

RESEARCH REPORT

The feasibility of a dysphagia procedure for identification, diagnosis, intervention and evaluation of dysphagia in adults with intellectual disabilities: a pilot study

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Table of contents

Introduction	3
Aim and research question	5
Method	6
Results	9
Discussion	11
Recommendations for further research and clinical practice	12
Conclusion	13
References	14
Tabels and figures	17
Nederlandse samenvatting	23
English abstract	24
Appendix I	25

Introduction

In people with intellectual disability (ID) problems related to feeding are common (1). Prevalence of dysphagia (difficulty in swallowing) in people with ID is estimated between 8% and 99% (2–8) and because life expectancy is increasing, dysphagia also occurs as a result of age-related conditions like dementia, Parkinson's disease and stroke (8,9).

Dysphagia is associated with an increased risk of aspiration (1,9,10), poor growth and nutritional status (1,5,9), recurrent lower respiratory tract infections and chronic lung diseases (2), choking and dehydration (1,9,11) and in some cases death (9,10).

Different challenges occur in the management of dysphagia in adults with ID.

A recent study (12) described the lack of awareness of dysphagia in people with ID amongst caregivers. This study compared the prevalence rates of dysphagia, measured with a standardized mealtime observation, within the population with ID aged 50 years and over, with the registration of dysphagia in medical files. Of the swallowing problems, 89.5% were not registered (12), which suggests caregivers tend to underestimate the eating and drinking problems (13).

Currently, identification, diagnosis, and intervention of dysphagia in adults with ID happens mainly reactive and depends on the therapist's experience. Challenges in current practise of managing dysphagia are varying expertise among health care professionals and lack of knowledge about evidence based practise. Therefore a standardized procedure to manage dysphagia is needed.

Another challenge in managing dysphagia in adults with ID, is the limited ability of the person with ID to follow the dysphagia recommendations, due to their intellectual disability (14).

Therefore, caregivers are often required to follow these recommendations instead. It is known that this often leads to non-compliance (13). Non-compliance to eating and drinking guidelines has a negative impact on lifespan, quality of life and health (13,15,16). Literature also shows other challenges at the level of the caregivers. The task of supporting people with their meals is often given to the least trained members of staff (15). Besides, caregivers tend to focus on those who need support when eating and drinking. The people who do not need support during their meal, are often the least observed group, while these people often need guidance during the mealtime situation, e.g. prompting to slow down their pace (15).

Furthermore, aspects like work experience, participation in writing guidelines, high staff turnover, poor cascade training between staff, etc., are described as challenging issues relevant when implementing safe eating and drinking recommendations (13,17).

Because of the high prevalence of dysphagia (2–8), the major health risks involved (1,2,5,9,10), the underestimation by caregivers (11,18), non-compliance to dysphagia recommendations (18), the lack of a standardized procedure and several other challenges described on caregiver level (13,15,17), a health improvement project started in March 2014

led by Ipse de Bruggen, a care provider service for people with ID. This project is part of the consortium 'Healthy Ageing and Intellectual Disability' (HA-ID), a cooperation between the department of intellectual disability medicine of the University Medical Centre Rotterdam and three care provider services for people with ID: Abrona , Amarant and Ipse de Bruggen, all situated in the Netherlands. The aim of this health improvement project is to develop and implement an evidence based standardized procedure to improve the identification, diagnosis and treatment of dysphagia in people with ID. Problems with implementing the standardized procedure on the level of the caregivers are expected, therefore this study aims to investigate the feasibility of this procedure.

Aim and research question

The aim of this study is to examine the feasibility of the standardized procedure for the identification, diagnosis, treatment and evaluation of dysphagia in adults with ID (henceforth referred to as the dysphagia procedure). The research question was whether it is feasible to implement the dysphagia procedure within Ipse de Bruggen, Zwammerdam. Sub questions related to this research question are:

- Do all involved speech and language therapists (SLT's) and multidisciplinary team members agree with the content of and their role in the dysphagia procedure?
- Do the SLT's manage to execute all the steps of the dysphagia procedure and collect pretest and post-test measurements?
- Is it feasible to involve the caregivers?

Method

Participants and setting

The design of this study is a quantitative feasibility design. The participants of this study were professionals involved in the daily care of 24 adults with ID and an expected dysphagia, working at Ipse de Bruggen, Zwammerdam. This group of professionals consisted of two speech and language therapists, 24 first responsible caregivers of the client's assisted living facility, 24 first responsible caregivers of the client's work or day-care facility, two dieticians, one physician for people with ID, one physical therapist, two occupational therapists, one behavioural specialist and one dental hygienist. The latter six disciplines are further referred to as the multidisciplinary team members. The adults with ID and expected dysphagia (henceforth called the clients) were selected by drawing a random sample of 50 clients from the population at risk of dysphagia of adults with ID living at Ipse de Bruggen, Zwammerdam. Clients belonged to the population at risk when one of the following criteria has been met: A diagnosis of Down syndrome (1), the use of Benzodiazepines with a long half-life time (12), wheelchair bound (12), dependent on others for feeding (10), aged 50 years and over, and/or diagnosis of cerebral palsy (2,5). Clients who fully or partially depend on tube feeding and/or have been treated by the multidisciplinary eating and drinking committee within the past two years were excluded.

Of the sample, the SLT's screened 48 clients for dysphagia with the Dysphagia Disorder Survey (DDS) (19) during one mealtime situation. The DDS was found to be one of the most clinically useful instruments to measure oropharyngeal dysphagia in people with ID (4) and is a reliable and valid instrument (7). In total, 24 clients had an expected dysphagia and 24 clients had non-expected dysphagia. See Figure 1 for flow chart of the inclusion of the clients. In the diagnostic stage, the two other mealtime moments were observed using this instrument, as differences between caregivers, between the living and working environment and between different moments of the day, were expected. Although data of test-retest reliability of the DDS are lacking (4), it has been decided that the DDS is still the best option to diagnose dysphagia in people with ID. Even though, there is a risk the test-retest measurement between the moment of screening and diagnosis is not reliable. Therefore, a clinical dysphagia evaluation, consisting of a medical history, physical exam of oral and motor functions, nutritional status and respiratory status (20), was added to support the process of diagnosis.

Besides diagnosing dysphagia, caregivers were asked to fill in the choking risk assessment (CRA); a standardized and valid instrument to estimate the risk of a choking incident in adults with ID (19). It is known that asphyxiation risk is highly prevalent amongst adults with ID and dysphagia (11). The CRA provides insight in possible risk factors of a choking incident during mealtime and calculates a risk score. Scores below 50% refer to a low risk of a choking

incident and scores of 50% and higher refer to a high risk of a choking incident. For the clients with dysphagia and a high risk of a choking incident, the factors that cause this risk during mealtime, will be part of the standardized intervention. The clients with no dysphagia and a high risk of a choking incident, will not be part of this study. These clients will be treated according to current usual care. Yet, we will report these data as this group has to be part of future management decisions related to risk factors of choking during mealtimes.

Dysphagia procedure

The dysphagia procedure is a standardized evidence based process developed by the first author, in cooperation with the project team. This team consisted of a first responsible caregiver of the assisted living facility, a behavioural specialist, a physician for people with intellectual disabilities, and a manager. These professionals were all working at Ipse de Bruggen, Zwammerdam. Two SLT's, working at Abrona and Amarant, were also part of the project team. The dysphagia procedure consists of four phases: the screening-, the diagnostic-, the intervention- and the evaluation phase. The screening phase of the dysphagia procedure has been used to select a sample of clients for this study and has not been further evaluated for feasibility. Each phase in the dysphagia procedure describes the recommended steps to take, instruments to use, people to involve and the scientific evidence. The main part of the dysphagia procedure is described in Appendix I. The accompanying appendixes of the dysphagia procedure are in Dutch and available from the first author upon request. Two SLT's working at Ipse de Bruggen, Zwammerdam, were responsible for following the dysphagia procedure in this study. An overview of all the actions involved for the participants in this study is visualized in Figure 2.

Outcomes

Feasibility is the main study outcome. Bowen et al. (21) described eight areas of focus addressed by feasibility studies. The feasibility criteria chosen for this study were based on the following areas of focus described by Bowen et al. (21): acceptability, implementation and, practicality. The participants were divided in three groups (caregivers, SLT's and multidisciplinary team members), as each group has different interests in terms of acceptability, implementation and, practicality of the dysphagia procedure. Furthermore, the feasibility criteria of this study were also based on the steps of the dysphagia procedure, which represents common practise in dysphagia management. The percentage of achievement of most of the criteria has been set on 95% or higher. The reason this percentage has been chosen relates to the high health risks involved with dysphagia (1,2,5,9–11).

The criteria for assessing success of feasibility are described in Table 1. All criteria must be met to achieve feasibility.

Sample size

As a rule of thumb, 10% of the estimated population was selected (22). Within Ipse de Bruggen Zwammerdam, the population at risk of dysphagia is approximately 200 clients. Therefore, 20 clients were needed in the diagnostic phase of the dysphagia procedure. In total 24 clients had the outcome 'expected dysphagia' and entered the diagnostic phase.

Analysis

Descriptive analysis were used to evaluate the feasibility criteria. The achievement of all feasibility criteria was expressed in percentages. The agreement of the role and content of the dysphagia procedure of the SLT's and the multidisciplinary team members were calculated. As well as the practicability of the steps of the dysphagia procedure within three months. Furthermore, the achievement of collecting pretest and post-test measurements were expressed in percentages. Finally, percentages of all caregiver criteria were calculated.

Ethical aspects

The Medical Ethics Committee of the Erasmus University Medical Centre Rotterdam, the Netherlands, has reviewed that the rules laid down in the Medical Research Involving Human Subjects Act do not apply to this study.

The study has been conducted according to the principles of the Declaration of Helsinki (64th version, October 2013) (23).

Results

Baseline data and flow of clients with expected dysphagia

The characteristics of the clients with expected dysphagia are displayed in Table 2.

All clients went through the diagnostic phase of the dysphagia procedure. Only the clients with dysphagia continued to the intervention- and evaluation phase. The flow of clients is shown in Figure 3.

Eleven clients were diagnosed with dysphagia, from this group six had a mild and five had a moderate dysphagia. The risk scores of a choking incident were calculated for the clients with dysphagia (n=11) and without dysphagia (n=12). These scores are summarized in Table 3.

Recruitment

From December 1st 2014 till January 21st 2015 appointments were made for mealtime observations needed for diagnosing the clients with dysphagia or no dysphagia.

Subsequently, the rest of the steps of the dysphagia procedure were followed. Three months after the first emailing contact the feasibility criteria have been evaluated.

Outcomes

The percentages of the achieved and aimed feasibility criteria are displayed in Table 4. The SLT's agreed with the content of the dysphagia procedure and managed to collect all pretest measurements. The SLT's only managed to go through all the steps of the dysphagia procedure when clients were found to have no dysphagia. When clients were diagnosed with dysphagia, the SLT's had problems going through all the steps of the intervention and evaluation phase, due to the restricted timeframe of three months. Summarized, this means the timeframe is enough to diagnose the dysphagia, but gets challenging when there is a need for intervention and evaluation.

The multidisciplinary team members agreed for 100% with the content of the dysphagia procedure and their role in this procedure. Of two clients, two caregivers attended the general dysphagia training. Of one client, only one caregiver attended the training and of the other six clients, no caregivers attended the training. Three first responsible caregivers of the assisted living facility attended an one-on-one session with the SLT to receive training about the content of the dysphagia management plan. They also managed to transfer the content of the dysphagia management plan to other members of the caregiver teams and to the first responsible caregivers of their clients work or day-care facility. The latter all felt confident to apply the items of the dysphagia management plan to the eating and drinking situation. Of the other five clients these steps of the dysphagia procedure have not been executed within

three months. The caregiver compliance of the dysphagia management plan has been evaluated for one client. 100% of the items in the plan were correctly executed. In summary, five of twelve feasibility criteria have been met.

Discussion

To evaluate the feasibility of the dysphagia procedure for identification, diagnosis and intervention of dysphagia in adults with ID, twelve feasibility criteria have been evaluated. Five of these criteria have been met. The seven criteria which have not been met, were criteria where close cooperation with the caregivers (mainly the first responsible caregivers of the assisted living facility of the client) was needed. These findings show that implementing the dysphagia procedure, is currently not feasible, due to challenges in cooperating with the caregivers. The main bottlenecks in the process on caregiver level are: 1) no or delayed return of questionnaires to the SLT, 2) not attending the general dysphagia training and, 3) no or delayed planning of an appointment with the SLT and the other involved multidisciplinary team members to discuss the safe eating and drinking recommendations. All further steps of the dysphagia procedure, like implementing the dysphagia management plan, evaluation of the effect of the intervention and caregiver compliance, therefore stagnated and could not be executed. This means the gaps on this level need to be solved first before clients with ID and dysphagia can receive the best possible care.

Findings of this study are in line with the results of other studies. According to Crawford et al. (13) problems related to the mealtime situation tend to be underestimated by client's caregivers. They mention several issues playing a role implementing safe eating and drinking recommendations. Some of these issues are a lack of caregiver awareness, salary, participation in writing guidelines, promotion and experience. In addition, the guideline of the Irish Association of Speech and Language Therapists (IASLT) on assessment and management of eating, drinking and swallowing difficulties in adults with ID (17) report comparable challenges. They name high staff turnover, poor cascade training between staff, difficulties identifying the problem, slow decline of people's swallowing function whereby caregivers will not always be alerted, etc.

Alternative explanations contributing to the findings of this study can be the overlap between the time of execution of this study and organisational changes where the management structure has been changed. These changes could possibly have an impact on the performance of the caregivers. The increased workload for the caregivers caused by filling in additional forms and questionnaires could be another possible explanation contributing to the outcome of this study. A final contribution to the outcome of this study could be the way clients were included. Instead of acting in response to a problem identified by the caregiver, client were randomly selected.

This study is clinically relevant for policymakers, management and therapists working with people with ID and dysphagia, because the bottlenecks in current care are highlighted. Even when the content of the care is improved by standardizing the procedure, the care does not always reach the people with ID and dysphagia.

A limitation of this study was the exclusion of clients who are partially or completely tube fed as it is known there is a significant association between tube feeding and pneumonia (10). Therefore, this group of people should be monitored frequently, to minimize the risk of pneumonia. In addition, Ball et al. reported (8) that not only the people with dysphagia, but also the people with high risk of asphyxiation and no dysphagia, need mealtime support. In this study, only the clients with expected dysphagia have been identified with a risk of a choking incident. The clients of the population at risk with non-expected dysphagia and the clients outside the population at risk of dysphagia, were not screened for a risk of a choking incident.

Strengths of this study were the use of the dysphagia procedure and the multidisciplinary evaluation of feasibility.

Recommendations for further research and clinical practice

For further research multiple suggestions can be done. The first priority is to improve the cooperation with the caregivers. Therapists can name many reasons why they think the caregivers do not cooperate, but these reasons have never been explored out of the perspective of the caregivers. Qualitative research to get more insight in the caregivers perspective would be a possible step towards better cooperation between caregivers and therapists. Another suggestion to achieve better cooperation, can be investing in a train the trainer education for caregivers. These trained caregivers can thereafter fulfil a task as coach. The advantage will be that caregivers will be coached by other caregivers instead of e.g. SLT's. This creates a feeling of equivalence which possibly has a positive effect on the identification and management of dysphagia. Also, it could be worth investigating changes in organisation structure, such as the obligation as a caregiver to have basic knowledge and skills about safe eating and drinking recommendations and the risks involved, before allowing them to work during mealtime hours. The knowledge and skills learned at the start of their employment needs to be kept up-to-date regularly. It would be even better to cooperate with the educational institutions. Knowledge and skills about feeding- and swallowing disorders, risk behaviour that can cause asphyxiation, and safe eating and drinking recommendations can be taught to future caregivers. A last consideration could be to create an overview of the people with dysphagia and the people at risk of a choking incident within the assisted living facilities. This data should be linked to employee skills, like level of education and work experience.

When the cooperation between caregivers and therapists has been improved, more work needs to be done on improving the quality of the dysphagia procedure. Some recommendations are: 1) measure the effect of the standardized intervention, 2) investigate long-term caregiver compliance and 3) further investigate the psychometric properties of the

instruments used in the dysphagia procedure, in particular the DDS and the quality of life questionnaire (SWAL-QOL).

Conclusion

The dysphagia procedure for the identification, diagnosis and intervention of dysphagia in adults with ID cannot be implemented yet, due to challenges executing all the steps of the dysphagia procedure within three months. Cooperation asked from the caregivers, such as the timely return of questionnaires, the required attendance of the general dysphagia training, etc. failed, whereby the process of intervention and evaluation of the dysphagia procedure, could not continue.

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Tables and figures

Figure 1. Flow chart inclusion clients (screening phase dysphagia procedure)

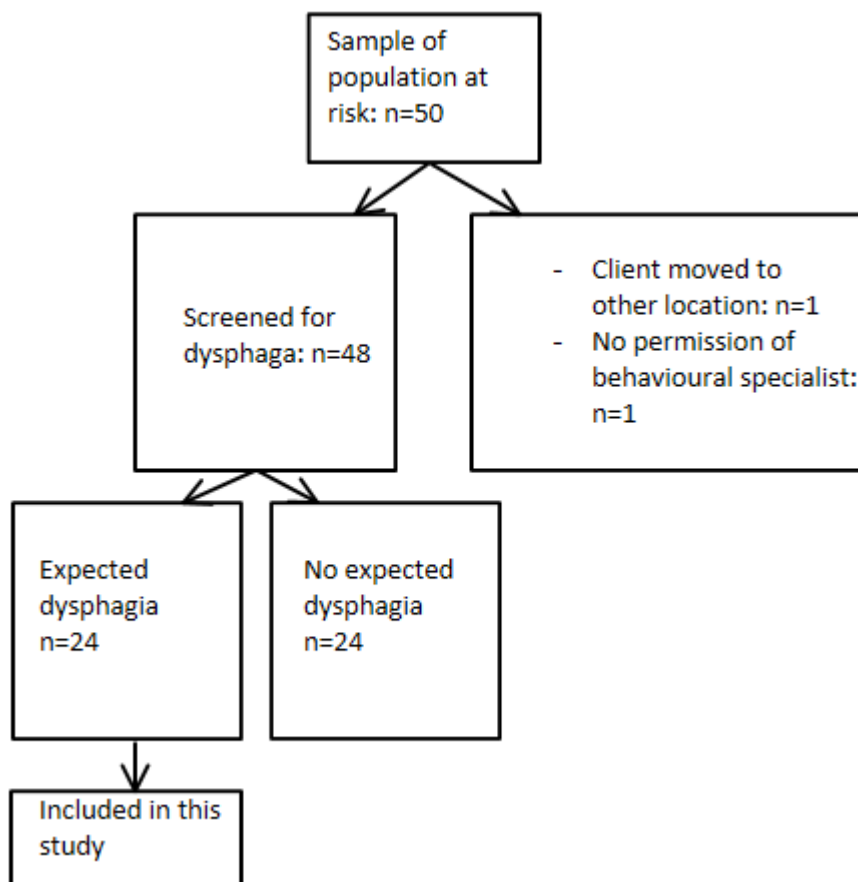


Figure 2: overview of all assessments involved for the participants in this study

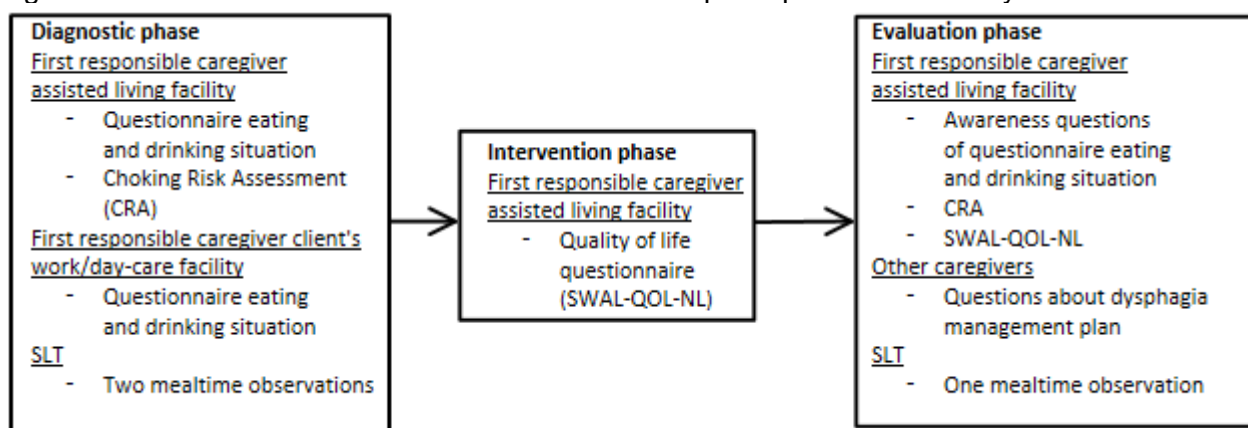


Table 1

Feasibility criteria

Participants	Criteria
SLT's (n=2)	<ul style="list-style-type: none"> - Agreement of 95% with the content of the dysphagia procedure. - 95% of the steps in the dysphagia procedure are executable within three months. - 100% successful in collecting pretest and post-test measurements of clinical symptoms of dysphagia, risk of a choking incident, quality of life and caregiver awareness, within three months.
Multidisciplinary team members:	<ul style="list-style-type: none"> - Agreement of 95% with the content of the dysphagia procedure. - Agreement of 95% with their role in the dysphagia procedure.
Caregivers	<ul style="list-style-type: none"> - At least two of the caregivers in the direct environment of the client are able to attend a general dysphagia training within three months. - The first responsible caregiver of the assisted living facility of the client is able to attend a one-on-one session with the SLT to receive training about the dysphagia management plan of the individual client within three months. - The first responsible caregiver of the assisted living facility of the client is able to transfer the dysphagia management plan of the individual client to other members of the caregiver team. - The first responsible caregiver at the client's work or day-care centre is aware of the existence of the dysphagia management plan and feels confident to apply the items in the plan to the eating and drinking situation of the client. - 95% of caregiver compliance of the dysphagia management plan will be achieved.

Table 2

Population characteristics clients with expected dysphagia

	Male	Female
Total (n)	12	12
Age (years)		
Mean (SD)	57.1 (12.7)	54.6 (14.8)
Median	53.5	53.5
Range	39-88	31-77
Severity of intellectual disability		
Mild (IQ 55-70)	2	0
Mild-moderate	1	0
Moderate (IQ 40-55)	4	4
Moderate-severe	1	3
Severe (25-40)	3	2
Profound (<25)	1	3
Down syndrome	1	3
Wheelchair bound	0	3
Use of Benzodiazepines	6	4
Dependent on others for feeding	0	2

Figure 3. Flow of clients

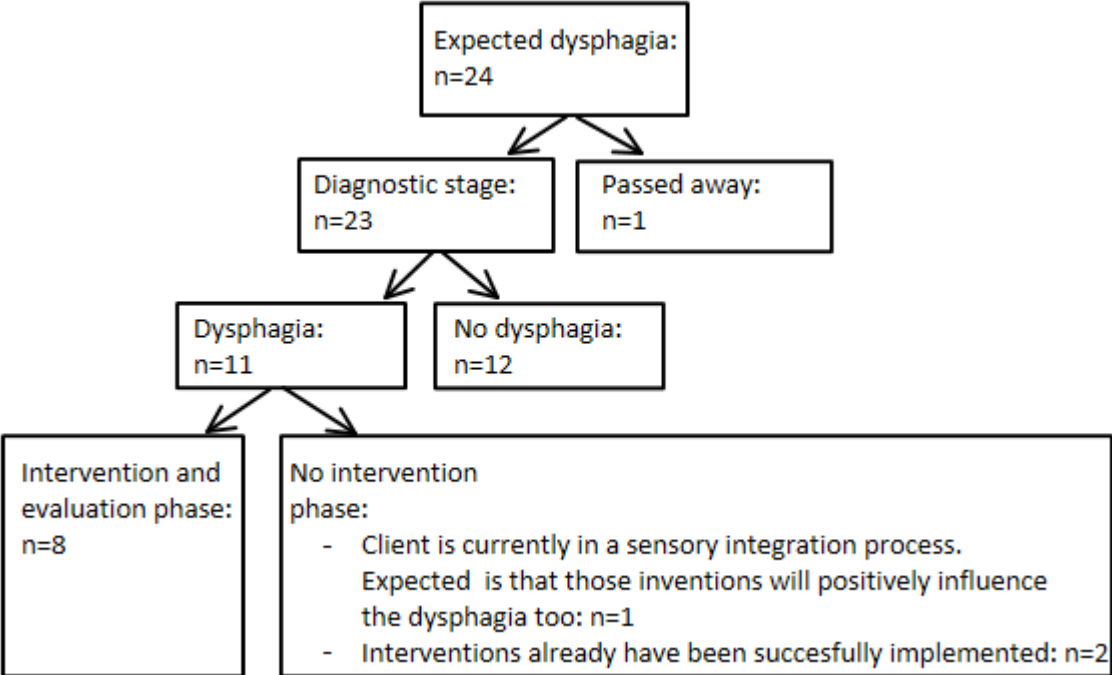


Table 3
Risk score of a choking incident

	Dysphagia	No dysphagia
High risk ≥ 50% (n)	10	6
Low risk < 50% (n)	1	6
Range (%)	30-90	20-70
Mean (%)	70	47.5

Table 4

Feasibility outcomes

Criteria	Achieved (Aimed)
The SLT's agree with 95% of the content of the dysphagia procedure	100% (95%)
95% of the steps in the dysphagia procedure are executable within three months:	
- For clients with outcome: dysphagia (have to go through all the steps)	12.5% (95%)
- For clients with outcome: no dysphagia (only have to go through the diagnostic phase)	100% (95%)
The SLT's are 100% successful in collecting pretest measurements of clinical symptoms of dysphagia, risk of a choking incident, quality of life and caregiver awareness, within three months.	100% (100%)
The SLT's are 100% successful in collecting post-test measurements of clinical symptoms of dysphagia, risk of a choking incident, quality of life and caregiver awareness, within three months.	12.5% (100%)
The multidisciplinary team members agree with 95% of the content of the dysphagia procedure	100% (95%)
The multidisciplinary team members agree for 95% with their role in the dysphagia procedure	100% (95%)
At least two of the caregivers in the direct environment of the client are able to participate in the general dysphagia training within three months	25% (100%)
The first responsible caregiver of the assisted living facility of the participant is able to attend a one-on-one session with the SLT to receive training about the dysphagia management plan of the individual client within three months	37.5% (100%)
The first responsible caregiver of the assisted living facility of the client is able to transfer the content of the dysphagia management plan of the individual client to other members of the caregiver team	37.5% (100%)

The first responsible caregiver at the client's work or day-care facility is aware of the existence of the dysphagia management plan and feels confident to apply the items in the plan to the eating and drinking situation of the client	37.5% (100%)
95% of caregiver compliance of the dysphagia management plan will be achieved.	100% (95%)*

*this percentage is based on one client. For seven clients this percentage could not be calculated.

Nederlandse samenvatting

Titel: De haalbaarheid van een dysfagie procedure voor de identificatie, diagnose, interventie en evaluatie van dysfagie in volwassenen met een verstandelijke beperking (VB): een pilot studie.

Inleiding: Door de hoge prevalentie van dysfagie in volwassenen met VB, de grote gezondheidsrisico's en de uitdagingen op het gebied van dysfagiemanagement, een zorgverbeteringsproject, getrokken door Ipse de Bruggen, een zorgaanbieder voor mensen met VB in Nederland, is gestart in maart 2014.

Doel en onderzoeksvragen: Het doel van deze studie is het onderzoeken van de haalbaarheid van de dysfagie procedure in volwassenen met VB. De bijbehorende onderzoeksvraag is 'Is het haalbaar om de dysfagie procedure te implementeren binnen Ipse de Bruggen, Zwammerdam?'.

Methode: Professionals (n=58) werkend met 24 volwassenen met VB en een vermoedelijke dysfagie hebben deelgenomen in deze studie. Alle relevante stappen van de dysfagie procedure moesten doorlopen worden binnen drie maanden. Haalbaarheid werd geëvalueerd aan de hand van de opgestelde criteria op het niveau van de logopedisten, multidisciplinaire teamleden en de begeleiders. Alle criteria moesten behaald worden voor het voldoen aan de haalbaarheid.

Resultaten: De logopedisten en de multidisciplinaire teamleden waren het voor 100% eens met hun rol en de inhoud van de dysfagie procedure. Het is de logopedisten niet gelukt om, binnen drie maanden, alle stappen van de procedure uit te voeren bij de cliënten met dysfagie. Tevens werden de begeleiderscriteria en het criterium voor het verzamelen van post-test data niet behaald. Vijf van de twaalf criteria zijn behaald.

Conclusie: De dysfagie procedure kan nog niet geïmplementeerd worden door problemen met de samenwerking tussen logopedisten en multidisciplinaire teamleden enerzijds en de begeleiders anderzijds.

Aanbevelingen: Verbeteren van de samenwerking met begeleiders door bijv. kwalitatief onderzoek naar het begeleidersperspectief, het overwegen van organisatorische veranderingen en investeren in een train de trainer opleiding.

Trefwoorden: dysfagie, haalbaarheid, verstandelijke beperking

English abstract

Title: The feasibility of a dysphagia procedure for identification, diagnosis, intervention and evaluation of dysphagia in adults with intellectual disabilities (ID): a pilot study.

Background: Because of the high prevalence of dysphagia in adults with ID, the major health risks involved and the different challenges managing dysphagia, a health improvement project started in March 2014 led by Ipse de Bruggen, a care provider service for people with ID in the Netherlands.

Aim and research questions: The aim of this study is to examine the feasibility of the dysphagia procedure in adults with ID. The accompanying research question is 'Is it feasible to implement the dysphagia procedure within Ipse de Bruggen, Zwammerdam?'

Method: Fifty-eight professionals working with 24 adults with ID and an expected dysphagia participated in this study. All the relevant steps of the dysphagia procedure must be executed within three months. Feasibility was evaluated using criteria based on the three groups of participants: speech and language therapists (SLT's), caregivers and multidisciplinary team members. All the criteria must be met to achieve feasibility.

Results: The SLT's and the multidisciplinary team members agreed for 100% with their role and content of the dysphagia procedure. The SLT's did not manage to execute all the steps of the dysphagia procedure for the clients with dysphagia. Also, the caregiver criteria and the criteria for collecting post-test measurements were not achieved. In summary, five of twelve feasibility criteria have been met.

Conclusion: The dysphagia procedure cannot be implemented yet, due to challenges in cooperation between the caregivers and both the SLT's and the multidisciplinary team members.

Recommendations: Improving cooperation with the caregivers through i.e. qualitative research to investigate the caregiver's perspective, considering different organisational changes and investigate in train the trainer education.

Keywords: dysphagia, feasibility, intellectual disability

Appendix I

Dysphagia procedure

Screening		
What	Whose task	Scientific evidence
1. Define clients at risk of dysphagia <ul style="list-style-type: none"> - A diagnosis of Down syndrome - Use of Benzodiazepines - Wheelchair bound - Dependent on others for feeding - Aged 50 years and over - A diagnosis of cerebral palsy 		Bastiaanse, Kamp van der, Evenhuis, & Echteld, 2014; Kuhn & Matson, 2004 Bastiaanse et al., 2014 Bastiaanse et al., 2014 Bastiaanse et al., 2014; Langmore et al., 1998 Benfer et al., 2013; Calis et al., 2008
2. Physician referral to the speech therapist for screening of dysphagia	General practitioner Physician for people with ID	
3. Executing screening during one mealtime using the Dysphagia Disorder Survey (DDS)	SLT	Benfer, Weir, & Boyd, 2012; Sheppard, Hochman, & Baer, 2014
4. DDS score ≥ 3 → expected dysphagia → Continue to diagnostic part. DDS score < 3 → no expected dysphagia → Report to referring physician, the first responsible caregiver(s) and the behavioural specialist → Report the year of periodic screening.	SLT	Sheppard et al., 2014
5. Guidelines for periodic screening: <ul style="list-style-type: none"> - No -mild dysphagia → 1x per 3 years - Moderate dysphagia → 1x per 2 years - Severe-profound dysphagia → annually 	SLT	Chadwick & Jolliffe, 2009; Sheppard, 2006 Expert opinion

Diagnostics		
What	Whose task	Scientific evidence
1. Inform referring physician, first responsible caregiver(s) and behavioural specialist of the outcome of the screening.	SLT	
2. Physician referral to the speech therapist for diagnostics of dysphagia using a standardized format.	General practitioner Physician for people with ID	
3. Send to first responsible caregiver assisted living facility: <ul style="list-style-type: none"> - Questionnaire eating and drinking situation (also send this form to the first responsible caregiver of the client's work/day-care facility). - Consent form for video recording the mealtime observation - Choking Risk Assessment (CRA) 	SLT (or secretarial support)	McCullough & Martino, 2013; Sheppard, 2006 Samuels & Chadwick, 2006
4. Observe and make video recordings of two mealtime moments (aim video recordings: view in multidisciplinary team) using: * the DDS * a standardized clinical dysphagia evaluation. Consider differences: <ul style="list-style-type: none"> - between work/day-care facility and living facility - during the moment of the day 	SLT	McCullough & Martino, 2013; Sheppard et al., 2014 McCullough & Martino, 2013; Sheppard, 2006
5. Determine severity of dysphagia using the Dysphagia Management Staging Scale (DMSS)	SLT	
6. Consider instrumental assessment of dysphagia	SLT, first responsible caregiver, physician for people with ID and the clients and/or the legal representative of the client.	Arvedson, 2013; Benfer et al., 2012; Calis et al., 2008; Chadwick & Jolliffe, 2009; Sheppard, 2006
7. Describe diagnosis of dysphagia using the International Classification of Functioning, Disability and Health (ICF).	SLT	NVLF & NPI, 2010
8. Report diagnosis to referring physician, behavioural specialist, first responsible caregiver(s) of work/day-care and living facility.	SLT	

Intervention		
What	Whose task	Scientific evidence
1. Send the SWAL-QoL-NL to the first responsible caregiver(s).	SLT	Chadwick, Jolliffe, Goldbart, & Burton, 2006
2. Invite the caregiver team to attend a general dysphagia training.	SLT (or secretarial support)	Chadwick et al., 2014, 2006; Langmore et al., 1998
3. Use the checklist 'intervention swallowing- and eating disorders)	Multidisciplinary team	The evidence is described in the checklist
4. Write a dysphagia management plan. Use the list of risk foods if necessary.	SLT in cooperation with multidisciplinary team	
5. Discuss the dysphagia management plan with the caregiver(s).	SLT in cooperation with the multidisciplinary team	Crawford, Leslie, & Drinnan, 2007
6. Discuss which support is needed for implementation of the dysphagia management plan in the caregiver team.	SLT and caregivers	Crawford, Leslie, & Drinnan, 2007
Evaluation		
1. Determine the effect of the standardized intervention	SLT	
2. Determine whether extra attention is needed for specific aspects of the intervention	SLT	
3. Agree when to evaluate the dysphagia management plan	SLT and first responsible caregiver	
4. Report the year of periodic screening: - No -mild dysphagia → 1x per 3 years - Moderate dysphagia → 1x per 2 years - Severe-profound dysphagia → annually	SLT	Chadwick & Jolliffe, 2009; Sheppard, 2006 Expert opinion