MASTER`S THESIS

Pain and physical function among nursing home patients and people with dementia

Cross-sectional analyses from the COSMOS-trial

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Acknowledgements

When my grandmother grew older and was diagnosed with dementia, she eventually moved into a nursing home. There, my role as a granddaughter grew into the role as a next of kin, with all the frustration and emotions that follow. I saw there how much happiness my grandmother received from having short walks outside in the yard, escaping for a moment the sedentary environment of the nursing home ward. There, my curiosity and interest for geriatrics and activity came into life. Ten years later, this master`s thesis is the result of that seed, that has grown into what you hold before you.

I would like to thank my supervisors, Liv Inger Strand and Bettina Husebø, who have pointed me in the right direction when my head has been covered in its own chaos. This project could not have been done without them, and their knowledge and experience – knowing when to push and when to pull.

Another thanks goes to my friends and family for supporting me throughout my project.

A special thanks to my dear friend Silje Thorstensen, for being my eternal cheerleader and psychologist through these two years. I would not have gotten through this without you.

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Samandrag:

Bakgrunn: Tidlegare studiar har vist at sjukeheimspasientar har dårleg fysisk funksjon, og er avhengige av hjelp til å gjennomføre daglegdagse aktivitetar. Desse pasientane høg førekomst av smerte, og er i stor grad kognitivt svekka, men i kor stor grad den fysiske funksjonsevna er påverka av smerte og kognitiv svikt, er ikkje undersøkt tidlegare. Målet med denne oppgåva er å kartlegge lokalisasjon og grad av smerte, fysisk funksjon og demens hos eit stort utval norske sjukeheimspasientar, og undersøke om fysisk funksjon har samanheng med grad av smerte og kognitiv funksjon, og om det er ulikskap i evna til å utføre spesifikke fysiske aktivitetar mellom pasientar med og utan demens.

Metode: Tverrsnittstudie med utgangspunkt i baseline-data frå 545 langtidspasientar ved norske sjukeheimar. Opplysningar om demografi, fysisk- og kognitiv funksjonsevne, og smertelokalisasjon og -grad vart innhenta. Demente og ikkje demente pasientar vart samanlikna med t-testar for uavhengige grupper ved kontinuerlege data og med Mann Whitney U-testar for ordinale data. Regresjonsanalysar vart utførte for å undersøke korleis øvrige variablar predikerer fysisk funksjon.

Resultat: Storparten av pasientane er avhengige av assistanse i ADL, og i nærleiken av 90% av pasientane har svekka kognitiv funksjon. Smerte var til stades hos 80% av pasientane, mest hos dei utan demens. Kognitiv funksjon påverka fysisk funksjon negativt ($p<0.001$), og pasientar med demens streva meir med å gjennomføre storparten av ADL-aktivitetane. Pasientane har meir smerter frå muskel-skjelettsystemet enn frå hovud, hud og indre organ.

Konklusjon: Norske sjukeheimspasientar er sterkt pleietrengande, og har redusert kognitiv- og fysisk funksjonsevne, i tillegg til høg grad av smerte. Eit større fokus bør setjast på reduksjon av fysisk funksjonstap, for å soleis minske forsterking av smertetilstandar blant sjukeheimspasientar.

Nøkkelord: Aktivitetar i Dagleglivet, Demens, Fysisk Funksjon, Kognitiv Funksjon, Sjukeheim, Sjukeheimspasient, Smerte

Abstract:

Background: Previous studies have shown how nursing home patients have poor physical functioning and are largely care dependent in activities of daily life. These patients have a high prevalence of pain and are mainly cognitively impaired, but to what extent the physical functioning is impaired by pain and cognitive impairment has not been investigated previously. This study aims to investigate the localization and degree of pain, physical functioning and dementia in a large sample of Norwegian nursing home patients, and to investigate how physical functioning is related to pain and cognitive functioning, and if the ability to perform specific physical activities differs among patient with- and without dementia.

Methods: Cross-sectional baseline data from a total of 545 long term care patients were collected. Patients' demographics were obtained, as well as assessing physical - and cognitive function, in addition to pain. T-test for independent groups were performed for continuous data, and Mann Whitney U-analyses for ordinal data. Regression analyses were conducted, examining the ability of demographic and test variables of pain and cognitive function to predict ADL.

Results: Most patients require help in performing ADLs, and approximately 90% of the patients are cognitively impaired. Pain is present among 80% of the patients, most frequent among the patients with dementia. Cognitive functioning impacted physical functioning negatively, and patients with dementia struggle with most ADLs investigated. Musculoskeletal pain is more common than pain from head, skin and internal organs.

Conclusions: Norwegian nursing home patients are very care dependent, and have reduced cognitive- and physical functioning, in addition to high prevalence of pain. A larger focus should be put into reducing physical loss of functioning, to minimize amplifying pain among nursing home patients.

Keywords: Activities of Daily Living, Physical Functioning, Cognitive Functioning, Dementia, Nursing Home, Nursing Home Patient, Pain

1.0 Challenges in nursing homes

When health is failing and the need for extensive health care increases, being admitted to a nursing home (NH) becomes a natural part of life for many, especially in the later stages of life. The risk for being admitted to a NH increases alongside age and with the prevalence of comorbidities (1). Considering the rising life expectancy in Norway, the need for resources related to NH patients are expected to increase the upcoming years (1, 2). In the next decades, the population receiving formal care in institutions is expected to rise by approximately 130% on average (3) .

One of the largest challenges to global health today is dementia, with more than 47 million people living with the condition worldwide (1). Patients with dementia and other cognitive impairments make up the majority of patients in NHs, and due to complications by frailty and multiple physical comorbidities, these patients have an extensive need for help with personal care from health care professionals (4, 5). It is estimated that dementia will become a trillion dollar disease by the end of 2018 (5).

To meet the increasing population in need of extensive health care, the Norwegian municipalities have been encouraged to develop and improve health care services and staff competence, hoping to reduce the costs and need of specialist health care in hospitals. This is a part of the Norwegian Coordination Reform, aiming to improve health in Norway (6). The Research Program on Health and Care Services was established to encourage researchers to develop and evaluate effective and large-scale interventions (7).

Previous research on this field has reported that the need for care varies a great deal depending on the individual`s cognitive and physical state of functioning. In addition, their need for medications and other resources related to health care will also impact their care dependency (8). Furthermore, pain may have an impact on patients` function in everyday life and could also influence the patients` care dependency. Pain can be a triggering factor to neuropsychiatric symptoms, such as agitation, apathy and depression (1). Non-pharmacological measures is suggested to reduce neuropsychiatric symptoms related to dementia, for example physical exercise (9, 10). Every measure that contributes to improve or relieve the symptoms, will potentially also contribute to a higher level of dignity in health care, and also reduce the work load among health care professionals (8, 11).

A randomized controlled trial (RCT) performed among Norwegian NH patients, investigated changes in physical functioning and mental health in connection with a high-intensity exercise program. The study was single blinded and included 170 NH patients with dementia. The intervention group (n=87) performed intensive strength- and balance training twice a week throughout a 12-week period, while the control group (n=83) performed leisure activities. This trial reported that the intervention group improved their balance significantly compared to the control group. After 12 weeks the intervention group also had significantly improved their strength. In addition to the physical improvements, the intervention group had lower levels of apathy post-intervention (12).

Despite encouragements to develop and evaluate effective and large-scale interventions aiming to improve health care services (6), there is a lack of sufficient research meeting the needs of the increasing population requiring long term care in NHs (5). Seeing how patients with dementia make out the majority of patients in NHs (1), it is important to investigate their needs. Knowing how physical impairment and pain are common issues among NH patients (1, 5, 13), the possible associations between these factors are important to highlight and investigate. What classifies the typical NH patients in different countries is also a valuable contribution of knowledge, as it serves as a point of reference for future research. We see that patients with dementia are able to perform and benefit from physical exercise (14), and by examining what activities patients in NHs struggle with performing, tailoring exercise towards improving their physical functioning becomes easier.

2.0 Regulations in the Norwegian municipalities

Norway has superior laws and regulations advising municipal authorities regarding criteria for admitting individuals to a NH or rather receiving health care in their own homes. The individual municipalities have more specified criteria as to admission, but collectively they are obliged to ensure that their inhabitants are being offered necessary healthcare services (15, 16). Long term care is defined as a permanent stay in a NH or an equivalent form of residence, which is adapted to around-the-clock care, with no end-date, where it is not expected that the patients gets discharged from the stay (15). In order to qualify for long term care in a NH, a person must be in need of extensive care in everyday life, and admission to a NH is seen as the only justifiable option remaining (16).

The Individual-based statistics for nursing and care (IPLOS) is a national health registry in Norway (17), where the municipalities are encouraged to survey the need for healthcare services. The IPLOS standard is frequently used to decide if an individual meets the criteria for admission to a NH (15, 17). In the different municipalities, the IPLOS health registry-score is used to evaluate the persons` need for assistance, which assesses the individuals` abilities to perform personal hygiene, feed themselves, move around independently, maintain their own health, and to what extent they need assistance in relations to somatic disease or cognitive impairment and dementia (15). The score ranges from 1-5, where 1 indicates that the individual does not need any help performing the different tasks, while 5 indicates an extensive need for help. For admission to long term care, patients most commonly have IPLOS-scores of 4 and 5, meaning that they have extensive need for assistance in performing activities of daily living (ADL) – and are more or less entirely care-dependent in their daily life (15). Older people with moderate to severe dementia are particularly in need of admission to a NH if they live alone, not having a spouse who can help care for them (18).

3.0 Different aspects revolving dementia

Most patients qualified for long term care in NHs are diagnosed with some sort of dementia (5, 19), and the diagnosis is diverse. Depending on how far along the dementia-diagnosis has developed, different symptoms dominate in the individual patient (1). Among patients with dementia, medication is often misused, especially analgesics (20). Experiencing pain is strongly associated with changes in behavior and may be an underlying factor as to other dementia related symptoms (21, 22), such as pacing, agitation and depression. In Norwegian NHs, 81% of the patients are diagnosed with dementia, and the majority of these patients also have other psychiatric- and behavioral symptoms (23).

3.1 The dementia diagnosis

Dementia is a disorder leading to a decline in cognitive functioning. Damage to brain cells is the underlying factor causing dementia, which impacts the cerebral neurons` abilities to communicate with other brain cells (24). Depending on what region of the brain the cell damage is located, distinct functions will be affected, and the functions related to the specific brain area will be reduced (1, 24). The condition leads to several disturbances in higher

cortical functions, and effects a number of dimensions of the patient`s daily life. The clinical symptoms of dementia are primarily significant changes and impairments of a persons` memory, ability to communicate, capability to pay attention and focus, trouble with visual perception as well as difficulties with reasoning and social cognition (25). Dementia is the most common reason to being admitted to a NH (1, 5), and as previously described – a rising challenge in the years to come.

3.2 Types of dementia

Alzheimer`s disease is the most common type of age-related dementia, representing approximately 60 per cent of all dementia diagnoses, where the histopathology is distinguished by neuronal loss, neurofibrillary tangles and senile plaques (26). Thereafter, Vascular dementia and Lewy Body-Dementia make up the most common types of dementia, followed by frontotemporal dementia. A combination of different dementia-types is estimated to represent about half of all dementia-cases (27). Telling the diverse types apart may be challenging, as the different dementia-types have overlapping symptoms.

3.3 Different stages of dementia

Dementia is often categorized into three different stages, depending on how severe the diagnosis has become. The early stage of dementia is characterized by the individual experiencing difficulties with short-term-memory, not remembering words, and getting lost in familiar places. This stage is often ignored and overlooked; as it considered a natural part of aging (13).

In the middle-stage, the loss of function will gradually become more apparent, and the person will experience an increasing difficulty keeping up with time and place. In addition, their need for assistance in daily life will also increase. Furthermore, the individual`s personality will also alter in this stage, combined with a possibility of the individual experiencing hallucinations, having to repeat questions, and experiencing sleep disturbances (13).

The final and advance stage of dementia is characterized by a great loss of function and inactivity. The individual may require assistance in all daily activity and will have great difficulties comprehending the world around them. How much the symptoms progresses, as

well as how the symptoms occur, varies a great deal from person to person, depending on how far along the diagnosis has come, and on the pre-diagnostic state of the person (25). In high income countries, people in the advanced stage of dementia are in long term care (5).

3.4 Prevention and treatment

As far as we know, there is no cure for dementia - despite an increasing worldwide focus on the subject. The treatment of these patients mainly revolves around improving the patients` quality of life, as well as prescribing medication slowing down the progress of the disease (24). Primarily, the treatment targets an early diagnosis, enhanced health, cognition, activity and quality of life, as well as discovering and treating neuropsychiatric symptoms related to behavior. Another important aspect of the treatment is giving information and support to the patient's next of kin (1, 13).

4.0 Physical functioning in nursing homes

In addition to having dementia and other types of cognitive impairments, the typical NH patient also has a reduced physical function. This is investigated in several studies. The dementia diagnosis itself affects the individuals' ability to function (1, 24), but it is important to understand what activities the patients struggles with performing, and if the institutionalized everyday life also impacts the patients physical functioning negatively.

4.1 Qualitative studies highlighting nursing home patients` view on activity

Being a difficult population to study due to cognitive impairment, qualitative studies have been important as to creating a foundation for understanding these patients and their level of functioning. James, Blomberg (28) interviewed 25 older persons with dementia and/or cognitive impairment – who were able to express themselves verbally and understand the meaning of an interview. The aim of their study was to reflect upon the patients` personal experience of daily life in NHs. Their main findings revolved around the subjects of patients experiencing being unable to perform activities they enjoyed, and of being forced to adapt to NH staff and ward routines. They lacked space to be themselves, and longed for something to happen (28). This reflects upon a passive everyday life, where the patients` wish to perform enjoyable activities are not seen or accommodated.

Hall, Longhurst (11) investigated how dignity was maintained in the NH setting, by interviewing 18 NH patients. One of the strongest concerns among the NH patients who were interviewed, was lack and loss of ability to function properly. The subjects described frustration regarding not being able to walk, bathe, dress or eat independently, or do enjoyable activities of their own liking. The patients described it as embarrassing to see their health fail, and to receive help for even the simplest activities they were used to do themselves (11). The patients describe a wish for the NH to be a place where they can have a meaningful everyday life, and not merely follow the routine of the NH ward.

Similar findings were found in a Nordic cross-country study, aiming to gain knowledge regarding maintaining dignity among NH residents in Sweden, Norway and Denmark (29). Dignity was defined as an aspect where autonomy and integrity were respected. Loss of physical functioning was suggested as a contributing factor to experiencing an absence of dignity in their everyday life (29). These studies reflect upon a person's wish to maintain a high level of physical functioning into old age and being able to care for themselves for as long as possible, but the patient`s wishes and the reality of their daily life is contradicting.

4.2 Investigating physical functioning among nursing home patients

Physical functioning among NH patients have been investigated in several quantitative studies as well, where the majority aims to describe everyday life in the NHs, with great variation in defining and screening physical functioning in the different studies. An American study from 1996 described the physical activity level among 95 NH patients, by monitoring the participants with motion sensors and performing time-sampled observations (30). The researchers also wanted to investigate what factors that could predict the patients` activity levels. The included patients were mainly observed either lying- or sitting down, and to large extents being passive throughout the day - in more than 80% of the observations. The study reported that patients who had a poor balance, reduced body strength, walked slowly and a high BMI had a higher risk of a poorer activity level in the NH-setting (30).

Another American study investigated how everyday life in the NH-setting was, especially regarding how NH patients spend their days (31). The study sample consisted of 27 NH patients, who were observed for 13 hours each, focusing on recording what body position,

localization and mood they were in, and what kinds of activities the patients were doing. The study reflected upon a daily schedule colored by the routine of an institution. Most of the patients spent their time passively in their rooms, being alone and doing little or nothing. During the day, the patients were most frequently observed in the sitting-position. Only 12% of the time, the residents took part in social activities (31).

A more recent cross-sectional observation study performed by Den Ouden, Bleijlevens (32), aimed to provide insight into daily activities among NH patients, especially among psychogeriatric and somatic NH patients. By performing 3282 observations from a self-developed observation list, the study found that the patients primarily took part in passive activities, for example sleeping, doing nothing and watching television. Other than that, the patients performed ADLs, mainly related to mobility and eating-situations. Most of the time, the patients were observed lying down or sitting still (32). The authors have discussed how similar the study results are across the counties, indicating that a poor functional status is not exclusive for either the studies or countries investigated.

A cross-sectional observational study aimed to investigate the activity level of 723 psychogeriatric and somatic NH patients in the Netherlands, to provide insight in which daily activities NH patients participate in. They used a self-developed observation list and observed the patients in the different wards at five random times in the daytime, scoring their body position and what kind of activity he/she was performing at the time. From 3282 observations, the researchers found that the NH patients spend most of their daily life doing little or nothing, remaining most of their time in their rooms, sitting alone and being passive (32).

A Swedish cross-sectional study investigated the prevalence of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among NH patients. They found that 56% of the assessed patients (N=4831) were dependent in ADL. ADL dependency was measured by using a modified version of the Katz Index of Independence in Activities of Daily Living. Each item was given a score of either 0 or 1, where 0 was given if the patient was dependent in performing the activity, and 1 if the patient was independent. The study demonstrated that showering/bathing-situations were the most challenging for the patients, followed by dressing and toileting (33). This study did not separate between patients with- and without dementias.

In Norway, a recent cross sectional study aimed to describe depression and physical

functioning in NH patients with dementia, separating the patients with- and without depression (34). They also wanted to assess the associations between depression, balance and strength in the lower limb musculature, as well as their capability to perform mobility- and ADL-tasks. The physical aspects of the study were investigated through the 30s Chair Stand Test (muscle strength), 6 m walking test (mobility) and the Barthel Index (ADLs). The study presents NH patients as a relatively heterogeneous group concerning physical functioning. They found that the patients who had better physical functioning (muscle strength, mobility and balance) also had less depressive symptoms – and highlights how level of cognitive functioning also may impact their ability to perform ADL-tasks (34), reflecting upon an area to investigate in future studies.

Helvik, Engedal (35) performed a longitudinal study among 932 Norwegian NH residents with dementia, aiming to investigate how different variables were associated with how ADL-functioning developed over a 52-month follow up period. The study focused especially on the importance of dementia, and how severe the degree of dementia was. This study reported that ADL-functioning deteriorated over time, and that the ability to perform different functional tasks was strongly associated with severe dementia, as well as other neuropsychiatric symptoms (35).

Findings demonstrate that little has changed from the mid-90`s until today regarding physical functioning in the NH-setting. More than half of the patients are care dependent, and spend little time being active in the wards. As seen from these studies, most NH patients spend their days doing little or nothing, and to small extents participate in physical or social activities. Primarily, the patients are sitting- or laying down, and are rarely observed standing or walking, and are to small extents stimulated into doing so. The activity performed is mainly related to ADLs, such as eating, drinking and being mobile in the wards. Therefore, the patients' physical abilities may be less challenged in the NH compared to in everyday life outside a NH, resulting in a natural decline in ability to perform other tasks.

4.3 Investigating differences in physical functioning between patients with and without dementia

Many of the studies mentioned above highlight the impact of dementia and cognitive functioning on patients' functional abilities when investigating NH patients as unit. A Swiss

study separated hospitalized patients with and without dementia, and investigated differences between the groups regarding prevalence of comorbid conditions, functional status and nutritional status (36). This study assessed 349 patients, and used the functional independent measure (FIM) to assess the patients' functionality (36). The FIM ranges from completely dependent to completely independent (18-126), and contains 18 items regarding physical, social and psychological functioning (37). The study found few differences between the groups regarding physical functioning and nutritional status, but indicated that patients with dementia in total had poorer function – and tended to have more undiagnosed illnesses and comorbidities. Their study sample consisted of 76% women and a mean age of 85 years, where approximately 40% of the patients had normal cognition, whilst the remaining patients had some form of dementia diagnosis (36). This study emphasized room for improvement regarding health care directed towards elderly people, where a larger focus should be put in detecting unreported problems in patients with dementias.

Jefferson, Byerly (38) aimed to explore to what extent patients with mild cognitive impairment differed from patients without cognitive impairment among 77 community dwelling individuals, with special focus on their ability to perform ADLs, and its relation to level of cognitive functioning. This study reported that patients who have mild cognitive impairment have clinically significant functional impairments, and that these patients had a more rapid decline in cognitive functioning. From this, we see that cognitive function and more severe dementia-diagnoses are both associated with worse physical functioning in performing ADLs (35, 38)

Henceforth, it may be difficult for NH patients to find meaning in everyday life, mostly due to shortcomings in elderly care (28), as the environment does not always enhance autonomy. Patients with dementia require more attention regarding physical ambulation and activity, and all patients are to a substantial extent reliant on health care professionals for assistance in ADLs. This can reduce their sense of dignity and QoL (11, 28). Most European countries have raised concerns regarding dignity in the NH setting (8), seeing how costs, resources and time does not always suffice in the hectic everyday life. Even though there is an overall consensus regarding a person-centered perspective in geriatric care (8), the framework becomes more abstract in everyday life – where the provision of care gets challenged by a complex reality - where disability, cognitive decline and chronic conditions exists

simultaneously.

5.0 Pain in dementia

Pain is a complex phenomenon. Per definition by the International Association for the Study of Pain, pain is "*an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage*" (39) and is a combination of physical and nonphysical aspects of an experience (40). As health care professionals, we need to regard pain as a symptom of a possibly underlying conditions. Pain is a common symptom among elderly people residing in NHs, and persistent pain affects up to 80% of NH patients (41, 42).

Elderly people are less likely to recover from chronic pain, and patients with dementia often have difficulties communicating their symptoms as well (22). In people with dementia, pain may be related to irritability and disinhibition, and proper pain treatment is believed to reduce agitation and other anomalous motor behavior (21), and may also reduce depressive symptoms (43). However, a systematic review performed by Husebo, Achterberg (19) highlights the lack of implementation of validated pain tools among patients with dementia, and argue that official guidelines regarding assessment and treatment of pain should come into place. Sufficient pain assessment and treatment regarding pain is often unsatisfactory among elderly people, especially among patients with dementia, and this issue is important to highlight.

5.1 Pain among nursing home patients

Previous studies have found a large variation of reported pain in NH patients, varying from country to country. A Swedish study reported a pain prevalence of 56.7% among 3724 participants, finding the pain treatment to be insufficient (44). In another European study performed in 7 EU-countries collecting data from 3926 patients, and 48.4% of these patients suffered from pain. The study also reported that pain was associated with female gender, falls, a number of drugs and depression, and negatively associated with dementia (45).

An international review-study investigating pain prevalence in the US, Netherlands, Canada, Australia, China, Iran, Norway, Singapore, Taiwan and the UK reported a great variance in

pain prevalence among the NH patients – from 3.7% to 79.5%, depending on where the study was conducted and methodological issues. In addition, the study also reported a strong correlation between higher pain intensities and limitations in ADL, and emphasized the importance of maintaining the fundamental rights of the patients regarding pain treatment (46). Pain prevalence and use of pain medication was investigated in a Norwegian study of 307 NH patients, finding that approximately half of the patients experienced pain on a regular basis – regardless if the pain was self-reported or proxy-rated (47).

Pain will often lead to a decrease in a person`s activity level, and affect their ability to perform ADLs – especially in a NH-setting (38). Moreover, pain affects a person`s quality of life, and causes higher costs related to health care, due to an increased care dependency (46, 48). Knowing how severely pain can affect all aspects of the individuals everyday life (46), it is crucial to highlight this as an important level of focus in NH healthcare services, tailoring the care for each patient. Existing evidence proposes that interventions aiming to reduce pain and behavioral symptoms has a positive effect, reducing pain and behavioral symptoms (41).

5.2 Pain among patients with dementia

It is reason to believe that patients who have cognitive impairment and dementia experience pain differently than patients without cognitive impairment – partly because of their lack of communicative abilities (22). When processing pain, the brain has primarily two interconnected areas which are equally important (49). The structures making out the medial pain system connects pathways between cognitive-evaluative and motivational-affective aspects of pain, as well as autonomic-endocrine features. In the lateral pain system, we find the primary somatosensory areas, in addition to the lateral thalamic nuclei. Where pain originates from, what intensity it reaches and what quality it has mediates from the lateral system (49, 50). A third area in the limbic pain system has been suggested as to mediating behavioral characteristics of pain, such as agitation and wandering (51), which is highly associated with dementia-related symptoms.

When experiencing pain, it can be communicated by changed facial expressions, expressed verbalizing and vocalization, as well as by changed body movements (52, 53). If the pain remains untreated over time, other behavioral symptoms may occur, such as interpersonal interaction-changes and changes in mental status (54), for example agitation, wandering and

confusion. It is difficult to separate between typical dementia-behavior, and behavior caused by untreated pain (19)

In Alzheimer's Disease and overall dementia, there are neuropathological changes in the brain which leads to a change in how the individual experiences pain. If there occurs a decrease in of gray matter, this is suggested as a reason to an increased tolerance of pain, whilst atrophy in white matter leads to poorer pain tolerance. The consequences of the disturbance in the excitatory and inhibitory balance is somewhat unclear, especially with regards to nociception (22). However, this may strongly affect pain assessment and treatment, and should be taken into consideration when performing pain management in geriatric care.

6.0 Key literature for the subject of the thesis

The literature listed in *Table 1* is a selection of the most relevant literature for this thesis. The literature is a combination of qualitative and quantitative studies performed among NH patients, describing their level of physical functioning, cognitive impairment and prevalence of pain. The literature also describes everyday life in NHs, with special emphasis of the activities performed, and how active the patients are in the wards.

The literature search was conducted using mainly Cochrane Library, PubMed, BMJ best practice, SveMed+ and UpToDate, with the descriptors: *nursing home patients, nursing home residents, dementia, cognitive impairment, pain, activities of daily living, ADL, physical function,* and different combinations of these descriptors. The search was conducted between January and April 2018.

Table 1: Relevant literature for the main subject of the thesis.

STUDY	DESIGN	RELEVANT TO PRESENT STUDY	SAMPLE SIZE	RELEVANT FINDINGS
Bjõrk, Juthberg, Lindkvist, Wimo, Sandman, Winblad, Edvardsson. *Exploring the prevalence of cognitive impairment, pain,*	Cross-sectional study	Explore the prevalence of cognitive impairment, ADL-dependency, pain and neuropsychiatric	4831 NHRs from 188 NHs	- More than half the patients in Swedish NHs were care dependent and have cognitive impairments - 92% had neuropsychiatric symptoms, and 47,9% had pain

***neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study. (*2016) BCM Geriatrics, 16(154)**		symptoms among NH patiens in Sweden		symptoms - Pain was more prevalent among care dependent patients and patients with cognitive impairment
Husebo, Strand, Moe-Nilssen, Borge Husebo, Aarsland, Ljunggren. *Who suffers mst? Dementia and Pain in Nursing Home Patients: A Cross-sectional Study.* (2008). Journal of the American Medical Directors Associatoon, 9(6).	Cross-sectional study	Exploring the connection between NH patients with different stages of dementia and use of pain medication according to their pain intensity.	181 ling-term stay patients, 43 primary caregivers 1 geriatric study nurse and 4 physicians in a Norwegian NH	- Patients with dementia does not experience less pain intensity - Patients with severe dementia demonstrated higher pain intensities and received less pain treatment - Patients with mixed- and severe dementia are in risk to suffer from severe pain
Onder, Carpenter, Finne-Soverim Gindin, Frijters, Henrard, Nikolaus, Topinkova, Tosato, Liperoti, Landi, Barnabei. *Assessment of nursing home residents in Europe: The Services and Health for Elderly in Long TERm care (SHELTER) study.* (2012) BCM Health Services Research, 12(5).	Prospective cohort study	To illustrate characteristics of European NH patiens in study entry.	4156 residents from 57 nursing homes	- Most NH-patients were females (73%) with ADL disability (81.3%) and cognitive impairments (68%). - Clinical complexity was confirmed by a high prevalence of behavioral symptoms, falls, pressure ulcers, pain and urinary incontinence.
Zekry, Herrmann, Grandjean, Meynet, Michel, Gold, Krause. *Demented versus non-demented very old inpatients: the same comorbidities but poorer functional and nutritional status.* Age and Ageing, 37(1).	Prospective study	To assess comorbidities among medically ill hospitalized patients, regarding functional status, separating between different dementia diagnoses and mild cognitive impairment	349 patients in a geriatric hospital.	- Most of the patients had cognitive impairment (MCI and dementia) - Physical functioning decreased with cognitive status - Functionality was significantly lower in demented patients compared to other patients
Den Ouden, Bleijlevens, Meijers, Zwakhalen, Braun, Tan, Hamers. (2015) *Daily*	Cross-sectional	Obtain insight into daily (in)activities of psyhogeriatric and	723 residents in 7	- Most NH patients spent their day inactive in the ward. - While engaged in ADLs, it mainly

***(In)Activities of Nursing Home Residents in Their Wards: An Observation Study.* Journal of the American Medical Directors Association, 16(11), 963-968.**	observation study	somatic NH patients during the day and their body positions during these (in)activities	nursing homes	revolved around activities related to walking around the ward, eating and drinking. - Patients were mainly observed when sitting or lying - Psychogeriatric patients are more mobile
Takai, Yamamoto-Mitani, Okamoto, Koyama, Honda. (2010) *Literature Review of Pain Prevalence Among Older Residents of Nursing Homes*. Pain Management Nursing, 11(4), 209-223.	Litterature review	To identify studies on pain prevalence among older residents in nursing homes and explore factors associated with pain.	27 studies	- Older residents suffer more from pain and serious pain-related problems - Musculoskeletal disorders and fractures were common causes of pain among residents - Higher pain intensity indicated higher limitations in ADL
Van Dalen-Kok, Pieper, de Waal, Lukas, Husebo, Achterberg, (2015). *Associations between pain, neuropsychiatric symtpoms, and physical function in dementia: a systematic review and meta-analysis.* BMC Geriatrics, 15(49),	Systematic review/meta -analysis	To examine possible strengths of associations between pain, NPS and functional impairment in patients with dementia.	22 articles, 18 studies	-Strongest associations between pain and agitation. - Some association between pain and NPS - Some association between pain and physical function - No strong associations between these variables.
James, Blomberg, Kihlgren (2014) *A meaningful daily life in nursing homes – a place of shelter and a space of freedom: a participatory appreciative action reflection study.*	Interviews, qualitative study	To describe older persons` experience and knowledge about obstacles, opportunities and solutions to developing a meaningful daily life for those living in the NHs.	25 older persons leaving 50 interviews in total	- A meaningful daily life consists of: having time to be yourself, restrained space to be yourself, belonging and security, not feeling insecure, and something happening. - Good interaction between staff and older NHRs leads to a more meaningful everyday life.
Hall, Longhurst, Higginson, (2009). *Living and dying with dignity: a qualitative study of the views of older people in nursing homes.* Age and Ageing, 38(4), 411-416,	Interview, qualitative study	To explore the generalizability of the dignity model to older people in NHs.	18 older persons.	- Dignity therapy may bolster older people in NHs sense of dignity. - Social aspects, illness-concerns and dignity conserving repertoire. - Symptoms and loss of function are a result of old age rather than illness. - Distress caused by multiple losses.

Kvæl, Bergland, Telenius, (2017). *Associations between physical function and depression in nursing home residents with mild and moderate dementia: a cross-sectional study.* BMJ Open, 7(7).	Cross sectional study	Describe physical function in NH patients with dementia, and investigate associations between depression and balance, lower limb muscle strength, mobility and ADLs.	170 NH patients from 18 NHs in and around Oslo.	- NHRs have poor physical functioning, which is connected to poorer muscle strength, balance and walking speed. - There is a possible relationship between dementia and poor physical function and depression-
Helvik, Engedal, Benth, Selbæk, (2014). *A 52 month follow-up of functional decline in nursing home residents – degree of dementia contributes. BMC Geriatrics, 14(45).*	Longitudinal study	Study variables which are associated with the development of personal-ADLs over time, with special focus on the impact of dementia-degree.	932 NH patients with dementia	- Personal-ADL functioning worsens over time, and is associated with dementia, neuropsychiatric symptoms and anxiolytics and antidementia medication.
Achterberg, Pieper, van Dalen-Kok, de Waal, Husebo, Lautenbacher, Kunz, Scherder, Corbett, (2013). *Pain management in patients with dementia.* Clinical Interventions in Aging, 8, 1471-1482.	Review	Investigate four key perspectives of pain management in dementia and make recommendations for practice and research		**- There is a lack of sufficient assessment and treatment regarding pain in the elderly.** **- It is reason to believe that patients with dementia experience pain differently than others.** **- Loss of communicative abilities leads to difficulties in detecting pain → expresses pain differently**

ADL = Activities of Daily Life

NH = Nursing Home

NPS = neuropsychiatric symptoms

7.0 Physical activity among nursing home patients

Physical activity is defined as any movement of the body which is produced by movement in skeletal muscles, resulting in expenditure of energy, and may regard daily life activities (55)- The ability to perform physical activity may be measured by certain tests. In the NH setting, activity is most commonly measured using observational tools (30, 32) as the patients themselves have difficulties with scoring their own performances. Having a mainly inactive everyday life, NH patients are exposed to an increased risk of developing and amplifying already established pain conditions (56). Consequentially, there is a rippling effect, where pain leads to more inactivity – and inactivity leads to more pain (56, 57). Persistent pain is associated with a more rapid decline in memory, as well as limiting a person`s ability to function in ADL (58).

Physical activity has been found to be beneficial for both cognitive and physical health, as well as reducing pain (59, 60). Physical activity may be used as supplementary therapy to improve some aspects of cognitive impairment (60, 61), and may help increase the patient`s balance, neuropsychiatric symptoms, and ability to function in everyday life (61). Furthermore, focusing on physical activity in NH-settings will also help to relieve caregivers` burden (62). The benefit of performing physical activity increases the more sessions the patients perform, and treatments focusing on several aspects seems to affect the patients` abilities to function – especially in ADLs (63, 64).

In Norway, studies have evaluated NHs to offer a high level of general care – while physical and social activities have been assessed to be relatively low (65, 66). Resultingly, the government has developed white papers and circulars highlighting the importance of increasing the level of activities in NHs (67-69). Despite the "*Regulation of quality of care",* describing a patient`s right to take part in leisure activities and going for walks and (70), the patients rarely take part in these kinds of leisure activities – neglecting the patients` autonomy (65).

Participation in activities is highly beneficial for patients with dementias` physical and mental health state. Being physically inactive leads to a decline in muscle strength, aerobic capacity, balance and physical performance (71). Such decline in physical fitness among the patients leads to an increased workload on NH staff, causing the patients to be more care dependent. From this knowledge, it is reason to believe that keeping the patients active will reduce the workload on the nursing staff, as well as an increase of the patient`s functioning and quality of life.

In total, there is only moderate evidence proving that physical activity has a preventive impact on decline in cognitive function. Nevertheless, the strong correlation between regular physical activity and individual's abilities to perform ADLs, it is reason to believe a larger focus on activating elderly people living in NHs will benefit their care dependency as well as reducing costs related to geriatric care in NH settings. Making the patients less care dependent will also give them a more meaningful daily life (28), and provide them with stimulating physical and cognitive actives to indicate a superior quality of the NH healthcare services. Participating in these activities allows the patients to express themselves, and helping them to fulfill one of

the basic human needs (72).

7.1 Dementia and activity

Multiple studies indicate how regular physical activity (PA) and an active lifestyle may be beneficial in preventing the development of Alzheimer disease and dementia (73-75). The explanation to how and why PA affects and benefits individuals with dementia remains unclear, but it has shown to help with cognitive improvement, as well as leading to structural changes in the brain (76). PA does not serve as a curative measure regarding dementia, but has been shown to offer the individual better functioning in ADLs, such as balance and motor sequencing (76).

A literature review has suggested that all investigated exercise-related interventions have had a positive effect on cognition - including longer sessions of aerobic exercise as well as multimodal programs (77). However, few studies have investigated what dosage or kind of activity that is most efficient. Resultingly, there are limited recommendations specified for patients with dementia, even though these patients have the same need for physical activity as healthy people (75). Furthermore, these patients are less able to perform activity independently, and need facilitation, encouragement and assistance in doing so.

A previously mentioned Norwegian randomized controlled trial study (EXDEM) investigated how high intensity exercise impacts physical functioning and mental health among NH patients with dementia. The patients improved both their balance, strength and reduced the prevalence of apathy (12), as well helping them to maintain an improved balance during the 12-weeks follow up period. Additionally, it also indicated a long term effect on agitation (14). Another study from the EXDEM-project showed that NH patients with good physical functioning regarding muscle strength, balance and walking speed, had a smaller amount of depressive symptoms than passive patients (34). These studies indicate that NH patients are able to improve their functioning, when given the opportunity – through guided exercise.

PA also tends to reduce symptoms related to pain. PA will modulate the individuals` ability to perceive pain, presumably increasing the pain threshold, as a result of the hearts pressure-receptors being activated. The activity should be performed regularly and continuously, where endurance-related activities are regarded as most efficient (78). It is suggested that a systematic approach to the management of pain regarding medication, safety and education of

health care professionals may also reduce pain behavior in patients with moderate to severe dementia (79). Considering the possible benefits of a systematic approach, it is reasonable to assume a correlation between level of activity, and level of pain - also among patients diagnosed with dementia.

Currently, there is limited evidence as to how pain behavior and level of physical activity inflicts one another among patients with dementia, even though many studies indicate it effecting both physical and psychological aspects of patients` health (62, 80). A systematic review investigated the associations between pain, physical functioning and neuropsychiatric symptoms, but did not find any strong association between the variables (81). The available knowledge indicates that physiotherapy interventions may benefit patients with dementia. However, the information is not definitive, and more carefully designed studies are required to establish to what extent physiotherapy interventions can alleviate symptoms related to dementia. One way to address these needs, is to highlight possible connections between activity and pain, as well as increasing the focus on the possible benefit of physiotherapy among patients with dementia.

8.0 Physiotherapy in the nursing home setting

Every Norwegian municipality is obliged to ensure that they provide health services that promotes public health, prevent health problems, and treats sickness and injuries. Encouraging medical habilitation and rehabilitation, the municipality is imposed to offer physiotherapy services – also in the NH settings; either by hiring physiotherapists in the specific NH, or by hiring physiotherapists from private practices (82).

Nevertheless, the provision of physiotherapy in Norwegian NHs is currently insufficient. Seeing how studies describe everyday life of NHs as largely inactive (32, 33), and how most of the NH patients are in need of help in ADLs (83), there is great room for improvement. Physiotherapists focus on adapting and implementing physical activity and exercise to the individual person, targeting to improve and maintain abilities required to function in daily life. Physical exercise aims to improve range of movement, balance, mobility, strength and endurance – in addition to leading to an improved quality of life (61). Focusing on improving musculoskeletal problems, mobility issues and reducing pain, a physiotherapist make a valuable contributions to the rehabilitation and habilitation of patients suffering from

dementia (84). However, physiotherapy resources are scarce in the NHs, and the potential for improving the patients` capacity and need for activity is generally not met.

Studies show how even the frailest and most disabled patients benefits from customized exercise (60, 63, 64, 85). Considering how many NH patients who also suffer from dementia, and often are mobile and physically active, it is important to maintain their physical level of functioning as long as possible (85) – consequently reducing care dependency and costs. Even small improvements in ability to perform ADL will make daily life easier, increasing safety and wellbeing among the patients. Focus should be what kind of physical activity that is best suited for the patients living in NHs.

A recent white paper accepted by the Parliament of Norway highlights the importance of quality of health care into old age and focuses on creating a health care service which implements activity, participation and social interaction in the daily life in NHs. This white paper highlights the importance of adapting the activities to the individual patient, where physiotherapists are suggested as a contributing profession (86). Ideally, this may inspire more structural changes in the Norwegian health care system,

Any form of intervention in the hectic everyday life in NHs is required to be time- and cost efficient. Being regarded as an appropriate form of physical activity, walking is suggested to be an ideal form of exercise in the NH setting, also it being a fundamental part of functioning in ADL (57, 64). In addition to being time- and cost efficient, walking has also proved to slow down the progression of cognitive impairments (64). Taking this into consideration, there is reason to believe that keeping patients physically active will be beneficial for the individual to obtain pain reduction as well as a reduction of other neuropsychiatric symptoms. If the exercise is also tailored to the individual patient, one may also additionally target improvement of social- and mental aspects of everyday life in NHs.

8.1 International Classification of Function (ICF)

The International Classification of Function (ICF) is a classification the World`s Health Organization (WHO) has developed to establish a foundation and language regarding health and health-related situations concerning function and disability (87), and is frequently used by physiotherapists in adapting treatment and exercise to the individual patient. The ICF

classifies functioning and disability as a single spectrum– being affected by context and the surrounding environment (68, 88), in a biopsychosocial view. By doing so, the ICF creates a foundation for comparing different conditions by focusing on the impact a said condition has on the functioning of the individual (87, 88)

In line with recommendations from the Norwegian Parliament (86), the ICF-model takes all aspects of the person into account. In clinical settings, the IFC-model is used to assess functioning, setting goals, and planning treatment for the individual patient (89, 90). Physiotherapists use the ICF-framework to focus the conceptual emphasis on positive abilities of the individual at a patient level, reviewing the physical, mental and societal aspects as a whole – and recognizing how these aspects are influenced by internal and external factors (89), in line with the wish to create a health care service which implements activity, participation and social interaction. In the NH setting, the ICF model could be used by physiotherapists to adapt the treatment to the individual patient, considering their level of cognitive impairment or dementia, as well as pain condition. In this way, one may ideally prevent functional decline and amplifying pain conditions.

9.0 Improving everyday life in nursing homes

Addressing the connection between physical inactivity and pain in older persons living in NHs is clinically relevant, as the awareness will help prevent undertreatment of pain in NH patients. Emphasizing the importance of preventing a decrease in everyday life functioning and activity may help to highlight the need for preventive measures in NHs – and could possibly also have a positive influence on cognitive functioning. Wishing to reduce and avert pain conditions among NH patients, by stimulating the patient's ability to function in everyday life – one may also positively affect patient`s quality of life, as well as augment the level of dignity in the NH setting – by creating an everyday life in which the patients are in control of, enhancing their autonomy.

10.0 Research article

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The association between physical- and cognitive functioning and pain among Norwegian nursing home patients: a cross sectional study

Ingunn Fleten Mo

Abstract

Background: Previous studies have shown that nursing home (NH) patients are characterized by poor physical functioning and high occurrence of dependency in activities of daily living (ADL), as well as by high prevalence of pain and cognitive impairment. This study aimed to investigate the prevalence of physical and cognitive impairment and pain in a random sample of Norwegian NH patients, and to examine the impact of cognitive impairment and pain on physical functioning.

Methods: Cross-sectional baseline data from a total of 545 long-term NH patients were collected in connection with a randomized controlled trial (COSMOS). Data on patients' demographics were obtained, as well as scores of ADL-abilities (Physical Self Maintenance Scale, PSMS), cognitive function (Mini-Mental State Examination, MMSE), and to pain (Mobilization Observation Behavior Intensity Dementia, MOBID 2, Pain Scale). Data analyses were performed using t-test for independent groups for continuous data, and Mann Whitney U-analyses for ordinal data. Spearman correlation was used to examine association between variables. Univariate and multivariate linear regression analyses were conducted, examining the ability of demographic and test variables of pain and cognitive function to predict ADL.

Results: Most patients were reported to have a high level of care dependency (PSMS mean score of 17.3), dementia defined as MMSE $\leq$20 was found in 88% of the patients and pain above 0 on MOBID 2 pain scale was found in 81% of the patients. Cognitive functioning was found to affect physical functioning, and patients with dementia struggle with most ADLs in nursing home daily life; toileting, feeding, dressing, grooming and bathing.

Conclusions: These findings indicate that physical- and cognitive impairment and pain are important issues in Norwegian NHs, and they contribute to a better understanding of NH patients` needs. A larger focus on preventing decline in physical function may help prevent pain-conditions from developing.

Trial registration: The COSMOS-trial registered in the ClinicalTrials.gov (NCT02238652) July 7th, 2014

Keywords: Activities of Daily Living, Physical Functioning, Cognitive Functioning, Dementia, Nursing Home, Nursing Home Patient, Pain

Background

Modern science and progress in medicine has extended our life expectancy, and many people spend their last living years in institutions. Ideally, our last living years would contain superior quality of life and dignity. To ensure this, we have evidence that performing regular physical activity into old age is beneficial for the individual and may help prevent dementia, pain and progression of functional decline (1, 73, 91).

Despite of this knowledge, a recent observational study performed on 732 nursing home (NH) patients reported that the participants performed very little physical activity, and spent their days being passive (32). A review study stated that inactivity is a risk factor for developing and amplifying pain-conditions (56), which has a rippling effect, leading to more inactivity and pain (1, 57). Regular physical activity is described in a review study to be beneficial for the individuals` ability to perform activities of daily life (ADLs) and to improve physical functioning (63). Gitlin, Kales (92) also highlighted strong evidence that non-pharmacologic approaches might enhance quality of life among NH patients and reduce behavioral symptoms, making them less care dependent (63, 92).

Patients with cognitive impairments make out approximately 65% of patients living in NHs (13, 25). The number of patients with dementia is expected to triple within the next thirty years, and reach 131 million by 2050 (1), leading to an increased need for long-term care (46, 48). Patients with dementia require extensive personal care, and their cognitive function tends to decrease their ADL-abilities (1, 58). Having difficulties communicating their functional problems and symptoms in an appropriate way, their needs are often left unnoticed (11, 22, 48).

This also applies to pain, which is a frequent problem among NH patients with dementia. Capturing pain among these patients is difficult, especially to distinguish dementia behaviors from pain behaviors (10). A cross-sectional study aimed to examine prevalence of excruciating pain among these patients, and found that 3.7% had such pain on a daily basis (93), whilst another study asked NH patients how often they experienced pain and how severe it was, finding a pain prevalence of 79.5% (94). In Norway, a study aimed to describe pain and use of analgesics in NH patients, and found that roughly 50% had current pain, of whom 50% described their pain as moderate or severe (47). Nonpharmacological interventions (10) and improved analgesic treatment (19, 44, 54) have been found to reduce pain and behavioral symptoms related to dementia, like agitation, apathy and depression (20).

Seemingly, physical- and cognitive functioning and pain intertwines. Few studies

explored the relationship between these factors. A Norwegian study investigated the relationship between pain and different stages of dementia (95), and found that patients with severe dementia are at high risk of suffering from severe pain. In Sweden, Björk, Juthberg (33) investigated the prevalence of pain, cognitive impairment, neuropsychiatric symptoms and ADL in NH patients, and found that pain was most prevalent in cognitively impaired and ADL-dependent patients. Zekry, Herrmann (36) explored functional status between patients with and without dementia and reported that patients with dementia had poorer functional status. However, the studies did not elucidate the impact of cognitive functioning and pain on physical functioning.

Criteria for being admitted to NHs varies between countries. In Norway, based upon national health policy and individual municipals` regulations, admittance revolves around the question whether or not a person has extensive need for care in everyday life, and lacks the ability to care for him-/herself (16).

Hence, the aim of this study was to investigate what in fact characterizes residents of Norwegian NHs, concerning demographic factors, level of functioning in ADL, cognitive functioning and pain in a representative sample of NH patients.

The following research questions were investigated:

- What are demographic and clinical characteristics of nursing home patients in a random Norwegian sample, and do they differ between patients with and without dementia?
- Is ADL-functioning associated with demographic characteristics, cognitive functioning and/or pain?

Method

A cross-sectional design was applied based upon baseline data from a large, multicenter randomized controlled trial called COSMOS. The abbreviation refers to the composition of the trial: *Co*mmunication through Advanced Care Planning (ACP), *S*ystematic assessment and treatment of pain, *M*edication review, *O*rganization of activities and *S*afety. The overarching aim of the COSMOS-study was to improve the quality of life in NH patients by proactively assessing and treating pain, discontinuing unnecessary medication and organizing activities -

to see if this multidisciplinary treatment package implementation was better than "treatment as usual" (96). Eight Norwegian municipalities were invited to participate, from three counties, including 72 NH units from 37 NHs, with a total of 765 patients. Aiming for a representative sample, long-term care units specialized on somatic patients and patients with dementia were both invited, from urban, rural, wealthy and poor municipalities. Suitable NH-units were randomized into an intervention- or control group. Eligible participants needed to be more than 65 years of age and to have stayed in the ward for more than two weeks before assessment. Having schizophrenia or a life expectancy ≤6 months qualified for exclusion. After excluding not-eligible patients, a total of 545 NH patients remained for baseline assessments. Verbal and written consent was obtained from the cognitively intact patients and from the patient and his/her legal guardian if the patient was cognitively impaired. The COSMOS-trial was approved by the Regional Committee for Medical Research Ethics, Western Norway (REK 2013/1765) and registered at clinicaltrials.gov (NCT02238652) (96). Health care professionals connected to the COSMOS-intervention group received invitations to an education seminar, containing education regarding advanced care planning with patients and their next of kin.

Demographic variables and assessment tools

In this study, age, gender, marital status and BMI were the demographic variables investigated and compared between the patients with and without dementia.

Activities of Daily Living (ADL) and physical functioning

ADL performance was assessed by Lawton and Brody`s Physical Self-Maintenance Scale (PSMS) (96). The scale is used to indicate how well a person is performing concerning physical functioning at the present time. Six different items, regarding toileting, feeding,

dressing, grooming, physical ambulation and showering/bathing are scored. Each individual item scale is ranged from 0-5, and the total score ranges from 0-30, where a high score indicates a higher level of care dependence (97). Scoring is performed by health care professionals who observe the patient in a NH setting, focusing on what the patient actually does perform in everyday-life – not what she/he is capable of doing when instructed to (97). A smaller study has rated this scale to have excellent inter-observer reliability, while test-retest reliability was considered as good (98)

Pain

Pain was assessed with the Mobilization Observation Behavior Intensity Dementia 2 (MOBID 2) Pain Scale (96). It is used by a proxy to observe pain-related behavior in everyday life-situations of nursing homes – seeing how a patient reacts to a number of movements related to morning care, and registers pain-related reactions connected to vocal sounds, facial expressions and body movements. The tool includes 10 items, which are scored by a health care professional on a 0-10 Numeric Rating Scale (NRS), and the sum score indicates the individuals` pain intensity as judged by the proxy assessor. The scale separates between musculoskeletal pain and pain from internal organs, head and skin (52). A total MOBID 2-score is derived from the overall assessment, where a score on single items between 0-2 indicates no or mild pain, 3-6 moderate pain, and 7-10 severe pain (99). The scale has been reported with excellent reliability, validity and good responsiveness (53).

Cognitive function and dementia

Cognitive function was investigated using the Mini-Mental State Examination (MMSE) (Range 0-30) (96), which is frequently used in cognitive screening, assessing the individual`s abilities related to orientation, registration, attention, recollection and language (100, 101). A

score from 20 points and below indicates a certain dementia diagnosis, while a score above 20 indicate that the patient does not have dementia, or only a very mild form of dementia (102). Particularly low MMSE scores correlate strongly with dementia diagnoses (103). The MMSE has shown high internal consistency, test-retest reliability and inter-rater reliability (27, 103).

Test procedures

After finishing the education seminar, a trained staff member performed the assessments of the participants at baseline. Being mostly registered and licensed practical nurses, most of them had clinical experience from working with NH patients in their daily work, in addition to being familiar personnel to the participants (96). Researchers contacted the participating NH units regularly, supporting the study implementation.

Statistics

Descriptive statistics was used to investigate patient characteristics, functioning in ADL, pain localization and intensity prevalence and cognitive functioning. Means, standard deviations, as well as minimum and maximum values in all the continuous data were calculated, and n (%) for categorical data. Patients were defined to be cognitively impaired if they scored $\leq$ 20 points on MMSE. To compare patients with and without dementia, t-tests for independent groups was used for continuous data, and chi-squared tests for categorical data. For ordinal data, Mann-Whitney U test analyses were performed. Spearman`s Correlation was used to investigate possible correlation between the scores from MMSE, MOBID 2 Pain Score and PSMS. To examine the ability of demographic and test variables of pain and cognitive function to predict ADL, we used univariate and multivariate linear regression analysis. The significance level was set to $p<0.05$.

Results

Table 1 presents the characteristics of the study population. The demographic- and test data were derived from a total of 545 NH-patients, but data were missing for cognitive functioning in 51 patients, and some missing data were also found for the other variables except gender. The study sample consisted of more women (74%) than men (26%), and the mean age was 86.7, ranging from 66-104 years. Most of the patients were widows and widowers (62%). On average, the patients had normal body compositions, with mean BMI 23.9. However, the BMI-range indicated patients that were both extremely underweight and extremely obese (13-47) (*See Table 1*). There was no statistical significant difference in demographic variables between patients with and without dementia

Table 1 Demographic characteristics, total N=545

Variables	**n**	**All**	**Patients with dementia MMSE ≤20 N=434* (88 %)**	**Patients without dementia, MMSE ≥21 N=60 (12 %)**	**Difference, p-value**
Age, years:	493				
mean (SD)		86.7 (7.5)	87.1 (7.3)	85.3 (9.1)	
min.-max.		66-104	66-104	67-99	0.153
Gender:	545				
women: n (%)		402 (74 %)	317 (73)	49 (81.7)	
men: n (%)		143 (26 %)	117 (27)	11 (18.3)	0.119
BMI:	479				
mean (SD)		23.9 (4.8)	23.9 (4.7)	24.5 (5.7)	
min.-max.		13-47	13-40	15-47	0.425
Marital status:	497				
married: n (%)		120 (24)	100 (25.1)	10 (17.5)	
widows/widowers: n (%)		307 (62)	254 (63.4)	37 (65.0)	
single: n (%)		70 (14)	46 (11.5)	10 (17.5)	0.265

*Missing data for Mini-Mental State Examination-assessment: N=51
BMI: Body Mass Index
% = valid percent

Data on cognitive functioning was missing in 9.3% of the patients, but among those who were assessed, 88% were found to have dementia (MMSE ≤20). The mean (SD) score of the MMSE for all of the patients was 10.8 (7.8). Regarding physical functioning, the patients scored 17.3 on average on PSMS. The mean value of the MOBID-2 Pain Scale indicated a

low degree of pain among the patients (2.81) (*See Table 2).*, and 18.9% of the patients did not have a pain score.

Comparing the groups with and without dementia regarding physical functioning, a highly statistical significant ($p<0.001$) difference was found between the groups, indicating a higher care dependency meaning reduced ability to function in ADL among patients with dementia (17.8) compared to patients without dementia (13.6).

The mean MMSE score of the patients with dementia was 9.0, while it was 24.1 in the patients defined as not having a certain dementia diagnosis (*See Table 2*). The difference in pain between the patients with and without dementia was not quite statistically significant, but pain tended to be higher among the patients without dementia. Pain intensity in the musculoskeletal system was the pain localization with highest pain score, with a mean value of 5.4 on the MOBID 2 Pain Scale, compared to 2.8 from internal organs, head and skin. The highest pain intensity was found for musculoskeletal pain in patients without dementia (7.1 on MOBID pain scale). Regarding physical functioning, the patients with dementia seemed to have overall performance difficulties, receiving higher total scores (17.8) than the patients without dementia (13.6) (*See Table 2).*

Table 2 Participants` scores on functional assessment tools, total N=545

Assessment tools	**n**	**All**	**Patients with dementia, MMSE ≤20 N=434* (88%)**	**Patients without dementia, MMSE ≥20 N=60 (12%)**	**Difference, p-value**
PSMS:	538		n=434	n=60	
mean (SD)		17.33 (5.35)	17.8 (5.3)	13.6 (4.8)	
min.-max.		5-30	5-30	7-23	<0.001
MMSE:	494		n=434	n=60	
mean (SD)		10.83 (7.76)	9.0 (6.3)	24.1 (2.5)	
min.-max		0-29	0-20	21-29	<0.001
MOBID 2, total:	463		n=381	n=48	
mean , (SD)		2.54 (2.58)	2.4 (2.5)	3.2 (2.9)	
min.-max.		0-10	0-10	0-9	0.073
MOBID 2, pain from head skin and body:	476		n=393	n=50	
mean (SD)		2.81 (4.53)	2.52 (4.1)	4.3 (7.0)	
min.-max.		0-33	0-20	0-33	0.083
MOBID 2, musculoskeletal pain:	483		n=398	n=50	
mean (SD)		5.44 (7.54)	5.2 (7.2)	7.1 (10.0)	
min.-max.		0-42	0-40	0-33	0.192

*Missing data for Mini-Mental State Examination-assessment: 51
PSMS: Physical Self Maintenance Scale
MMSE: Mini-Mental State Examination
MOBID 2: Mobilisation Observation Behaviour Intensity Dementia 2

When inspecting the different tasks of PSMS, patients with dementia had more difficulties with performing all the tasks, except ambulation, which was found to be similarly impaired in the two groups of patients. The most difficult ADLs for patients with dementia were grooming situations, followed by bathing and dressing. The patients without dementia had the highest scores on physical ambulation, followed by bathing and grooming situations. The patients with dementia demonstrated substantial variability in how they scored on the separate ADLs and minimum- and maximum values ranged from 0-5 in all activities (*See Table 3*).

Table 3 Comparing ability to perform physical activities in Physical Self Maintenance Scale (PSMS) in patients with and without dementia, p-values calculated with Mann-Whitney U test

Physical Self Maintenance Scale (PSMS)	**All N=538 Mean (SD) Median, min-max**	**Patients with dementia, MMSE ≤20 N=434 Mean, (SD) Median, min-max**	**Patients without dementia, MMSE ≥21 N=60 Mean, (SD) Median, min-max**	**Asymp. Sig. (2-tailed), p-value**
Toileting (scale 0-5)				
Mean (SD)	2.9 (1.5)	3, (1.5)	1.9 (1.2)	<0.001
Median, min.-max.	3, 0-5	3, 0-5	2, 0-5	
Feeding (scale 0-5)				
Mean (SD)	1.8 (1.1)	1.9 (1.2)	1.2 (0.4)	<0.001
Median, min.-max.	1, 0-5	1, 0-5	1, 1-2	
Dressing (scale 0-5)				
Mean (SD)	3.1 (1.2)	3.2 (1.2)	2.3 (1.3)	<0.001
Median, min.-max.	4, 0-5	4, 0-5	2, 1-4	
Grooming (neatness, hair, nails, hands, face, clothing) (scale 0-5)				
Mean (SD)	3.4 (1.0)	3.5 (0.9)	2.7 (1.2)	<0.001
Median, min.-max.	4, 0-5	4, 0-5	3, 1-5	
Physical ambulation (scale 0-5)				
Mean (SD)	2.8 (0.9)	2.8 (0.9)	2.9 (0.8)	0.830
Median, min.-max.	3, 0-5	3, 0-5	3, 0-5	
Bathing (scale 0-5)				
Mean (SD)	3.4 (1.0)	3.4 (1.0)	2.8 (0.9)	<0.001
Median, min.-max.	3, 0-5	3, 0-5	3, 1-4	
TOTAL (scale 0-30)				
Mean (SD)	17.3 (5.4)	17.8 (5.2)	13.6 (4.4)	<0.001
Median, min.-max.	18, 5-30	18, 5-30	12.5, 7-23	

Spearman`s Correlation, r, was -0.5 ($p<0.001$) between PSMS and MMSE, and r was 0.1 ($p<0.001$) between PSMS and MOBID 2 pain scale. When performing regression analyses with the patients` scores on PSMS as the dependent variable, and their demographics (age, gender, BMI and marital status), scores on MOBID 2 pain scale (both musculoskeletal and from head, skin and body) and MMSE as dependent variables. In the multivariate analysis a highly statistical significant relationship between PSMS and the total score of MMSE (*See Table 4*), indicating a decrease in ADL-functioning alongside a decrease in MMSE-score, implying a worsening of cognitive function ($p<0.001$). There was also a statistical significant

relationship between PSMS and gender (p=0.008) with a higher total PSMS-score in women. The likelihood for impaired ADL was close to being significant for musculoskeletal pain (p=0.0.54), but no statistical relationship between PSMS and age, marital status, BMI, overall pain or pain from head, skin and body.

Table 4 Regression analyses, PSMS (ADL-functioning) as dependent variable

Independent variables:	Standardized Coefficients, beta	p-value
Age	-.081	0.103
Gender (women)	-0.123	0.008
Marital status	0.011	0.835
BMI	-.036	0.433
MMSE, total score	-0.519	<0.001
MOBID 2, total score	0.076	0.331
MOBID 2, musculoskeletal pain:	0.134	0.054
MOBID 2, pain from head skin and body	0.008	0.877

BMI: Body Mass Index

PSMS: Physical Self Maintenance Scale

MMSE: Mini-Mental State Examination

MOBID 2: Mobilisation Observation Behaviour Intensity Dementia 2

Discussion

In this study we investigated the demographic and clinical characteristics of a representative sample of 545 Norwegian NH patients, focusing on aspects considered important for ADL-functioning. In order to explore what characterized patients with and without dementia the sample was divided into two groups according to a cut point in MMSE. Approximately 88% of the patients had MMSE scores ≤ 20, indicating a certain cognitive impairment and/or a dementia-diagnosis, and only 12% were without dementia or had an uncertain cognitive impairment Most of the patients were female (74%), and widowers (62%), and the mean-age was 86.7 years. The mean score of the MMSE was 10.8, PSMS 17.3 and MOBID 2 Pain Scale 2.8, indicating poor cognitive functioning, high care dependency, and a low overall prevalence of pain. However, 81.1% of the study sample experience some sort of pain, and patients without dementia were found with the highest MOBID 2 Pain Score (7.1) of musculoskeletal pain. When comparing the groups with and without dementia, a highly significant difference (p<0.001) was found regarding physical functioning, where patients

with dementia had higher overall scores. Women also seemed to have more difficulties with ADL-tasks and reported a lower overall score regarding the different items. Musculoskeletal pain was close to being significantly associated with impaired ADL (p=0.054).

The study shows a relatively high mean score of care dependency among the patients. Other studies investigating ADL and physical functioning among NH patients have used different scales, and comparison is difficult. A study of how NH patients with dementia`s abilities to perform ADLs develop over time also used the PSMS (35). The study reported a trend towards poorer physical functioning over time, and overall higher mean-values than our study, but did not report which specific activities the patients struggled most with performing. They also found a strong correlation between cognitive functioning and ability to perform ADLs with a regression analysis showing an r-value of 0.19 ($p<0.001$) among the patients. Our study has only investigated the linear relationship between two variables at a time, but report similar p-values ($p<0.001$) between ability to perform ADLs and cognitive functioning. Seeing how the patients struggle with most ADLs in the NH setting (*Table 3)*, and patients with dementia struggling most, physical exercise and ADL training could be a possible measure worth trying, aiming to enhance the patients` physical functioning.

Compared to a previous study, the percentage of cognitively impaired patients (88%) is higher than in a study performed on a Swedish population, which reported cognitive impairment among roughly 70% (33). This study used the Gottfried` cognitive scale to assess the patients` cognitive functioning. A Swiss study also using the MMSE-scale to assess and separate the patients was Zekry, Herrmann (36), where 43% had Alzheimer`s disease, 11% had mild cognitive impairment, and 46% being without cognitive impairment. By splitting cognitive functioning into three categories, this study used different cut off-points than our study (104). In our study, we had no category labeled “mild cognitive impairment” and have only dichotomized the patients according to a more definite status of dementia with a MMSE-score $\leq$20, which may explain why our results differ. Still, the percentage of patients with dementia patients seems to be higher in our study reflecting Norwegian NH patients.

Pain-prevalence have varied tremendously in previous studies, sometimes measured entirely or partly by self-report (45, 47, 105) or – as in this study, indirectly by proxy assessors (33, 96). This enormous variation in pain-prevalence reported of NH patients may be explained by the different classifications of “pain” in the different studies. In our study, pain was classified

by a MOBID-score >0 (81.1%), while another study which reported only 3.7% pain, categorized “pain” as “excruciating” and on a daily basis (93). This makes comparison difficult, as different studies classifies pain in several ways. Another study from the COSMOS-trial separated the cognitive functioning into normal (3%), mild dementia (7%), moderate dementia (36%) and severe dementia (47%) (106). From this, one may believe that most patients experience some level of pain, but extreme pain is less frequent. Extreme pain may be easier to detect, as the symptoms of pain are more visible to observers and easier to treat with the correct analgesics.

Cultural differences regarding laws and regulations related to NH-admission may also impact the high prevalence of pain in this study. Rules for admission and health care services differ greatly from country to country and could possibly explain why the range between the lowest and highest reported pain prevalence is high. In high income countries, between one third and half of the people with dementia are cared for and live in NHs, while only approximately 6% of patients with dementia in low- and middle income countries are living under similar conditions (13). Norwegian regulations only allows admission to long term care in NHs if an individual is not considered able to care for him/herself (16). The public health services in Norway also facilitates for patients to live in their own homes for as long as possible, making patients with mild- to moderate degrees of dementia able to live at home into older age, receiving home nursing care and help from their families (18). This may contribute to explain some of our findings.

In this study, pain was measured by a pain behavior measure with excellent reliability, validity and good responsiveness (53). A similar study of Dutch NH patients, also using MOBID 2 as a measure of pain, reported that pain was present among close to 43% of the patients, where roughly 33% of the patients were reported having moderate to severe pain. Patients with dementia were observed having more pain than patient without dementia (107). With pain being present in a substantial number of patients in both studies, this indicates a lack of sufficient pain treatment. In our study, there is only a close-to significant relationship between pain and physical activity, but previous studies have reported that physical activity may improve pain conditions – especially musculoskeletal (108). Hence, non-pharmacological measures like physiotherapy and tailored exercise should be considered as a preventive measure, reducing the use of analgesics in NH patients.

Limitations

A small number of participants in the group without dementia (N=60) is a partial weakness of the statistical analyses – influencing the basis for comparison between patients with- and without dementia. It is still an important finding, reflecting that the majority of patients in Norwegian NHs have dementia or other cognitive impairments.

Another possible weakness of the study is how the baseline data were gathered by several different NH-staff members, making complete standardization difficult. Despite having systematic training, there is no guarantee that the data were collected in line with standard testing procedures, as human error always must be taken into consideration (109). Another weakness is that the NH-staff may be biased by knowing the patients – and may care about the individual and rate the patients differently than they would an unknown patient. However, this may also serve as a strength of the study, as the NH-staff know the patients` normal behavior, and can easier identify changes in the individual patient.

The external validity concerns whether the sample is representative of the study population of Norwegian NH patients or not (109). Representativeness for the study population may seem high, since the number of included patients is relatively high (N=545) and derived from 72 different units in eight Norwegian municipalities. Still, the NH units had to accept to participate in the study, and we cannot know whether this can have influenced representativeness of the study sample or not.

The only exclusion criteria in our study were having schizophrenia and/or a life expectancy $\leq$6 months. This may have excluded the patients with the poorest physical- and cognitive functioning, as well as the patients in most pain. Our study results should, however, take this fact into account, as it does reflect Norwegian NH patients in general, except those with schizophrenia and/or a life expectancy <6 months.

External validity may also be influenced by missing data. In the present study, there are missing data in the majority of the analyses. Missing data is the data value not stored for a variable in the observation of interest (110), and is a common problem in most studies. The issue with missing data is that it may reduce statistical power in the performed analyses, and lead to biased estimates, resultingly making the conclusions invalid (109). Our study results

were based on a large number of participants, but might still be biased by missing data, impacting external validity if the study.

Relevance for clinical practice and future research

In the present study we have focused on NH patients' abilities to perform physical activities and the impact of pain and cognitive impairment on functioning. We conclude that most NH patients have dementia and to a large degree lack the ability to care for themselves in daily life activities. Musculoskeletal pain tends to limit daily functioning, especially in the patients who does not have dementia. The results call for an effort to practice ADLs in NH patients, especially in patients with dementia, and to treat pain in painful conditions. The knowledge could ideally benefit the next generation of health care professionals and may inspire structural changes in the NH-setting. This study will also serve as a point of reference to future research.

Conclusions

The findings in this study indicates that the majority of Norwegian NH patients are female, with a mean age of 86.7 years. Most patients are widows and widowers and have normal body compositions. how physical- and cognitive impairment and pain are relevant and common issues among Norwegian NH patients. These characteristic does not differ between patients with and without dementia. However, patients with dementia have significantly more difficulties with performing ADLs in the NH-setting, making physical functioning significantly associated with cognitive functioning. Patients without dementia have more pain, and evidently, musculoskeletal pain is the most common among all of the patients. The results contribute to a greater understanding of NH patients` needs, and what characterizes the typical NH patient. As health care professionals specialized to adapting activity to the individual person, physiotherapists in the nursing home setting will be able to contribute positively on improving QoL among NH patients, as well as decreasing workload on NH staff.

Abbreviations

ADL: Activities of Daily Life, MMSE: Mini-Mental State Examination, MOBID 2: Mobilization Observation Behavior Intensity Dementia 2, NH = Nursing Home, PSMS = Physical Self-Maintenance Scale, SPSS = Statistical Package for Social Sciences, QoL = Quality of Life

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Availability of data materials

Data can be made available by request to the corresponding author (?)

Authors` contribution

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Ethics approval and consent to participate

The Regional Ethical Committee for Medicine and Health Research Ethics, West Norway, approved The COSMOS-trial was approved by the Regional Committee for Medical Research Ethics, Western Norway (REK 2013/1765) and registered at clinicaltrials.gov (NCT02238652).

Consent for publication

Not applicable

Competing interests

The authors declare having ho competing interests.

Author details:

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References

1. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. The Lancet. 2017;390(10113):2673-734.
2. Tan ZS, Spartano NL, Beiser AS, DeCarli C, Auerbach SH, Vasan RS, et al. Physical Activity, Brain Volume, and Dementia Risk: The Framingham Study. The Journals of Gerontology: Series A. 2017;72(6):789-95.
3. Larson EB, Wang L, Bowen JD, et al. EXercise is associated with reduced risk for incident dementia among persons 65 years of age and older. Annals of Internal Medicine. 2006;144(2):73-81.
4. Den Ouden M, Bleijlevens MHC, Meijers JMM, Zwakhalen SMG, Braun SM, Tan FES, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.
5. Plooij B, Scherder EJA, Eggermont LHP. Physical inactivity in aging and dementia: a review of its relationship to pain. Journal of Clinical Nursing. 2012;21(21-22):3002-8.
6. Ashe MC, Miller WC, Eng JJ, Noreau L. Older Adults, Chronic Disease and Leisure-Time Physical Activity. Gerontology. 2008;55(1):64-72.
7. Blankevoort CG, van Heuvelen MJG, Boersma F, Luning H, de Jong J, Scherder EJA. Review of Effects of Physical Activity on Strength, Balance, Mobility and ADL Performance in Elderly Subjects with Dementia. Dementia and Geriatric Cognitive Disorders. 2010;30(5):392-402.
8. Gitlin LN, Kales HC, Lyketsos CG. Managing Behavioral Symptoms in Dementia Using Nonpharmacologic Approaches: An Overview. JAMA : the journal of the American Medical Association. 2012;308(19):2020-9.
9. International AsD. World Alzheimer Report. London; 2009.
10. Prince M, Prina M, Guerchet M. World`s Alzheimer`s Report 2013: journey of caring - an analysis of long-term care in dementia. London: Alzheimer`s Disease International; 2013.
11. Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature Review of Pain Prevalence Among Older Residents of Nursing Homes. Pain Management Nursing. 2010;11(4):209-23.
12. Weiner DK, Hanlon JT. Pain in nursing home residents: Management strategies. Drugs and aging. 2001;18(1):13-29.
13. Whitlock EL, Diaz-Ramirez L, Glymour M, Boscardin W, Covinsky KE, Smith AK. Association between persistent pain and memory decline and dementia in a longitudinal cohort of elders. JAMA Internal Medicine. 2017;177(8):1146-53.
14. Achterberg WP, Pieper MJC, van Dalen-Kok AH, de Waal MWM, Husebo BS, Lautenbacher S, et al. Pain management in patients with dementia. Clinical Interventions in Aging. 2013;8:1471-82.

15. Hall S, Longhurst S, Higginson I. Living and dying with dignity: a qualitative study of the views of older people in nursing homes. Age and Ageing. 2009;38(4):411-6.
16. Oliveira AMd, Radanovic M, Mello P, #xed, de cCH, Buchain P, et al. Nonpharmacological Interventions to Reduce Behavioral and Psychological Symptoms of Dementia: A Systematic Review. BioMed Research International. 2015;2015:9.
17. Teno JM, Kabumoto G, Wetle T, Roy J, Mor V. Daily Pain That Was Excruciating at Some Time in the Previous Week: Prevalence, Characteristics, and Outcomes in Nursing Home Residents. Journal of the American Geriatrics Society. 2004;52(5):762-7.
18. Tse MM, Pun SP, Benzie IF. Pain relief strategies used by older people with chronic pain: an exploratory survey for planning patient-centred intervention. Journal of Clinical Nursing. 2005;14(3):315-20.
19. Torvik K, Kaasa S, Kirkevold Ø, Rustøen T. Pain in patients living in Norwegian nursing homes. Palliative Medicine. 2009;23(1):8-16.
20. Husebo BS, Achterberg W, Flo E. Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review. CNS Drugs. 2016;30(6):481-97.
21. Lövheim H, Sandman P-O, Kallin K, Karlsson S, Gustafson Y. Poor staff awareness of analgesic treatment jeopardises adequate pain control in the care of older people. Age and Ageing. 2006;35(3):257-61.
22. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Treatment of Pain in European Nursing Homes: Results from the Services and Health for Elderly in Long TERm Care (SHELTER) Study. Journal of the American Medical Directors Association. 2013;14(11):821-31.
23. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and Psychological Symptoms of Dementia. Frontiers in Neurology. 2012;3:73.
24. Husebo B, Strand LI, Moe-Nilssen R, Borgehusebo S, Aarsland D, Ljunggren AE. Who Suffers Most? Dementia and Pain in Nursing Home Patients: A Cross-Sectional Study. Journal of The American Medical Directors Association. 2008;9(6):427-33.
25. Björk S, Juthberg C, Lindkvist M, Wimo A, Sandman P-O, Winblad B, et al. Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study. BMC Geriatrics. 2016;16(1):154.
26. Zekry D, Herrmann FR, Grandjean R, Meynet M-P, Michel J-P, Gold G, et al. Demented versus non-demented very old inpatients: the same comorbidities but poorer functional and nutritional status. Age and Ageing. 2008;37(1):83-9.
27. Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven), Helse- og omsorgstjenesteloven - hol(2011).

28. Husebo BS, Flo E, Aarsland D, Selbaek G, Testad I, Gulla C, et al. COSMOS—improving the quality of life in nursing home patients: protocol for an effectiveness-implementation cluster randomized clinical hybrid trial. Implementation Science. 2015;10(1):131.
29. Lawton MP, Brody EM. Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living1. The Gerontologist. 1969;9(3_Part_1):179-86.
30. Edwards MM. The Reliability and Validity of Self-Report Activities of Daily Living Scales. Canadian Journal of Occupational Therapy. 1990;57(5):273-8.
31. Husebo BS, Ostelo R, Strand LI. The MOBID-2 pain scale: Reliability and responsiveness to pain in patients with dementia. European Journal of Pain (London, England). 2014;18(10):1419-30.
32. Husebo BS. Mobilization-Observation-Behaviour-Intensity-Dementia-2 Pain Scale (MOBID-2). Journal of Physiotherapy. 2017.
33. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE. Pain in older persons with severe dementia. Psychometric properties of the Mobilization–Observation–Behaviour–Intensity–Dementia (MOBID-2) Pain Scale in a clinical setting. Scandinavian Journal of Caring Sciences. 2010;24(2):380-91.
34. Crum RM, Anthony JC, Bassett SS, Folstein MF. Population-based norms for the mini-mental state examination by age and educational level. JAMA. 1993;269(18):2386-91.
35. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975;12(3):189-98.
36. Perneczky R, Wagenpfeil S, Komossa K, Grimmer T, al e. Mapping scores onto stages: Mini-mental state examination and clinical dementia rating. The American Journal of Geriatric Psychiatry. 2006;14(2):139-44.
37. Strobel C, Engedal K. MMSE-NR. The Standardized Norwegian MMSE. Oslo: Norwegian National Advisory Unit on Ageing and Health; 2008.
38. Jellinger KA, Attems J. Prevalence of dementia disorders in the oldest-old: an autopsy study. Acta Neuropathologica. 2010;119(4):421-33.
39. Helvik A-S, Engedal K, Benth JŠ, Selbæk G. A 52 month follow-up of functional decline in nursing home residents – degree of dementia contributes. BMC Geriatrics. 2014;14(1):45.
40. Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. Mild cognitive impairment: Clinical characterization and outcome. Archives of Neurology. 1999;56(3):303-8.
41. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Pain characteristics and pain control in European nursing homes: Cross-sectional and longitudinal results from the services and health for elderly in long term care (SHELTER) study. J Am Med Dir Assoc. 2013;14.

42. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Treatment of pain in european nursing homes: Results from the services and health for elderly in long term care (SHELTER) study. J Am Med Dir Assoc. 2013;14.

43. Aasmul I, Husebo BS, Flo E. Description of an advance care planning intervention in nursing homes: outcomes of the process evaluation. BMC geriatrics. 2018;18(1):26.

44. Lystrup LS, Lillesveen B, NygГЃrd A-M, Engedal K. Omsorgstilbud til hjemmeboende personer med demens. Tidsskrift for Den norske legeforening. 2006.

45. van Kooten J, Smalbrugge M, van der Wouden JC, Stek ML, Hertogh CMPM. Evaluation of a Pain Assessment Procedure in Long-Term Care Residents With Pain and Dementia. Journal of Pain and Symptom Management. 2017;54(5):727-31.

46. Morey MC. Physical activity and exercise in older adults: UpToDate Inc.; 2018 [Available from: https://www.uptodate.com/contents/physical-activity-and-exercise-in-older-adults?search=pain%20exercise&source=search_result&selectedTitle=3~150&usage_type=default&display_rank=3.

47. Polit DF, Beck CT. Nursing Research : generating and assessing evidence for nursing practice. 10th ed. ed. Philadelphia: Wolters Kluwer; 2017.

48. Kang H. The prevention and handling of the missing data. Korean Journal of Anesthesiology. 2013;64(5):402-6.

11.0 Methodological issues

In the following part, I will describe the method for studying the research question, and discuss strengths and weaknesses, in addition to validity of the study.

11.1 Aim of the study and research question

As seen throughout this thesis and research article, most patients living in long term care in NHs are care dependent. The majority of the patients suffer from cognitive impairment and dementia and have a high prevalence of pain. These functional issues are related to quality of life and sense of dignity of health care services offered in NHs, which are superior measures when living in an institution. This study aims to investigate the connections between physical- and cognitive functioning and pain in the NH setting. Followingly, these research questions were formulated and investigated:

- What are demographic and clinical characteristics of nursing home patients in a random Norwegian sample, and do they differ between patients with and without dementia?
- Is ADL-functioning associated with demographic characteristics, cognitive functioning and/or pain?

11.2 The COSMOS-study

This master's thesis is based upon baseline data in connection with an ongoing cluster randomized controlled trial (rRCT), called COSMOS (Communication through Advanced Care Planning (ACP), Systematic assessment and treatment of pain, Medication review, Organization of activities, and Safety), executed between August 2014 to December 2015. The COSMOS abbreviation refers to the trial composition, and the primary aim of the study is to improve QoL in NH patients my implementing ACP in the NH setting, and to see if the implementation of this multidisciplinary care package is better than "treatment as usual". Secondly, the COSMOS trial also aims to determine how effective the intervention is with regards to physical and mental health, sleep, safety, pain, total drug use, cost-effectiveness and admission to hospitals (106).

Eight municipalities from urban, rural, rich and poor areas of Norway were invited to

participate in the COSMOS-study, adding up to a total of 765 NH patients invited to participate in the study. To attain a representative study sample, the study included patients above 65 years of age who had stayed in the ward for more than two weeks before baseline assessments. If the patients had a life expectancy $\leq$6 months or had schizophrenia, the patients were excluded from the study. After exclusion, a total of 545 eligible NH patients remained for baseline assessments (96).

Baseline assessment included demographic information about the included patients, medications and drug use, and patients` scores on Functional Assessment Staging (FAST), Cornell Scale for depression, Neuropsychiatric Inventory-Nursing Home Version (NPI-NH), Cohen-Mansfield Agitation Inventory, Lawton and Brody`s Physical Self Maintenance Scale (P-ADL/PSMS), QUAlity of Life In late-stage Dementia (QUALI-DEM), Mobilization-Observation-Behavior-Intensity-Dementia 2 (MOBID 2) Pain Scale, Resource Utilization in Dementia-Formal Care (RUD-FOCA), European Quality of Life-5 Dimensions(EQ-5d), Mini-Mental State Examination (MMSE) and Clinical Global Impression of Change (CGIC), as well as Actigraphy to assess sleeping patterns (96).

The COSMOS-trial is registered at clinicaltrials.gov (NCT02238652), as well as approved and permitted by the Reginal Committee for Medical and Health Research Ethics, West Norway (REK 2013/1765). Among cognitively intact patients with sufficient capability to consent, written and verbal consent has been obtained through direct conversations with the patients. Patients who lacked the ability to consent were informed written and verbally, and presumed consent was attained through direct conversations with the patient him-/herself, or the persons legal guardian – most commonly an advocate or next of kin (96).

11.3 Limiting the assignment

Answering the research question, it was necessary to reduce the amount of data collected in the COSMOS-study. The aim of this study was to investigate to what extent the patient`s ability to function in ADL is connected to the level of pain-related behavior and severity of dementia. Hence, it was necessary to include data related to the patients` activity level – gathered through the Physical Self-Maintenance Scale (PSMS). Secondly, it was necessary to include data from the MMSE-test, as to separating the patients regarding their cognitive functioning. Lastly, the patient`s scores on MOBID-2 pain scale regarding pain localization

and intensity was included. In addition to these measurement tools, the patients` demographic information was also used in the statistical analyses.

11.4 The Mini-Mental State Examination (MMSE)

The Mini-Mental State Examination (MMSE) is frequently used in cognitive screening of patients suffering from dementia, and assesses the individual`s ability to orientation, registration, attention, recollection and language, and is used in NHs worldwide (101). It has also been used to assess and measure changes in patient`s cognitive status over time (103) Cognitive function was investigated using the Mini-Mental State Examination (MMSE) (Range 0-30), which is frequently used in cognitive screening, assessing the individual`s ability to orientation, registration, attention, recollection and language (100, 101). A score from 20 points and below indicates a certain dementia diagnosis, while a score above 20 indicate that the patient does not have dementia, or only a very mild form of dementia (102). Particularly low scores correlate strongly with dementia diagnoses.

11.5 MOBID- 2 Pain Scale

The Mobilization-Observation-Behavior-Intensity-Dementia-2 (MOBID-2) Pain Scale was used to assess pain in this study. The MOBID 2 Pain Scale is developed to observe pain-related behavior among patients in the advanced stages of dementia, and is administered by health care professional, as a proxy rater. Considering how patients with dementia have difficulties expressing themselves, and their pain situation, MOBID-2 is designed with the purpose of observing the patients in everyday life-situations of NHs. The tool aspires to assess the patient`s reaction to a number of movements related to daily life, and registers pain-related reactions connected to vocal sounds, facial expressions and body movements. MOBID-2 uses a numeric rating scale (0-10) to assess the different movements, separating between pain from the musculoskeletal system and pain from internal organs, head and skin. A single-item-score between 0-2 indicates having no or mild pain, a score between 3-6 indicates having moderate pain, and a score <7 indicates having severe pain when performing the individual movements (52, 99). MOBID-2 has shown to be reliable and responsive to change in use among patients with dementia (52), and is the only pain tool to follow the recommendations from COSMIN (19). In addition, MOBID 2 is already an established and familiar assessment tool used by a number of NHs in Norway.

11.6 Physical Self-Maintenance Scale (PSMS)

There is a large variety of different scales recording ADL functioning among different groups of patients. In the COSMOS-study, this information has been gathered through the Physical Self-Maintenance Scale (PSMS). The scale was developed to evaluate disability in elderly people, for example in NHs (97). Basing itself upon ADLs, the PSMS gauges the patient`s ability to perform tasks relevant for the daily life in NHs, and mainly targets observable behaviors. It is used to determine if there is a skill reduction connected to a dementia-related disease, as well as considering what the patient is able to do in ADL. The overall aim of the scale is to decide what kind of measures should be put in place for the individual patient (Davis et. al, 1997).

The scale used on the COSMOS-study is six-item-based, there a 5-point scale for responses ranges from total independence to total dependence. The items used in this study has shown to have a test-retest reliability of 0.94, as well as having good validity (111). The PSMS is completed by a proxy rater, who scores how well the persons` highest level of functions when performing toileting, feeding, dressing, grooming, physical ambulation and bathing (97).

11.6 Weaknesses in this study

Data collection has been performed by a number of different health care professionals. There is no guarantee for a completely homogenous and standardized data collection, despite customized training. Therefore, there is a possibility for human error in the data material, as it is in every large data sample (109). However, the educational program was thoroughly planned and implemented, and based on previous studies, clinical experience and systematic reviews (96), ideally reducing the room for human error.

Another weakness may be the fact that external factors impact the results and the assessment of the patients. Proxy raters have performed the assessments, who all are health care professionals familiar to the patients. This may create an artificial situation, where the assessor may under-report symptoms and overestimate the accomplishments of the individual being assessed. Simultaneously as this may serve as a strength of the study, as the NH-staff easier can detect changes in the individual patient, and easier identify for example pain behavior or decline in ability to perform functional tasks.

11.7 Strengths in this study

Firstly, the study is a part of a well-designed randomized controlled trial with many included participants (N=545), making findings easier to generalize. Included patients are both male and female, in ages above 65, from both rural and urban areas of Norway, as well as being from both dementia- and somatic wards. This makes the results applicable to similar populations, as the sample size is of a sufficient size and the study sample is random.

Secondly, the study design allows this project to collect a substantial number of variables at a time and making it possible to measure prevalence for the investigated factors. Followingly, it allows assessment of how demographic variables, cognitive functioning, physical functioning and pain affects each other, and permits descriptive analyses of the material. The data are consistent and precise, and the research results are normally independent of the researcher (109), making the results reproducible.

11.8 Validity

Every study is affected by internal- and external validity, deciding to what extent inferences made in a project are precise. Polit and Beck (109) defines internal validity as how much the results in a study in fact are affected by experimental interventions - instead of being confounding factors. Furthermore, they define external validity is to what level the results are reproduceable and possible to generalize into other samples than the one in question (109).

In this study, the study sample is representative – especially in a national level, to the NH patient-population, as it has been collected from NHs across Norway, only excluding dying patients and patients with schizophrenia (96). The sample size is large enough to estimate prevalence of pain, physical functioning and dementia with adequate accuracy, collecting data from 545 patients. The fact that some of the patients have missing results in some of the assessment tools, creates a potential bias in this study.

Furthermore, the skewness of cognitively impaired and not cognitively impaired patients may have impacted the analyses, as this difference is quite large. On the other hand, this represents an important finding, as cognitively impaired patients outnumber patients without cognitive impairment in the NH-setting. Simultaneously, these analyses are based upon baseline data, no interference of maturation, mortality or historic events is suggested.

Researcher expectancies may also threat construct validity (109), where the person conducting the project will influence communication regarding the desired outcome. As I have not been a part of the intervention and/or data collection, this factor is reduced in this study. However, my expectancies and believes regarding the study outcomes will possibly impact the results and how I look upon the findings.

The Hawthorne effect may impact every study, meaning that a participant reacts to the study situation, behaving in a particular manner as a result of being aware of their role in a study (109). This effect is possible to minimize, such as in the COSMOS-study - with participant blinding and collecting demographic data not susceptible to reactivity. Another aspect to this, is that the participants to various extents are cognitively impaired, not necessarily being aware of their own participation in a project.

12.0 List of references

1. Livingston G, Sommerlad A, Orgeta V, Costafreda SG, Huntley J, Ames D, et al. Dementia prevention, intervention, and care. The Lancet. 2017;390(10113):2673-734.
2. Folkehelseinstituttet. Folkehelserapporten 2014: Helsetilstanden i Norge. Oslo; 2014.
3. Pickard L, Comas-Herrera A, Costa-Font J, Gori C, Maio Ad, Patxot C, et al. Modelling an entitlement to long-term care services for older people in Europe: projections for long-term care expenditure to 2050. Journal of European Social Policy. 2007;17(1):33-48.
4. Folkeheleinstituttet. Folkehelserapporten, Helsetilstanden i Norge. 2014.
5. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagianniduou M. World Alzheimer Report 2016. Global Observatory for Ageing and Dementia Care; 2016.
6. Samhandlingsreformen: Rett behandling - på rett sted - til rett tid, (2008-2009).
7. Innovasjon i omsorg, (2011).
8. Cass E, Robins D, Richardson A. Adults` Services Practice Guide 9: Dignity in care. London: Social Care Institute for Excellence; 2008. Available from: http://www.scie.org.uk/publications/practiceguides/practiceguide09/files/pg09.pdf.
9. Tible OP, Riese F, Savaskan E, von Gunten A. Best practice in the management of behavioural and psychological symptoms of dementia. Therapeutic Advances in Neurological Disorders. 2017;10(8):297-309.
10. Oliveira AMd, Radanovic M, Mello P, #xed, de cCH, Buchain P, et al. Nonpharmacological Interventions to Reduce Behavioral and Psychological Symptoms of Dementia: A Systematic Review. BioMed Research International. 2015;2015:9.
11. Hall S, Longhurst S, Higginson I. Living and dying with dignity: a qualitative study of the views of older people in nursing homes. Age and Ageing. 2009;38(4):411-6.
12. Telenius EW, Engedal K, Bergeland A. Effect of a high-intensity exercise program on physical function and mental health in nursing home residents with dementia: an assessor blinded randomized controlled trial. PLoS ONE. 2015;10(5):e0126102.
13. Prince M, Prina M, Guerchet M. World`s Alzheimer`s Report 2013: journey of caring - an analysis of long-term care in dementia. London: Alzheimer`s Disease International; 2013.
14. Telenius EW, Engedal K, Bergland A. Long-term effects of a 12 weeks high-intensity functional exercise program on physical function and mental health in nursing home residents with dementia: a single blinded randomized controlled trial. BMC Geriatrics. 2015;15(1):158.
15. Forskrift til helse og omsorgstjenesteloven om kriterier for rett til tilbud om opphold i sykehjem eller tilsvarende bolig særskilt tilrettelagt for heldøgstjenester , Bergen Kommune, Hordaland, (2017).
16. Lov om kommunale helse- og omsorgstjenester m.m. (helse- og omsorgstjenesteloven), Helse- og omsorgstjenesteloven - hol(2011).
17. Bjerkan J, Hallem UL, Brataas HV. Hvordan forstås og praktiseres IPLOS-kartlegging? - En kvalitativ studie i helse- og omsorgstjenesten i én kommune. Tidsskrift for omsorgsforskning. 2016;2(03):222-31.
18. Lystrup LS, Lillesveen B, NygГґrd A-M, Engedal K. Omsorgstilbud til hjemmeboende personer med demens. Tidsskrift for Den norske legeforening. 2006.
19. Husebo BS, Achterberg W, Flo E. Identifying and Managing Pain in People with Alzheimer's Disease and Other Types of Dementia: A Systematic Review. CNS Drugs. 2016;30(6):481-97.
20. Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and Psychological Symptoms of Dementia. Frontiers in Neurology. 2012;3:73.
21. Habiger TF, Flo E, Achterberg WP, Husebo BS. The Interactive Relationship between Pain, Psychosis, and Agitation in People with Dementia: Results from a Cluster-Randomised Clinical Trial. Behavioural Neurology. 2016;2016:8.
22. Achterberg WP, Pieper MJC, van Dalen-Kok AH, de Waal MWM, Husebo BS, Lautenbacher S, et al. Pain management in patients with dementia. Clinical Interventions in Aging. 2013;8:1471-82.

23. Selbaek G, Kirkevold O, Engedal K. The prevalence of psychiatric symptoms and behavioural disturbances and the use of psychotropic drugs in Norwegian nursing homes. Int J Geriatr Psychiatry. 2007;22.
24. Larson EB. Evaluation of cognitive impairment and dementia. UpToDate. 2018.
25. International AsD. World Alzheimer Report. London; 2009.
26. Qiu C, De Ronchi D, Fratiglioni L. The epidemiology of the dementias: an update. Current Opinion in Psychiatry. 2007;20(4):380-5.
27. Jellinger KA, Attems J. Prevalence of dementia disorders in the oldest-old: an autopsy study. Acta Neuropathologica. 2010;119(4):421-33.
28. James I, Blomberg K, Kihlgren A. A meaningful daily life in nursing homes - a place of shelter and a space of freedom: a participatory appreciative action reflection study. BMC Nursing. 2014;13:19-.
29. Nåden D, Rehnsfeldt A, Råholm M-B, Lindwall L, Caspari S, Aasgaard T, et al. Aspects of indignity in nursing home residences as experienced by family caregivers. Nursing Ethics. 2013;20(7):748-61.
30. MacRae PG, Schnelle JF, Simmons SF, Ouslander JG. Physical Activity Levels of Ambulatory Nursing Home Residents. Journal of Aging and Physical Activity. 1996;4(3):264-78.
31. Ice G. Daily life in a nursing home: Has it changed in 25 years?2002. 345-59 p.
32. Den Ouden M, Bleijlevens MHC, Meijers JMM, Zwakhalen SMG, Braun SM, Tan FES, et al. Daily (In)Activities of Nursing Home Residents in Their Wards: An Observation Study. Journal of the American Medical Directors Association. 2015;16(11):963-8.
33. Björk S, Juthberg C, Lindkvist M, Wimo A, Sandman P-O, Winblad B, et al. Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study. BMC Geriatrics. 2016;16(1):154.
34. Kvæl LAH, Bergland A, Telenius EW. Associations between physical function and depression in nursing home residents with mild and moderate dementia: a cross-sectional study. BMJ Open. 2017;7(7).
35. Helvik A-S, Engedal K, Benth JŠ, Selbæk G. A 52 month follow-up of functional decline in nursing home residents – degree of dementia contributes. BMC Geriatrics. 2014;14(1):45.
36. Zekry D, Herrmann FR, Grandjean R, Meynet M-P, Michel J-P, Gold G, et al. Demented versus non-demented very old inpatients: the same comorbidities but poorer functional and nutritional status. Age and Ageing. 2008;37(1):83-9.
37. Linacre JM, Heinemann AW, Wright BD, Granger CV, Hamilton BB. The structure and stability of the Functional Independence Measure. Archives of physical medicine and rehabilitation. 1994;75(2):127-32.
38. Jefferson AL, Byerly LK, Vanderhill S, Lambe S, Wong S, Onzoff A, et al. Characterization of activties of daily living with mild cognitive impairment. The American Journal of Geriatric Psychiatry. 2008;16(5):375-83.
39. IASP. Pain Terms, A Current List with Definitions and Notes on Usage: IASP Task Force on Taxonomy; 1994 [209-14]. Available from: http://www.iasp-pain.org.
40. Pope JE, Deer TR. Treatment of chronic pain conditions : a comprehensive handbook: Springer; 2017.
41. Pieper MJ, Van Dalen-Kok AH, Francke AL, van der Steen JT, Scherder EJ, Husebo BS, et al. Interventions targeting pain or behaviour in dementia: a systematic review. Ageing Res Rev. 2013;12.
42. Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature review of pain prevalence among older residents of nursing homes. Pain Manag Nurs. 2010;11.
43. Erdal A, Flo E, Selbaek G, Aarsland D, Bergh S, Slettebo DD, et al. Associations between pain and depression in nursing home patients at different stages of dementia. Journal of Affective Disorders. 2017;218:8-14.

44. Lövheim H, Sandman P-O, Kallin K, Karlsson S, Gustafson Y. Poor staff awareness of analgesic treatment jeopardises adequate pain control in the care of older people. Age and Ageing. 2006;35(3):257-61.
45. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Pain characteristics and pain control in European nursing homes: Cross-sectional and longitudinal results from the services and health for elderly in long term care (SHELTER) study. J Am Med Dir Assoc. 2013;14.
46. Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature Review of Pain Prevalence Among Older Residents of Nursing Homes. Pain Management Nursing. 2010;11(4):209-23.
47. Torvik K, Kaasa S, Kirkevold Ø, Rustøen T. Pain in patients living in Norwegian nursing homes. Palliative Medicine. 2009;23(1):8-16.
48. Weiner DK, Hanlon JT. Pain in nursing home residents: Management strategies. Drugs and aging. 2001;18(1):13-29.
49. Scherder EJA, Sergeant JA, Swaab DF. Pain processing in dementia and its relation to neuropathology. The Lancet Neurology. 2003;2(11):677-86.
50. Farrell MJ, Katz B, Helme RD. The impact of dementia on the pain experience. PAIN. 1996;67(1):7-15.
51. Monroe TB, Gore JC, Chen LM, Mion LC, Cowan RL. Pain in People With Alzheimer Disease:Potential Applications for Psychophysical and Neurophysiological Research. Journal of Geriatric Psychiatry and Neurology. 2012;25(4):240-55.
52. Husebo BS, Ostelo R, Strand LI. The MOBID-2 pain scale: Reliability and responsiveness to pain in patients with dementia. European Journal of Pain (London, England). 2014;18(10):1419-30.
53. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE. Pain in older persons with severe dementia. Psychometric properties of the Mobilization–Observation–Behaviour–Intensity–Dementia (MOBID-2) Pain Scale in a clinical setting. Scandinavian Journal of Caring Sciences. 2010;24(2):380-91.
54. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Treatment of Pain in European Nursing Homes: Results from the Services and Health for Elderly in Long TERm Care (SHELTER) Study. Journal of the American Medical Directors Association. 2013;14(11):821-31.
55. Caspersen CJ, Powell KE, Christenson GM. Physical activity, exercise, and physical fitness: definitions and distinctions for health-related research. Public Health Reports. 1985;100(2):126-31.
56. Plooij B, Scherder EJA, Eggermont LHP. Physical inactivity in aging and dementia: a review of its relationship to pain. Journal of Clinical Nursing. 2012;21(21-22):3002-8.
57. Ashe MC, Miller WC, Eng JJ, Noreau L. Older Adults, Chronic Disease and Leisure-Time Physical Activity. Gerontology. 2008;55(1):64-72.
58. Whitlock EL, Diaz-Ramirez L, Glymour M, Boscardin W, Covinsky KE, Smith AK. Association between persistent pain and memory decline and dementia in a longitudinal cohort of elders. JAMA Internal Medicine. 2017;177(8):1146-53.
59. Busse AL, Gil G, Santarém JM, Jacob Filho W. Physical activity and cognition in the elderly: A review. Dementia & Neuropsychologia. 2009;3:204-8.
60. Koščak., Tivadar., Blanka. Physical activity improves cognition: possible explanations. Biogerontology. 2017;18(4):477-83.
61. Brett L, Traynor V, Stapley P. Effects of Physical Exercise on Health and Well-Being of Individuals Living With a Dementia in Nursing Homes: A Systematic Review. Journal of the American Medical Directors Association. 2016;17(2):104-16.
62. Zeng Z, Deng Y-H, Shuai T, Zhang H, Wang Y, Song G-M. Effect of physical activity training on dementia patients: A systematic review with a meta-analysis. Chinese Nursing Research. 2016;3(4):168-75.
63. Blankevoort CG, van Heuvelen MJG, Boersma F, Luning H, de Jong J, Scherder EJA. Review of Effects of Physical Activity on Strength, Balance, Mobility and ADL Performance in Elderly Subjects with Dementia. Dementia and Geriatric Cognitive Disorders. 2010;30(5):392-402.

64. Rolland Y, Pillard F, Klapouszczak A, Reynish E, Thomas D, Andrieu S, et al. Exercise Program for Nursing Home Residents with Alzheimer`s Disease: A 1-Year Randomized, Controlled Trial. Journal of American Geriatrics Society. 2007;55(2):158-65.
65. Kirkevold O, Endedal K. The quality of care in Norwegian nursing homes. Scand J Caring Sci. 2006;20:177-83.
66. Kjøs BØ, Havig AK. An examination of quality of care in Norwegian nursing homes – a change to more activities? Scandinavian Journal of Caring Sciences. 2016;30(2):330-9.
67. Innhald of kvalitet i omsorgstenestene. Omsorg 2000, (2000).
68. helsedirektoratet S-o. Internasjonal klassifikasjon av funksjon, funksjonshemming og helse: Norsk brukerveiledning. KITH, editor: AIT Otta AS; 2004.
69. Mestring, muligheter og mening. Framtidas omsorgsutfodringer, (2006).
70. Forskrift om kvalitet i pleie- og omsorgstjenestene for tjenesteyting etter lov av 19. november 1982 nr. 66 om helsetjenesten i kommunene og etter lov av 13. desember 1991 nr. 81 om sosiale tjenester m.v., (2009).
71. Ikezoe T, Asakawa Y, Shima H, Kishibuchi K, Ichihashi N. Daytime physical activity patterns and physical fitness in institutionalized elderly women: An exploratory study. Archives of Gerontology and Geriatrics. 2013;57(2):221-5.
72. Hancock GA, Woods B, Challis D, Orrell M. The needs of older people with dementia in residential care. International Journal of Geriatric Psychiatry. 2006;21(1):43-9.
73. Larson EB, Wang L, Bowen JD, et al. EXercise is associated with reduced risk for incident dementia among persons 65 years of age and older. Annals of Internal Medicine. 2006;144(2):73-81.
74. Laurin D, Verreault R, Lindsay J, Macpherson K, Rockwood K. Physical Activity and Risk of Cognitive Impairment and Dementia in Elderly Persons. Archives of Neurology. 2001;58(3).
75. Helbostad JL, Taraldsen K, Saltvedt I. Aktivitetshåndboken: Fysisk aktivitet i forebygging og behandling: Demens. 3 ed. Bergen: Fagbokforlaget; 2015.
76. Faulk S, Edwards L, Sumrall K, Shelton T, Esalomi T, Payton C, et al. Benefits of physical activity on Alzheimer's disease: A literature review2014. 19-24 p.
77. Learner NA, Williams JM. Can physical activity be used to maintain cognitive function in nursing home residents with dementia? A literature review. Physical Therapy Reviews. 2016;21(3-6):184-91.
78. Bõrjesson M, Mannerkorpi K, Knardahl S, Karlsson J, Mannheimer C. Aktivitetshåndboken: Fysisk aktivitet i forebygging og behandling: Smerte. 3 ed. Bergen: Fagbokforlaget; 2015.
79. Husebo BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. BMJ: British Medical Journal. 2011;343(7816):193-.
80. Eggermont LHP, Swaab DF, Luiten PGM, Scherder EJA. Exercise, cognition and Alzheimer's disease: More is not necessarily better. Neuroscience and Biobehavioral Reviews. 2006.
81. van Dalen-Kok AH, Pieper MJC, de Waal MWM, Lukas A, Husebo BS, Achterberg WP. Association between pain, neuropsychiatric symptoms, and physical function in dementia: a systematic review and meta-analysis. BMC Geriatrics. 2015;15:49.
82. omsorgsdepartementet H-o. Offentlig fysioterapitjeneste: Regjeringen; 2014 [Available from: https://www.regjeringen.no/no/tema/helse-og-omsorg/helse--og-omsorgstjenester-i-kommunene/offentlig-fysioterapitjeneste/id444281/.
83. Barca ML, Selbaek G, Laks J, Engedal K. Factors associated with depression in Norwegian nursing homes. International Journal of Geriatric Psychiatry. 2009;24(4):417-25.
84. Marshall M, Marshall M. Perspectives on rehabilitation and dementia. London: Jessica Kingsley Publishers; 2004.
85. de Souto Barreto P, Morley JE, Chodzko-Zajko W, H. Pitkala K, Weening-Djiksterhuis E, Rodriguez-Mañas L, et al. Recommendations on Physical Activity and Exercise for Older Adults Living in Long-Term Care Facilities: A Taskforce Report. Journal of the American Medical Directors Association. 2016;17(5):381-92.

86. omsorgsdepartementet H-o. Stortingsmelding 15: Leve hele livet - En kvalitetsreform for eldre. In: omsorgsdepartementet H-o, editor. Regjeringen.no2018.
87. Organization WH. Classifications: International Classification of Functioning, Disability and Health (IFC): World Health Organization; 2017 [Available from: http://www.who.int/classifications/icf/en/.
88. Organization WH. International Classification of Functioning, Disability and Health (ICF): World Health Organization; 2017 [Available from: http://www.who.int/classifications/icf/icf_more/en/.
89. Escorpizo R, Stucki G, Cieza A, Davis K, Stumbo T, Riddle DL. Creating an Interface Between the International Classification of Functioning, Disability and Health and Physical Therapist Practice. Physical Therapy. 2010;90(7):1053-63.
90. Rauch A, Cieza A, Stucki G. How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. European Journal of Physical and Rehabilitation Medicine. 2008;44(3):329-42.
91. Tan ZS, Spartano NL, Beiser AS, DeCarli C, Auerbach SH, Vasan RS, et al. Physical Activity, Brain Volume, and Dementia Risk: The Framingham Study. The Journals of Gerontology: Series A. 2017;72(6):789-95.
92. Gitlin LN, Kales HC, Lyketsos CG. Managing Behavioral Symptoms in Dementia Using Nonpharmacologic Approaches: An Overview. JAMA : the journal of the American Medical Association. 2012;308(19):2020-9.
93. Teno JM, Kabumoto G, Wetle T, Roy J, Mor V. Daily Pain That Was Excruciating at Some Time in the Previous Week: Prevalence, Characteristics, and Outcomes in Nursing Home Residents. Journal of the American Geriatrics Society. 2004;52(5):762-7.
94. Tse MM, Pun SP, Benzie IF. Pain relief strategies used by older people with chronic pain: an exploratory survey for planning patient-centred intervention. Journal of Clinical Nursing. 2005;14(3):315-20.
95. Husebo B, Strand LI, Moe-Nilssen R, Borgehusebo S, Aarsland D, Ljunggren AE. Who Suffers Most? Dementia and Pain in Nursing Home Patients: A Cross-Sectional Study. Journal of The American Medical Directors Association. 2008;9(6):427-33.
96. Husebo BS, Flo E, Aarsland D, Selbaek G, Testad I, Gulla C, et al. COSMOS—improving the quality of life in nursing home patients: protocol for an effectiveness-implementation cluster randomized clinical hybrid trial. Implementation Science. 2015;10(1):131.
97. Lawton MP, Brody EM. Assessment of Older People: Self-Maintaining and Instrumental Activities of Daily Living1. The Gerontologist. 1969;9(3_Part_1):179-86.
98. Edwards MM. The Reliability and Validity of Self-Report Activities of Daily Living Scales. Canadian Journal of Occupational Therapy. 1990;57(5):273-8.
99. Husebo BS. Mobilization-Observation-Behaviour-Intensity-Dementia-2 Pain Scale (MOBID-2). Journal of Physiotherapy. 2017.
100. Crum RM, Anthony JC, Bassett SS, Folstein MF. Population-based norms for the mini-mental state examination by age and educational level. JAMA. 1993;269(18):2386-91.
101. Folstein MF, Folstein SE, McHugh PR. “Mini-mental state”: A practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research. 1975;12(3):189-98.
102. Perneczky R, Wagenpfeil S, Komossa K, Grimmer T, al e. Mapping scores onto stages: Mini-mental state examination and clinical dementia rating. The American Journal of Geriatric Psychiatry. 2006;14(2):139-44.
103. Strobel C, Engedal K. MMSE-NR. The Standardized Norwegian MMSE. Oslo: Norwegian National Advisory Unit on Ageing and Health; 2008.
104. Petersen RC, Smith GE, Waring SC, Ivnik RJ, Tangalos EG, Kokmen E. Mild cognitive impairment: Clinical characterization and outcome. Archives of Neurology. 1999;56(3):303-8.
105. Lukas A, Mayer B, Fialová D, Topinkova E, Gindin J, Onder G, et al. Treatment of pain in european nursing homes: Results from the services and health for elderly in long term care (SHELTER) study. J Am Med Dir Assoc. 2013;14.

106. Aasmul I, Husebo BS, Flo E. Description of an advance care planning intervention in nursing homes: outcomes of the process evaluation. BMC geriatrics. 2018;18(1):26.
107. van Kooten J, Smalbrugge M, van der Wouden JC, Stek ML, Hertogh CMPM. Evaluation of a Pain Assessment Procedure in Long-Term Care Residents With Pain and Dementia. Journal of Pain and Symptom Management. 2017;54(5):727-31.
108. Morey MC. Physical activity and exercise in older adults: UpToDate Inc.; 2018 [Available from: https://www.uptodate.com/contents/physical-activity-and-exercise-in-older-adults?search=pain%20exercise&source=search_result&selectedTitle=3~150&usage_type=default&display_rank=3.
109. Polit DF, Beck CT. Nursing Research : generating and assessing evidence for nursing practice. 10th ed. ed. Philadelphia: Wolters Kluwer; 2017.
110. Kang H. The prevention and handling of the missing data. Korean Journal of Anesthesiology. 2013;64(5):402-6.
111. Lawton MP, Brody EM. Assessment of Older People - Self-Maintaining and Instrumental Activities of Daily Living. Gerontologist. 1969;9.