HOGESCHOOL ZUYD

Opleiding Logopedie

– TOR-BSST© –

A feasible and reliable screening for patients with dementia?

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Summary

Dysphagia is a dangerous illness, which significantly reduces a patient's quality of life. It often occurs in combination with dementia and can be fatal mainly as a result of malnutrition or pneumonia. Although this is well known, there is no dedicated swallowing screening for patients with dementia.

To determine whether the TOR-BSST©, a valid and reliable screening method that detects dysphagia in stroke patients, is equally feasible for patients with dementia, it was conducted with 51 residents of the psycho-geriatric ward of a nursing home.

To find out more about the interraterreliability of the TOR-BSST©, two measurements were taken on the same day with an intermission of one hour and were carried out by two independent examiners. Information about the intraraterreliability was obtained by conducting two further measurements two weeks later.

The screening's feasibility for dementia patients was determined with the help of a constructed scale that was filled in after each patient's first measurement.

The results show a good interraterreliability of the TOR-BSST© (k=0.68) and a less satisfying intraraterreliability (k_{r1}=0.34 & k_{r2}=0.5). However, analysing the feasibility scale showed that adaptations to the TOR-BSST© become necessary to make it a feasible screening for patients with dementia.

Keywords: dysphagia · dementia · TOR-BSST© · feasibility · reliability

Samenvatting

Dysfagie is een gevaarlijk ziekte, die de levenskwaliteit van betrokkenen beperkt. Het treedt vaak in combinatie met dementie op en kan erge consequenties hebben zoals malnutritie of longontsteking. Ondanks dat dit bekend is, bestaat er geen speciale slikscreening voor patiënten met dementie.

Om te onderzoeken of de TOR-BSST© – een valide, betrouwbare en hanteerbare slikscreening om dysfagie bij CVA-patiënten op te sporen – ook bruikbaar is voor dementiepatiënten, is deze screening bij 51 bewoners van een psychogeriatrische afdeling van een zorgcentrum afgenomen.

Om de interraterreliabiliteit van de TOR-BSST© te onderzoeken vonden op een dag twee metingen per patiënt plaats met een tijdperk van een uur ertussen, die door twee onafhankelijke onderzoekers uitgevoerd werden.

Informatie over de intraraterreliabiliteit werd twee weken later door het uitvoeren van twee verdere metingen verzameld.

De hanteerbaarheid van de TOR-BSST© bij deze patiëntengroep werd aan de hand van een eigen geconstrueerde vragenlijst onderzocht, die per patiënt na de eerste meting ingevuld werd.

De resultaten geven een goede interraterreliabiliteit van het screening (k=0.68) en een lage tot gemiddelde intraraterreliabiliteit (k_{r1}=0.34 & k_{r2}=0.5) aan.

De analyses van de hanteerbaarheidsschaal laten zien, dat aanpassingen van de TOR-BSST© nodig zijn om het voor patiënten met dementie gebruiken te kunnen.

Sleutelwoorden: dysfagie · dementie · TOR-BSST© · hanteerbaarheid · reliabiliteit

Index

Appendix

1. Introduction

Dysphagia is a dangerous and life-restricting illness. It restrains the ones who suffer from it in many different areas of their lives. Not only is the apparently 'normal' ingestion affected but also social factors such as having dinner or drinking coffee with family and friends. It is the health risks like malnutrition and pneumonia caused through aspiration that make dysphagia so dangerous (Smithard et al., 1996). In the worst case these consequences can lead to death (Smithard et al., 1996).

Dysphagia can be caused by several incidents or diseases, one of them is dementia. Until now the relation between dementia and dysphagia is little investigated. Only few examinations have been carried out to find exact data about the prevalence of dysphagia in dementia patients. It is well known that 0.4% of the worldwide population is suffering from dementia (Wimo, Winblad, Aquero-Torres&von Strauss, 2003). In nursing homes the prevalence ranges from 60-80% (Rappold, 2001; Kastner & Löbach, 2007). It is also known that generally 30-50% of all dementia patients develop swallowing problems (Rappold, 2001; Easterlings, 2008; Böhme, 2006a).

To prevent the incidence of its serious consequences, it is important to detect dysphagia as early as possible. People who suffer from dementia might no longer be able to communicate that they have problems with ingestion and swallowing, due to their mental state. This is only one of the reasons why one needs to pay special attention to dysphagic symptoms in this patient group. Another reason is that dementia patients are not indicated as a high risk group for dysphagia, which is why nursing staff often struggles to detect the problems until they are severe (Motzko & Weinert, 2005).

There are different methods to detect dysphagia. They can be divided into invasive and non-invasive procedures. Invasive procedures like videofluoroscopy and fiberoptic endoscopy of the swallowing process often put a higher strain on the patients than the non-invasive ones. In addition to that, these methods are also quite expensive. In contrast to invasive procedures the non-invasive instruments, such as screenings, are more prone to bias but can be conducted more easily with a minimal effort required from both examiners and patients.

Many screenings have been developed so that they can be conducted with bed-ridden patients. There are many different versions of these so called bedside swallowing screenings (Bours et al., 2008). Most of them have been developed for stroke patients and not especially for patients with dementia.

Screenings that are fast, reliable and valid could reduce the risk of detecting dysphagia in dementia patients too late. Sevagram, the principal investigator of this study, is looking for a new 'gold standard' which will enable them to detect dysphagia in this patient group more easily and as early as possible.

The 'Toronto Bedside Swallowing Screening Test' (TOR-BSST©) seems to fulfil the criteria (Martino et al., 2009). Not only are the economic factors *time* and *money* strong arguments for using it; being a non-invasive instrument this screening only puts a low level of strain on the patient, which makes it especially attractive.

The TOR-BSST© is a valid, reliable and feasible tool to detect dysphagia caused by strokes. In this patient group (stroke patients) 97% of those suffering from a potential swallowing disorder are already being identified. In addition to that, the screening can be conducted by all trained staff of an institution (Martino et al., 2009).

The aim of this study is to prove whether the TOR-BSST© can be equally successful to detect dysphagia in patients with dementia. Therefore the aspects feasibility and reliability will be explored.

Hence the following questions were formulated and will be answered in this thesis:

1. How feasible is the TOR-BSST© when used in patients with dementia?
2. What is the interrater- and intraraterreliability of the TOR-BSST© when conducted with dementia patients?

To answer these questions a feasibility and reliability study was designed. As part of this the TOR-BSST© will be carried out four times per dementia patient (subject). Each examiner will take two measurements. During the screening the subjects will be asked to swallow up to ten teaspoons of water and give a voice example to check whether there is a change in voice quality.

To equip the reader with the theoretical background of this study, chapter 2 gives an overview of the normal swallowing process and dysphagia. In addition, several

instruments to detect dysphagia will be described, before the relation between dysphagia and dementia will be outlined. The chapter ends with the description of the professional relevance of this study.

Chapter 3 (Methodology) then summarises the existing problems around the relation between dysphagia and dementia, before the resulting questions are being constructed. The chapter closes with an overview of the research design, the study population, the instruments used, the procedure as well as the steps used to process the data.

In the following chapter (chapter 4) the results of the measurements and the statistical analysis are described. This will then allow answering the research questions in chapter 5 (Conclusion). Afterwards the procedure of the study and the results will be critically discussed and recommendations for possible further examinations on this topic will be given in chapter 6 (Discussion).

2. Dysphagia and dementia - Theoretical background

The following chapter will give an overview of the theoretical background of dysphagia and dementia. The terms 'dysphagia' and 'dementia' are specified by their definition in 2.1 before the normal swallowing process is described in 2.2.
Section 2.3 presents the causes and consequences of the disorder 'dysphagia' before a summary of existing tests and screening methods to detect dysphagia is given in 2.4. Section 2.5 introduces different instruments to determine the phases of dementia before the relation between dysphagia and dementia is described and outlined afterwards (2.6). An explanation of the professional relevance of this thesis can be found at the end of the chapter (2.7).

2.1 Defining dysphagia and dementia

Dysphagia is a disorder of the ingestion, mastication or transportation of food and liquids at the oral, pharyngeal or esophageal stage, including saliva and secretion.
The medical term dysphagia has its origin in the Greek language:

dys= difficulty or disorder

phagia= “to eat”

(“Das Präfix dys”, 2011; “The word element -phagia”, 2011)
However, to translate dysphagia as a 'difficulty to eat' seems inadequate considering its multiple potential causes and the serious consequences it can have.

Dementia is a descriptive term for a chronically progressive deterioration of the brain which leads to the loss of the cognitive abilities. The loss of these abilities results in impairments of the memory, reasoning, planning and personality. Dementia is not part of the normal ageing process and although memory loss is a typical symptom of dementia, memory loss does not mean that a person has dementia. Dementia is medically diagnosed if two or more brain functions are impaired (“Definition of Dementia”, 2002; Pschyrembel Klinisches Wörterbuch, 2004). *Alzheimer’s disease* is the most common cause of dementia. It usually leads to a gradual decline of the cognitive abilities and affects nearly all brain functions (“Definition of Dementia”,

2002; “What are the different kinds”, 2010).

2.2 The normal swallowing process

The swallowing process can be divided into three or four stages – depending on whether the first – the oral stage – is split into two independent stages or not. Both classifications are equally respected.

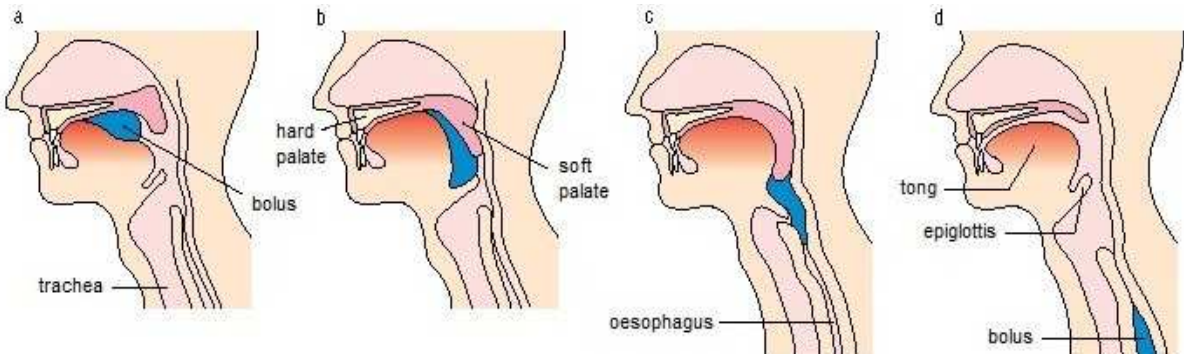
In this study the traditional classification, which defines the following three stages of the swallowing process, were used:

1. The oral stage
2. The pharyngeal stage
3. The oesophageal stage

During the *oral stage* food gets chewed and mixed up with saliva (oral preparatory stage). This results in a bolus which is transported – along the palate – into the oropharynx (oral transit stage). This first stage ends with the initiation of the swallowing reflex.

The *pharyngeal stage* takes about 0.7 seconds and happens involuntarily. It cannot be stopped once it is started because of the initiated swallowing reflex. With the reactive movement the bolus is carried through the pharynx into the oesophagus. The airway is closed during this process.

During the oe*sophageal stage* the bolus is transported through the oesophagus into the stomach. This happens through peristaltic movements (Neumann, 1999; Schalch, 1999).



a= oral stage, b, c= pharyngeal stage, d= esophageal stage

Figure 1: The swallowing process (adapted from Urban&Fischer 2003 – Roche Lexikon Medizin, 5th edition)

2.3 The causes and consequences of dysphagia

There are various causes of dysphagia which can be classified into three groups (Schalch, 1999). The first group are *disorders of the sensorimotor control.* This group contains (amongst others) cerebrovascular diseases, degenerative diseases (e.g. dementia), tumours, Parkinson's disease and amyotrophic lateral sclerosis (ALS).
Changes in the structure of the 'swallow organs', (the second group) *c*an occur in the oral cavity, the pharyngo-laryngeal area and the oesophagus. The third group contains *psychogenic disorders and functional adaption.*

Strokes (group 1) are the most frequent cause of neurogenic dysphagia (Bonnert & Kaiser, 2006). At least 54% of all stroke patients suffer from dysphagia which emphasises how important it is to detect and medicate it at an early stage (Stroud, Lawrie & Wiles, 2002).
Not being able to swallow, having pain while swallowing, bringing food back up, coughing or choking when eating (penetration/aspiration), coughing or gagging when swallowing (penetration/aspiration) or having the feeling of food being stuck in one's throat or chest are symptoms of dysphagia. Besides that, an unexplained weight loss and frequent lung infections (pneumonia) can be indications for a patient suffering from dysphagia.
Diagnosing dysphagia at an early stage is important. Otherwise it can be fatal as a result of malnutrition or serious pneumonia (Chouinard, Lavigne & Villeneuve, 1998; Hudson, 2000).

2.4 Tests and screenings to detect dysphagia

There are numerous methods to examine and diagnose dysphagia, all of which can be distinguished into objective (using a tool or technology of some sort) and subjective (using mainly observation) methods.

Radiographic examination using fluoroscopy has been proven to be the most useful objective method to probe a suspected dysphagia (Linden & Siebens, 1983; Baker, Fraser & Baker, 1991). However, even this method comes with certain disadvantages, such as the need for cooperation of the patient and the risks associated with radiation exposure.

A further objective method to examine swallowing problems is videofluoroscopy. This method is often named the 'gold standard', due to its meaningful results (Leslie, Drinnan, Finn, Ford & Wilson, 2004; Stroud et al., 2002). For the same reason fiberoptic endoscopic evaluation of swallowing (FEES) is equally respected to diagnose dysphagia (Langmore et al. 1991, Rao et al. 2003).

Other objective methods to examine a patient's swallowing functions include ultrasonography, scintigraphy, manometry and nasoendoscopy.

All of them require expensive equipment, invasive procedures and sophisticated interpretation. Since the nasoendoscope is the only transportable tool, nasoendoscopy is the only objective method that can be used for bed-ridden patients (Takahashi, Groher & Michi, 1994).

The most common subjective method to detect dysphagia is the bedside swallowing screening. Whilst there are many different variations of this screening, its execution and main aspects are mostly the same. They are outlined in the following paragraph:

During the bedside swallowing screening the patient is seated in an upright position and is asked to swallow small amounts of water. The exact amount depends on the particular screening protocol. While swallowing the water, the patient is being observed by the examiner who pays attention to several factors, such as the position of the patient's head, the time of commencement of the swallowing process (delay), drooling, reflux, coughing during or after the swallow and dysphonia. The screening can be enhanced by using pulse oxymetry to control the oxygen content in the lungs

(Sitoh, Lee, Phua, Lieu & Chan, 2000).
Not only water can be used to conduct the screening: Food of other consistencies (dry, juicy, something that has to be chewed) can also be used to observe to which extend the patient is able to swallow it.

The main method used during the examinations performed for this thesis is the Toronto Bedside Swallowing Screening Test (TOR-BSST©).
A detailed description of the TOR-BSST© is provided in chapter 3.4.

2.5 Classifying dementia

Dementia is a progressive illness. The progress of dementia can be classified into different stages. Screenings can be used to define in which stage of the illness the patient currently resides. The stages' classifications vary from screening to screening which is mostly due to the lack of consensus in the descriptive literature (Gifford & Cummings, 1999). However, most commonly they are classified as '(very) mild', '(very) moderate' and '(very) severe'. The following paragraph describes two screenings that classify dementia in slightly different ways. One of them is the Clinical Dementia Rating Scale. It splits the severity of the illness into four categories ('very mild dementia', 'mild', 'moderate' and 'severe dementia'), using a scale from 0.5 to 3 (Morris, 2001).
A second screening is the Mini-Mental State Examination (MMSE). In this screening the highest score is 30 and the severity of dementia is split into three categories, 'mild' (30 -25 points), 'moderate' (24-18 points) and 'severe' (17-0 points) ("Mini-Mental State Examination", 2010).

In this thesis the 'Cognitive Performance Scale' (CPS), another instrument to classify the progress of dementia was used. It correlates closely with the above described MMSE screening (Morris et al., 1994). The scale used by the CPS is outlined in chapter 3.7.3.

2.6 The relation between dysphagia and dementia

The relation between dysphagia and dementia is a highly discussed topic in the literature. Despite this, there is little exact data about the prevalence of dysphagia in people suffering from dementia. “The worldwide number of cases with dementia in 2000 was [...] estimated at about 25.5 million people, which is about 0.4% of the worldwide population […]” (Wimo et al., 2003). It is known that dementia patients frequently develop dysphagia as a consequence of their illness.
It is also said that 60-80% of the people living in nursing homes suffer from dementia. 45% of them also show symptoms of dysphagia (Easterling, 2008).

Horner et al. (1994) examined the swallowing process of 25 dementia patients in one of their studies. Whilst the results of 4 patients were inconspicuous “the remaining 21 showed a variety of swallowing abnormalities” (Horner, Alberts, Dawson & Cook, 1994). They also found aspiration in 28.6% (6 subjects) during an observation with videofluoroscopy (Horner et al., 1994).
These results are emphasised by another study where only 3 of 37 subjects with dementia “showed entirely normal swallowing of all consistencies” during videoendoscopic examinations (Rösler, Lessmann, von Renteln-Kruse & Stanschus, 2008).
Furthermore, Horner et al. (1994) compared the results of subjects with moderate dementia with those suffering from severe dementia. 4 of the 9 subjects with severe dementia aspirated (44%). Looking at the 16 subjects with moderate dementia only 2 patients aspirated (12.5%). Although these results have no statistical significance (due to the small examination group) they were able to proof that subjects with more severe dementia “tend to have lower total and global videofluoroscopic scores” (Horner et al., 1994).
Not only Horner et al. (1994) examined the oral and pharyngeal functions with advanced dementia. Feinberg et al. (1992) conducted a similar study with 131 elderly subjects and found that only in 7% (9 subjects) the findings were unsuspicious. Looking at the different phases of the swallowing process, “oral-stage dysfunction was observed in 93 subjects (71%), pharyngeal dysfunction in 56 (43%), and

pharyngoesophageal-segment abnormalities in 43 subjects (33%). Multiple-stage dysfunction was noted in 55 subjects (42%)" (Feinberg, Ekberg, Segall &Tully, 1992).

Studies about the swallowing abilities of healthy elderly subjects found that "the oldest subjects had a significant longer reflex initiation time than middle-aged and young groups, but no elderly subject aspirated" (Horner et al., 1994).
Taking a closer look at the duration of the swallowing process it becomes obvious that subjects with Alzheimer's disease "demonstrated significantly prolonged swallow durations for the oral transit duration (cookie), pharyngeal response duration (liquid), and total swallow duration (liquid)" compared to healthy subjects of the same age (Priefer & Robbins, 1997).

2.7 Professional relevance

Dysphagia is a disease that often occurs as a consequence of a stroke. At least 54% of stroke patients suffer from dysphagia (Stroud et al., 2002). However, many elderly people simply suffer swallowing difficulties due to the normal ageing process (Kastner & Löbach, 2007). Dysphagia also often occurs in combination with dementia (Horner et al., 1994). It is important to detect it as early as possible to prevent the (serious) consequences (e.g. pneumonia or malnutrition) caused by the swallowing disorder. It is especially important to pay attention to any dysphagic symptoms in dementia patients as they are not officially indicated as a high risk group, which often means that nurses do not detect the problems until they are severe. Despite existing swallowing problems the diagnosis dysphagia is never confirmed with around 60% of dementia patients. Only 33% of them receive treatment as a result of their swallowing problems (Rappold, 2001).
A screening which is easy to use, affordable and which can be accomplished in a short period of time could reduce the risk of detecting dysphagia too late.

3. Methodology

3.1 Problem

Dementia is a problem that affects many elderly people. In Germany, 7.2 % of the people who are older than 65 years suffer from dementia (Kastner & Löbach, 2007). The prevalence of affected people rises with increasing age. This is the reason why the majority of nursing home residents (60-80%) is affected (Rappold, 2001; Kastner & Löbach, 2007). Dementia patients also often suffer from dysphagia (45%) (Horner et al., 1994; Easterling, 2008). People with dementia are in many cases no longer able to identify or communicate whether they have swallowing problems or other limitations that affect their ingestion, which is why it is important that the nursing staff pays special attention and detects swallowing problems as early as possible. A swallowing screening that can be conducted quickly and without or only little effort for both the patient and the examiner would help gaining a first impression of the swallowing state of a patient. The Toronto Bedside Swallowing Screening Test (TOR-BSST©) is such a screening. Not only the economic factors time (feasible in 10 minutes or less) and money (only a cup of water, a teaspoon and a screening form are needed) are strong arguments for using it. It is also a reliable and valid method to identify stroke patients with dysphagia and can be used by all trained staff of an institution (Martino et al., 2009). However, until now there has been no evidence about the extent to which the TOR-BSST© can be effectively used to identify dysphagia in patients who suffer from dementia.

3.2 Aims of the thesis

The first aim of this thesis is to show whether or not the TOR-BSST© can also be a feasible instrument to detect dysphagia in patients with dementia or if adaptations to the screening become necessary. The second aim is to find out more about the interrater- and intraraterreliability of the TOR-BSST©.

3.3 Research questions

1. How feasible is the TOR-BSST© when used in patients with dementia?
2. What is the interrater- and intraraterreliability of the TOR-BSST© when conducted with dementia patients?

3.4 Research design

In this study an observational research design with four measurements taken within a time frame of two weeks was used to evaluate the feasibility and reliability of the TOR-BSST© when used with dementia patients (figure 2).

In order to obtain information about the feasibility, the screening will be initially conducted in its original version. This will give the required insight as to whether or not an adaptation of the screening becomes necessary in order to achieve the designated outcome.

Throughout the process, the inter- and intraraterreliabilty of the TOR-BSST© will be documented. Reliability is described as ‘the extent to which scores for patients who have not changed are the same for repeated measurements under several conditions’ (Mokkink et al., 2010). There are two conditions under which the measurements will take place, the first being that the screening will be carried out by two different examiners to ensure interraterreliability and the second being that the screening will be conducted twice by each examiner to gain knowledge about the intraraterreliability. In total, four measurements will be taken per patient as shown in figure 2.

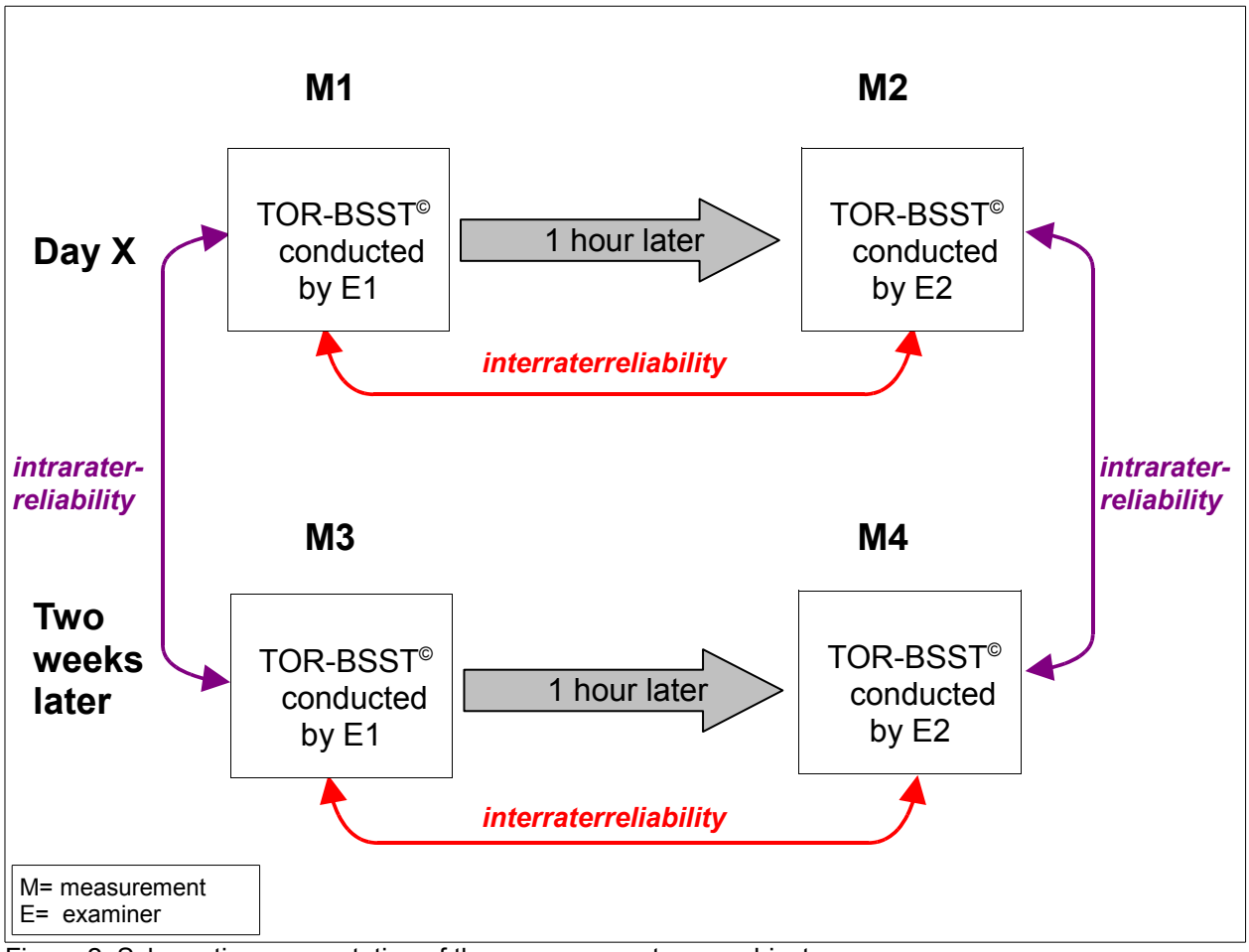


Figure 2: Schematic representation of the measurements per subject

3.5 Study population

All subjects who are part of the study are currently living on a psycho geriatric ward of a nursing home. They previously have been diagnosed with dementia by psychologists and medical doctors. To assess their present status of cognition the cognition performance scale (chapter 3.7.3) will be applied for each subject (Morris et al., 1994). Possible comorbidities, age, course of disease, gender and stage of dementia will be documented. It is planned to examine around 60 patients as part of this study. All patients of the psycho geriatric ward who meet the inclusion criteria and where a declaration of agreement is signed by their legal guardian will be part of the

study. If the number of patients who qualify is not sufficient in one ward, another ward will be searched for eligible patients. The inclusion and exclusion criteria are presented in the table below (table 1).

Inclusion criteria	Exclusion criteria
• Diagnosis Dementia • Able to sit upright • Able to do ingestion orally • Inhabitants of Sevagram • Present declaration of agreement signed through legal guardian	• Head-neck tumours • Percutaneous endoscopic gastrostomy (PEG)

Table 1: In- and exclusion criteria

3.6 Instruments

In the following paragraph all instruments used during this study will be described. This includes the Toronto Bedside Swallowing Screening Test (TOR-BSST©), a feasibility scale and the cognitive performance scale (CPS). The TOR-BSST© was used to examine the swallowing process. To determine how feasible the TOR-BSST© is for the use in patients with dementia, a feasibility scale was constructed, which will be described in more detail below. To obtain information about the cognitive status of each patient, the CPS was filled in by a nurse and afterwards analysed by the examiners of this study.

3.6.1 Toronto Bedside Swallowing Screening Test (TOR-BSST©)

The Toronto Bedside Swallowing Screening Test (TOR-BSST©) is an accurate method to identify dysphagia in stroke patients (Martino et al., 2009). Both the validity and the reliability of this screening are proven for this patient group (Martino et al., 2009).

The TOR-BSST© looks at four sections: ‘voice before’, ‘tongue movement’, ‘water swallow’ and ‘voice after’ and can be conducted by all trained staff, which means that the examiner does not have to be an expert for dysphagia. The test is a simple, yet feasible tool to identify dysphagia in stroke patients. It only takes 10 minutes or less and only a cup of water, a teaspoon and a screening form to document the findings.

The different sections of the TOR-BSST©, which are documented on the screening form, are outlined below:

A. Before water intake

1. Voice before

The speaking voice quality of the patient pronouncing 'ah' for five seconds is being assessed. Any difference in the voice quality has to be marked as abnormal by the examiner.

2. Tongue movement

The patient sticks out his or her tongue and moves it from one side to the other. The movement is being assessed by the examiner and any deviation in the movement is marked as abnormal. If the patient is not able to protrude the tongue, this will also be marked as abnormal.

B. Water intake (water swallow)

The patient swallows ten teaspoons of water. After every single swallow the patient is asked to say 'ah'. During the first few swallows the examiner slightly palpates the patient’s throat to monitor the movement of the larynx, and takes note of any abnormalities like coughing, drooling or changes to the voice quality. If any of the above occurs, it will be marked as abnormal and the test has to be stopped immediately. The examiner has to pay special attention to stifled or suppressed

cough. These have to be marked as a cough and the screening needs to be stopped. If nothing is marked as abnormal until the tenth teaspoon is swallowed, the patient is asked to drink a cup of water. The voice quality is being assessed again afterwards.

C. After water intake (voice after)

One minute after the last water swallow the voice quality of the patient is being assessed again. The procedure is the same as outlined in section A: The patient is asked to say 'ah' for 5 seconds. Any anomalies have to be marked as abnormal.

D. Results

If any of the items is marked as abnormal the patient is scored as ‘failed’. Further diagnostic tests through speech and language therapists or doctors are recommended.

3.6.2 Feasibility scale

In order to examine the feasibility of all aspects of the TOR-BSST©, a feasibility scale was constructed prior to conducting the screening. It includes the time needed, the patient’s ability of comprehension, the level of strain put on the patient and the feasibility of each section.

The time needed was recorded and noted down on the screening form. The patient’s comprehensive abilities (to what extent is the patient able to understand the instructions?) got classified by the examiner as follows: 'everything', 'almost everything', 'varying', 'almost nothing' and 'nothing (no reaction)'. To measure the strain for the patient, examiner and patient (if possible) were asked to rate the effort as 'high', 'moderate' or 'low'. To make a statement about the feasibility of each section, those that could not be completed got marked. There was also the possibility of marking that all sections or no section could be completed.

In order to get a general impression of the feasibility of the TOR-BSST©, the examiner could choose to rate it as 'good', 'difficult' or 'not possible'.

The feasibility scale also offered space for additional notes.

(See appendix II)

3.6.3 Cognitive performance scale

The 'cognitive performance scale' (CPS) is an instrument to identify the cognitive state of people. It is based on the 'Mini-Mental State Examination' and the ‘Test for Severe Impairment’ (TSI). The CPS contains the following five categories: ‘coma’, ‘short-term memory’, ‘cognitive skills for daily decision making’, ‘making self understood’ and the activities of daily living (ADL) performance indicator ‘eating’. The outcome of the CPS is divided into seven categories from zero to six: 0=intact, 1=borderline intact, 2=mild impairment, 3=moderate impairment, 4=moderate severe impairment, 5=severe impairment, 6=very severe impairment. To summarise, it can be said, that “the CPS presents a functional view of cognitive performance, defining residents’ status in the nursing home setting” (Morris et al., 1994).

3.7 Procedure

The TOR-BSST© will be conducted with around 60 subjects who suffer from dementia. Each subject will be screened four times.
During the examinations for this thesis there will be one modification to the original procedure of the TOR-BSST©: The original version asks the examiner to stop the assessment if one item is marked as abnormal. However, during the pre-tests with 8 subjects it became obvious that many of the psycho geriatric patients already failed the section 'voice quality before'. This can be due to several factors which are part of the normal ageing process – factors which were not relevant to the screening when conducted with stroke patients (i.e. in its original purpose). Taking into account the specific conditions when conducting the screening with dementia patients, the TOR-BSST© will only be cancelled after the section 'voice quality before' if there is any risk for the patient. Otherwise the screening will continue as normal.

On the first day the subject will be screened twice. The first measurement will be taken by examiner one and the second by examiner two. There will be a period of at least one hour between the two measurements.
Two weeks later, the screening will be conducted a third and fourth time (retest) by

the same two examiners who conducted screening number one and two (test). To avoid an order-bias, the order in which the examiners see the subjects changes during the tests, i.e. if examiner one had conducted the first screening, s/he will now conduct screening number four as opposed to screening number three (see figure 2). Before starting the examination, informed consent was obtained from each subject's legal guardian.

To be in a position to answer the first research question (whether or not the TOR-BSST© is feasible when used in patients with dementia) the feasibility scale will be filled in once per subject by each examiner directly after taking the first measurement.

To get information about the present state of cognition of the subject, the CPS will be completed once per subject by a nurse. Changes to the daily (physical and mental) condition of the subject and possible incidents were also noted.

In addition to the aims of the thesis described earlier, the results will deliver a general view about the relation between the results of the screening and the subjects' state of cognition.

3.8 Data processing

3.8.1 Data collection and data control

The collected data was entered into the statistic computer program SPSS 18. To ensure that the data was imported correctly, 5% of the data sets were randomly scanned on a sample control basis.

3.8.2 Data analysis

The subjects' characteristics (e.g. age, gender, comorbidity) were analysed using descriptive statistics. The same method was used again to analyse the data collected using the feasibility scale.

The inter- and intraraterreliability of the TOR-BSST© were determined using the Cohen's kappa coefficient. The Cohen's kappa can be used with nominal or dichotomic variables and is measured on a scale from 0 to 1, with 1 indicating a perfect agreement between the measuring results. A kappa value of 0.4 or less indicates little agreement and a value of 0.75 indicates a good agreement (Bouter & van Dongen, 2000).

The Spearman's rank correlation coefficient was used to examine the relation between the general feasibility of the TOR-BSST© and the state of cognition of the subjects. Additionally it was used to calculate the correlation between the subjects' state of cognition and the results of the TOR-BSST©.
The correlation coefficient is a statistic measure for the relation of two, minimal ordinal scaled variables (Kerlinger, 1979). The values of the Spearman's rank correlation coefficient range from -1 to 1, which means that there can be a positive relation as well as a negative relation. There are different ways to interpret the rank correlation coefficient (r_s).

One possible interpretation is as follows:

$0.0 \leq r_s \leq 0.2$ = no – little correlation

$0.2 \leq r_s \leq 0.5$ = slight – moderate correlation

$0.5 \leq r_s \leq 0.8$ = conspicuously correlation

$0.8 \leq r_s \leq 1.0$ = high – perfect correlation

(“Rangkorrelationskoeffizient”, 2011)

4. Results

In the following chapter the results of this study are presented. First, the characteristics of the study population are described (4.1), before the results of the feasibility scale are outlined (4.2). A representation of the results of the conducted TOR-BSST© screenings is given in chapter 4.3. On the basis of these results, the inter- and intraraterreliability are calculated and presented in chapter 4.4. The relation between the general feasibility of the TOR-BSST© and the subjects' state of cognition is outlined in chapter 4.5.

4.1 Characteristics of the study population

The population of this study consisted of 51 subjects of which 19 are male and 32 are female. The age ranged from 69 to 95 years with an average age of 82.25 years. Table 2 shows that with a mean age of 83.97 years the female subjects were older than their male counterparts whose mean age was 79.37 years. 20 of the 51 subjects had comorbidity. Most of them have had a cerebrovascular accident (CVA) (table 2). Regarding the subjects' state of cognition, most subjects had a severe impaired cognition. An overview of the occurrences of the different states of cognition is given in table 2.

Characteristics of the study population		n=51 (%)
Gender	Male	19 (37)
	Female	32 (63)
Age [SD]	Male	79.4 [5.76]
	Female	84.0 [6.38]
Comorbidity	No comorbiditiy	32 (63)
	CVA	11 (21)
	Other neurological diseases*	8 (16)
State of Cognition	Borderline intact	9 (18)
	Mild impairment	1 (2)
	Moderate impairment	12 (23)
	Moderate severe impairment	1 (2)
	Severe impairment	19 (37)
	Very severe impairment	9 (18)

*TIA, Parkinson's disease, Epilepsy, ALS and Apraxia

Table 2: Characteristics of the study population

4.2 Analysis of the feasibility scale

First the subjects' ability of comprehension (judged by the examiner) was determined. It showed that 39% of the subjects were able to understand each instruction.

When asked to judge the effort needed to participate in the examination, 61% of the subjects said it was low. The judgement of the examiners showed a low effort for 80% of the subjects.

The feasibility of the different sections of the TOR-BSST© (e.g. voice proof, tongue movement, water intake) was subdivided in three categories: 'all sections could be completed', 'none of the sections could be completed' and 'some of the sections could not be completed'. The majority (63%) of the subjects could participate in all sections. Regarding the sections that could not be completed, most subjects (82%) were not able to do the 'tongue movement'.

The general feasibility of the TOR-BSST© for patients with dementia was found to be 'good' in 59% of the cases. In 28% of the cases the execution of the TOR-BSST© was difficult. The screening could not be completed with 13% of the subjects.

The time to conduct each screening ranged from 1 to 13 minutes. The mean execution time was 4.5 minutes.

A detailed overview of all results can be found in table 3.

Sections of the feasibility scale			n (%)
Comprehension	The patient understands...	...everything	20 (39)
		...almost everything	8 (16)
		...changing	7 (13)
		...almost nothing	8 (16)
		..nothing/no reaction	8 (16)
Exposure	Judged by patient	low	31 (61)
		moderate	1 (2)
		high	0 (0)
		not possible	19 (37)
	Judged by examiner	low	41 (80)
		moderate	8 (16)
		high	2 (4)
		not possible	0 (0)
Feasibility of the different sections		all sections could be completed	32 (63)
		none of the sections could be completed	8 (16)
		some of the sections could not be completed	11 (21)
		sections that could not be completed:	
		voice before	6 (55)
		tongue movement	9 (82)
		water intake	1 (9)
		voice after	5 (46)
		total**	11 (100)
General feasibility		good	30 (59)
		difficult	14 (28)
		not possible	7 (13)
Total			51 (100)
Used time	In minutes [SD]	range	1-13
		mean time	4.5 [1.62]

*more than one answer possible

** of all patients that could not take part in each section

Table 3: results of the feasibility scale

4.3 Results of the TOR-BSST©

During each of the measurements taken, 5-7 subjects passed the screening, while either 34 or 35 subjects failed. An execution of the TOR-BSST© was not possible with either 10 or 11 subjects per measurement. The detailed results of all four measurements can be found in table 4.

Result of the screening	Number of subjects per measurement n (%)					
	M1	M2	M3	M4	Total	Average
passed	7 (14)	5 (10)	7 (14)	6 (12)	25 (12)	6.25 (12)
failed	34 (67)	35 (69)	34 (67)	34 (67)	137 (67)	34.25 (67)
not possible	10 (19)	11 (21)	10 (19)	11 (21)	42 (21)	10.5 (21)

Table 4: results of the TOR-BSST© per measurement

During the screening the subjects were asked to swallow teaspoons of water. Ideally, the subject swallowed ten teaspoons of water and a cup of water. Taking a closer look at the time where most of the subjects failed, it became obvious that the majority (23%) failed during the third swallow (figure 3). More than 80% of the subjects could only half-finish the screening because they failed between swallow one to five (figure 3).

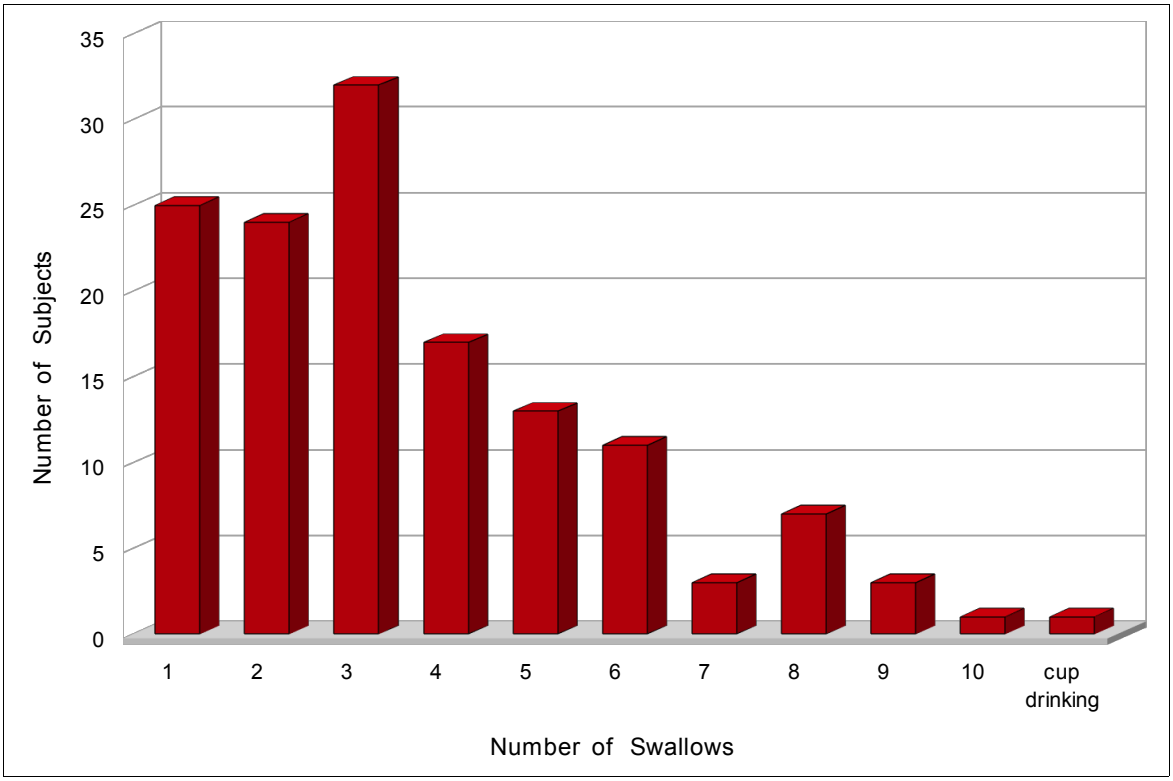


Figure 3: overview of swallows

The most common reason for failing the TOR-BSST© during this study was an observed change of the subject's voice quality in 83% of the cases (table 4). Of all failing subjects, 13% failed the screening because they coughed during or after the swallow and the screening was stopped with 4% because the subject started drooling.

Furthermore it was examined how many subjects reached the same result in all four measurements. No subject passed the screening four times. A total of 47% of all subjects failed the TOR-BSST© during all four measurements. With 10% of the subjects the execution of the screening was not possible at any of the four measurements (table 5).

Frequency of Occurrence of the Results	Number of Subjects n (%)		
	Passed	Failed	Not possible
0	38 (74)	6 (12)	35 (68)
1	4 (8)	7 (13)	4 (8)
2	6 (12)	8 (16)	3 (6)
3	3 (6)	6 (12)	4 (8)
4	0	24 (47)	5 (10)
Total	51	51	51

Table 5: occurrence of the different results

To obtain information about the correlation between the results of the TOR-BSST© and the subjects' state of cognition the Spearman's rank correlation coefficient was calculated. A significant correlation was found between the state of cognition and the subjects who passed the screening (-0.354) and the subjects where an execution of the TOR-BSST© was not possible (0.497).

4.4 Inter- and intraraterreliability

In order to analyse the inter- and intraraterreliability, cross tables were used to calculate the Cohen's kappa coefficient (table 6).

The kappa value of the interraterreliability was 0.68. Concerning the intraraterreliability, two kappa values, one per examiner, were calculated. Examiner one reached a kappa value of 0.5 and examiner two reached a value of 0.34.

Intraraterreliability Rater 1		Results TOR-BSST© M1 and M4			
		Passed	Failed	Not possible	Total
Results TOR-BSST© M2 and M4	Passed	**2**	3	/	5
	Failed	3	**29**	2	34
	Not possible	1	3	**8**	12
	Total	6	35	10	**51**

k_{r1}= 0.5

Intraraterreliability Rater 2		Results TOR-BSST© M1 and M4			
		Passed	Failed	Not possible	Total
Results TOR-BSST© M2 and M4	Passed	**2**	4	1	7
	Failed	5	**26**	4	35
	Not possible	/	3	**6**	9
	Total	7	33	11	**51**

k_{r2}= 0.31

Interraterreliability		Results TOR-BSST© M1 and M4			
		Passed	Failed	Not possible	Total
Results TOR-BSST© M2 and M4	Passed	**8**	5	1	14
	Failed	3	**61**	4	68
	Not possible	/	3	**17**	20
	Total	11	69	22	**102**

k= 0.68

Relevant data for calculation

Table 6: Cross tables of observed agreements

4.5 Relation between the general feasibility of the TOR-BSST© and the state of cognition

The Spearman's rank correlation coefficient was used to figure out whether there is a correlation between the general feasibility of the TOR-BSST© and the state of cognition of the subjects. The calculated correlation was 0.551.

Concerning the group of subjects where the feasibility was good, most participants had a moderate cognitive impairment (36.67%). With regards to the group where the general feasibility was difficult, most showed a severe impaired cognition (figure 4).

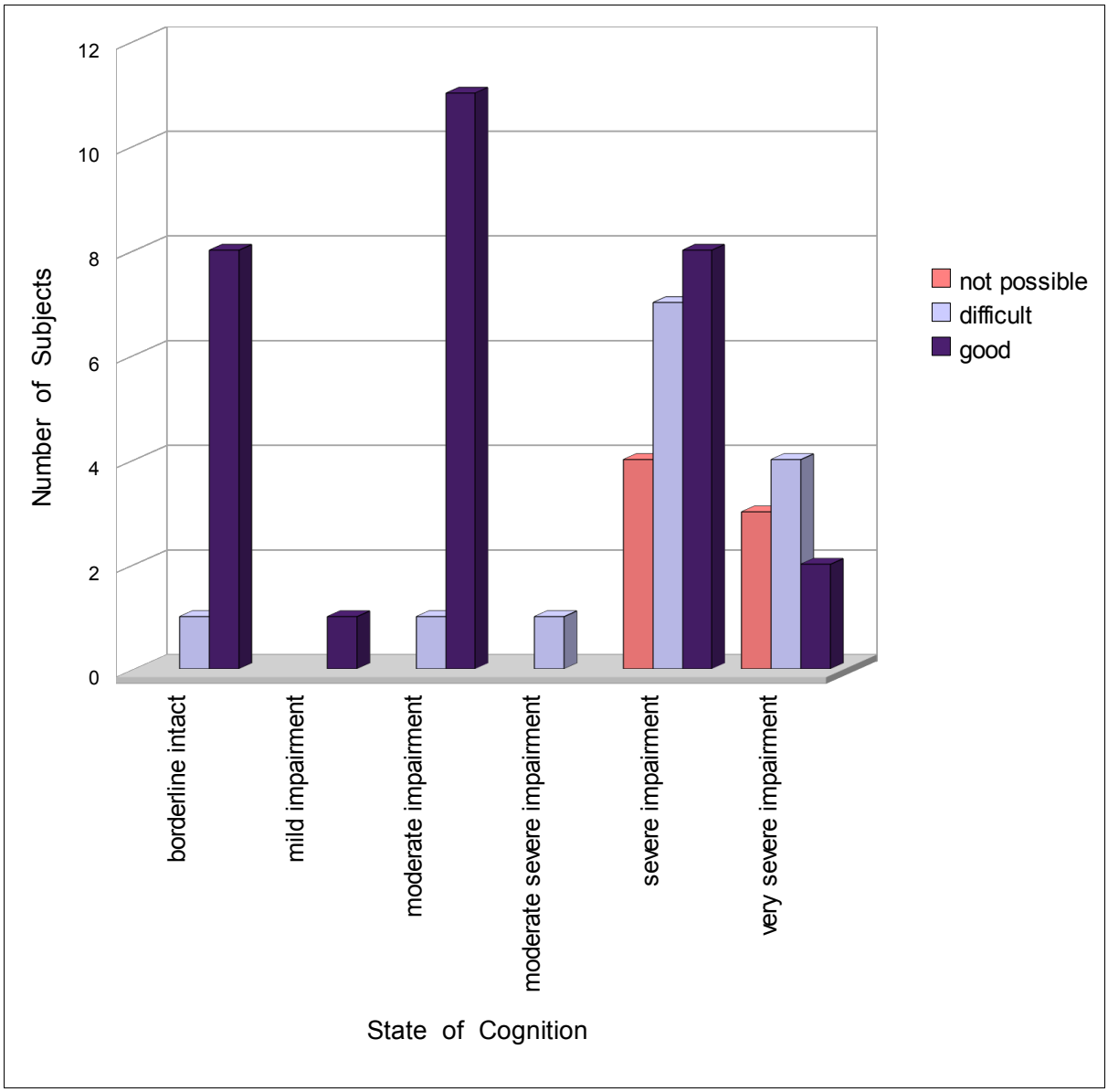


Figure 4: relation of the cognitive state and the general feasibility

5. Conclusion

Results of the feasibility scale

The TOR-BSST© seems to be a practical tool for patients with dementia. Firstly becuase both, examiners and patients, rated the effort as low and secondly because of the short execution time, with an average of only 4.5 minutes. Of all subjects, 63% were able to participate in all sections of the screening. Amongst those subjects who could not participate in all screening sections the majority was not able to carry out the tongue movement. This was not due to an inability of moving their tongue but rather the lack of understanding the instructions or a resistance towards sticking their tongue out, as this is often perceived as rude behaviour for patients of this specific generation.

Throughout this study it became obvious that there is a conspicuous correlation between the general feasibility of the TOR-BSST© and the subjects' state of cognition. Those who were not able to participate in the screening either suffered from a severe impaired cognition or a very severe cognitive impairment. This shows that the screening is less feasible for people with a more severe cognitive impairment.

Although the screening seems to be a practical tool for patients with dementia it is not fully feasible yet. The screening was feasible for only 59% of the subjects. This leads to the conclusion that adaptations become necessary in order to make the TOR-BSST© a fully feasible instrument to identify dysphagia in patients with dementia. The suggested adaptations are outlined in chapter 6.

Results of the TOR-BSST©

Looking at the results of the conducted TOR-BSST© screenings, 5-7 subjects passed the screening during each of the measurements taken, while either 34 or 35 subjects failed.

More than 80% of the subjects were not able to complete the screening because they failed between the first and the fifth swallow. This leads to the question whether the

TOR-BSST© is too difficult for dementia patients or if the majority of the participants really suffer from dysphagia.
A factor which needs to be considered at this point is the variable daily condition (i.e. physical and mental state) of the subjects: No subject passed the screening all four times and only 57% of the subjects reached the same result during each of the measurements.

The results show that there is a slight to moderate correlation between the state of cognition of the subjects and passing the screening. There is also a moderate correlation between the subjects who could not complete the screening and their state of cognition. This leads to the conclusion that the possibility to pass the TOR-BSST© decreases with a worsening state of cognition.

Results of the inter-and intraraterreliability
The interraterreliability of the TOR-BSST© equals 0.68 which means that a good agreement between the measures taken by examiner one and those taken by examiner two is given. The intraraterreliability for the first examiner resulted in a kappa value of 0.5 and for examiner two in a kappa value of 0.34. A kappa value of 0.5 proves that there is an agreement between the measurements taken by examiner one. Little agreement is indicated by the kappa value of 0.34.
Usually (i.e. in other studies) a good interraterreliability occurs in combination with a good intraraterreliability. The reason for the absence of this combination in this thesis is that the swallowing function is a fluctuating variable in every human, but especially in patients with dementia.
Moreover it is important to note that although the subjects are described as stable, dementia is an illness with fluctuating symptoms influencing the individuals' daily condition (Lind, 2000; Ouldred & Bryant, 2008; Maier, Schulz, Weggen & Wolf, 2010). Factors like the motivation to participate or even to communicate, the time and date of the examination (still in bed, directly after lunch, returning from activities) and the general physical and mental condition of a person influenced the results of the intraraterreliability.

The results of the measurements which were used to calculate the intraraterreliability were collected on two different days. This is why the possibility of a changed condition of the subject is higher compared to a time range of only one hour between the two measurements, as given for the values of the interraterreliability. That explains the unequal results of the intraraterreliability.

6. Discussion

When comparing the frequency in which subjects failed the TOR-BSST© in this study (67-69% depending on the measurement) with results that can be found in the common literature, it becomes obvious that the number of subjects who failed here is considerably higher.

It is known that an estimated 30% to 50% of all dementia patients also suffer from dysphagia (Rappold, 2001; Easterlings, 2008; Böhme, 2006a). However, in this study it could not be proven that the subjects who failed the TOR-BSST© are really suffering from dysphagia. It is also not possible to give a statement about the state of the swallowing function of the 19-21% (percentage varies per measurement) who could not participate in the screening. Nevertheless, even if only half of the subjects who failed the screening would be diagnosed with dysphagia, the prevalence of dysphagia in dementia patients in this study would still match the generally known prevalence rate of 30% - 50%.

The results of the intraraterreliability in this study were not as good as expected due to the fact that the results of the screening depended on each subjects' cooperation. Here the fluctuating daily condition of the subjects became especially obvious to the examiners. The varying conditions can influence all aspects of life, including the swallowing function. The fluctuations of dementia that could be observed here match those described in the literature (Lind, 2000; Ouldred & Bryant, 2008; Maier et al., 2010).

The majority of patients who participated in this study failed the TOR-BSST©. As a next step, it is suggested to examine whether the used screening method is too difficult for this specific patient group or if all subjects are actually suffering from dysphagia. To find out if the latter is the case, it is advisable to compare the results of the TOR-BSST© with the results of an alternative and objective screening method (such as the FEES or videofluoroscopy).

In order to make the TOR-BSST© as feasible as possible for patients with dementia some adaptations become necessary. The first screening section that should be adapted is the 'voice quality'. The original version of the TOR-BSST© demands that

the screening is aborted if a subject shows an abnormal voice quality prior to swallowing water. During the pretest conducted for this thesis it became obvious that many subjects already showed an abnormal voice quality prior to the screening because a change of voice can be a consequence of the general ageing process (Böhme, 2003). This led to the decision that the screening was not cancelled if the voice quality before the water intake showed an abnormality which was not due to a medically proven swallowing dysfunction.

During the main examination it was found that 46% of the subjects have an abnormal voice quality before the screening started, which proves that this adaptation is useful for this sample group (dementia patients). However, it is important that the trained examiner is able to decide whether the voice change is caused by an existing swallowing problem or the ageing process.

In the original version of the TOR-BSST© the section 'tongue movement' is necessary due to the fact that a tongue deviation can be a consequence of a stroke and thereby influences the swallowing process. For patients with dementia this section seems to provide no significant information about the swallowing function. The majority of the subjects could complete this task without any problems. Those who did not participate in this section did either not understand the instruction or did not want to participate.

The intraraterreliability in this study showed little to moderate agreement. As described above this is due to the fact that the swallowing function is a fluctuating variable within patients with dementia.

A limitation of this study is that the feasibility scale was only filled in once per patient which might lead to a solely partial view of the general feasibility as changes of the daily condition of the subjects could not be considered.

Recommendations for further research

Although the TOR-BSST© is a practical tool for this sample group (dementia patients) it cannot be implemented as the main screening method in its original version. As mentioned before, adaptations become necessary in order to improve the feasibility

of the screening. The adaptation that was made in this study (continuing the screening if the voice was abnormal due to the normal ageing process), should be retained in further studies. Otherwise too many subjects would not be eligible to participate in the screening. Therefore it is very important that the screener is able to identify the cause of the abnormal voice quality.

Further recommendations are to remove the 'tongue movement' section when conducting the screening with dementia patients and to reduce the number of swallows due to the fact that more than 80% of the subjects failed the screening within the first five swallows. Moreover the feasibility scale should be filled in at least on each day a measurement is taken.

As mentioned above, it is necessary to compare the results of the screening with the results of an objective method, to prove that the subjects who failed the screening really suffer from dysphagia.

After implementing these adaptations and recommendations it would be an advantage to re-test the reliability of the TOR-BSST© with dementia patients. In addition, subsequent examinations regarding the validity and generalisability could be conducted.

Recommendations for praxis

It is very important to develop a special screening for patients with dementia to detect swallowing problems. During the examinations it became obvious, that the nurses had only little knowledge about the signs of dysphagia and did not know how to handle it. For this reason it is urgently necessary to offer special training which will help the nursing staff detect and appropriately address swallowing problems of their patients. Through this, serious consequences can be prevented and this patient group will get the special attention they need.

Concerning the subjects who were part of this study, it is advisable to take a closer look at the swallowing function of those who failed the TOR-BSST© twice or more. Especially subjects with a (very) severe impaired cognition need further examination because they failed the TOR-BSST© more frequently than all other participants and

are often not able to communicate their problems. Additionally, those subjects who were not able to participate in the screening due to medical constraints should receive further examinations in order to identify whether they are suffering from dysphagia.

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Appendix I

TOR-BSST©
The Toronto Bedside Swallowing Screening Test

(addressograph)

DATE: _____ *(mm/dd/yyyy)* TIME: _____ *(hh/mm)*

A) Before water intake:

(Mark either abnormal or normal for each task.)

	Abnormal	*Normal*
1. Have patient say 'ah' and judge voice quality	☐	☐
2. Ask patient to stick their tongue out and then move it from side to side.	☐	☐

B) Water intake:

Have the patient **sit upright** and give water. Ask patient to **say "ah"** after each intake. Mark as abnormal if you note any of the following signs: **coughing, change in voice quality** *or* **drooling.** If abnormal, stop water intake and advance to 'C'.

1) One Tsp Swallows	***Cough during/after swallow***	***Voice change after swallow***	***Drooling during/after swallow***	***Normal***
Swallow 1	☐	☐	☐	☐
Swallow 2	☐	☐	☐	☐
Swallow 3	☐	☐	☐	☐
Swallow 4	☐	☐	☐	☐
Swallow 5	☐	☐	☐	☐
Swallow 6	☐	☐	☐	☐
Swallow 7	☐	☐	☐	☐
Swallow 8	☐	☐	☐	☐
Swallow 9	☐	☐	☐	☐
Swallow 10	☐	☐	☐	☐
2) Cup drinking	☐	☐	☐	☐

C) After water intake:

(Administer at least a minute after you finish Section B.)

	Abnormal	*Normal*
1. Have patient say 'ah' again and judge voice quality.	☐	☐

D) Results: ☐ Passed → Initiate referral to SLP

(no abnormal signs) ☐ Failed (1 or more abnormal signs)

Nurse's Signature: _____

January 2007 version

Appendix II

Protocol of feasibility

Name patient:_____ Date:_____(dd/mm/yyyy)

Date of birth:_____ Gender:_____

Time

Start of examination:_____(hh/mm)

End of examination:_____(hh/mm)

Time in minutes:_____

Comprehension

To what extent is the patient able to understand the instructions?*

The patient understands:

□ Everything

□ Almost everything

□ Changing

□ Almost nothing

□ Nothing (no reaction)

* judged by examiner

Exposure

Strain of the patient while doing the screening:

a. Judged by patient (if possible):

□ High □ Moderate □ Low

b. Judged by examiner:

□ High □ Moderate □ Low

Feasibility of the different sections

Are there sections that could not be done?

□ All sections could be done

□ None of the sections could be done

□ Following sections could not be done:

- □ Voice before
- □ Tongue movement
- □ Water intake
- □ Voice after

Impression of feasibility

Impression of the general feasibility through the examiner:

□ Good

□ Difficult

□ Not possible

Notes

State of cognition

The patients state of cognition investigated with the CPS*:

□ Intact cognition
□ Cognition questionable
□ Mild cognitive impairment
□ Moderate cognitive impairment
□ Significant cognitive impairment
□ Seriously impaired cognition
□ Severe cognitive impairment

*Cognitive Problemen Schaal (=Cognitive Problems Scale)

Changes between the days of measurement

Was there a worsening in the patients state between the two weeks of measurement?

□ No
□ Yes, _____

_____

Did other (important) incidents happen that might affect the patients achievement at the screening?

□ No
□ Yes, _____

_____

Appendix III

Sevagram

TOR-BSST©: een slikscreening bij psychogeriatrische verpleeghuisbewoners

Heerlen, november 2010

Geachte mevrouw/mijnheer,

Wij vragen u vriendelijk, als bewindvoerder van dhr./mw. ..... om aan een wetenschappelijk onderzoek mee te werken. In deze brief willen wij u informatie geven over het doel van het onderzoek, de te gebruiken onderzoeksprocedure en de voor- en nadelen ervan. Met behulp van deze informatie kunt u beslissen of u toestemming geeft om dhr./mw. aan het onderzoek te laten deelnemen.

Inleiding
Hoewel er nog weinig onderzoek gedaan is naar exacte cijfers over het voorkomen van slikproblemen bij psychogeriatrische verpleeghuisbewoners is bekend, dat slikproblemen veel voorkomen. Voor een optimale begeleiding bij en behandeling van eventuele slikproblemen, is het van belang deze problematiek vroegtijdig te onderkennen.

Om genoemde problematiek op een eenvoudige, accurate maar voor de bewoner niet belastende wijze op te sporen, is er door de vakgroep logopedie gezocht naar een screeningsinstrument dat voldoet aan deze criteria. Er blijkt een dergelijk instrument te bestaan, genaamd 'The Toronto Bedside Swallowing Screening Test' kort de TOR-BSST©. Dit instrument is ontwikkeld en wetenschappelijk getest door het "Swallowing Lab" in Toronto. De screening is speciaal getest bij mensen die slikproblemen als gevolg van een beroerte ontwikkeld hebben.
De resultaten van de onderzoeken hebben aangetoond, dat het gebruik van bovengenoemd screeningsinstrument 97 % van de mensen eruit filtert, waarbij sprake is van een mogelijk slikprobleem .

Doel van en toelichting bij dit onderzoek
Het doel van dit onderzoek is, om de werkbaarheid van de TOR-BSST© bij psychogeriatrische bewoners te onderzoeken. Hiervoor wordt door onze instelling meegewerkt aan een onderzoek door studenten van de Hogeschool Zuyd, sectie gezondheidszorg, logopedie.
Het onderzoek wordt uitgevoerd door twee studenten. Zij werken onder supervisie van de vakgroep logopedie Sevagram, gelicenseerde gebruikers van de TOR-BSST©. Daarnaast is er nauwe samenwerking met de ontwikkelaar van de TOR-BSST©, Dr. Rosemary Martino.

Het onderzoek bestaat uit vier meetmomenten waarvan ieder meetmoment ongeveer tien minuten tijd in beslag zal nemen. Op de eerste dag wordt de screening twee keer afgenomen met een uur rust ertussen en dan twee weken later volgen de andere twee metingen ook met een uur rust ertussen. Tijdens de meetmomenten zal de bewoner gevraagd worden om een maximum van tien theelepels water, gevolgd door een beker water te slikken. Daarbij wordt door de onderzoekers gelet op diverse relevante aspecten. De meetmomenten zullen tussen begin december 2010 en eind januari 2011 plaats vinden.
Aan het einde van het onderzoek zal gekeken worden of het gebruikte meetinstrument geschikt is voor de doelgroep en of er items vervangen cq. weggelaten dienen te worden.
De screening op zichzelf voorziet er reeds in dat deelnemers geen enkel risico lopen op enig lichamelijk letsel. Bij enige twijfel zal door de studenten beslist worden het onderzoek direct te beëindigen.

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Vertrouwelijkheid van de gegevens
De gegevens die in het kader van dit onderzoek verzameld worden, zullen vertrouwelijk worden behandeld. De gegevens worden op aparte formulieren ingevuld, waarop alleen een nummer en voor het onderzoek belangrijke gegevens zijn vermeld, niet de naam en persoonlijke gegevens. De informatie over het onderzoek wordt dus onder een code verwerkt. In evt. publicaties zal de naam niet zijn terug te vinden.

> *Wanneer het nodig is om de juistheid van de genoteerde gegevens te controleren kunnen de ingevulde formulieren door daartoe bevoegde buitenstaanders vergeleken worden met de gegevens in uw medisch dossier. Zij kunnen hiervan gebruik maken om de kwaliteit van het onderzoek na te gaan.*
> *Als u instemt met deelname geeft u tegelijk toestemming tot deze vertrouwelijke inzage in uw medische gegevens.*

Wij zullen de specialist ouderengeneeskunde, de teamleider en de locatiemanager informeren over uw deelname aan dit onderzoek.

Uw medewerking wordt gevraagd
In totaal worden 60 bewoners en hun bewindvoerder benaderd om hun medewerking te verlenen.

Wij adviseren u voldoende tijd te nemen om erover na te denken of u aan dit onderzoek wilt meewerken. Ook zult u er wellicht met anderen over willen praten. Hiervoor krijgt u uiteraard de gelegenheid.
U bent er geheel vrij in om aan dit onderzoek mee te doen. Verder heeft u altijd het recht om zonder opgave van redenen af te zien van verdere deelname aan het onderzoek.
Een beslissing om uw medewerking te beëindigen zal geen nadelige gevolgen hebben en geen invloed hebben op de zorg en aandacht waarop u in ons verpleeghuis recht hebt.

Mocht u na het lezen van deze brief, vóór of tijdens de onderzoeksperiode, nog nadere informatie willen ontvangen of komen er nog vragen bij u op dan kunt u altijd contact opnemen met de uitvoerders van het onderzoek (de studenten logopedie zoals hieronder vermeld).
Als u besluit mee te werken dan zullen wij u vragen bijgevoegde toestemminsverklaring te ondertekenen en deze uiterlijk 30 november in te leveren op de afdeling waar de deelnemende bewoner verblijft. Hiermee bevestigt u uw voornemen om aan het onderzoek mee te werken. U blijft de vrijheid behouden om wegens voor u relevante redenen uw medewerking te stoppen.

Liv Kaiser, studente logopedie, Hogeschool Zuyd, 0049-1788990555
Miriam Degutsch, studente logopedie, Hogeschool Zuyd, 0049-17666115867

Afdeling logopedie, Sevagram, 045-5602712
R. Hoonings, locatiemanager VKH-B, Sevagram

bijlage: toestemmingsverklaring

Sevagram

TOESTEMMINGSVERKLARING

voor de deelname aan een wetenschappelijk onderzoek

TOR-BSST©: een slikscreening bij psychogeriatrische verpleeghuisbewoners

Mij is als vertegenwoordiger gevraagd om toestemming te verlenen voor deelname aan bovenvermeld onderzoek door:

Naam deelnemer:

Geboortedatum:

Ik ben over het onderzoek geïnformeerd. Ik heb de schriftelijke informatie gelezen. Ik ben in de gelegenheid gesteld om vragen over het onderzoek te stellen. Ik heb over zijn/haar deelname aan het onderzoek kunnen nadenken. Ik heb het recht mijn toestemming op ieder moment weer in te trekken zonder dat ik daarvoor een reden behoef op te geven.

Ik stem toe met deelname van bovenvermelde persoon aan het onderzoek, en geef hierbij tevens toestemming voor het gebruik van zijn/haar medische- en onderzoeksgegevens, zoals omschreven in de informatiebrief.

Mijn naam :

Relatie tot de deelnemer :

Handtekening :

Datum :

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