely that poor oral health, such as untreated caries and edentulism (Mac Giolla Mac Giolla Phadraig et al., 2021), cerebral palsy (Henderson et al., 2009; Seo et al., 2019; Yi et al., 2019), or behavioural factors, such as eating quickly, drinking quickly, and cramming food, contribute to swallowing difficulties in people with an intellectual disability (Robertson et al., 2018). Future studies that investigate factors associated with swallowing difficulties should include behavioural factors and explore other aspects that may be related to swallowing difficulties.

A strength of our study is that we used data from the HA-ID study, which is a nearly representative sample for the total Dutch client population aged 50 years and over (Hilgenkamp et al., 2011). This will help to generalise our results to a larger population of people with intellectual disability in a similar setting.

A limitation of this study is that the DDS has not been developed as a stand-alone instrument. The DDS measures swallowing and feeding competency and some related factors. To further examine and confirm a diagnosis of swallowing difficulties, a more detailed clinical swallowing evaluation is needed (Sheppard et al., 2014) with attention to other related factors such as behavioural and environmental factors. It is possible that we misclassified some participants (false positives) as having swallowing difficulties. On the other hand, we may have missed participants (false negatives) who aspirate silently and can only be identified by instrumental assessment such as FEES or videofluoroscopic swallow study (VFSS). Nevertheless, the DDS is currently the only validated instrument specifically developed for people with an intellectual disability. Also, the DDS can only be used by certified professionals who are trained to classify swallowing difficulties. In contrast, in other populations the use of self-report

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

TABLE 5 Multivariable, independent, associations with swallowing difficulties (post-hoc model excluding frailty).

	B	Wald	Odds ratio (95% CI) model excluding frailty	*p*-Value
Age	0.03	5.50	1.03 (1.01–1.06)	.02
Level of intellectual disability				
Borderline/mild[a]		5.61		.06
Moderate	0.10	0.19	1.11 (0.71–1.73)	.66
Severe/profound	0.61	4.53	1.83 (1.05–3.21)	.03
Down syndrome	0.43	2.40	1.54 (0.89–2.67)	.12
Stroke	0.15	0.13	1.17 (0.50–2.70)	.72
Mobility				
Walks independently[a]		7.86		.02
Walks with support	0.01	0.00	1.01 (0.61–1.70)	.96
Wheelchair	1.24	7.60	3.47 (1.43–8.40)	.01
Spasticity	0.76	4.66	2.13 (1.07–4.24)	.03
Mealtime dependency				
Independent[a]		27.30		.00
Partial dependent	1.05	24.44	2.85 (1.88–4.31)	.00
Dependent	1.34	7.16	3.81 (1.43–10.14)	.01
Dementia	0.22	0.28	1.24 (0.58–2.76)	.60
Sarcopenia	0.71	6.03	2.04 (1.15–3.59)	.01
Anticonvulsant drugs	0.40	2.60	1.49 (0.92–2.42)	.11
Antipsychotic drugs	0.42	4.14	1.52 (1.02–2.27)	.04
Benzodiazepines with a long half-life time	0.52	1.22	1.69 (0.67–4.26)	.27

Note: Proportion of variance explained by the model (Nagelkerke R^2) = 0.32.
Abbreviation: CI, confidence interval.
[a]Reference category.

questionnaires are common to identify swallowing difficulties, but this is less suitable for people with an intellectual disability, possibly due to limitations concerning their intellectual disability. Another limitation is the method we used to estimate the agreement between the classification of swallowing difficulties by the DDS and the registration of swallowing difficulties in the medical file. The medical files are only accessible for the general practitioner and the physician specialised in care for people with intellectual disabilities. Other professional caregivers, like the speech and language therapist and professional caregivers, report in a different file. Therefore, it is possible that swallowing difficulties had not been reported in the medical file but were recognised by the professional caregiver.

5 | CONCLUSION

We classified over 40% of older adults with intellectual disability as having swallowing difficulties; however, in most of these cases there was no reference to swallowing problems in their medical record. This may indicate an under-recognition of swallowing difficulties, potentially resulting in adverse health outcomes. Structural screening for swallowing difficulties in older people with intellectual disability is of utmost importance. Frailty may be a good indicator for population-based screening; however, for a more detailed individual recognition of swallowing difficulties, clinical characteristics such as sarcopenia, impaired mobility, spasticity, use of antipsychotics, and mealtime dependency should be considered.

ACKNOWLEDGEMENTS

The authors thank the management and professionals of the care organisations, Abrona (Huis ter Heide), Amarant (Tilburg), and Ipse de Bruggen (Zoetermeer), involved in the HA-ID consort for their support. We also thank all the participants, their family members, and caregivers, for their collaboration. This study was carried out with the financial support of ZonMw (grant number 57000003).

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

REFERENCES

Altman, D. G. (1999). *Practical statistics for medical research*. Chapman & Hall/CRC Press.

Bahat, G., Yilmaz, O., Durmazoglu, S., Kilic, C., Tascioglu, C., & Karan, M. A. (2019). Association between swallowing difficulties and frailty in

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universitatsbibliothek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License

community dwelling older adults. *The Journal of Nutrition, Health & Aging*, *23*(6), 571–577.

Baijens, L. W., Clavé, P., Cras, P., Ekberg, O., Forster, A., Kolb, G. F., & Walshe, M. (2016). European Society for Swallowing Disorders: European Union Geriatric Medicine Society white paper: Oropharyngeal swallowing difficulties as a geriatric syndrome. *Clinical Interventions in Aging*, *11*, 1403–1428.

Bastiaanse, L. P. (2014, December 2). Nutrition, nutritional state and related conditions in older adults with intellectual disabilities. Chapter 4. Doctoral dissertation, Erasmus University Rotterdam. http://hdl.handle.net/1765/77210

Bastiaanse, L. P., Hilgenkamp, T. I., Echteld, M. A., & Evenhuis, H. M. (2012). Prevalence and associated factors of sarcopenia in older adults with intellectual disabilities. *Research in Developmental Disabilities*, *33*(6), 2004–2012.

Blake, J. M., Estrada Gomez, D., Skotko, B. G., Torres, A., & Santoro, S. L. (2021). Pneumonia and respiratory infection in Down syndrome: A 10-year cohort analysis of inpatient and outpatient encounters across the lifespan. *American Journal of Medical Genetics. Part A*, *185*(10), 2878–2887.

Calis, E. A., Veugelers, R., Sheppard, J. J., Tibboel, D., Evenhuis, H. M., & Penning, C. (2008). Swallowing difficulties in children with severe generalized cerebral palsy and intellectual disability. *Developmental Medicine and Child Neurology*, *50*(8), 625–630.

Cha, S., Kim, W. S., Kim, K. W., Han, J. W., Jang, H. C., Lim, S., & Paik, N. J. (2019). Sarcopenia is an independent risk factor for swallowing difficulties in community-dwelling older adults. *Swallowing Difficulties*, *34*(5), 692–697.

Chadwick, D. D., & Jolliffe, J. (2009). A descriptive investigation of swallowing difficulties in adults with intellectual disabilities. *Journal of Intellectual Disability Research*, *53*(1), 29–43.

Chen, S., Cui, Y., Ding, Y., Sun, C., Xing, Y., Zhou, R., & Liu, G. (2020). Prevalence and risk factors of swallowing difficulties among nursing home residents in eastern China: A cross-sectional study. *BMC Geriatrics*, *20*(1), 352. https://doi.org/10.1186/s12877-020-01752-z

Coppus, A. M. (2013). People with intellectual disability: What do we know about adulthood and life expectancy? *Developmental Disabilities Research Reviews*, *18*(1), 6–16.

Eglseer, D., Halfens, R. J. G., Schols, J., & Lohrmann, C. (2018). Swallowing difficulties in hospitalized older patients: Associated factors and nutritional interventions. *The Journal of Nutrition, Health & Aging*, *22*(1), 103–110.

Field, A. (2009). Logistic regression. In *Discovering statistics using SPSS* (pp. 760–813). Sage Publications.

Henderson, C. M., Rosasco, M., Robinson, L. M., Meccarello, J., Janicki, M. P., Turk, M. A., & Davidson, P. W. (2009). Functional impairment severity is associated with health status among older persons with intellectual disability and cerebral palsy. *Journal of Intellectual Disability Research*, *53*(11), 887–897.

Heslop, P., Hoghton, M., Blair, P., Fleming, P., Marriott, A., & Russ, L. (2013). The need for FASTER CARE in the diagnosis of illness in people with intellectual disabilities. *The British Journal of General Practice*, *63*(617), 661–662.

Hilgenkamp, T. I., Bastiaanse, L. P., Hermans, H., Penning, C., van Wijck, R., & Evenhuis, H. M. (2011). Study healthy ageing and intellectual disabilities: Recruitment and design. *Research in Developmental Disabilities*, *32*(3), 1097–1106.

Jukic Peladic, N., Orlandoni, P., Dell'Aquila, G., Carrieri, B., Eusebi, P., Landi, F., Volpato, S., Zuliani, G., Lattanzio, F., & Cherubini, A. (2019). Swallowing difficulties in nursing home residents: Management and outcomes. *Journal of the American Medical Directors Association*, *20*(2), 147–151.

Kim, J. H. (2019). Multicollinearity and misleading statistical results. *Korean Journal of Anesthesiology*, *72*(6), 558–569.

Mac Giolla Phadraig, C., Ishak, N. S., van Harten, M., Al Mutairi, W., Duane, B., Donnelly-Swift, E., & Nunn, J. (2021). The Oral status survey tool: Construction, validity, reliability and feasibility among people with mild and moderate intellectual disabilities. *Journal of Intellectual Disability Research*, *65*, 437–451.

Madhavan, A., LaGorio, L. A., Crary, M. A., Dahl, W. J., & Carnaby, G. D. (2016). Prevalence of and risk factors for swallowing difficulties in the community dwelling elderly: A systematic review. *The Journal of Nutrition, Health & Aging*, *20*(8), 806–815.

Mahoney, F. I., & Barthel, D. W. (1965). Functional evaluation: The Barthel index. *Maryland State Medical Journal*, *14*, 61–65.

Michel, A., Vérin, E., Gbaguidi, X., Druesne, L., Roca, F., & Chassagne, P. (2018). Oropharyngeal swallowing difficulties in community-dwelling older patients with dementia: Prevalence and relationship with geriatric parameters. *Journal of the American Medical Directors Association*, *19*(9), 770–774.

Nawaz, S., & Tulunay-Ugur, O. E. (2018). Swallowing difficulties in the older patient. *Otolaryngologic Clinics of North America*, *51*(4), 769–777.

Robertson, J., Chadwick, D., Baines, S., Emerson, E., & Hatton, C. (2017). Prevalence of swallowing difficulties in people with intellectual disability: A systematic review. *Intellectual and Developmental Disabilities*, *55*(6), 377–391.

Robertson, J., Chadwick, D., Baines, S., Emerson, E., & Hatton, C. (2018). People with intellectual disabilities and swallowing difficulties. *Disability and Rehabilitation*, *40*(11), 1345–1360.

Schoufour, J. D., Echteld, M. A., Boonstra, A., Groothuismink, Z. M., & Evenhuis, H. M. (2016). Biochemical measures and frailty in people with intellectual disabilities. *Age and Ageing*, *45*(1), 142–148.

Schoufour, J. D., Echteld, M. A., & Evenhuis, H. M. (2017). Comparing two frailty concepts among older people with intellectual disabilities. *European Journal of Ageing*, *14*(1), 63–79.

Schoufour, J. D., Mitnitski, A., Rockwood, K., Evenhuis, H. M., & Echteld, M. A. (2013). Development of a frailty index for older people with intellectual disabilities: Results from the HA-ID study. *Research in Developmental Disabilities*, *34*(5), 1541–1555.

Seo, H. G., Yi, Y. G., Choi, Y. A., Leigh, J. H., Yi, Y., Kim, K., & Bang, M. S. (2019). Oropharyngeal swallowing difficulties in adults with dyskinetic cerebral palsy and cervical dystonia: A preliminary study. *Archives of Physical Medicine and Rehabilitation*, *100*(3), 495–500 e491.

Sheppard, J. J. (2002). Swallowing and feeding in older people with lifelong disability. *Speech Language Pathology*, *4*(2), 119–121. https://doi.org/10.1080/14417040210001669341

Sheppard, J. J., Hochman, R., & Baer, C. (2014). The swallowing difficulties disorder survey: Validation of an assessment for swallowing and feeding function in developmental disability. *Research in Developmental Disabilities*, *35*(5), 929–942.

Sura, L., Madhavan, A., Carnaby, G., & Crary, M. A. (2012). Swallowing difficulties in the elderly: Management and nutritional considerations. *Clinical Interventions in Aging*, *7*, 287–298. https://doi.org/10.2147/cia.S23404

Takizawa, C., Gemmell, E., Kenworthy, J., & Speyer, R. (2016). A systematic review of the prevalence of oropharyngeal swallowing difficulties in stroke, Parkinson's disease, Alzheimer's disease, head injury, and pneumonia. *Swallowing Difficulties*, *31*(3), 434–441. https://doi.org/10.1007/s00455-016-9695-9

Yi, Y. G., Oh, B. M., Seo, H. G., Shin, H. I., & Bang, M. S. (2019). Swallowing difficulties-related quality of life in adults with cerebral palsy on full Oral diet without enteral nutrition. *Swallowing Difficulties*, *34*(2), 201–209.

How to cite this article: Sanders, K. J. V., Elbers, R. G., Bastiaanse, L. P., Echteld, M. A., Evenhuis, H. M., & Festen, D. A. M. (2024). Prevalence of swallowing difficulties and associated factors in older people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *37*(3), e13209. https://doi.org/10.1111/jar.13209

14683148, 2024, 3, Downloaded from https://onlinelibrary.wiley.com/doi/10.1111/jar.13209 by Erasmus University Rotterdam Universiteitsbibliotheek, Wiley Online Library on [06/03/2024]. See the Terms and Conditions (https://onlinelibrary.wiley.com/terms-and-conditions) on Wiley Online Library for rules of use; OA articles are governed by the applicable Creative Commons License