

A Norwegian Survey of Nursing Home Workers' knowledge about Dysphagia  
Management in Dementia and Work Related Stress

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## Summary

This research interconnects the topic of dementia, dysphagia and caregiving in Norwegian nursing homes which will be comprehensively explained throughout. The aim was to first study staff's knowledge in dysphagia management and its relation to work related stress, and *it was hypothesised that higher levels of knowledge would be related to lower levels of stress*. Furthermore, this research question was also extended to study whether other confounding variables effects this association. Mainly, it was tested whether the association between knowledge and stress depends on years of experience as a function of a third, moderating variable. Hence, secondly, *it was hypothesised that the relationship between knowledge and stress would be effected by years of experience, and there would be a change in stress scores with variations in reports of knowledge and experience*. A total of 49 participants were collected using an online self-administered questionnaire. The results did not support the hypothesis of this research as knowledge in dysphagia management and work related stress were unrelated, and there was not a difference in the association between work stress and knowledge among participants with different amounts of experience. However, due to some variability in knowledge scores, this topic can mark the importance of including speech therapists in interdisciplinary teams to improve the level of competence and care provided within long-term care facilities.

## A Special Thanks.....

This Master's thesis marks the end of my educational journey, and hopefully, soon I can present myself as a Speech and Language Therapist. I wish to give a special thanks to both my supervisors of this research, Sonia Muñoz Llord and Henrik Daae Zachrisson. Thank you for your wisdom and sincere advice throughout. Thank you for being highly available and engaged, for constantly providing exhaustive feedback, and for also guiding me through with your warmth and understanding.

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## 1. Introduction

Long-term care facilities play an important role in providing care for the elderly. They are required to meet the multidimensional and complex needs of the residents (Folkehelse rapport, 2019; Spilsbury, Hewitt, Stirk & Bowman, 2011), and the working conditions in long-term care can be perceived as stressful (Ingstad & Kvande, 2011). This research is targeted towards health care workers in Norwegian long-term care facilities in order to assess their knowledge about interventions used for dementia related swallowing problems (dysphagia), and its relation to work related stress. Dysphagia may develop in the later stages of dementia (Alzheimer's Society, 2017), and the mechanisms by which swallowing difficulties occur vary with different types of dementia (Alagiakrishnan, Bhanji & Kurian, 2013). Further, health care workers bear a substantial amount of responsibility in stressful working conditions, and as per the Norwegian law, they are required to have the right competence when managing with patient care (Cohen-Mansfield, 1995; Helsedirektoratet, 2016). However, care workers' actual knowledge about dysphagia management with dementia in Norwegian long-term care units is yet unknown, and therefore a reasonable argument for conducting this research. The chapters of this thesis will thoroughly take you through this issue.

Planning and preparing research is to some degree an art, an iterative and often negotiated process (Cohen, Morrison & Manion, 2018). There are typically compromises between what one would like to do and what is actually possible (Cohen, Morrison & Manion, 2018). Initially, the aim of this research was to recruit family caregivers of patients with dementia. During the recruitment process, several limitations arose: (1) patients with dementia and dysphagia outside of institutions was challenging to detect. (2) As swallowing difficulties in dementia typically occurs during late stages of the disease, many family caregivers may not encounter this issue. (3) Gaining responses and achieving a reliable sample was therefore confined and too narrow. For these reasons, some adjustments were made to achieve greater research outcomes, and the perspective was changed to health care workers in long-term care facilities. The target population was changed from family caregivers to health care workers because (1) patients with dementia in Norway are admitted to long-term care facilities when the condition requires it. (2) Nursing home staff would therefore play an important role in caregiving and would encounter dysphagia-related situations more frequently compared to informal caregivers. (3) nursing home staffs are not

typically specialised in dysphagia, yet they are required to deliver a comprehensive care as per the law, and thus, it is essential to assess their knowledge on this topic.

The University of Oslo's requirements of structuring a thesis will be used as a foundation in this current work. An article-based format is used to construct this dissertation, which is outlined in two main parts: a so-called '**kappe**' and an **article draft**. Firstly, this thesis will provide a brief introduction to the field of speech and language therapy and its arrangement in Norway. Thereafter, the research problem will be described. Subsequently, the following topics will be elaborated in-depth within the 'kappe': (1) dementia, (2) dysphagia in dementia, and (3) caregiving by health personnel. In addition, the 'kappe' will include a description of the research design, procedure and outcomes, as well as a discussion of the limitations of the study.

The article draft is written to specifically fit the journal of Geriatric Nursing as their goals, content, research design and the sample size suits the purpose and the scope of this research. Geriatric Nursing is a comprehensive source which provides clinical information and management advice for the care of older adults, and the journal welcomes topics of interest related to long-term care facility with the aim to encourage information, education and guidelines to maximize caregivers' ability to help older adults to prevent or modify ill health (Elsevier, 2020). The 'Guide for authors' created by Elsevier will be followed and used precisely in structuring this article draft.

## 2. Speech and Language Therapy and its Constrains in Norway

Speech and language therapy covers all stages of life, from early childhood to old age, including problems with speech, language, voice and swallowing. There is no other profession that provides the same competence in these specific areas (Norsklogopedlag, 2014). Therefore, sufficient logopedic expertise in all populations is extremely important for the quality of life of many people (Norsklogopedlag, 2014). The following definition provides an understanding of the field:

*“Speech and language Pathology and Logopaedics is both a scientific domain and autonomous profession. As a science, it is at the intersection of medical, linguistic, educational and psychological sciences and focuses on etiology, assessment and intervention of communication and swallowing disorders... including screening, identification, evaluation,*

*and diagnosis...including promotion, prevention, counselling, treatment, consultation, management, (re-)habilitation and education”* (Norsklogopedlag, p. 2, 2014).

Dysphagia (swallowing problems) is one essential part of the logopedic field, and also the focus of this research. Dysphagia may develop in the later stages of dementia (Alzheimer’s Society, 2017), and its management is a team collaboration with many professionals being involved in the intervention and treatment process (Sura et al., 2012). Yet, Speech and language pathologists (SLPs) play a central role in behavioural management and therapy of dysphagia as they have the unique skills to distinguish normal ageing versus disease process impacting communication and swallowing function (Faraday, Salis & Barrett, 2019; Sura et al., 2012). Additionally, they have expertise in providing services to support and educate both formal and informal carers to facilitate positive mealtime environments (Faraday, Salis & Barrett, 2019). Moreover, as dysphagia is one feature of late stage dementia, several international guidelines for dementia specifically mention that SLPs must be included in training others who are engaged in caregiving (Alzheimer’s Society, 2017; Faraday, Salis & Barrett, 2019). This involves recommendation of strategies associated to improve the effectiveness and safety of feeding and swallowing (Faraday, Salis & Barrett, 2019).

Though the involvement of SLPs in dysphagia management is important, it seems still difficult to get access to logopedic competence in many places in Norway both for children and adults who need it (Norsklogopedlag, 2020). The municipality has a duty to provide special education where children and adults meet the conditions for requiring this, and speech therapy services can be included as a part of the special education offer (Norsklogopedlag, 2020). However, situations where assistance is provided as a part of special education must be distinguished from cases where there is a need for care as a result of illness, injury or defect. Nonetheless, this is problematic to apply in practice as the laws and regulations are not yet clear (Norsklogopedlag, 2020). From 2018, it was required that all municipalities must be committed to hire a doctor, a nurse, a physiotherapist and a midwife (Norsklogopedlag, 2020). From 2020, it was also required to have an occupational therapist, a psychologist and a dentist. However, speech therapists are not included in the list of necessity-services, and still, the municipality must ensure that the population receives the services they need in terms of health and care policies, as they are obliged to do so by law (Norsklogopedlag, 2020). Nevertheless, it is recognised that several municipalities do not fulfil their responsibility when it comes to speech therapy as the service is not on the necessity list (Norsklogopedlag, 2020). Consequently, this may affect the quality of care provided to elderly patients with dementia

and dysphagia, especially in long-term facilities, which are not specialised in logopedic competence. Therefore, this research aims to interconnect the topic of dementia, dysphagia and caregiving which will be presented in the following sections.

### 3. Research Question

Health personnel's competence is crucial for the quality of health care provided in long-term care units (Hopøy, Bakken & Bing-Jonsson, 2020). The Norwegian Health and Care Act describes the following: (1) "the individual patient or user must be given a comprehensive and coordinated health and care, (2) the individual patient or user must be given a dignified service offer, (3) the health and care service and personnel performing the services are able to comply with their statutory duties and (4) sufficient professional competence is ensured in the services" (Helsedirektoratet, p. 18, 2016). Taking care of all patients' needs can be challenging and demanding for the employees due to the medical complexity of the patients, and the working conditions in long-term care can be perceived as stressful (Ingstad & Kvande, 2011). These care settings are also confronted with situations which require certain amount of logopedic competence, especially within dysphagia. After an informal literature review of former studies, there is lack of research in Norway to assess health personnel's knowledge in dementia related swallowing problems, mainly in long-term care settings. Thus, the current research aims to first study staff's knowledge in dysphagia management and its relation to work related stress, and *it is hypothesised that higher levels of knowledge is related to lower levels of stress*. Furthermore, this research question will also be extended to study whether other confounding variables effects this association. Mainly, it will be tested whether the association between knowledge and stress depends on years of experience as a function of a third, moderating variable. Hence, secondly, *it is hypothesised that the relationship between knowledge and stress is effected by years of experience, and there would be a change in stress scores with variations in reports of knowledge and experience*. This topic can mark the importance of including speech therapists in the necessity list of services in order to improve the level of interdisciplinary competence within long-term care facilities.



# PART 1: KAPPE

Word Count: 8216

## 4. Dementia

Dementia is one of the major causes leading to disability and dependency among elderly worldwide (World Health Organisation, 2020). This disease leads to a progressive deterioration in cognitive and physical health which affects daily function, and it has become one of the greatest global challenge for health and social care workers, worldwide (Alagiakrishnan, Bhanji & Kurian, 2013; Livingston et al., 2017). In 2015, the prevalence of dementia worldwide was already at 47 million (Livingston et al., 2017) and it is estimated that the number of individuals affected will double every 20 years (Ferri et al., 2005). As the world's population ages, there will be an increasing numbers of individuals living with dementia. While the prevalence of dementia in Norway is not yet well established as many still remain undiagnosed (Folkehelse rapport, 2021; Reneflot et al., 2018), it is assumed that the number of individuals living with dementia in Norway today varies between 80 000 and 100 000 (Folkehelse rapporten, 2021).

Dementia is related to impairment in functional abilities, and in many cases, behavioural and psychiatric disturbances to such an extent that it hampers daily functioning in an individual. Not only does it affect physically, it also has a psychological, social and economic impact, on the individual affected, also on their caregivers, families and the society at large (World Health Organisation, 2020). Since Dementia is caused by various factors and has such varied symptoms, several definitions of dementia exist (National Collaborating Centre for Mental Health, 2007). One described by the International Statistical Classification of Diseases and Related Health Problems (ICD-10), which will also be utilised in this current, work, ges as follows:

*“a disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning, capability, language, and judgement. Consciousness is not impaired. Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. It occurs in Alzheimer's disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain”.* (National Collaborating Centre for Mental Health, p. 67, 2007).

The term “dementia” describes a wide range of neurodegenerative pathologies that

may include memory loss, difficulties with thinking, problem-solving and language, as well as changes in personality, mood or behaviour (Alzheimer's Society, 2017). According to the ICD-10, the diagnostic criteria for dementia includes:

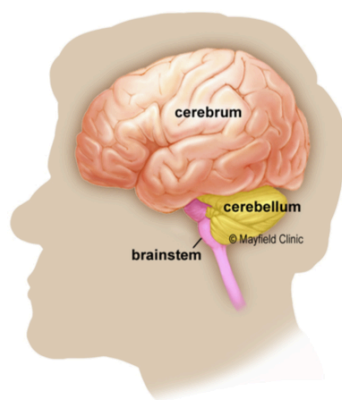
1. Impaired memory, especially recent events
2. Decline in other cognitive abilities (ex. judgment, thinking, planning)  
    The cognitive impairment must affect the functions of daily living
3. Clear consciousness
4. Decline in emotional control, motivation, or change in social behaviours with one or more of the following:
  - emotional lability
  - irritability
  - apathy
  - coarsening of social behaviours
5. The condition must have a duration of six months or more (Gjøra et al., 2020).

Due to the diversity in pathologies and symptoms of Dementia, there are several procedures to go forward with in making the diagnoses. Typically, it is recommended to collect background history of the patient, take a review of medications, administer structured cognitive assessments, gather blood tests (in some countries) and analyse neuroimaging (Livingston et al., 2017). The specific symptoms that an individual with dementia experiences depends on the parts of the brain that are damaged and the disease that is causing dementia (Alzheimer's Society, 2017). There are several common clinical conditions that result in dementia, such as Alzheimer's disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia (Alzheimer's Society, 2017).

## 4.1 The Brain and Dementia

As dementia develops and progresses, several parts of the brain are damaged (Dementia Care Central, 2020). Some factors that are important for the preservation of brain reserves are hearing, social, cognitive and physical activity (Folkehelse rapporten, 2021). Nevertheless, knowledge regarding the brain and how the disease contributes to detriment of brain tissues is crucial to understand the loss of functioning as the disease progresses (Dementia Care Central, 2020).

Figure 1. Three main parts of the brain (Brain, 2019)



The brain is composed of the cerebrum, cerebellum and the brainstem (see Figure 1). **The cerebrum** is the largest part of the brain and is composed of right and left hemispheres (Brain, 2019). It is responsible for some functions such as interpreting touch, vision and hearing, as well as speech, reasoning, emotions, learning and fine control movement (Brain, 2019). The entire cerebrum is typically divided into 4 lobes: frontal, temporal, parietal and occipital, and damage to the parietal lobes is mainly related to swallowing problems which is described subsequently (Alzheimer's Society, 2019) (see Figure 2).

*The frontal lobes* are large and complex. It is the brain's management centre, and it is responsible for handling our 'executive functions' (Alzheimer's Society, 2019). These briefly involves functions such as our attention, interest, motivation, social behaviour, our ability to solving problems, setting goals, making decisions as well as body movements (e.g. producing speech, smiling, clapping etc.). In addition, our working memory is also processed by the frontal lobes, where information is stored and processed, enabling us to make rational decisions and judgments. Thus, damage to this area may result in difficulties with following conversations, and individuals may show

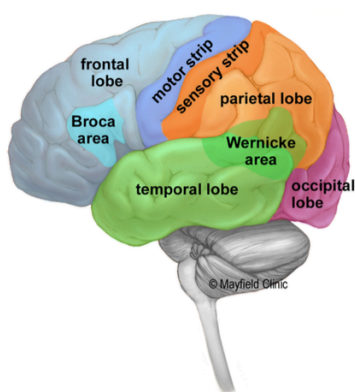
signs of apathy, lack of energy, inappropriate social behaviour etc. (Alzheimer's Society, 2019).

*The temporal lobes* are involved with some other key functions, such as general knowledge, e.g. facts (semantic memory), understanding language, hearing, dealing with visual information, such as recognising familiar objects and faces (Alzheimer's Society, 2019). Within each temporal lobe, there is a region called the hippocampus which is an area important for memory of events and experiences (episodic memory) Thus, damage to this area makes it difficult to learn new information and recall recent events (Alzheimer's Society, 2019).

*The parietal lobes* are the upper-rear part of the brain. They mainly control information about our senses – about space, sizes, touch, pain, temperature etc. (Brain, 2019). These areas help in spatial understanding of the body and objects aiding in coordinated function, such as bringing a fork to the mouth when eating (Alzheimer's Society, 2019). Damage to this area can show symptoms including impaired judgment of food temperature, as well as the ability to judge distances.

*The occipital lobes* are located at the back of the brain and interprets vision, which also involves analysing colours, shapes, light and movement (Brain, 2019). Thus, damage to this area may cause difficulties with visual perception (Alzheimer's Society, 2019).

Figure 2. The lobes of the brain (Brain, 2019)



**The cerebellum** is located under the cerebrum. It helps in coordinating muscle movements, main posture and balance (Brain, 2019). The cerebellum stores a different type of memory: skilled memory. These are procedural learned memories, such as tying a show,

playing an instrument or driving a car (Brain, 2019). Damage to this area may result in the loss of procedural skills, such as hand washing, cooking etc.

**The brainstem** plays an important role in connecting the cerebrum and cerebellum to the spinal cord. It regulates automatic functions such as breathing, heart rate, body temperature, wake and sleep cycles, digestion, sneezing, coughing, vomiting and swallowing (Brain, 2019). Damage to this area may for example lead to dizziness, fainting, sleep problems, swallowing difficulties etc. (Alzheimer's Society, 2019).

#### 4.2 Structural and Chemical Changes to the Brain

Dementia changes the structural and chemical system of the brain, which in turn affects its ability to function (Dementia Care Central, 2020). Protein clusters known as 'beta-amyloid plaques' develop and gather *between* nerve cells and twisted strands of protein called 'tau tangles' gather *inside* nerve cells, causing damage to nerve cells. These proteins are formed in areas where memory, learning and thinking occurs, causing loss of function (Dementia Care Central, 2020).

Inflammation which is a normal response to trauma caused by the build-up, also impacts the nerve cells. When in excess, the inflammation itself may also increase the tangles and therefore the damage (Dementia Care Central, 2020). Beta-amyloid and tau are also responsible for cellular damage to the brain itself. They interfere with the cell's ability to function and send messages to other neurons. As a result, less neurotransmitters are produced and communication between neurons is decreased. This creates changes in the brain (see Figure 3) where cells within the brain eventually die, brain tissue is lost and the overall size of the brain shrinks, affecting function (Dementia Care Central, 2020). As a consequence of these changes and damage to the parts of the brain, one can recognise some common signs in the main types of dementia (Alzheimer's Association, 2018), which are related to the ICD-10 symptoms.

### 4.3 Stages of Progress and Prognoses

With Dementia being a progressive disease, more parts of the brain are damaged gradually over time, and there is valuable evidence that by the time most individuals develop symptoms of dementia, the underlying disease has been causing damage to their brains for years (Alzheimer's Society, 2017). However, the first symptoms may commonly appear from the mid 60s and later, though there are many cases known as 'young-onset dementia' which typically develops before the age of 65 (Alzheimer's Society, 2017). Furthermore, the progression of dementia is often broadly distinguished between three main 'stages': mild (or early), moderate (or middle) and severe (or late). However, the stages may overlap and are not so easily distinguished as each individual will experience the disease uniquely, in their own way. (Alzheimer's Society, 2017; Alzheimer's Society, 2020; Dementia Care Central, 2020) (see Table 1). Despite that, a patient is classified into a particular stage based on their symptoms, progression and severity (Dementia Care Central, 2020), and the course of the disease ranges between 8-10 years on average (Gjøra et al., 2020). Yet the development varies greatly, and some may experience a faster rate of progression compared to others (Alzheimer's Society, 2017).

Table 1. Stages of Dementia

The mild stage	Individuals in the mild stage are mostly able to function independently, although some assistance to maximize independence and remain safe may be required. They may still be functional to drive, work and attend favourite activities (Alzheimer's Association, 2018). Patients at this stage may only present slight lapses in memory, such as misplacing items and difficulties finding the right word. On average, this stage may last between 2 and 4 years (Dementia Care Central, 2020).
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<p>The moderate stage</p>	<p>In the moderate stage, which for some may be the longest, lasts between 2 and 10 years (Dementia Care Central, 2020). Problems with performing a sequence of tasks, confusion, changes in mood and behaviour may become visible in this stage (Alzheimer's Association, 2018). Mood and behaviour disturbances may include aggression, difficulties sleeping, depression, paranoia, wandering and hoarding. Memory issues are more severe than earlier. They might forget their living address, be unable to recall personal history or become confused with the time and space. Communication becomes harder, and they might not be able to follow conversations and may experience trouble understanding what others are saying (Dementia Care Central, 2020).</p>
<p>The severe stage</p>	<p>In the severe stage of the diseases, some individuals might develop difficulties with swallowing (Alzheimer's Society, 2017), and symptoms involving the individual's physical health becomes especially apparent (Alzheimer's Association, 2018). Due to damage to areas of the brain involved in movement, individuals become bed-bounded, and may require support with basic activities of daily living such as eating, bathing, dressing and using the bathroom. Ultimately, their ability to verbalise is</p>



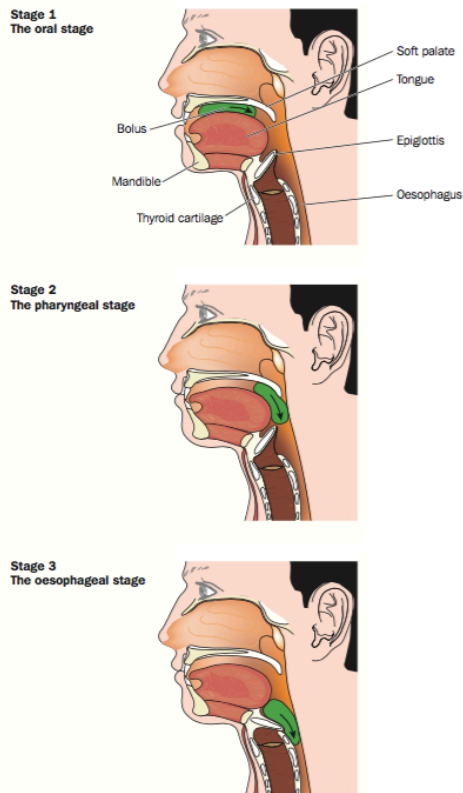
	<p>limited, and for some, hallucinations and delusions may appear (Alzheimer's Association, 2018). The severe stage of dementia typically lasts for approximately 1 to 3 years (Dementia Care Central, 2020).</p>
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## 5. Dysphagia in Dementia

It is estimated that 45% of institutionalised dementia patients have dysphagia, though the numbers are not yet well documented (Easterling & Robbins, 2008). Also in Norwegian research, this prevalence is yet unrecognised. Nonetheless, SLPs play a central role in management of patients with dysphagia, also in Norway (Sura et al., 2012; Norsklogopedlag, 2014), as they have the unique skills to distinguish normal ageing versus disease process impacting the swallowing function. They also have expertise in providing services to support and educate both formal and informal carers to facilitate positive mealtime environments (Faraday, Salis & Barrett, 2019; Sura et al., 2012).

Eating and swallowing are complex behaviours including both volitional and reflexive activities involving more than 30 nerves and muscles (Matsuo & Palmer, 2008). Individuals in the later stages of dementia may develop difficulties with swallowing (dysphagia) and chewing as a result of diminished muscle and reflex function, and thus, individuals may be at a risk of food or saliva going into the trachea (windpipe), leading to choking and/or causing an infection (Alzheimer's Society, 2017). Therefore, the process of swallowing a bolus from the mouth to the stomach without aspiration must be supported (Easterling & Robbins, 2008). In order to do so, the process of swallowing and causes of dysphagia must be understood. There are four overlapping phases involved in swallowing: the oral preparatory, the oral, the pharyngeal and the esophageal phase (See figure 4) (Easterling & Robbins, 2008).

Figure 3. Stages of swallowing (Morris, 2006)



### **The oral preparatory and the oral phase**

The oral preparatory phase is the first stage of swallowing, and it is the only phase which requires voluntary control (Kyle, 2011). It involves taking food or fluids into the mouth. The teeth, tongue and the muscles of the cheeks help in mastication of food. The food is mixed with saliva and formed into a soft mass (bolus) ready for swallowing (Kyle, 2011). During the oral phase, the muscles of the tongue and cheeks push the bolus backward in the groove between the tongue and the palate, triggering the pharyngeal swallowing response (Kyle, 2011).

### **The pharyngeal and the oesophageal phase**

Pharyngeal swallow is a rapid sequential activity, occurring within a second (Matsuo & Palmer, 2008). During this stage, several movements are involved which must be timed and coordinated precisely. The soft palate raises and closes the nasopharynx at about the same time the bolus comes into the pharynx, this is to prevent bolus' regurgitation into the nasal cavity (Matsuo & Palmer, 2008). The base of the tongue retracts, pushing the bolus against the pharyngeal walls, and the pharyngeal constrictor muscles contract sequentially from the

top to bottom, squeezing the bolus downward. Furthermore, several mechanisms contribute in preventing aspiration of foreign material to the trachea before or during swallowing (Matsuo & Palmer, 2008). The epiglottis tilts backward to seal the laryngeal vestibule and the vocal folds close to seal the glottis (the space between the vocal folds). The upper esophageal sphincter (UES), which consists of clusters of muscles, is essential for the bolus entry into the esophagus, during swallowing, it opens to allow entry of the bolus into the esophagus and reduce backflow of food and liquids from the esophagus into the pharynx (Matsuo & Palmer, 2008). During the oesophageal stage, the bolus passes through the oesophagus to the stomach (Kyle, 2011). The esophagus is a tubular structure from the lower part of the UES to the lower esophageal sphincter (LES). Once the food bolus enters the esophagus passing the UES, a peristalsis wave carries the bolus down to stomach through the LES (Matsuo & Palmer, 2008).

Dysphagia can be caused by deficits in the oral, pharyngeal or oesophageal sphincters, and can be present in a number of ways (Matsuo & Palmer, 2008; Morris, 2006). It is explained as “*difficulty moving food from the mouth to the stomach and includes problems with behavioural, sensory, and preliminary motor acts in preparation for the swallow, as well as cognitive awareness of the upcoming eating situation, visual recognition of food, and all of the physiologic responses to the smell and presence of food*” (Logemann, p. 1, 1988). Signs which may indicate possible dysphagia may include: recurrent chest infections (resulting from food or liquid entering the lungs), coughing during or after swallowing, a rattling or gurgling sound, oral regurgitation of food or liquid, nasal regurgitation, weak chewing or prolonged chewing time, loss of smell and/or taste, lack of awareness of the movement of food in the mouth, delayed swallowing reflex, weight loss and dehydration (Morris, 2006).

The high prevalence of dysphagia in individuals with dementia is a combined result of both age-related changes in sensory and motor functions as well as changes produced by the disease (Easterling & Robbins, 2008). Research shows dysfunction in certain oral motor functions with advancing age. For instance, weakened lip posture and masticatory muscle functions, as well as increasing dysfunction of the tongue might affect the ability to prepare food for swallowing (Baum & Bodner, 1983). Contrarily, results also prove that eating abilities are not a direct consequence of the aging process and many seniors in their 80s and 90s maintain their oral-motor skills (Fucile et al., 1988). Some research present that the

prevalence of swallowing impairment is higher in elderly patients with Alzheimer’s disease than in normal ageing elderly (Horner, Alberts, Dawson & Cook, 1994).

Mechanisms by which swallowing difficulties occur vary with different types of dementia (Alagiakrishnan, Bhanji & Kurian, 2013). Sensory damage can produce difficulty with bolus organization, mastication, and propulsion in the oral preparatory and oral phases. This is commonly seen in Alzheimer’s disease, leading to delayed oral transit time. While in Vascular dementia, there is a motor damage which can disrupt airway closure and pharyngeal transport, resulting in difficulty with bolus formation and mastication. Cognitive damage, on the other hand, can produce confusion and lack of recognition of the meaning of food, seen mostly in frontotemporal dementia. It presents itself a tendency to eat rapidly and compulsively, while take larger bolus sizes (Easterling & Robbins, 2008).

Table 2. Dementia types and swallowing disorders (Rogus-Pulia, Malandraki, Johnson & Robbins, 2015)

Dementia type	Findings with videofluoroscopy/FEES
Alzheimer’s disease	<p>Mild: Longer oral transit duration (OTD) for solid boluses; Longer pharyngeal response durations (PRD) and total swallow durations (TSD) for liquids; reduced hyplaryngeal movement</p> <p>Moderate: inadequate pharyngeal clearance, reduced upper esophageal opening, penetration/aspiration</p>
Vascular dementia	Difficulty with formation and mastication of semi-solid boluses; reduced hyolaryngeal movement; decreased epiglottic inversion

Dementia with Lewy bodies	Delayed pharyngeal initiation, residue, penetration/aspiration
Frontotemporal dementia	Rapid and compulsive eating; inappropriate choices for eating; larger bolus sizes; early leakage of food into pharynx during mastication; pharyngeal residue

### 5.1 Strategies to Manage Dysphagia in Dementia

As dysphagia is one feature of late stage dementia, SLPs must be included in training others who are engaged in caregiving (Alzheimer’s Society, 2017; Faraday, Salis & Barrett, 2019). This involves recommendation of strategies associated to improve the effectiveness and safety of feeding and swallowing (Faraday, Salis & Barrett, 2019). However, SLPs in Norway are not adequately included in primary health care services (Norsklogopedlag, 2020). It is argued that in order to improve the primary health care systems, interdisciplinary must be a fundamental principle, and more interdisciplinary teams must be established (Ministry of Health and Care Services, 2014), especially in cases with large and complex needs (Helsedirektoratet, 2019). As per the law, services included in the municipality’s health and care services must be integrated into a unified interdisciplinary re-/habitation programme (Forskrift om habilitering og rehabilitering, 2011, § 5). This is largely relevant in terms of dementia patients with dysphagia symptoms as they already present multidimensional needs (Hopøy, Bakken & Bing-Jonsson, 2020). In such circumstances individually adapted service offers is advised with greater collaboration across several disciplines (Helsedirektoratet, 2019). Indeed, by involving SLPs in interdisciplinary teams, several recommendations for dysphagia management can be advised to the primary health care systems to facilitate the care provided.

There are several successful swallowing interventions that can be suggested and which may benefit the oral intake of food and liquid to also protect against pneumonia and diminished nutritional status (Sura et al., 2012). A variety of strategies are available that can be applied to the characteristics of the swallowing impairment and the individual patient. No single strategy is appropriate; and a combination of multiple modifications are utilised to benefit the swallowing process (Sura et al., 2012). For instance, postural adjustments,

swallow manoeuvres, diet modification and swallow rehabilitation are some interventions that are utilised for patients with dysphagia (Sura et al., 2012). However, considering dementia and the individual's cognitive skills, and consequently their ability to follow instructions, not all of the mentioned strategies may be useful. Some most commonly recommended strategies to manage dysphagia in dementia are on one hand compensatory interventions, which involves postural adjustments and diet modifications, and on the other hand, some strategies are related to environmental modifications (Egan, Andrews & Lowit, 2020). These will be explained in depth in the following paragraphs.

### **Compensatory intervention**

Some compensatory strategies include postural adjustments of the patient and diet modifications. Compensatory therapies redirect the flow of the bolus but do not change the physiology of swallowing (Easterling & Robbins, 2008). These are aimed to have an immediate benefit on functional swallowing through simple adjustments that allow patients to continue oral diet safely (Sura et al., 2012).

Postural adjustments. Adjustments to the body and head posture may be recommended to reduce the risk of aspiration or residue (Sura et al., 2012). Patients with dementia must be placed in the optimum position; upright with 90° flexion of the hips and knees, the feet supported flat on the floor, the body and head in midline and the head flexed slightly forward and the chin down. If necessary, the patient's head and neck must be supported with the hand (Kyle, 2011).

Dietary modification. Altering the consistency of food and liquids is a fundamental aspect of dysphagia management (Garcia & Chambers, 2010). The goal of diet modification is to improve the safety and ease of oral consumption, as well as to maintain adequate intake of food/liquid (Sura et al., 2012). The degree of dietary modification must be evaluated and adjusted based on each patients' swallowing capacity and nutritional need. There are several international methods of fluid and food modifications that vary from one care setting to another (Garcia & Chambers, 2010). According to the Norwegian National Guidelines, dietary modifications are classified into several hierarchical levels ranging from 7-0 (see Helsedirektoratet, 2018 for full overview). Improper ingestion may cause problems such as recurrent pneumonias, and thus greatly affect the patient's health and general condition (Helsedirektoratet, 2018). For that reason, it is important to provide food with the appropriate

consistency level involving a multidisciplinary team for a holistic investigation to the condition (Helsedirektoratet, 2018).

### **Environmental modifications**

Research shows that eating and drinking difficulties in dementia goes beyond establishing a functional swallow (Steele et al., 1997). In dementia, challenges with mealtime can be associated with decline in physical, mental and behavioural status (Steele et al., 1997). Cognitive changes can impact the ability to anticipate, prepare for and engage at mealtimes. This may include difficulties initiating eating, maintaining attention, or recognising food or cutlery (Egan, Andrews & Lowit, 2020). These difficulties can lead to aspiration pneumonia, malnutrition and dehydration unless appropriate intervention strategies are utilised (Steele et al., 1997). Therefore, many patients are dependent on caregivers for assistance at mealtimes, and some most commonly recommended strategies that goes beyond the swallowing disorder in itself are indirect interventions (see Egan, Andrews & Lowit (2020) for full description.). These include advising caregivers and families, reducing distractions at mealtime, changing quantities of food provided, advising adapted utensils, and recommending changes to the mealtime environment (Egan, Andrews & Lowit, 2020).

Since, dysphagia in dementia can be a leading cause of death, its detection is urgently needed to initiate appropriate therapeutic measures (Rösler et al., 2015). Unfortunately, in the field of mealtime assistance for elderly, incorrect and often dangerous feeding techniques are sometimes practiced due to insufficient knowledge to apply safe and appropriate interventions (Steele et al., 1997). Therefore, caregivers must be educated and trained to meet the multiplicity of needs at mealtimes in order to recognise the need for, and initiate intervention in a proper manner (Steele et al., 1997). This must especially be recognised in long-term care facilities as health care workers in these units typically have lower educational background (Bing-Jonsson, Hofoss, Kirkevold, Bjørk & Foss, 2016), and yet they are responsible to meet complex cases where some training may be required. This is elaborated in the following section.

## 6. Caregiving by Health Personnel

Nursing homes, also called long-term care facilities have a vital role in providing care for the elderly. As the world's population is increasing, the need for nursing home care will also increase (Spilsbury, Hewitt, Stirk & Bowman, 2011). In Norway itself, approximately 80% of patients in nursing homes suffer with dementia, and nursing home staff are required to meet the multidimensional and complex needs of the residents (Folkehelse rapport, 2021; Spilsbury, Hewitt, Stirk & Bowman, 2011). Even though, according to the National Guidelines for Health Care in Norway, health personnel are required to have competence in dementia, person-centred care and treatment (Helsedirektoratet, 2019), the actual competence in dysphagia management in dementia among staff in nursing homes is yet unknown. Elderly, frail patients in the municipal health service need health personnel with sufficient clinical assessment competence, especially those with dementia (Hopøy, Bakken & Bing-Jonsson, 2020). Due to the patient's reduced ability to communicate, the risk is higher that signs of illness, symptoms and ailments are under communicated, misunderstood or are undetected (Hopøy, Bakken & Bing-Jonsson, 2020).

In Norway, most nursing homes are owned and operated by municipalities, and there are no formal staffing standards for nursing homes allowing nursing homes to decide their own staffing levels (Harrington et al., 2012). Approximately 30% of the nursing staff in Norwegian community based elderly care, are assistants without any formal health care training, and 60% of the assistant nurses are only qualified through a degree from upper secondary school (Bing-Jonsson et al., 2016). Additionally, there is little distinction between the roles and responsibilities of different types of nursing staff (Bing-Jonsson et al., 2016). Consequently, nursing staff do not have sufficient competence to secure the required care and treatment of the elderly (Bing-Jonsson et al., 2016). They lack basic nursing competence in observation, systematic assessment, initiating nursing measures, performing advanced procedures, documenting their work, and cooperating with co-workers when required (Bing-Jonsson et al., 2016). In addition, there are several areas of competence that need to be improved in order to achieve safe patient care in community based elderly care (Bing-Jonsson et al., 2016), and research from a Norwegian study revealed that staff's clinical assessment and evaluation abilities is poor in cases that are complex, difficult and diffuse. If new, unclear symptoms arise, higher competence is required to assess the right course of action (Hopøy, Bakken & Bing-Jonsson, 2020). For patients with dementia, these conditions are relevant



since cognitive impairment and age-related psychiatric diagnoses can camouflage symptoms of worsening condition and make clinical assessment more difficult (Hopøy, Bakken & Bing-Jonsson, 2020).

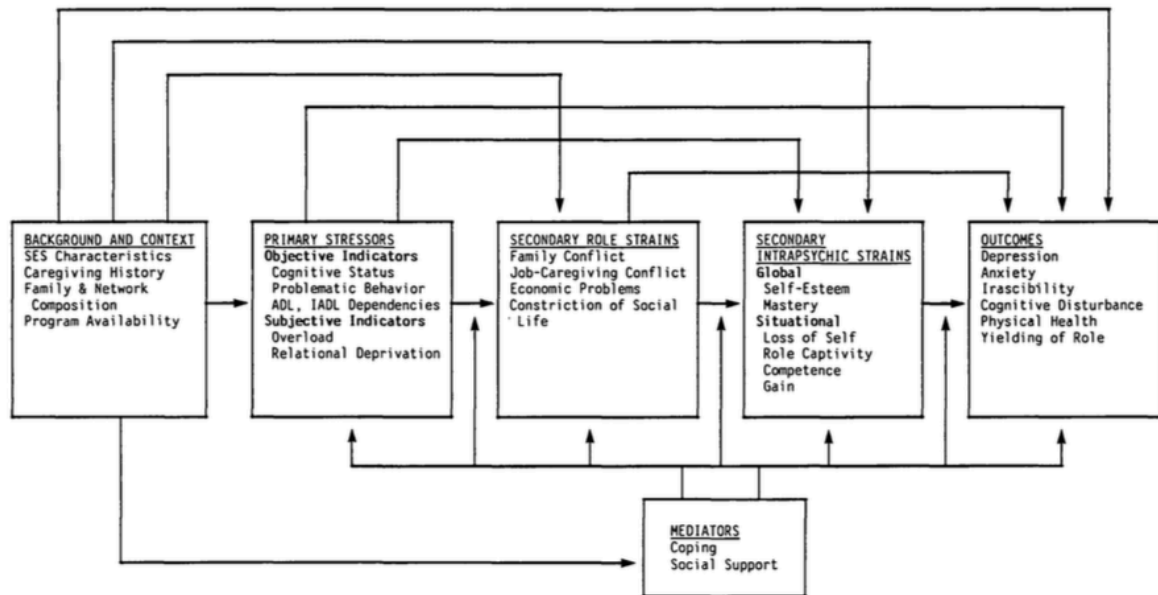
### 6.1 A Conceptual Model of Caregivers' Stress

Occupational stress is considered a major problem in nursing homes, which results in staff turnover, absenteeism and low morale (Cohen-Mansfield, 1995). The definitions of stress are many and controversy. However, most commonly it is defined as "*a physiological and psychological response to a demand or challenge leading to arousal and mobilization of an individual's capacity for coping*" (Cohen-Mansfield, p. 445, 1995). The basic concept is that stress "*relates both to an individual's perception of the demands being made on them and to their perception of their capability to meet those demands*" (McVicar, p. 633, 2003). When a discrepancy occurs, an individual's stress threshold is exceeded, triggering a stress response (McVicar, 2003).

Pearlin, Mullan, Semple & Skaff (1990) developed a framework of stress which arises when caring for individuals suffering from Alzheimer's disease, and this will be used as a basis of this research. This framework was initially developed in relation to informal caregiving, and research presents several variables associated with caregiver stress (Brodaty & Donkin, 2009). For instance, female gender, spousal caregivers, lower income or financial inadequacy are related to greater caregiving strain. Further, severity of the disease, such as more neuropsychiatric disturbances and behavioural problems, as well as impairment in basic activities is linked to higher levels of caregiver stress. Moreover, poor relationship quality, a low sense of confidence in the caregiving role, and some coping strategies is also associated with greater caregiving strain (Brodaty & Donkin, 2009). Furthermore, several elements from the framework of stress developed by Pearlin et al. (1990) could also be applied to formal caregivers as they are also closely involved in providing welfare and are committed to protect or enhance patient's well-being. For example, evidence presents that lack of professional recognition, tension in professional work relationships as well as tensions in nurse-patient relationships, work overload, lack of support, poor wages, night shifts, high job demands and job complexity are some workplace stressors among nurses (Khamisa, Peltzer & Oldenburg, 2013). These factors could be linked to the stress process model by Pearlin et al. (1990), which outlines four main areas that contribute to caregiver stress: the background and context of the caregiver, the stressors, the mediators of stress, and the outcomes or manifestations of

stress (see Figure 6). Only those that are transferable to the formal caregiving setting are elaborated subsequently.

Figure 4. A conceptual model of caregivers' stress (Pearlin et al., 1990)



**The background and context of the stress process.** Caregiving and its consequences is influenced by key characteristics of the caregiver. The effects of age, gender, and ethnicity, along with educational, occupational, and economic attainments are expected to be threaded throughout the entire stress process. These factors signify where individuals stand among others and influences the distribution of rewards, privileges, opportunities and responsibilities. The personal and social resources available to cope with the stress and the way it is expressed are all accountable to the effects of these characteristics (Pearlin et al., 1990).

**Primary and secondary stressors.** Pearlin et al. (1990) divides stressors into primary and secondary indicators. One indicator of a primary stressor is the cognitive status of the patient, such as memory loss, communication deficits, and recognition failures. In addition, the problematic behaviour of the patient and the extent of dependency for activities are also some primary source of stressors. These influence the overload and burnout felt by the caregivers.

Secondary stressors are further distinguished between roles strains and intrapsychic

strains. *Role strains* can involve conflict between caregivers and other family members. For instance, conflicts may arise due to issues of impairment: beliefs about the disability of the patients, its seriousness, and appropriate strategies for dealing with it. Moreover, *intrapsychic strains* involve dimensions of self-concept and psychological states such as self-esteem and mastery, as well as competence and gain (Pearlin et al., 1990). An aging population has led to an increased demand for competence among health personnel in nursing homes, and major knowledge gaps in several areas of competence among employees in elderly care is identified (Bing-Jonsson, 2016; Omsorg, Dale & Eikemo, 2018). Importantly, research shows that inadequate knowledge and skills for role functions is a source of work-related stress (Cohen-Mansfield, 1995).

**Buffering effects.** Some buffering effects related to caregiver stress involves coping and social support. *Coping* involves management of the situation giving rise to stress, management of the meaning of the situation, and management of the stress symptoms that result from the situation. Furthermore, *social support* consisting of assistance, caring, trustworthiness etc., may also play a buffering effect of the development of stressors (Pearlin et al., 1990). Social support explained in this model could be related to the interdisciplinary teamwork when it comes to formal caregiving. Health teams often consists of various professionals, each with specialized knowledge and responsible for different tasks (Human Resources for Health, 2021). Team work in itself can be an important intervention in health units because clinical care is becoming more complex and specialised, which may pressure health care workers to attempt complicated health services. With an interdisciplinary team, health workers can find support, communicate, share resources, and they are found to be more satisfied with their work (Human Resources for Health, 2021), which may in turn indicate reduced stress.

**Outcomes.** The outcomes typically involve the caregivers' physical and mental health. In terms of mental health outcomes, the effects of stressors may include symptom measures of depression, anxiety, irascibility, and cognitive disruptions, whereas the effects of physical health may cover limitations in their ability to engage in usual activities, and the occurrence of injuries (Pearlin et al., 1990).

**To conclude.** This theoretical framework provides a helpful grounding in understanding work related stress among nursing home staff. Pearlin et al. (1990) outlines *competence* as a secondary stressor, which makes it important to consider given the standards

of Norwegian nursing homes. Competence among nursing home staff regarding dysphagia in dementia has drawn little attention. Therefore, assessment of knowledge among nursing home staff, particularly about dysphagia management and its relation to work related stress will be the focus of this current research. In addition, other possible explanatory variables will also be included to the equation, such as educational levels, years of experience and working title, to investigate whether these effect the outcomes of stress, and mainly it will be assessed whether the association between knowledge and stress depends on years of experience as a third, moderating variable.

## 7. Research Procedure and Design

Self-administered, internet survey was used to collect information regarding knowledge about dysphagia management and work related stress among caregivers in Norwegian nursing homes. Internet surveys are becoming a predominant method of surveys as they are effective and mostly free or at low-cost. In addition, a wide target population can be attained rapidly within a short period of time (Cohen, Morrison & Manion, 2018). The aim was to collect between 40-80 participants during 16.02.21-13.04.21. Snowball sampling and purposive sampling was used as a strategy to gain access to participants for this research (e.g. via social networks and targeting various nursing homes across Norway).

Moreover, University of Oslo's safe, easy and free solution of designing an online survey, called 'Nettskjema', was used to construct a self-administered questionnaire. The survey was delivered for a pre-pilot to the supervisors involved in this research. Thereon, after receiving some clarifications and comments, the survey was sent for pilot testing to a representative of the target population. Pilot testing is an essential part of questionnaire design (Nieuwenhuijsen, 2005). It has several functions, such as to increase the reliability, validity and practicability of the questionnaire (Cohen, Morrison & Manion, 2018). The aim was to mainly gain feedback on the validity of the questionnaire items, such as to check the clarity and the wording of the questionnaire items, to identify whether the items are relevant to the respondents' experience, and to make sure that the questions are not misinterpreted. After piloting the questionnaire, a couple of items were slightly modified accordingly, and the changes were also confirmed by the mentors of this search, and only then, the survey was distributed for data collection. The changes that were made to the instruments will be further

described in the measures section.

Additionally, University of Oslo's guidelines for planning and implementing the research project was followed, which includes consent, privacy rights and data security (University of Oslo, 2018). The Norwegian Center for Research Data (NSD) provides data protection services to Norwegian research and education institutions to ensure safeguarding privacy. The University of Oslo has an agreement with NSD, and therefore, the current research project was notified to the service. Nonetheless, as the research project does not include any personal data, such as a national ID number, name or email/IP address, there was no scrambling key linking the data to a name or other identifier. For these reasons, NSD concluded that no further application to register the research project was required. Furthermore, in line with the University's routine to create a project, a consent form was prepared to the respondents. Also, confidentiality, anonymity and non-traceability of responses was ensured with the use of Nettskjema, and it also allowed for secure storage, transmission and analysis of data. However, due to anonymous responses, participants lost their rights to withdraw in the research as a clear link between each participant and their recorded response was disturbed. This was clearly explained before consent was collected, and the survey opened with an introduction which described the topic, the research problem and the aims of the research. (see Appendix).

## 8. Measures

The measurements used to develop the survey was taken from existing and relevant literature about dementia, mealtime, caregiving, nursing, and dysphagia, and supplemented with some items based on the authors' experiences of supporting individuals with dementia, and discussions with the supervisors of this research. Three topics were covered in the survey: (1) knowledge about dysphagia management in dementia, using the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ), (2) mealtime emotions, adopted from the Mealtime Emotions Measure for adolescents (MEM-A) and, (3) work stress was evaluated with the Work Stress Scale (WSS). In addition, some background variables were generated and initially assessed (see Table 5). All questions related to the three main topics were taken from international instruments which were translated by the researcher from English to Norwegian, and then modified and adjusted to suite the topic by conducting a pre-pilot and a pilot test.

**Background variables.** The first part of the questionnaire comprised questions about the respondents' background, and about their experience with, and attitude towards the topic (see Table 5).

Table 5. Background variables

<ol style="list-style-type: none"><li>1) Do you work in the elderly health care with dementia patients? (dichotomous question)</li><li>2) Where are you employed? (multiple choice question)</li><li>3) What is your working title? (multiple choice question)</li><li>4) What is your educational level? (multiple choice question)</li><li>5) Age (multiple choice question)</li><li>6) Is your education within health and social care? (dichotomous question)</li><li>7) Working experience provided in the number of months or years (open question)</li><li>8) Do you work with older or younger patients with dementia? (multiple choice question)</li><li>9) Do any of the patients have swallowing problems? (dichotomous question)</li><li>10) Are you aware that swallowing problems can develop with dementia? (dichotomous question)</li></ol>
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**Caregiver Mealtime and Dysphagia Questionnaire (CMDQ).** This instrument was constructed to assess the reasons for caregiver noncompliance with SLP recommendations (Colodny, 2008). The CMDQ was developed in three phases. During the first phase, dysphagia and mealtime needs was assessed by two SLPs in the same nursing home over a three-month period. In the second phase, non-health professional (NHP) caregivers of dependent dysphagia patients participated in a group process in which they were asked to provide their reasons for noncompliance and to rank them in order of importance. In the third and final stage, 36 NHP caregivers were interviewed individually to share their reasons for not complying with the mealtime and dysphagia recommendations of the SLP. A total of 50 items was created and reviewed by a national (in the United States of America) panel of professional SLPs who had research experience in the field. Some items were reworded and others were removed because of redundancy or lack of clarity resulting in an instrument containing 33 items using a Likert-type response modes ranging from strongly disagree (1) to

strongly agree (5). Using factor analysis, three main factors were identified based on the content: quality of life, disagreement with the SLP, and avoidance. These items in the factor analysis achieved a KMO statistic of 0.92, and all reliability of  $\alpha=0.96$  (quality of life),  $\alpha=0.87$  (disagreement with the SLP),  $\alpha=0.79$  (avoidance). Discriminant validity analysis showed that the subscales were unrelated to the demographic characteristics of the sample. Further, the intercorrelations of the three scales ranged from 0.42 to 0.73, and the distribution approximated normal curves.

Though this instrument was originally developed to assess the reasons for caregiver noncompliance with SLP recommendations, I selected nine questions which I consider to cover “knowledge about dysphagia management” addressed in the present study, and hence, these were included in the current questionnaire with some readjustments. In addition, I created nine more questions based on existing literature within dysphagia management as these cover the topic to a wider extent including more elements of compensatory interventions and environmental modifications (see Table 6). A total of 18 items were added to the questionnaire (see Appendix). Among these, 11 items were included to the analysis, showing a reliability of 0.89. Those 11 items were: *“I know what food thickeners are”*, *“I know how much food thickeners to use”*, *“I understand why food thickeners should be used”*, *“I am sure how to provide food with the appropriate consistency level”*, *“I understand why dietary modifications are recommended”*, *“I am familiar with the consistency levels that are recommended”*, *“it is necessary to give small amounts of food”*, *“I is necessary to give enough time between mouthfuls and sips”*, *“thickened liquids improves the swallowing function”*, *“it is necessary to increase concentration and reduce distractions to improve the swallowing function”*, *“I am prepared for the right course of action if the patient is choking food or liquid”*. Only these items were included to the analysis as I consider these to have face validity to cover the knowledge concept for its relevance.

Table 6. Questions created for the purpose of this study.

<ol style="list-style-type: none"> <li>1) I know what food thickeners are</li> <li>2) I am sure how to provide food with the appropriate consistency level</li> <li>3) I understand why dietary modifications are recommended</li> <li>4) I am familiar with the consistency levels that are recommended</li> <li>5) It is necessary to consider swallowing problems when choosing a diet</li> </ol>
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- 6) It is necessary to increase concentration and reduce distractions to improve the swallowing function
- 7) The atmosphere (ex. noise level) does not have anything to do with the swallowing function
- 8) I am sure which specific postural techniques to use (ex. sitting position)
- 9) I am prepared for the right course of action if the patient is choking food or liquid (ex. Heimlich Maneuver)

**Mealtime Emotions Measure for adolescents (MEM-A).** This measurement is a self-report developed to assess adolescents' emotional responses to family mealtimes (White et al., 2015). This measure was used because I was unable to find any published scale designed to measure mealtime emotions in nursing home staff. The MEM-A covered the emotional qualities I identified as relevant in the introduction. Hence, I consider the MEM-A to have face validity as a measure for the target group of the present study. The measure was developed based on existing mealtime literature from both the adolescent and clinical eating disorders field, and in collaboration with psychologists and psychiatrists working in the eating disorders and obesity fields. Finally, 13 items were retained related to three subscales: anxiety-related mealtime emotions, anger-related mealtime emotions and positive mealtimes emotions. The original measure is based around the anchor question "*how often do you feel the following during typical family mealtimes?*" (see Appendix). Participants rate how often different emotional responses are experienced on a seven-point Likert scale from never (1) to always (7). The reliability for the MEM global score was 0.86, and the concurrent validity analysis showed that MEM was largely unrelated to a measure of family mealtime atmosphere.

In this research, the original question was slightly modified to: "*how often do you feel the following during mealtimes with the patient*", and 11 items of the MEM were included, whereas the remaining 2 items were excluded as they were irrelevant for this topic. The reliability for these items were 0.83, after reverse coding two items. Instead of a seven-point scale, the Likert-scale was modified to a five-point scale ranging from never (1) to always (5) for the purpose of streamlining the response categories across scales (see Appendix).

**Work Stress Scale (WSS).** The work stress items were designed to evaluate the stress



score created by work stressors and their stress reactions among care attendants in nursing homes within Taiwan (Hsu et al., 2007). The work stress items included the characteristics of the tasks (eight items), working environment and management (nine items), interactions with patients and family (four items), knowledge and skills of the task (five items), and stress reactions (two items). The validity of the WSS was originally examined and modified by three professionals in the fields of gerontology, survey research, and health behaviour, who scored the importance, appropriateness, and accuracy of each item. Thereon, the questionnaire was pre-tested on 50 caregivers in nursing institutions in Taiwan, and based on the results, a final version of the instrument was generated with 28 items of work stress. The reliability for these items were 0.92, and the overall stress score was unrelated to background factors like age, education and salary, and related in meaningful ways to enjoyment and work schedule. Using factor analysis, six factors were extracted: insufficient ability, stressful reactions, heavy workload, care trouble, poor management, and the working time problem.

In this study, 8 questions related to insufficient ability (e.g., *“feeling lack of care skills/knowledge, unable to handle the patient’s emotional problems, unable to care well”*) stressful reactions (*“afraid of sudden change in patient’s health, nervous about taking care of severely ill, afraid of causing damage”*), heavy workload (*“lack of help from coworkers”*) and work trouble (*“patient’s bad temper”*) were included. These items were selected because I considered them to be most relevant and relatable for this specific patient target on the basis of some personal working experience in a Norwegian nursing home (see Appendix). The reliability for these items were 0.80, after reverse coding one item (“I am able to care well for the patient”). While the original response categories for WSS was “never, seldom, sometimes, usually, or always (1-5), I included a Likert-type response mode ranging from “always, almost always, sometimes, almost never, never” (1-5) because of practical reasons as to be coherent with the MEM scale.

## 9. Statistical Analysis

Correlational analysis was used to assess the relationship between staff’s knowledge in dysphagia management and work related stress. Correlation is one of the most commonly used statistical concepts (Asamoah, 2014). In general, correlational study involves two or more quantitative variables from the same group of subjects to determine whether there is a

relationship between variables, without any manipulation of variables in a controlled setting (Asamoah, 2014). Though correlation cannot prove a causal relationship, it can be used to predict a phenomena or support a theory, and thus, the stronger the relationship between variables, the more accurate the prediction is (Asamoah, 2014). However, while correlational analysis helps to determine if two variables have a relationship, it does not allow researchers to detect if one variable causes changes in another variable (Asamoah, 2014). Hence, it cannot be concluded that higher levels of knowledge *causes* low levels of work stress, or that higher levels of knowledge *decreases* work related stress.

One reason for this is that other variables might play a role, such as educational level, years of experience, working title etc., and therefore, it is always possible that there is an unknown third variable that is the true cause behind the changes in the variable that is explained (Asamoah, 2014). For these reasons, the statistical analysis was extended to multiple linear regression. However, it must be borne in mind that the results may still be biased due to other unobserved variables. Multiple linear regression is used to predict and weight the relationship between two or more independent variables and a dependent variable (Cohen, Morrison & Manion, 2018). In this research, multiple regression analysis was used to study whether knowledge, years of experience, educational levels and working title predicts a change in work related stress, and to examine their shared proportion of variance with the outcomes of stress.

Moreover, interaction terms (the product of the mean centered predictor and moderator) was included to the regression model in order to expand the understanding of knowledge and experience and its effect on work related stress. This concept was added to the regression model to investigate the moderating effects, i.e., of whether one variable varies over the values of another variable. To be more specific, moderator analyses was used to test whether the association between knowledge and work stress differs with different amounts of experience.

## 10. Summary of Results

The results of correlational analysis presented that scores of knowledge and work related stress are unrelated ( $r = -0.18$ ,  $p = 0.218$ ), and results from multiple regression analysis showed that knowledge scores did not significantly predict work related stress ( $b = -.011$ ,  $p = 0.575$ ), even after controlling for years of experience, working title and educational levels. Thus, this is inconsistent with the hypothesis which predicted that there is a relationship between knowledge in dysphagia management and work related stress. However, multiple regression analysis presented that years of experience is a significant predictor of work related stress, ( $b = -.06$ ,  $p = 0.003$ ), after controlling for knowledge scores, working title and educational levels. Thus, it seems more experience leads to reduced work related stress, but this effect is not seen with mealtime stress,  $b = -.06$ ,  $p = 0.147$ . Furthermore, moderator analyses indicate that there is not a difference in the association between work stress and knowledge among participants with different amounts of experience,  $b = 0.03$ ,  $p = 0.301$ . This is not consistent with the hypothesis as it was predicted that there would be a change in work stress scores with variations in knowledge and experience.

## 11. Research Limitations

Being able to critique research is an important skill, and consideration must be not only given to the results of the study but also the rigour of the research (Heale & Twycross, 2015). Due to the limited time scope of this thesis, and the crisis of the coronavirus disease, the sample size collected was too small and the statistical power was low. Statistical significance varies according to the size of the sample, and hence, a Type II error is likely to occur, creating a false negative result (Cohen, Morrison & Manion, 2018). Therefore, this could be one reason for the inadequate proof of the data, and it could be likely that statistical significance will be found if larger samples are used. It was calculated that a sample size of approximately 250-280 would be required to obtain statistical power of .8 in order to detect significant ( $p < .05$ ) results given the effect size obtained from the regression models.

Moreover, content validity refers to the extent to which a research instrument accurately measures all aspects of the construct, whereas construct validity refers to which a research instrument measures the intended construct (Heale & Twycross, 2015). Measurement

of knowledge in dysphagia management is a novel research idea in evidence-based practice, and thus, there are no instruments previously developed to assess this construct. Therefore, face validity was used to select appropriate questions and instruments to assess this topic. Face validity is anyhow a less rigorous method in reviewing the measure and making the determination of content. It depends highly on the researcher's judgment, and thus, this may be affected by research bias (McGartland Rubio & Kimberly, 2005). Consequently, some important items to cover the content may have been omitted. In addition, the measurement scales that were utilised were translated from English to Norwegian, and thus, some content might have been lost in translation. Therefore, this may limit both the content and construct validity of this research. Moreover, though there are National Guidelines for dietary modification in Norway, the practice varies greatly among health institutions as they have their own guidelines and systems for diet consistencies and interpretation of terms (Brierley, 2017). Consequently, the high reports of knowledge scores in this research may not truly reflect the concept being studied. Thus, future research could for instance specify the questions related to diet modifications to the National Guidelines to make sure that the intended measure is appropriately reflected in the outcome scores.

Furthermore, older adults are vulnerable at the onset of natural disasters and crisis, and this has been especially true during the coronavirus disease 2019 (covid-19) (Wang et al., 2020). With the rapid spread of severe acute respiratory syndrome, the death toll has risen worldwide, and the covid-19 pandemic has caused terrible worry for people living with dementia. To decrease the chances of infection among elderly in nursing homes, several restrictions are made by local authorities (Wang et al., 2020). For instance, visitors to nursing homes and long-term care facilities were banned. Thus, residents lost face-to-face contact with their family members, and they became more isolated. Due to the combination of fear of infection and concerns about the residents' condition, the levels of exhaustion and burnout among nursing staff was increased (Wang et al., 2020). Consequences of full lockdown of facilities might influence reports of work stress in this current research. This must be borne in mind during interpretation of the results as external validity – generalising from one situation to another might be disrupted. As well as that, we cannot anticipate the results without the crisis of the coronavirus disease. Other limitations of this study which hampers the generalizability of the findings is the study sample. There were approximately equal proportions of nurses (27%) and assistants (31%) in this study which could be one reason for high reports of knowledge scores. Therefore, it would be worthwhile to investigate whether

the results are obtained with a greater discrepancy between the proportions of nurses and assistants collected.

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# PART 2: Article Draft

A Norwegian Survey of Nursing Home Workers' knowledge about Dysphagia  
Management in Dementia and Work Related Stress

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## Abstract

*Background.* Knowledge about dementia-related dysphagia management is understudied. This topic remains important to explore as 45% institutionalised patients with dementia have dysphagia. *Aims.* The aims of this research was to explore the relationship between knowledge in dysphagia management and work-related stress among health care workers in Norwegian Nursing homes. In addition, other possible confounding variables were also included to study the outcomes of work-related stress, such as years of experience, working title and educational background. Specifically, years of experience was further studied to test its moderating role between knowledge and work stress. *Method.* Data from an online self-administered questionnaire was utilised ( $n=49$ ). *Outcomes & results.* The results revealed that scores of knowledge and work related stress are unrelated ( $r = -0.18$ ,  $p = 0.218$ ), and results from multiple regression analysis showed that knowledge scores did not significantly predict work related stress ( $b = -.011$ ,  $p = 0.575$ ), but years of experience did ( $b = -.06$ ,  $p = 0.003$ ), after controlling for years of experience, working title and educational levels. Moderator analyses showed that there is not a difference in the association between work stress and knowledge among participants with different amounts of experience,  $b = 0.03$ ,  $p = 0.301$ . *Conclusions & implications.* It would be worthwhile for future research to investigate whether the results are obtained with a larger sample size. This topic can mark the importance of including speech therapists in the necessity list of services in order to improve the level of interdisciplinary competence within long-term care facilities.

*Keywords:* knowledge, dysphagia management, dementia, nursing home

## **Introduction**

Dementia is a progressive deterioration in cognitive and physical health which hampers daily functioning in an individual. It leads to disability and dependency among elderly, and it has become one of the greatest global challenge for health and social care workers worldwide (Alagiakrishnan, Bhanji & Kurian, 2013; Livingston et al., 2017; World Health Organisation, 2020). The term “dementia” covers a wide range of neurodegenerative pathologies that may include memory loss, difficulties with thinking, problem-solving and language, as well as changes in personality, mood or behaviour. In addition, some physical symptoms may be related to reduced mobility, weight loss, difficulties with eating independently, and swallowing (Alzheimer’s Society, 2017). It affects not only physically, it also has a psychological, social and economic impact, on the individual affected, also on their caregivers, families and society at large (World Health Organisation, 2020). There are several common clinical conditions that result in dementia, such as Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementia, and these have different pathological conditions, and thus, variations in symptoms displayed (Alzheimer’s Society, 2017). In 2015, the prevalence of dementia worldwide was already at 47 million, and the numbers are expected to double every 20 years as the world’s population is aging (Ferri et al., 2005; Livingston et al., 2017). In Norway, the prevalence of dementia varies between 80 000 and 100 000, though these numbers may still be unclear as many are yet undiagnosed (Folkehelse rapport, 2021; Reneflot et al., 2018).

The clinical course of dementia, which typically ranges between 8-10 years on average (Gjøra et al., 2020), is broadly divided in three main stages: mild (or early), moderate (or middle) and severe (or late). A patient is classified into a particular stage based on their symptoms, progression and severity (Dementia Care Central, 2020). Individuals in the later stages of dementia may develop difficulties with swallowing (dysphagia) and chewing (Alzheimer’s Society, 2017), and it is estimated that 45% of institutionalised dementia patients have dysphagia (Easterling & Robbins, 2008), though the exact prevalence is yet unidentified in Norwegian statistics. Dysphagia in dementia is a result of both age-related changes in sensory and motor functions as well as changes produced by the disease (Easterling & Robbins, 2008), and mechanisms by which swallowing difficulties occur vary with different types of dementia (Alagiakrishnan, Bhanji & Kurian, 2013). For instance, sensory damage can produce difficulty with bolus organization, mastication, and propulsion in the oral preparatory and oral phases. This is commonly seen in Alzheimer’s disease,

leading to delayed oral transit time (Easterling & Robbins, 2008). While in Vascular dementia, there is a motor damage which can disrupt airway closure and pharyngeal transport, resulting in difficulty with bolus formation and mastication (Easterling & Robbins, 2008). Cognitive damage, on the other hand, can produce confusion and lack of recognition of the meaning of food, seen mostly in frontotemporal dementia. It presents itself a tendency to eat rapidly and compulsively, while take larger bolus sizes (Easterling & Robbins, 2008). With these disturbances, individuals may be at a risk of food or saliva going into the trachea (windpipe), leading to choking and/or causing an infection (Alzheimer's Society, 2017). Therefore, consequences of dysphagia may lead to weight loss, dehydration, and in worst case, a leading cause of death (Morris, 2006; Rösler et al., 2015). Its detection is therefore urgently needed to initiate appropriate therapeutic measures (Rösler et al., 2015).

Some most commonly recommended strategies to manage dysphagia in dementia involves compensatory interventions on one hand, such as postural adjustments and diet modifications, and on the other hand, some strategies are related to environmental modifications. Though compensatory interventions are aimed to reduce the risk of aspiration or residue, and to improve the safety and ease of oral consumption (Sura, Madhavan, Carnaby & Crary, 2012), eating and drinking difficulties in dementia goes beyond establishing a functional swallow (Steele et al., 1997). Cognitive changes with the disease can impact the ability to anticipate, prepare for and engage at mealtimes. This may include difficulties initiating eating, maintaining attention, or recognising food or cutlery, and many patients are dependent on caregivers for assistance at mealtimes (Egan, Andrews & Lowit, 2020). Therefore, some most commonly recommended strategies that goes beyond the swallowing disorder in itself are indirect interventions related to environmental modifications, such as advising caregivers and families, reducing distractions at mealtime, changing quantities of food provided, advising adapted utensils, and recommending changes to the mealtime environment (see Egan, Andrews & Lowit, 2020).

Importantly, dysphagia management is a team collaboration involving many professions, especially Speech and Language Pathologists (SLPs) as they play a central role in behavioural management and therapy of dysphagia (Sura, Madhavan, Carnaby & Crary, 2012). However, in Norway, it seems difficult to get access to SLPs many places despite the urgent need for more involvement of their role (Norsklogopedlag, 2014). Each and every municipalities in Norway are obliged to hire a doctor, a nurse, a physiotherapist, a midwife, an occupational therapist, a psychologist and a dentist. However, speech therapists are not included in the list of necessity-services, and still, the municipality must ensure that the



population receives the services they need in terms of health and care policies, as they are obliged to do so by law (Norsklogopedlag, 2020). Nevertheless, it is recognised that several municipalities do not fulfil their responsibility when it comes to speech therapy (Norsklogopedlag, 2020). Yet, it is argued that in order to improve the primary health care systems, interdisciplinary must be a fundamental principle, and more interdisciplinary teams must be established (Ministry of Health and Care Services, 2014), especially in cases with large and complex needs (Helsedirektoratet, 2019). In such circumstances individually adapted service offers is advised with greater collaboration across several disciplines (Helsedirektoratet, 2019). This is largely relevant in terms of dementia patients with dysphagia symptoms as they already present multidimensional needs (Hopøy, Bakken & Bing-Jonsson, 2020). Indeed, by involving SLPs in interdisciplinary teams, several recommendations for dysphagia management can be advised to the primary health care systems to facilitate the care provided. This may consequently affect the quality of care provided in some care settings, especially long-term facilities, which are not specialised in logopedic competence.

Nursing homes, also called long-term care facilities have a vital role in providing care for the elderly. In Norway itself, approximately 80% of patients in nursing homes suffer with dementia, and nursing home staff are required to meet the multidimensional and complex needs of the residents (Folkehelse rapport, 2021; Spilsbury, Hewitt, Stirk & Bowman, 2011). According to the The Norwegian Health and Care Act, the individual patient must be given a comprehensive and coordinated health and care services, the individual patient must be given a dignified service offer, the personnel performing the services must be able to comply with their statutory duties, and sufficient professional competence must be ensured in the services (Helsedirektoratet, 2016). Unfortunately, the actual competence in dysphagia management in dementia and the personal consequences among staff in nursing homes is yet unknown. This requires sufficient research as approximately 30% of the nursing staff in Norwegian community based elderly care are assistants without any formal health care training, and 60% of the assistant nurses are only qualified through a degree from upper secondary school (Bing-Jonsson, Hofoss, Kirkevold, Bjørk & Foss, 2016). Furthermore, research in Norwegian nursing homes show that there are several areas of competence that need to be improved in order to achieve safe patient care in community based elderly care and many employees lack basic nursing competence in observation, systematic assessment, initiating nursing measures, performing advanced procedures, documenting their work, and cooperating with co-workers

when required (Bing-Jonsson et al., 2016). This may especially be a matter of worry when it comes to dysphagia in dementia as the risk is higher that signs of illness, symptoms and ailments are under communicated, misunderstood or are undetected due to the patient's reduced ability to communicate (Hopøy, Bakken & Bing-Jonsson, 2020).

Moreover, facing these complex and under communicated symptoms in elderly patients with dementia, occupational stress among the staff is considered a major problem in nursing homes, which results in staff turnover, absenteeism and low morale (Cohen-Mansfield, 1995). Pearlin, Mullan, Semple & Skaff (1990) developed a framework of stress which arises when caring for individuals suffering from Alzheimer's disease, which will also be used in this current study. It outlines four main areas that contribute to caregiver stress: *the background and context of the caregiver* (e.g. age, gender, ethnicity, educational, occupational and economic achievements), *the primary and secondary stressors* (e.g. primary stressors, such as patient's cognitive status, problematic behaviour and the extent of dependency for each activity, as well as secondary stressors, such as relational conflicts, self-esteem, competence and gain), *the mediators of stress* (e.g. coping strategies and social support), and *the outcomes or manifestations of stress* (e.g. the caregivers' physical and mental health). Some work related stressors for care attendants could be viewed in relation to this framework. For instance, studies show that work stressors comes from a variety of sources (Hsu et al., 2007), such as working place/nursing role, lack of professional recognition, professional uncertainty, interpersonal and family conflicts, tension in professional work relationships as well as tensions in nurse-patient relations. In addition, working over-time and too frequent night duties, poor wages, lack of support and inadequate nursing personnel, high job demands and job complexity are also some predictors of emotional exhaustion and mental distress (Khamisa, Peltzer & Oldenburg, 2013).

Importantly, Pearlin et al. (1990) outlines *competence* as one secondary stressor, and which makes it important to consider given the standards of Norwegian nursing homes where caregivers are not typically specialised in dysphagia, and yet they are required to deliver a comprehensive care as per the law. According to the National Guidelines for Health Care in Norway, health personnel are required to have competence in dementia, person-centred care and treatment (Helsedirektoratet, 2019). However, the actual competence in dysphagia management in dementia among staff in Norwegian nursing homes is yet unknown. This understudied topic is essential because clinical care is becoming more complex and specialised, which may pressure health care workers to attempt complicated health services (Human Resources for Health, 2021). Due to this, services included in the health and care

services must be integrated into a unified interdisciplinary re-/habitation programme (Forskrift om habilitering og rehabilitering, 2011, § 5). Interdisciplinary teamwork can be related to *social support* explained in Pearlin et al. (1990)'s model, which can be an important intervention in health units to find support, communicate and share resources. Hence, staff's knowledge in dysphagia management and its relation to work related stress will be the focus of this research in order to justify the need for including SLPs in interdisciplinary teams within primary health care units. In addition, this research question will also be extended to study whether other confounding variables effects this association, such as years of experience, working title and educational levels. Mainly, it will be tested whether the association between knowledge and stress depends on years of experience as a function of a third, moderating variable. Thus, firstly it is hypothesised that higher levels of knowledge is related to lower levels of stress. Secondly, it is hypothesised that the relationship between knowledge and stress is affected by years of experience, and there would be a change in stress scores with variations in reports of knowledge and experience.

## **Method**

### *Design and Procedure*

University of Oslo's safe, easy and free solution of designing an online survey, called 'Nettskjema', was used to construct a self-administered questionnaire which took approximately 10-15 minutes to complete. The University of Oslo's guidelines for planning and implementing a research project was thoroughly followed, which involves consent, privacy rights and data security (University of Oslo, 2018). The survey opened with an introduction which described the topic, the research problem and the aims of the research, followed by explaining the guarantees of confidentiality, anonymity and non-traceability. However, due to anonymous responses, participants lost their rights to withdraw in the research as a clear link between each participant and their recorded response was disturbed. This was clearly explained before consent was collected (see Appendix). As the research project does not include any personal data, such as a national ID number, name or email/IP address, there was no scrambling key linking the data to a name or other identifier. For these reasons, The Norwegian Center for Research Data (NSD) concluded that no further application to register the research project was required.

### *Participants*

The study used a targeted sampling strategy, i.e. snowball sampling and purposive sampling to access nursing home staff. Initially, snowball sampling was used to identify individuals and to put in touch with others who qualify for inclusion, and then, purposive sampling was chosen to target nursing homes to access staff who encounter with the subject of interest. The data collection commenced between 16.02.21 and 13.04.21. A total of 49 participants were included. Inclusion criteria for the targeted sample were nursing home staff with the following working titles: “nurses, auxiliary nurses, health care workers, social educators, assistants, unskilled assistants”, with no minimum experience specified. Sampling across Norway was considered as appropriate as their long-term care facilities are comparable. For further description of sample characteristics see Table 1.

### *Measures*

Survey items were developed based on dementia, mealtime, caregiving and dysphagia literature, and supplemented with some items based on the authors’ experiences of supporting individuals with dementia, and discussions with the supervisors of this research. Three topics were covered in the survey: (1) knowledge about dysphagia management in dementia, using the Caregiver Mealtime and Dysphagia Questionnaire (CMDQ), (2) mealtime emotions, adopted from the Mealtime Emotions Measure for adolescents (MEM-A) and (3) work stress was evaluated with the Work Stress Scale (WSS). In addition, some background variables were generated and initially assessed. All questions were taken from international instruments which were translated by the researcher from English to Norwegian, and then modified and adjusted to suite the topic after a pre-pilot and pilot test (see Appendix).

**Background variables.** The first part of the questionnaire comprised questions about the respondents’ background and about their experience with, and attitude towards the topic.

**Caregiver Mealtime and Dysphagia Questionnaire (CMDQ)** was used to assess knowledge about dysphagia management. This instrument was originally developed in American nursing home settings which was constructed to assess the reasons for caregiver noncompliance with SLP recommendations, including 33 items (Colodny, 2008). Using factor analysis, three main factors were identified based on the content: quality of life, disagreement with the SLP, and avoidance. These items in the factor analysis achieved a KMO statistic of 0.92, and all reliability of  $\alpha=0.96$  (quality of life),  $\alpha=0.87$  (disagreement with the SLP),

$\alpha=0.79$  (avoidance). Discriminant validity analysis showed that the subscales were unrelated to the demographic characteristics of the sample. Further, the intercorrelations of the three scales ranged from 0.42 to 0.73, and the distribution approximated normal curves.

Though this instrument was originally developed to assess the reasons for caregiver noncompliance with SLP recommendations, I selected nine questions which I consider to cover “knowledge about dysphagia management” addressed in the present study, and hence, these were included in the current questionnaire with some readjustments. In addition, I created nine more questions based on existing literature within dysphagia management in order to cover the topic more broadly, including more elements of compensatory interventions and environmental modifications. A total of 18 items were added to the questionnaire in this study using a Likert-type response modes ranging from strongly disagree (1) to strongly agree (5). Among these, 11 items were included to the analysis, showing a reliability of 0.89.

**Mealtime Emotions Measure for adolescents (MEM-A)** is a self-report developed to assess adolescents’ emotional responses to family mealtimes (White et al., 2015). This measurement was used because equivalent instruments for the current target population is lacking. The MEM-A comprises items with high face validity for the target population of the present study. In total, 13 items were retained related to three subscales: anxiety-related mealtime emotions, anger-related mealtime emotions and positive mealtimes emotions. The reliability for the MEM global score was 0.86, and the concurrent validity analysis showed that MEM was largely unrelated to a measure of family mealtime atmosphere. The measure is based around the anchor question “*how often do you feel the following during typical family mealtimes?*”.

This question was slightly modified to suite the target of this research (“*how often do you feel the following during mealtimes with the patient?*”), and 11 items of the MEM-A were included using a Likert-type response modes ranging from never (1) to always (7), whereas the remaining 2 items were excluded as they were viewed as irrelevant for this topic. The reliability for these items were 0.83, after reverse coding two items. Instead of a seven-point scale, the Likert-scale was modified to a five-point scale ranging from never (1) to always (5), to streamline response categories across measures.

**The Work Stress Scale (WSS)** consists of 28 items which were designed to evaluate the stress score created by work stressors and their stress reactions among care attendants in nursing homes within Taiwan (Hsu et al., 2007). These items included the characteristics of the tasks (eight items), working environment and management (nine items), interactions with patients and family (four items), knowledge and skills of the task (five items), and stress reactions (two items). The reliability for these items were 0.92, and the overall stress score was unrelated to background factors like age, education and salary, and related in meaningful ways to enjoyment and work schedule. Using factor analysis, six factors were extracted: insufficient ability, stressful reactions, heavy workload, care trouble, poor management, and the working time problem.

In this study, 8 questions related to insufficient ability (e.g., *“feeling lack of care skills/knowledge, unable to handle the patient’s emotional problems, unable to care well”*) stressful reactions (*“afraid of sudden change in patient’s health, nervous about taking care of severely ill, afraid of causing damage*), heavy workload (*“lack of help from coworkers”*) and work trouble (*“patient’s bad temper”*) were included. These items were selected because I considered them to be most relevant and relatable for this specific patient target on the basis of some personal working experience in a Norwegian nursing home. The reliability for these items were .80, after reverse coding one item. While the original response categories for WSS was “never, seldom, sometimes, usually, or always (1-5), I included a Likert-type response modes ranging from “always, almost always, sometimes, almost never, never” (1-5) because of practical reasons as to be coherent with the MEM scale.

## **Results**

**Descriptive and Preliminary Analyses.** Mean values, standard deviations (for continuous measures) and percentages (for categorical measures) can be seen in Table 1. There were no missing responses. Of particular note is that the means for work related stress and stress related to the feeding situation is 2.54 and 2.49 on a 5-point scale (i.e., approximately [2] “almost never” on the Likert scale), yet with some variability (standard deviations of 0.94 and 0.54, respectively). Moreover, my key predictor, knowledge, had a rather high mean value (4.16 on a 5-point scale), indicating that the survey participants were rather knowledgeable with regard to the feeding situation. Yet, again, a standard deviation of 0.76 shows that there is sample variability. It could be interesting to further explore in staff’s knowledge due to this variability, which may highlight the importance of involving more

SLPs in interdisciplinary teams within long-term care units. Moreover, in terms of work experience (the moderator in research question 2), participants had a mean of 7.68 years of experience, with a standard deviation of 6.92. Hence, participants had quite extensive work experience.

Table 1. Descriptive statistics. (N=49)

	M (SD)/%	Min-Max
Experience	7.68(6.92)	0.50 – 30.00
Mealtime stress	2.49(0.94)	1-5
Knowledge	4.16(0.76)	1.73 – 5.00
Work-related stress	2.54(0.54)	1.25 – 4.25
Working title		
Nurse	27 %	
Health care worker	14 %	
Auxiliary nurse	14 %	
Social educators	2 %	
Assistant	31 %	
Unskilled assistant	10 %	
Other	2 %	
Educational level		
Higher education more than 3 years	47 %	
Higher education between 1- 3 years	29 %	
Higher education between 1-3 years/upper secondary school with specialization in studies	2 %	
Upper secondary school with specialization in studies	8 %	
Other	2 %	

In Table 2 I present bivariate correlations (Pearson's  $r$ ) between all key variables in the analyses. In these bivariate analyses, work related stress and stress in the feeding situation was correlated .58 ( $p < .001$ ), which means that participants who report more work related stress, also tend to report higher stress in the feeding situation. Yet, with a shared (standardised) variance of about .3, the two constructs should be considered as quite independent, and can thus be included as separate dependent variables in the subsequent analyses. Knowledge and work stress are, in these bivariate analyses unrelated ( $r = -0.18$ ,  $p = 0.218$ ), and stress related to the feeding situation and knowledge is also unrelated ( $r = -0.05$ ,  $p = 0.709$ ). Hence, these result are inconsistent with the hypothesis which predicted that there is a relationship between knowledge in dysphagia management and work related stress. Inspections of scatter plots indicated that there were no non-linear relationships among the variables in Table 2.

Table 2. Correlation Matrix

		Knowledge	Work stress	Experience	Mealtime stress
Knowledge	Pearson's r	—			
	p-value	—			
Work stress	Pearson's r	-0.18	—		
	p-value	0.218	—		
Experience	Pearson's r	0.38	-0.43	—	
	p-value	0.008	0.002	—	
Mealtime stress	Pearson's r	-0.05	0.58	-0.11	—
	p-value	0.709	<.001	0.472	—

**Multivariate Analyses of Work-Related Stress and Knowledge.** In order to further probe research question one, I used multiple linear regression to investigate whether the association between work related stress and knowledge is conditional on years of experience, working title and educational levels. Initial data inspection showed that with regard to “experience”, there were a few extreme values (20-30 years of experience). I therefore truncated this variable at the 90<sup>th</sup> percentile (13.69 years) to avoid biased estimates from these extreme values. The results can be seen in Table 3. Conditional on these background variables, knowledge scores did not significantly predict work related stress,  $b = -.011$ , ( $p = 0.575$ ). However, years of experience is a significant predictor of work related stress, after controlling for knowledge scores, working title and educational levels,  $b = -.06$  ( $p = 0.003$ ). This indicates that less experience is related to higher levels of work stress, which is coherent with the assumptions. Moreover, the R square of the full model (including covariates) was .45, which suggests that the full model accounts for a meaningful proportion of reported work related stress. I also checked model assumptions (residual plots, shapiro-wilk, collinearity) which indicated that the analysis did not violate any basic regression assumptions.

**Moderator Analyses of Work-Related Stress, Knowledge, and Experience.** In the next analyses, I tested research question 2, whether the association between knowledge and work related stress varies as a function of work experience. I added an interaction term (the product of the mean centered predictor and moderator) to the model described above. The



results did not show an interaction effect,  $b=0.03$  ( $p=0.301$ ). This indicates that there is not a difference in the association between work stress scores and knowledge among participants with different amounts of experience. This is not consistent with the hypothesis as it was predicted that there would be a change in work stress scores with variations in knowledge and experience.

Table 3. Work Related Stress

	Model 1: Main effects	Model 2: Interaction effects
Knowledge	-0,03 (0,14) [0,803]	0,11 (0,2) [0,575]
Experience	-0,05 (0,02) [0,004]	-0,06 (0,02) [0,003]
Educational level: Reference level: 1 (higher education more than 3 years)		
Higher education between 1-3 years – 1	-0,03 (0,18) [0,85]	-0,03 (0,18) [0,863]
Higher education between 1-3 years/Upper secondary school with specialization in studies – 1	0,34 (0,56) [0,549]	0,34 (0,56) [0,542]
Upper secondary school with specialization in studies – 1	-0,53 (0,31) [0,098]	-0,55 (0,32) [0,087]
Upper secondary school with vocational studies – 1	-0,38 (0,27) [0,179]	-0,34 (0,28) [0,219]
Other– 1	-0,19 (0,55) [0,737]	-0,11 (0,56) [0,85]
Working title: Reference level: 1 (Nurse)		
Health care worker – 1	0 (0,31)	-0,02 (0,31)

		[0,988]	[0,959]
Auxiliary nurse – 1	-0,2	(0,26)	(0,26)
		[0,45]	[0,437]
Social educators – 1	-0,19	(0,51)	(0,53)
		[0,708]	[0,524]
Assistant – 1	-0,2	(0,23)	(0,23)
		[0,375]	[0,386]
Unskilled assistant – 1	-0,5	(0,36)	(0,36)
		[0,172]	[0,202]
Other – 1	-1,48	(0,53)	(0,53)
		[0,008]	[0,01]
Knowledge X Experience			0,03
			(0,03)
			[0,301]

*Note:* Standard error in parantheses and partial correlations in brackets.

**Multivariate Analyses of Mealtime Stress and Knowledge.** Next, I used the same analyses as described above to investigate whether the association between mealtime stress and knowledge is conditional on years of experience, working title and educational levels. The results can be seen in Table 3a. Conditional on these background variables, knowledge scores did not significantly predict mealtime stress,  $b = -.08$ , ( $p = 0.835$ ), even after controlling for some background variables. Neither was years of experience a significant predictor of mealtime stress, after controlling for knowledge scores, working title and educational levels,  $b = -.06$  ( $p = 0.147$ ). Moreover, the R square of the full model (including covariates) was .33. These results are not consistent with the assumptions.

#### **Moderator Analyses of Mealtime Stress, Knowledge, and Experience.**

Again, in the next analyses, I tested research question 2, whether the association between

knowledge and mealtime stress varies as a function of work experience. I added an interaction term (the product of the mean centered predictor and moderator) to the model described above. The results did not show an interaction effect,  $b=0.04$  ( $p=0.525$ ). This indicates that there is not a difference in the association between mealtime stress scores and knowledge among participants with different amounts of experience. This is not consistent with the hypothesis as it was predicted that there would be a change in mealtime stress scores with variations in knowledge and experience.

Table 3a. Mealtime Stress

	Model 1: Main effects	Model 2: Interaction effects
Knowledge	-0,25 (0,26) [0,349]	-0,08 (0,37) [0,835]
Experience	-0,04 (0,03) [0,18]	-0,06 -0,04 [0,147]
Educational level: Reference level: 1 (higher education more than 3 years)		
Higher education between 1-3 years – 1	-0,11 (0,34) [0,756]	-0,1 -0,34 [0,766]
Higher education between 1-3 years/Upper secondary school with specialization in studies – 1	1,3 (1,05) [0,224]	1,31 (1,06) [0,226]
Upper secondary school with specialization in studies – 1	-0,94 (0,6) [0,122]	-0,97 (0,6) [0,117]
Upper secondary school with vocational studies – 1	0,54 (0,52) [0,302]	0,58 (0,53) [0,279]
Other– 1	0,12 (1,04) [0,912]	0,21 (1,06) [0,844]

Working title:

Reference level: 1 (Nurse)		
Health care worker – 1	-0,05 (0,59) [0,929]	-0,08 (0,6) [0,898]
Auxiliary nurse – 1	-0,5 (0,48) [0,308]	-0,51 (0,49) [0,306]
Social educators – 1	-0,37 (0,97) [0,703]	-0,54 (1,01) [0,594]
Assistant – 1	-0,57 (0,43) [0,188]	-0,57 (0,43) [0,197]
Unskilled assistant – 1	-1,33 (0,67) [0,057]	-1,29 (0,68) [0,068]
Other – 1	-2,2 (1) [0,034]	-2,15 (1,01) [0,04]
Knowledge X Experience		0,04 (0,06) [0,525]

*Note:* Standard error in parantheses and partial correlations in brackets.

**Post Hoc Power Analyses.** I conducted a post hoc power analyses to test the statistical power of the knowledge variable. Unfortunately, due to the small effect, this was very low ( $>.1$ ). Subsequently, I tested the power of the interaction term. This was .22. Thus, there may be a substantial risk for making a Type II error when concluding that knowledge is not associated with stress and work related stress. A sample size of approximately 250-280 would be required to obtain statistical power of .8 in order to detect significant ( $p<.05$ ) results given the effect size obtained from the regression models.

## Discussion

Knowledge about dysphagia management, especially related to dementia has drawn little attention in current literature, and there are no studies up to date targeting health care workers in long-term care settings with this subject of interest. Consequently, the aim of this research was to investigate knowledge in dementia-related dysphagia management and its relation to work related stress among health care workers in long-term care units, especially in Norwegian nursing homes. Pearlin et al. (1990) stated competence as one source related to outcomes of stress, however, participants in this study presented high scores of knowledge in dysphagia management, and knowledge scores were unrelated to work-related stress. This therefore did not support the hypothesis of this research. Nevertheless, though there are National Guidelines for dietary modification in Norway, the practice varies greatly among health institutions as they have their own guidelines and systems for diet consistencies and interpretation of terms (Brierley, 2017). Consequently, the high reports of knowledge scores in this research may not truly reflect the concept being studied. In addition, scores of knowledge showed some variability, indicating that there might still be some knowledge gaps in dysphagia management among health care workers in nursing homes, which may require further investigation. Therefore, as Pearlin et al. (1990) presents social support as a buffering effect of stress, involvement of SLPs in an interdisciplinary team might be beneficial, not only in terms of work stress, but also in terms of educating and improving the interdisciplinary care delivered in primary health care units.

Additionally, it seems like less amount of experience is related to higher levels of work-related stress, and this outcome is coherent with some previous findings (Cohen-Mansfield, 1995). This could also relate to the theoretical framework by Pearlin et al. (1990), which presented that caregivers background, such as occupational attainments are relatable to an individual's availability to cope with the stress. Furthermore, Pearlin et al. (1990) also explained that some sources related to stress could be considered as buffering effects, and years of experience was therefore included as a possible moderator between work-related stress and knowledge. The results however, revealed that years of experience did not function as a moderator, and there is no difference in the association between work-stress and knowledge among participants with different amounts of experience. Hence, this outcome is also inconsistent with the hypothesis.

Nonetheless, the stress process model by Pearlin et al. (1990) may serve with some

limitations. Though it includes several individual characteristics and relational factors related to outcomes of stress in terms of informal caregiving, it does not emphasise organisational, contextual or cultural factors associated with formal caregiving which could be applied to the Norwegian primary health care system. Additionally, Pearlin et al. (1990) presents outcomes of stress as an overall well-being without a clear definition, where other terms such as ‘burnout’ and ‘strain’ are also used simultaneously. Work stress presented in this research is however not related to an individual’s overall health, but rather to stress felt by care attendants in common situations within nursing homes, and thus, this must be given some consideration in interpretation of the concept of ‘stress’.

Furthermore, one reason for not finding supporting data could be related to the small sample size. Due to the limited time scope of the research, and the crisis of the coronavirus disease, the sample size collected was too narrow and the statistical power was low, and thus, making a Type II error, such as false negative is likely. A larger sample size of approximately 250-280 may be required to detect supporting results given the effect size obtained from the regression models. Secondly, measurement of knowledge in dysphagia management is a novel research idea in evidence-based practice, and thus, there are no instruments previously developed to assess this construct. Therefore, face validity was used to select appropriate questions and instruments to assess this topic. Face validity is anyhow a less rigorous method in reviewing the measure and making the determination of content. It depends highly on the researcher’s judgment, and thus, this may be affected by research bias (McGartland Rubio & Kimberly, 2005). Consequently, some important items to cover the content may have been omitted. In addition, the measurement scales that were utilised were translated from English to Norwegian, and thus, some content might have been lost in translation. Therefore, this may limit both the content and construct validity of this research and the intended measure may not be appropriately reflected in the outcome scores. Moreover, other limitations of this study which hampers the generalizability of the findings is the study sample. There were approximately equal proportions of nurses (27%) and assistants (31%) in this study which could be one reason for high reports of knowledge scores. Therefore, it would be worthwhile for future research to investigate whether the results are obtained with a greater discrepancy between the proportions of nurses and assistants collected as well as with a larger sample size.

**Conclusion**

This topic can mark the importance of including speech therapists in the necessity list of services in order to improve the level of interdisciplinary competence within long-term care facilities. Thus, it could be interesting to explore this topic further and not reject the research hypothesis as there is a knowledge gap in existing literature on this issue. It could be valuable for future research to develop instruments in collaboration with professionals over a sufficient period of time to accurately measure the 'knowledge' construct, perhaps with specifying the questions related to diet modifications to the National Guidelines to make sure that the intended measure is appropriately reflected in the outcome scores. Additionally, with the aim for collecting a large sample size, one can justify for further investigation.

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## Appendix A

### Caregiver Mealtime and Dysphagia Questionnaire (CMDQ)

1*	It takes too long to thicken liquids. (A)	1	2	3	4	5
2	I am embarrassed for my fm/so when they serve the modified food or thickened liquids. (Q)	1	2	3	4	5
3	I don't want to deprive my fm/so of food. (Q)	1	2	3	4	5
4	I'm not sure how much thickener to use. (A)	1	2	3	4	5
5	I don't use thickener because my fm/so does not want it. (Q)	1	2	3	4	5
6	The modified foods look unappetizing. (Q)	1	2	3	4	5
7	My fm/so does not drink as much when he/she is on thickened liquids.	1	2	3	4	5
8	I am not sure whether my fm/so is on thickened liquids. (D)	1	2	3	4	5
9	A few sips of a drink or a mouthful of food will not negatively affect the health of my fm/so. (Q)	1	2	3	4	5
10	They don't send up enough thickener on the meal tray. (A)	1	2	3	4	5
11	Without regular food or liquid, the quality of life of my fm/so is negatively affected. (Q)	1	2	3	4	5
12	Sometimes I forget to use thickener. (A)	1	2	3	4	5
13	My fm/so occasionally drinks his/her liquids before I get a chance to thicken them. (A)	1	2	3	4	5
14	I'm not sure why my fm/so is on thickened liquids. (D)	1	2	3	4	5
15	I don't thicken liquids because I have too much to do. (A)	1	2	3	4	5
16	No one showed me how to thicken the liquids. (A)	1	2	3	4	5
17	My fm/so does not need thickened liquids. (D)	1	2	3	4	5
18	Thickened liquids improve my fm/so's swallowing function. (D)/R	1	2	3	4	5
19	I am not sure which specific feeding techniques to use (e.g., double swallow and small boluses given slowly). (D)	1	2	3	4	5
20	I don't have time to follow through on swallowing recommendations given by the SLP. (D)	1	2	3	4	5
21	It is not necessary to give my fm/so small amounts and wait between mouthfuls and sips. (D)	1	2	3	4	5
22	I don't understand why specific feeding techniques were recommended by the SLP. (D)	1	2	3	4	5
23	My fm/so does not like the taste of modified foods or thickened liquids. (Q)	1	2	3	4	5
24	My fm/so does not like the texture of modified foods. (Q)	1	2	3	4	5
25	My fm/so can handle a regular diet. (Q)	1	2	3	4	5
26	My fm/so enjoys eating regular food and liquid with me. (Q)	1	2	3	4	5
27	I feed my fm/so regular food because it is what he/she wants. (Q)	1	2	3	4	5
28	It is difficult to feed my fm/so during mealtimes. (A)	1	2	3	4	5

(Continued)

29	Eating normal foods and liquids is worth the risk of developing respiratory problems or choking. (Q)	1	2	3	4	5
30	I want my fm/so to experience the taste of food. (Q)	1	2	3	4	5
31	Regular food is comforting and will help heal my fm/so. (Q)	1	2	3	4	5
32	The experience of eating regular food improves well-being. (Q)	1	2	3	4	5
33	My fm/so has been eating regular food all his/her life and I'm not going to stop that now. (Q)	1	2	3	4	5

fm/so = family member/significant other; (A) = Avoidance; (D) = Disagreement with SLP; (Q) = Quality of Life; R = reversed item.

1 = strongly disagree; 2 = somewhat disagree; 3 = neither agree nor disagree; 4 = somewhat agree; 5 = strongly agree.

\*Items removed from the analysis.

## Work Stress Scale (WSS)

Work stress scale: The following are some common situations that care attendants may confront in nursing homes. Please answer according to your situation, and answer never, seldom, sometimes, usually, or always (score 1–5). There are no right or wrong answers. Please just comment on your situation	Mean	s.e.
1. Sometimes you have conflicts with residents or family because of the rules in the NH (such as visiting time, fee, diet control, etc.)	1.89	0.78
2. An unreasonable schedule makes you uncomfortable.	2.01	0.81
3. An unfair evaluation in job performance makes you uncomfortable.	1.95	0.86
4. Strict requirements of the NH make you feel nervous.	2.64	0.99
5. There is little support from the NH.	2.34	0.98
6. The duty turnover is not clear and makes you feel uneasy.	1.85	0.80
7. An insufficient workforce in the NH makes you feel exhausted.	2.71	1.08
8. There is always too much work and it seems never to be finished.	2.71	0.98
9. You have trouble dealing with Rt's incontinence.	1.83	0.87
10. You have trouble dealing with Rt's bad temper.	2.06	0.78
11. You have trouble with time arrangements with your own family.	2.63	0.99
12. You have a heavy burden in moving Rts.	2.27	0.83
13. You are bored with repetitive tasks.	1.86	0.86
14. Your duty obligation to the nurses is unclear.	2.10	0.85
15. The CA job lacks autonomy.	2.12	0.81
16. You cannot find helps from coworkers, which causes anxiety.	1.97	0.66
17. You don't have enough personal interaction with coworkers.	1.98	0.89
18. You consider changing to another NH.	2.05	0.90
19. Rt's family members are picky and that makes your nervous.	2.23	0.85
20. You are afraid of causing damages when taking care of Rt.	2.50	1.02
21. You are nervous when taking care of severely ill Rts.	2.52	0.96
22. You are unable to handle Rt's emotional problems (such as their fear or hysteria).	2.10	0.63
23. You are afraid of explaining the care situation to Rt/family.	2.26	0.76
24. You feel lack essential skills/knowledge.	2.32	0.86
25. You are unable to care well for Rt although you would like to.	2.28	0.85
26. You are afraid of sudden changes in Rt's health.	2.36	0.94
27. You consider quitting the CA job.	2.06	0.05
28. You usually need to work overtime	2.22	0.98

$N = 110$ .

Note 1: The scale was scored from 1 to 5, indicating never to always.

Note 2: Rt (residents), CA (care attendants), NH (nursing homes).

## Mealtime Emotions Measure for adolescents (MEM-A)

How often do you feel the following during typical family mealtimes? (Please rate your response on the scale by selecting the answer that best describes your experience).

	Never		Sometimes			Always	
	1	2	3	4	5	6	7
1. Anxious							
2. Stressed							
3. Guilty							
4. Relaxed							
5. Nervous							
6. Embarrassed							
7. Distressed							
8. Emotionally confused							
9. Happy							
10. Angry							
11. Frustrated							
12. In control of the way you feel emotionally during mealtimes							
13. Comfortable within the physical mealtime environment							

### Scoring of the MEM-A

The MEM-A yields three specific subscales and a global subscale.

Subscale scores are calculated based on the mean of the items within each subscale: **Anxiety-related mealtime emotions**: items 1, 3, 5, 6, 7 and 8; **Anger-related mealtime emotions**; items 2, 10 and 11; and **Positive mealtime emotions**; 4, 9, 12 and 13.

In order to calculate the **global score**, the four items from the Positive mealtime emotions subscale are required to be reverse scored. The global score is then calculated based on a mean of all 13 items. A higher global score is indicative of a more negative emotional response to family mealtimes.

# Appendix B

27.4.2021

Helsepersonells kunnskap om tiltaksstrategier for dysfagi ved demens og arbeidsrelatert stress – Vis - Nettskjema

## Helsepersonells kunnskap om tiltaksstrategier for dysfagi ved demens og arbeidsrelatert stress

### Vil du delta i forskningsprosjektet?

Dette er et spørsmål til deg om å delta i et forskningsprosjekt hvor formålet er å få et innblikk i helsepersonells kunnskap om tiltaksstrategier for svelgevansker ved en demenssykdom og arbeidsrelatert stress. I dette skrevet gir vi deg informasjon om målene for prosjektet og hva deltakelse vil innebære for deg.

### Formål

En økende andel eldre i befolkningen har medført et økt krav til kompetanse blant helsepersonell. Som en del av masteroppgaven i logopedi ved Universitet i Oslo, skal jeg måle kunnskap om tiltaksstrategier ved svelgevansker, samt kartlegge følelser tilknyttet til en spisesituasjon, og undersøke arbeidsrelatert stress hos ansatte. Ved analysen av data skal jeg blant annet avdekke behov for opplæring innenfor dysfagi. Videre skal jeg undersøke sammenhengen mellom kunnskap og arbeidsrelatert stress hos ansatte. Opplysningene vil ikke bli brukt til noe annet formål enn masteroppgaven.

### Hvem er ansvarlig for forskningsprosjektet?

Instituttet for spesialpedagogikk, Universitet i Oslo er ansvarlig for prosjektet. Prosjektet er utviklet i samarbeid med veileder Sonia Munoz Llort, epost [sonimu@sunaas.no](mailto:sonimu@sunaas.no) og Henrik Daae Zachrisson, epost [h.d.zachrisson@isp.uio.no](mailto:h.d.zachrisson@isp.uio.no)

### Hvorfor får du spørsmål om å delta?

Du får et forespørsel om å delta i studien da det er ønskelig å inkludere ansatte som jobber innen eldreomsorgen.

### Hva innebærer det for deg å delta?

Undersøkelsen vil foregå gjennom et spørreskjema som vil ta ca. 10 -15 minutter å gjennomføre. Spørreskjemaet inneholder kunnskapsspørsmål om svelgevansker og måltid, og spørsmål om hvilke følelser du opplever knyttet til en spisesituasjon, samt spørsmål om arbeidsrelatert stress. Dine svar fra spørreskjemaet blir registrert elektronisk.

### Det er frivillig og anonymt å delta

Det er frivillig å delta i prosjektet, og spørreundersøkelsen er helt anonym. Det vil si at ingen personopplysninger blir registrert og datamaterialet kan derfor ikke spores tilbake til deg. Dermed er det heller ikke mulig å trekke samtykket eller slette datamaterialet til en eller flere enkeltpersoner. Det vil ikke ha noen negative konsekvenser for deg hvis du velger å delta i prosjektet. Istedet kan du bidra til å avdekke eventuelle kunnskapshull og dermed hvordan fagpersoner kan ta hensyn til faglignivå hos ansatte.

### Hvordan vi oppbevarer og bruker informasjonen fra deg

Forskningsdataet blir lagret i universitets tjenester som oppfyller strenge krav til behandling og lagring av forskningsdata. Forsker og veiledere inkludert i dette prosjektet vil ha tilgang til datamaterialet under bearbeiding av data.

### Hvor kan jeg finne ut mer?

Hvis du har spørsmål til studien, ta kontakt med:

prosjektveileder Sonia Munoz Llort, epost [sonimu@sunaas.no](mailto:sonimu@sunaas.no) og/eller Henrik Daae Zachrisson, epost [h.d.zachrisson@isp.uio.no](mailto:h.d.zachrisson@isp.uio.no) eller student Mehak Chawla [mehaksc@student.uv.uio.no](mailto:mehaksc@student.uv.uio.no)

### Samtykkeerklæring

Jeg har mottatt og forstått informasjon om at datamaterialet ikke spores tilbake til meg og at det ikke er mulig å trekke samtykket eller slette datamaterialet ved en senere anledning. Jeg samtykker til:

å delta i spørreundersøkelsen



## Bakgrunnsspørsmål

Jobber du i eldreomsorgen med demenspasienter? \*

- Ja
- Nei

Hvor er du ansatt? \*

Kryss av flere hvis aktuelt

- Sykehjem
- Helsehus
- Bo og avlastningshjem
- Dagsenter
- Annet

Hva er din ansettelsesform? \*

- Sykepleier
- Helsefagarbeider
- Hjelpepleier
- Miljøarbeider/miljøterapeut
- Assistent
- Ufaglært assistent
- Annet

Hva er ditt utdanningsnivå? \*

- Høyere utdanning mer enn 3 år
- Høyere utdanning mellom 1-3 år
- Videregående skole med studiespesialisering
- Videregående skole med yrkesfag
- Annet

Din alder \*

- 18-29 år
- 30-49 år
- 50-69 år

Har du utdanning innen helse- og sosialfag? \*

(F.eks psykologi, sykepleie, helsefagarbeider, vernepleier, sosionom eller liknende)

- Ja
- Nei

Hvor lang erfaring har du i arbeid med personer med demens? Oppgi antall mnd eller år \*

Jobber du med yngre eller eldre pasienter med demens? \*

- Yngre (under 65 år)
- Eldre (over 65 år)
- Begge deler

Har noen av pasientene med demens svelgevansker? \*

- Ja
- Nei
- Vet ikke

Kjenner du til at svelgevansker ved en demenssykdom kan oppstå? \*

- Ja
- Nei

**Under finner du spørsmål om svelgevansker og måltid**

Det er vanskelig å mate pasienten(e) under en spisesituasjon \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig

Delvis enig

Helt enig

Jeg vet hva fortykningsmiddel er \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Jeg er sikker på hvor mye fortykningsmiddel jeg skal bruke \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Ingen viste meg hvordan jeg bruker fortykningsmiddel \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Jeg er sikker på hvorfor fortykningsmiddel kan brukes \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Jeg vet at fortykningsmiddel bedrer svelgeprosessen \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Jeg er sikker på hvordan jeg skal gi mat med rett konsistensnivå \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Jeg forstår hvorfor konsistenstilpasset mat er anbefalt \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Jeg er kjent med konsistensnivåene som er anbefalt \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Det er nødvendig å gi pasienter med svelgevansker mindre porsjoner \*

- Helt uenig
- Delvis uenig

- Verken enig eller uenig
- Delvis enig
- Helt enig

Det er nødvendig å gi pasienter med svelgevansker god tid og å vente før neste påfyll \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Pasienter med svelgevansker kan håndtere et normalt kosthold \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Det er nødvendig å ta hensyn til svelgevansker ved valg av kosthold \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig
- Delvis enig
- Helt enig

Det er viktig å øke konsentrasjonen ved å redusere distraksjoner for å bedre svelgeprosessen \*

- Helt uenig
- Delvis uenig
- Verken enig eller uenig

Delvis enig

Helt enig

Det fysiske miljøet (f.eks lydnivået) har ikke så mye å si for svelgeprosessen \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Jeg trenger mer kunnskap og trening i spisehjelpemidler \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Jeg er sikker på hvilke (n) teknikker jeg skal bruke for fysisk tilrettelegging (f.eks sittestilling) \*

Helt uenig

Delvis uenig

Verken enig eller uenig

Delvis enig

Helt enig

Dersom pasienten skulle sette noe fast i halsen på tross av all forsiktighet vet jeg hva jeg skal gjøre (f.eks Heimlich Manøver) \*

Helt uenig

Delvis uenig

Verken enig eller uenig

## Hvor ofte føler du følgende under en spisesituasjon med pasienten(e)?

### Engstelig \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

### Stresset \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

### Skyldig \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

### Avslappet \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Nervøs \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Flau \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Nedtrykt \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Forvirret \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Glad \***

- Aldri
- Nesten aldri



- Av og til
- Nesten alltid
- Alltid

**Sint \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Frustrert \***

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

**Under finner du noen typiske situasjoner som kan medføre stress**

Du har vansker med å takle pasientens temperament \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

Det er vanskelig å få hjelp fra kollegaer, noe som kan forårsake angst \*

(F.eks ved fysisk eller psykisk krevende situasjoner)

- Aldri
- Nesten aldri
- Av og til

Nesten alltid

Alltid

Du er redd for å forårsake skader når du tar vare på pasienten \*

Aldri

Nesten aldri

Av og til

Nesten alltid

Alltid

Du er nervøs når du tar vare på alvorlig syke pasienter \*

Aldri

Nesten aldri

Av og til

Nesten alltid

Alltid

Det er vanskelig å håndtere pasientens emosjonelle problemer (som frykt eller hysteri) \*

Aldri

Nesten aldri

Av og til

Nesten alltid

Alltid

Du føler at du mangler ferdigheter/kunnskap \*

Aldri

Nesten aldri

Av og til

Nesten alltid

Alltid

Du er i stand til å ta godt vare på pasienten selv, dersom du ønsker det \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

Du er redd for plutselige endringer i pasientens helse \*

- Aldri
- Nesten aldri
- Av og til
- Nesten alltid
- Alltid

Tusen takk for ditt bidrag!

