

# **Psychosocial interventions and Quality of life for people with dementia living in care homes**

Rue Kroken

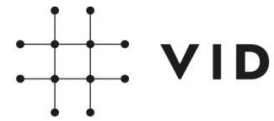
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## Foreword

It is hard to believe that this two-year journey has finally come to an end. It has been an intense couple of years and juggling full-time studies with a full-time job has been quite an experience. The twelve-hour train rides from Mosjøen to Oslo and back again were an adventure on their own, requiring me to dig deep inside myself and find that special reservoir of patience I did not know existed! Nonetheless, every step of this journey has been worth it. I have gained an incredible amount of knowledge, skills and confidence that could only have been gained from completing this study. I feel extremely lucky and privileged to work with older people with dementia and I know I can make a meaningful contribution to the quality of their lives.

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Nå er det ferie!

## Abstract

**Background:** Dementia is a major cause of disability and dependency among the older population and one of the most prevalent psychiatric disorders among people in care homes. Neuropsychiatric symptoms (NPS) are common with the progression of dementia and the subsequent treatment with psychiatric medications can have serious side effects, including increased mortality rate and poor quality of life (QOL). Psychosocial interventions have been recommended as preferable options. Inquiring and facilitating the QOL for people with dementia is an important goal in dementia care.

**Aim:** To find out what the relationship is between psychosocial interventions and quality of life for people with dementia in care homes.

**Method:** Scoping review. A systematic search was conducted in CINAHL, Ovid, PubMed and Scopus from November 25<sup>th</sup>, 2018 to January 15<sup>th</sup>, 2019. Eleven studies were found eligible and analyzed. These studies measured QOL in care home residents with dementia after the implementation of one or more psychosocial interventions.

**Results:** Findings show that psychosocial interventions include a wide range of interventions, all with the ability to improve QOL for people with dementia in care homes. Simple nursing tasks, domestic chores and self-care are interventions that tend to be overlooked by care staff. Lack of knowledge about dementia, people with dementia and psychosocial interventions lead to the underuse of interventions. Tailor-made interventions that promote personhood and respect the interests and abilities of the person with dementia have the largest impact on QOL.

**Conclusion:** There is a need for care staff to recognize simple tasks like domestic chores and self-care as viable psychosocial interventions with the potential to improve the quality of life for people with dementia in care homes. Tailor-made interventions that respect personhood should be encouraged.

**Keywords:** Dementia, quality of life, psychosocial intervention, non-pharmacological intervention, care home

## Sammendrag

**Bakgrunn:** Demens er en betydelig årsak til nedsatt funksjon og pleie behov hos de eldre og en av de mest rådende sinnssykdom blant sykehjemsbeboere. Neuropsykiatrisk symptomer (NPS) øker med grad av demens og antipsykotika behandling kan føre til alvorlig bivirkninger, inkludert økt dødelighetsprosent og dårlig livskvalitet. Psykososiale tiltak er anbefalt alternative. Det å spørre og legge til rette for en god livskvalitet for personer med demens er et viktig mål i demensomsorg.

**Hensikt:** Hensikten er å finne ut sammenheng mellom psykososiale tiltak og god livskvalitet hos eldre med demens i sykehjem.

**Metode:** «Scoping review». Et systematisk søk ble gjennomført i CINAHL, Ovid, PubMed og Scopus fra 25. november 2018 til 15. januar 2019. Elleve studier ble valgt og deretter analysert. Disse studiene målte livskvalitet hos sykehjemsbeboere med demens etter implementasjon av ett eller flere psykososiale tiltak.

**Resultat:** Resultatene viste at psykososiale tiltak innebærer en rekke handlinger, alle med evnen til å forbedre livskvalitet hos sykehjemsbeboere. Enkle sykepleietiltak, husarbeid og personlig stell er tiltak som ofte blir oversett av helsepersonellet. Manglende kunnskap om demens, personer med demens og psykososiale tiltak fører til dårlig bruk av tiltakene. Skreddersydde tiltak som fremmer «personhood» og tar til hensyn de interessene og ferdighetene av personen med demens har den største innflytelsen på livskvalitet.

**Konklusjon:** Det er et behov for at helsepersonellet innser at enkle tiltak som husarbeid og personlig stell er psykososiale tiltak med evne til å forbedre livskvalitet hos sykehjemsbeboere. Skreddersydde tiltak som fremme «personhood» bør oppmuntres.

**Nøkkelord:** Demens, livskvalitet, psykososiale tiltak, «ikke-psykofarmaka» tiltak, sykehjem.

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# 1 Introduction<sup>1</sup>

## 1.1 Dementia and background for the study

Dementia is a syndrome caused by disease of the brain and is characterized by chronic and irreversible deterioration in cognitive function. Characteristics of dementia include poor memory and attention span, reduced ability to perform daily activities and personality changes. Alzheimer's disease is the most common form and contributes to over 50% of dementia cases (Wyller, 2018). The World Health Organization (WHO, 2017) estimates that around 50 million people in the world have dementia, with approximately 10 million new cases every year. This number can be expected to reach 82 million by 2030, and 152 million by 2050. Dementia is a major cause of disability and dependency among the older population. The physical, psychological, and social impact of the disease affects both the individual and society at large. Decline in cognitive function often leads to difficulties with emotional control and social behavior and are common with the progression of dementia (WHO, 2017).

Symptoms associated with dementia include depression, anxiety, agitation, hallucinations, and restlessness, and are usually referred to as Behavioral and Psychological Symptoms of Dementia (BPSD) (Wyller, 2018). BPSD are also referred to as Neuropsychiatric symptoms (NPS) and most people with dementia can expect to experience these symptoms at some point in the disease process (Engedal & Haugen, 2018). NPS tend to be more prominent as the disease progresses and usually leads to increased disability and use of health services. They can also be a strain for the person with dementia and those around them as everyone tries to adjust to the behavioral disturbances and functional difficulties (WHO, 2017; Engedal & Haugen, 2018). Family carers can often tolerate the forgetfulness and decline in function, but the paranoi

a, aggressiveness and personality changes associated with NPS are often too distressing for them to handle (Engedal & Haugen, 2018) and can result in care home admission (Douglas, James & Ballard, 2004; Engedal & Haugen, 2018).

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<sup>1</sup> Care homes are referred to as nursing homes, LTCF and residential homes, depending on the country of origin of the authors. I will mainly use the term care homes but may in some cases refer to the other names. The terms psychosocial interventions and non-pharmacological interventions are used interchangeably in much of the literature. The former term will be used in this project as it is more positive in tone

Engedal & Haugen (2018) estimate that there are 80 000 people with dementia in Norway, 30% of whom live in a care home. Goyal, Bergh, Engedal, Kirkevold & Kirkevold, (2018) puts this figure at around 40%. Dementia is one of the most prevalent psychiatric disorders among the elderly in care homes, and it is estimated that well over 60% of nursing home residents in western countries have dementia (Seitz, Purandare & Conn, 2010). There is currently no cure for dementia, thus assessment of quality of life (QOL) for people with dementia has become an important principal goal in dementia care, especially in the care home setting (Crespo, de Quiros, Gomez & Hornillos, 2011; Moniz-Cook et al., 2008; WHO, 2017).

The World Health Organization (2017) defines quality of life as “the individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards.” A study by Beerens, Zwakhalen, Verbeek, Ruwaard & Hamers (2013) associated depressive symptoms and behavioral disturbances with lower QOL for people with dementia living in care homes. Other factors that negatively influence the QOL for residents with dementia living in care homes include neuropsychiatric symptoms such as depression and anxiety (Mjørud, Kirkevold, Røsvik, Selbæk & Engedal, 2014; Hoe, Hancock, Livingston & Orrell, 2006), feelings of isolation, absence of meaningful activity (Clare, Rowlands, Bruce, Surr & Downs, 2008) and psychotropic drug use (Wyller, 2018; Harrison et al., 2018).

According to Engedal & Haugen (2018), the use of antipsychotics in care homes is very common, with 1 in 3 residents receiving some form of these medications daily. Reducing the use of these drugs is an international priority and more focus should be made on the use of psychosocial interventions (Casper, Davis, Douziech & Scott, 2018; Wetzels, Zuidema, Jonghe, Verhey & Koopmans, 2010). Psychosocial interventions are defined as physical, cognitive, or social activities that aim to uphold and better the functioning, relationships and quality of life for people with dementia (McDermott et al., 2018; Moniz-Cook, Vernooji-Dassen, Woods, Orrell & INTERDEM Network, 2011). Examples include music therapy, dance therapy, animals and reminiscence (Lawrence, Fossey, Ballard, Moniz-Cook & Murray, 2012). Findings from a meta-synthesis study conducted by Lawrence et al., (2012) revealed that psychosocial interventions that support the self-determination and autonomy of a person with dementia not only benefit the individual, but can also promote their clinical usefulness. These interventions should aim to promote and preserve “personhood”. Kitwood

defined personhood as: “A standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997a, p.8). However, implementation of these interventions in care homes has been poor and challenging due to a variety of reasons such as healthcare professionals’ lack of knowledge and misconceptions about people with dementia (Edvardsson, Petersson, Sjoren, Lindkvist & Sandman, 2014; Clare et al, 2008). An appraisal of 28 research reviews conducted by Vernooij-Dasses, Vasse, Zuidema, Cohen-Mansfield & Moyle, (2010) found that psychosocial interventions in care homes have the potential to improve QOL for residents with dementia, but that they were not routinely used, and more research is required on implementation strategies. Research should focus on facilitating interventions that enhance the quality of life for people with dementia living in care homes (Smit, de Lange, Willemse, Twisk & Pot, 2016). Providing the best possible quality of life for these individuals should be a top priority for all health care professionals (Beerens et al., 2013; Smit et al., 2016).

More work is required to determine the association between the development and implementation of psychosocial interventions and QOL for residents with dementia in care homes (Beerens et al., 2013). Few studies have investigated the role of these interventions on QOL, despite its apparent importance, point out Ballard et al., (2018). Inquiring about and facilitating the QOL for residents with dementia in care homes is an important way of recognizing them as individuals and can be a useful way to evaluate the effect of interventions (Edelman, Fulton, Kuhn, Chang, 2005). Another important reason for prioritizing the QOL for residents in care homes is because some people with dementia are at risk for suboptimal and potentially harmful practices that can violate their rights to privacy, independence, autonomy, respect and equality (Alzheimer Europe, Cahill, 2018, p.100). A care home is the person’s *home* and the permanent place of residence for a person with dementia. Therefore, the quality of life and quality of care for people with dementia living in care homes should be prioritized (Cahill, 2018). Clare et al., (2008) state that many residents with dementia in care homes experience feelings of loss, isolation, frustration, uncertainty, and anger. To improve the quality of care and the quality of life for people with dementia in care homes the authors stress the importance of encouraging opportunities that allow people with dementia to feel useful and independent. Measures to alleviate boredom and feelings of worthlessness must be taken, and activities that are meaningful and appropriate according to the person’s abilities should be implemented (Clare et al., 2008).

With this in mind, and given the pressing urgency to promote quality of life for older people with dementia living in care homes, the research question for this study is as follows:

**What is known about the link between psychosocial interventions and improved quality of life in care homes for people with dementia?**

The aims of this study are to:

- Review and critically appraise the evidence of psychosocial interventions in care homes in relation to QOL
- Identify which psychosocial interventions have the strongest evidence base and make recommendations for how to implement these in Norwegian care homes.

## **1.2 Overview**

Chapter one includes the background and purpose of the thesis, including the research question, personal professional standpoint and definition of terms. Chapter two covers the theoretical background of this study. It discusses the types of dementia, Kitwood's psychosocial needs for people with dementia, the theories of dementia care, and the psychological perspectives that aim to promote personhood. Chapter three is the methodology section and justifies the use of the scoping review as a method design. The five stages of the framework are presented. Chapter four examines the ethical considerations, while chapter five presents the findings from the review. These findings are discussed in chapter six with respect to the theoretical perspective, earlier research results and respect to practice. Chapter seven includes the conclusion and implications for future practice and completes this study.

## **1.3 Specifications**

There are several different causes of dementia (Alzheimer's Association, 2016). To better understand the symptoms and behavior associated with dementia, only the four most common types are discussed in this thesis. The neuropsychiatric symptoms associated with dementia, and the challenges that those affected are likely to encounter are explored. As my professional and educational interest lies in elderly dementia care, the population for this study is limited to people 65 years and older. Elderly in all phases of the disease are included, but only those whose disease progression has required care-home admission. Dementia is dependent on

many factors and several perspectives exist that aim to better understand the disease. This study seeks to better understand the relationship between psychosocial interventions and quality of life, therefore theory is approached from a psychological perspective. The key task with psychological perspectives is to promote personhood by working together with the person with dementia to find acceptable individualized therapeutic interventions (Cantley, 2001).

#### **1.4 Personal professional standpoint**

I currently work as a staff nurse on a dementia unit that accommodates 30 residents with varying degrees of dementia. My interest in dementia care is something that developed recently over the last few years. I have seen the impact this disease can have on several aspects of the person's life, and how living with dementia in a care home can be especially challenging for certain individuals, including their family members and the care staff. Residents often lead a passive and sedentary lifestyle, steered by the facilities' rules and regulations. The activities that take place in the care home are often group activities that are convenient for the staff and suit their time schedule. They are rarely tailored to promote the strengths or interests of the person with dementia. A study conducted by Mjørud et al., (2017) found, amongst other things, that life in a care home for residents with dementia was boring and lonely, with little attention given to psychosocial needs. Mjørud et al. (2017) discovered that although the residents accepted their new lives in the care home, they had little to do and this could have an impact on their QOL. While many residents and their families express satisfaction with the care provided, I feel that the *person* has been forgotten in the bureaucracies and efficiency of dementia care. I discovered Kitwood in the early stages of this course. His work and insight helped me realize how vital my role as a nurse is in dementia care. Equipped with the right tools and knowledge, I know I can make a paramount difference to the life of someone with dementia. Elderly with dementia in care homes have a right to a meaningful and fulfilling life. The knowledge and skills I gained from taking this course and conducting this can study will contribute to giving these individuals the best possible life in their last years. Furthermore, I hope to inspire and encourage my colleagues to *see* and *remember* the person behind the dementia diagnosis and focus not only the delivery of quality care, but on the promotion of interventions that improve each resident's quality of life.

## **1.5 Definitions of key terms**

### **1.5.1 Quality of life (QOL)**

As defined earlier, WHO (2017) defines quality of life as “the individual’s perceptions of their position in life in the context of the culture and value system in which they live, and in relationship to their goals, expectations, and standards.” Although QOL is a challenging concept to define, the consensus is that assessment of QOL is multidimensional and involves both subjective and objective variables (Crespo et al., 2011; Logsdon, Gibbons, McCurry, Teri, 2002). In addition, it varies according to the person with dementia and the intervention being evaluated (Logsdon et al., 2002). Some people with mild to moderate dementia are aware and able to communicate their own QOL and their own views should be considered whenever feasible, as this provides a unique and subjective perspective (Crespo et al., 2011). A study conducted by Logsdon et al., (2002) to assess the QOL for people with dementia using the Quality of Life- Alzheimer’s Disease (QOL-AD) revealed that people with dementia can often rate their own QOL well into later stages of the disease. Dementia is chronic and incurable, and the progressive deterioration in cognitive function affects the individual’s memory, thinking, comprehension, language, and judgement, making a subjective account of QOL challenging. In these cases, reliable dementia-specific QOL assessment scales like the Quality of Life in Late-Stage Dementia (QUALID) or the Quality of Life – Alzheimer Disease (QOL-AD) are used (Logsdon et al., 2002). Residents with dementia are often in frequent contact with the nursing personnel and these proxy-based scales are based on the care staff’s direct observations of the behavior, needs and emotions of the people with dementia. They are considered reliable and appropriate ways of determining the QOL (Logsdon et al., 2002; Goyal et al., 2018; Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2007).

### **1.5.2 Quality of care, person-centered care and personhood**

The chronic and progressive nature of dementia results in deterioration in cognitive function that often leads to care home admission (WHO, 2017; Vernooij-Dasses et al., 2010). As pointed out earlier, care homes are “home” for people with dementia, and in most cases, their permanent place of residence (Cahill, 2018). It is vital that these facilities *feel* like home for the person with dementia, as this is crucial in maintaining their wellbeing and dignity (Wyller 2018, p.40). Vernooij-Dassen et al., (2010) point out that admission into a care home is often

out of necessity and the new life in an institution, coupled with the challenges of dementia, can make it difficult for individuals to “feel at home”. They state that to provide the best dementia care possible it is important to use best practices and psychosocial interventions that aim to improve quality of life.

Downs & Bowers (2014) state that delivery of quality dementia care aims to understand what the person is communicating with the behavior, and then provide the intervention that targets it. The goals of care as described by the authors should be to improve the quality of life and wellbeing of the person with dementia. Good care for people with dementia in care homes requires empathy. All care activities should be used as an opportunity to show compassion and promote autonomy and respect for the person with dementia (Downs & Bowers, 2014). Unfortunately, people with dementia in care homes are often treated as part of a group, with activities and interventions that rarely satisfy individual abilities and interests. Downs & Bowers (2014) stress the importance of promoting personhood and remembering the individual when working with people with dementia.

Personhood “is what makes us essentially human” and person-centered care is central to maintaining and nurturing personhood (Brooker & Latham, 2016). Personhood can be undermined when an individual’s needs and rights are ignored, their emotions invalidated, and their human relationships ignored. According to Brooker & Latham (2016), Kitwood observed the various ways residents’ personhood was undermined in care homes and day centers, and he named this occurrence “Malignant Social Psychology”, (MSP). Intimidation, manipulation and disempowerment are examples of what people with dementia are exposed to when subjected to MSP. Kitwood was quick to point out that episodes of MSP are rarely done willingly, but they can quickly become a part of the care culture and part of the “normal” care in working with people with dementia. The personhood of the individual is therefore continuously undermined (Brooker & Latham, 2016). The personhood of people living with dementia in nursing homes is further weakened by poor quality care and support, according to Brooker & Latham (2016). To preserve and promote the personhood of individuals with dementia, they must be given the opportunity to maintain their relationships, uphold their independence and autonomy, and participate in meaningful activities. Services must be person-centered (Brooker & Latham, 2016).

Seeing the value in all people, regardless of mental capacity is central in person-centered care and the perspective of the person with dementia should always be the starting point when

delivering care (Brooker, 2003; de Boer, Hamers, Zwakhalen, Tan & Verbeek, 2017).

Brooker (2003) developed a person-centered care framework (VIPS) that aims to promote the personhood of people with dementia and improve the delivery of care. It strives to promote wellbeing by viewing the person as a unique individual and tailor interventions and care to meet their specific individual needs. The four elements are:

1. Valuing people with dementia (**V**)
2. Treating people as individuals (**I**)
3. Looking at the world from the perspective of the person with dementia (**P**)
4. A positive social environment (**S**) (Brooker, 2003, p. 216)

When working with people with dementia, quality of life cannot be discussed without considering quality of care and person-centered interventions that put the person with dementia at the center. Downs & Bowers (2014) summarize this by stating that dementia care should always aspire to promote the personhood of people with dementia by using interventions that promote autonomy and respect.

### **1.5.3 Non-pharmacological interventions and Psychosocial interventions**

According to Ruddy & House (2010) and Richter, Meyer, Mohler (2012), psychosocial interventions consist of various forms of non-pharmacological measures and involve the use of psychological and social interventions with a psychosocial focus. They exclude biological interventions such as medications and invasive procedures. Non-pharmacological interventions include but are not limited to aromatherapy, animal therapy and music therapy (The National Institute for Health Care and Excellence [NICE], 2007). They include various approaches and they can be behavior-oriented, emotion-oriented, cognition-oriented, or stimulation-oriented (Vernooij-Dassen et al., 2010).

According to Gitlin, Kales & Lyketsos (2012), non-pharmacological interventions are defined for what they are not, namely, they are not medications. They can either be generalized and include caregiver education and support, or targeted to a specific behavior by eliminating unwanted conditions. Non-pharmacological interventions can be focused on the patient by implementing interventions that directly affect the individual, like reminiscence therapy. They can have focus on another agent, like the caregiver, by improving communication methods, or focus on alternating the environment, like through music or art. According to Gitlin et al.,



(2012, p.5), non-pharmacological interventions aim to manage challenging behaviors by alternating the environment, behaviors, cognitions or precipitating events of the individual and / or caregiver. Major treatment goals of these interventions include prevention and management of behavioral occurrences, decreasing caregiver distress, and / or prevention of harmful consequences (Gitlin et al., 2012).

“Non-pharmacological interventions” are often referred to as “psychosocial interventions” state, McDermott et al., (2018) They argue that the term “non-pharmacological intervention” has an unfavorable tone, where it seems to imply symptom and problem management without being clear about what it actually is. The authors go on to add that “interventions that aim to improve psychological, social and everyday functional abilities of people with dementia should go beyond just problem-management”, hence the preferred use of the term “psychosocial intervention” (McDermott et al., 2018).

#### **1.5.4 Neuropsychiatric symptoms with dementia (NPS)**

Neuropsychiatric symptoms (NPS) is a broad term that encompasses many different types of symptoms. The likelihood of developing NPS increases as the disease progresses. The main groups of NPS are agitation, psychotic symptoms, apathy, and sleep disturbances (Engedal & Haugen, 2018, p. 246 - 253).

Agitation in people with dementia is often characterized by emotional tension and anxiety. It is not uncommon for the individual to express their agitation by making repetitive movements and sounds (Engedal & Haugen, 2018, p. 249). However, the authors point out that these actions do not necessarily indicate agitation and could be unconscious movements on the part of the person with dementia. Other characteristics of agitation include confused behavior, behavior changes or challenging behaviors. Agitation is one of the most common NPS for people with dementia, especially for the elderly living in care homes. Agitation is often an expression of an uncovered need, therefore, pharmaceutical management of this symptom should be the last option. Interventions for the successful treatment of agitation should be focused on the environment and structured activities (Engedal & Haugen, 2018, p. 249 – 251).

According to Engedal & Haugen (2018), psychotic symptoms usually indicate a more severe course of the dementia and calls for prompt action and treatment (if necessary) of the symptoms. Delusions and hallucinations are the most common forms of psychotic symptoms

for people with dementia. People with these symptoms are often suspicious of others and of their surroundings and are unable to differentiate reality from the unreal. Visual hallucinations tend to be more common than auditory hallucinations for people with dementia. Detailed visual hallucinations are common in dementia with Lewy bodies. Auditory hallucinations are experienced as unspecific sounds and simple words. They are not controlling, as often seen in schizophrenia. Olfactory hallucinations in people with dementia are often linked to delirium. According to Engedal & Haugen (2018, p. 252) treatment of psychotic symptoms should focus on preventions. For example, visual hallucinations could be the result of poor eyesight, while defective hearing aids could lead to auditory hallucinations. Once again, the authors point out that medicinal options should be avoided, and treatment should be aimed at promoting psychosocial and environmental interventions (Engedal & Haugen, 2018, p. 251 – 252).

Apathy is described as the most common NPS for people with dementia and is characterized by lack of motivation and interest without an emotional component (Engedal & Haugen, 2018, p.253). People with apathy are often overseen by care staff, as they tend to be more withdrawn and less engaged in their environment. Care staff frequently view apathy symptoms as easier to manage in comparison to other NPS like aggression or unrestrained behaviors. Apathy in people with dementia has been linked to poorer quality of life and increased risk for mortality. Apathy can be a side effect of medications such as antipsychotics and sedatives. Little is known about the best way to treat apathy, but physical activity, music therapy and animal therapy has shown some promising results (Engedal & Haugen, 2018, p. 253).

Disturbances in the circadian rhythm are common for people with dementia during all stages of the disease (Wyller, 2018). Dementia, depression and insomnia is a common triad of symptoms for elderly with dementia (Wyller, 2018, p. 108). Around 40% of people with dementia suffer from insomnia. This is likely because of decreased melatonin production caused by the damage and death of neurons. Individualized light therapy and activity interventions during the day could be useful in managing insomnia in people with dementia. Due to the lack of knowledge about the best way to treat insomnia, caution should be exercised when prescribing pharmacological therapy, especially benzodiazepines, which can cause more harm than good (Engedal & Haugen, 2018, p. 253).

## **2 Theoretical perspectives**

As already discussed, the concept of personhood is critical in work with people with dementia. The importance of psychological perspectives is integral in dementia care and this chapter is going to explore how these perspectives play a central role in current and future dementia care approaches. People with dementia use their behavior to communicate feelings and needs, but the neurological damage caused by the condition affects this behavior (Engedal & Haugen, 2018). Therefore, to appreciate the value of these perspectives, it is important to first understand the presentation of dementia as a brain disease, and the subsequent effects of it on the psychological needs and life of the person with dementia. The initial part of this chapter provides a brief overview of the most common types of dementia, including clinical features and pathology. Thereafter, the six psychological needs of people with dementia as described by Kitwood are discussed, followed by three evidence-based models (theories) and interventions targeted to improve the quality of life for people with dementia. The theory psychological perspectives sum up this chapter.

### **2.1 Causes of dementia and characteristics**

Distinct symptoms are associated with the different causes of dementia. This section discusses the most common causes of dementia and their characteristics.

#### **2.1.1 Alzheimer's disease**

Dementia caused by Alzheimer's disease is the most common form of dementia. The progressive accumulation of beta-amyloid (plaques) outside neurons and protein tau (tangles) inside the neurons leads to the inevitable damage and death of neurons (Alzheimer's Association, 2016, p. 461). It is estimated that at least 60% of people with dementia have Alzheimer's disease. People who develop Alzheimer's disease after the age of 65 years tend to have fewer symptoms and the disease progression is often less dramatic. Some of the risk factors associated with the development of Alzheimer's disease include age, Down's syndrome, depression, head trauma, and mental and physical inactivity. Advanced age is linked to greater chances of developing Alzheimer's disease, with some studies estimating that 50% of people over 90 years have the disease. Difficulty remembering names, events and conversations are often early clinical symptoms (Engedal & Haugen, 2018, p. 60-83). Later

symptoms include difficulty swallowing, walking and talking (Alzheimer's Association, 2016, p. 461).

### **2.1.2 Vascular dementia**

Vascular dementia is the next most common cause of dementia after Alzheimer's disease and often results from blood vessel blockage, damage leading to infarcts or bleeding in the brain. It is very common in older people with dementia, with 50% exhibiting symptoms of vascular dementia (Alzheimer's Association, 2016, p.461). The greatest risk factors connected to development of Vascular dementia are inadequate treatment of high blood pressure, diabetes and familial lipoproteinemia. Related symptoms are difficulty finding the right words, dysphagia, poor motor function, slow gait often with small staggering steps, and in some cases, paralysis (Engedal & Haugen, 2018, p. 110-117).

### **2.1.3 Dementia with Lewy bodies**

Dementia with Lewy bodies (DLB) is characterized by Lewy bodies, which are abnormal aggregations of a protein called alpha-synuclein in neurons. Dementia results when aggregations form in the cortex of the brain. People with Parkinson's disease have Lewy bodies, but the disease is marked by motor impairment, in contrast to the cognitive impairment seen in DLB (Alzheimer's Association, 2016, p.461). Around 10% - 25% of people with dementia have DLB, and it appears that it is more common in people between 60 and 70 years, and among the male population. It is still unknown what the risk factors for developing DLB are. Symptoms include sleep disturbances, visual hallucinations, gait imbalances, visuospatial impairment and fluctuating changes in level of consciousness (Engedal & Haugen, 2018, p. 105-108).

### **2.1.4 Frontotemporal dementia**

Frontotemporal dementia results from damage to the nerve cells in the frontal and temporal lobes, leading to marked atrophy in these areas. It includes dementias such as Pick's disease and corticobasal degeneration (Alzheimer's Association, 2016, p. 461). Most of those affected are under the age of 65 years, but occurrence after this age is not uncommon. It is estimated that between 500 to 700 people living in Norway have Frontotemporal dementia as of 2018. Specific risk factors for the development of Frontotemporal dementia are yet to be identified,

although diabetes and cerebrovascular diseases have been singled out as possible risk factors. Personality and behavior changes, speech and comprehension difficulties, and echolalia are some of the symptoms associated with Frontotemporal dementia (Engedal & Haugen, 2018, p. 90 – 93).

As noted earlier dementia progression increases the likelihood of developing neuropsychiatric problems. Unmet “needs” for the person with dementia are a possible explanation for some of these symptoms. Due to the nature of the disease, people with dementia can experience difficulties with communicating or covering these needs, and behavior becomes the only way they can interact with those around them. Examples of these needs are pain, lack of social contact, boredom, and under or over stimulation (Engedal & Haugen, 2018, p. 262). There are six universal needs for people with dementia according to Kitwood (1997b), and these are discussed below.

## **2.2 Psychosocial needs for people with dementia**

According to Kitwood (1997b), the psychological needs for people with dementia are often not met. The author defines the term “need” as: “that without which a human being cannot function, even minimally as, as a person” (Kitwood, 1997b, p.19). Needs are grounded in our evolutionary past and closely connected to a person’s culture, meaning and values. The greatest need for people with dementia is love. There are five main needs that encompass the central need for love, and they are comfort, attachment, inclusion, occupation and identity (Kitwood, 1997b, p. 19).

### **2.2.2 Comfort**

Comfort in the literal sense means to help a person to become “thoroughly strong” and implies assisting a person to “keep it together” when their world is falling apart. A sense of loss is high for people with dementia, as the disease often robs them of their abilities and way of life (Kitwood, 1997b, p.19).

### **2.2.3 Attachment**

The formation of special bonds and attachments is a vital need in any stage of a person’s life and is essential for them to function well. The need for attachment is even greater for people

with dementia as life is full of uncertainties and worries as the disease takes away most of what was familiar and “safe” for the person (Kitwood, 1997b, p.19 – 20).

#### **2.2.4 Inclusion**

The social network for people with dementia tends to shrink as the disease progresses, largely due to the decline in cognitive function. When the social needs for these individuals are not met, the person is likely to retreat and decline into a seclusive state. There is a high probability that the person with dementia can come out of this state of reclusion if the need for inclusion is reinstated (Kitwood, 1997b, p.20).

#### **2.2.5 Occupation**

Kitwood (1997b, p.20) describes being occupied as “being involved in the process of life in a way that is personally significant, whether this consists of action, reflection or relaxation”. The absence of occupation results in boredom, anomie and apathy. Occupation relates to a meaningful goal or task that a person sets out to achieve. It can be work or leisure related. The need for occupation is still very real in people with dementia, but the decline in cognitive abilities makes this challenging. They need the skill and imagination of those around them to keep them occupied. The more that is known about a person’s interests and life history, the easier it is to fulfill this need (Kitwood, 1997b, p.20).

#### **2.2.6 Identity**

Having identity is knowing who one is and involves maintaining a relationship with the past and the future. Identity is a narrative story of one’s own life and conveys the way others see and respond to us. The cognitive and social impairments connected with dementia threaten the identity of the person with dementia. Therefore, the maintenance of identity is largely dependent on those around the individual with dementia (Kitwood, 1997b, p. 20).

The main goal of dementia care is to promote and maintain personhood. If one of the five great needs mentioned above is recognized, the other needs will be affected as well. If the cluster of needs are met then the person with dementia is likely to experience improved self-worth and well-being (Kitwood, 1997b, p.20). The models of dementia care described below

attempt to explain how care staff can better understand dementia and meet these psychosocial needs.

## **2.3 Models / theories of dementia care**

### **2.3.1 Need-Driven Dementia-Compromised Behavior Model (NDB)**

This model states that behaviors that are commonly characterized as “challenging” or “disruptive” can be explained as expressing a need and responding appropriately can better the individual’s quality of life. This model holds that behavior is the result of four background factors which are the disease itself, personal demographics, poor health status, and personality traits. These background factors cannot be changed or treated. Behavior is also the result of “proximal” influences which are unmet needs that can be addressed based on the specific needs of the person. These needs can be psychosocial, for example, the need for comfort or inclusion. They can be physiologic needs like pain relief, or environmental issues like noise or a resident’s need to alleviate boredom and inactivity. Environments that encourage activities that promote activity and socialization and relieve boredom can be useful ways to reduce “challenging” behaviors (Mitty & Flores, 2007, p. 285 – 286).

### **2.3.2 Progressively Lowered Stress Threshold Model (PLST)**

This model is centered around two main points. Firstly, a person’s stress threshold is set and stabilized by adulthood; and secondly, the stress threshold of a person with dementia reduces with the progression of the disease. Examples of stressors that the person with dementia can be faced with include sleep disturbances, caregiver and environmental changes, and tasks that exceed the capabilities of the person. The PLST focuses on modifying the environment and making it less stressful so the person with dementia can process cues more easily. Principles of the PLST for people with dementia include unconditional respect, attentive listening, simplifying personal care tasks and routines, and modifying the environment to reduce potential stress triggers (Mitty & Flores, 2007, p. 286).

### **2.3.3 Self-Identity Roles for Designing Interventions**

As dementia progresses, the person experiences increased problems with communication and memory, and preservation of their self and identity. This model strives to maintain personhood by encouraging social contact, stimulating the memory and making environmental changes. Person-centered interventions targeted to improve the self-identity and well-being for people with dementia are centered around four domains: family, professional, leisure/recreational activities and personal activities. Information used includes former roles or jobs, significant family members, specific interests or hobbies, capabilities of the individual, educational level and language skills. Interventions must have meaning and a sense of purpose for the individual and include discussing family photos, cooking projects, listening and reminiscing using music and increased participation in activities (Mansfield et al; Mitty & Flores, 2007, p.286 – 287).

## **2.4 Psychological perspectives**

As stated earlier, psychological perspectives strive to promote the personhood of the person with dementia. The main goal is to respect and encourage the person's individuality and provide interventions that are acceptable and suitable for the person with dementia. There are five main types of psychological perspectives that contribute significantly to a better understanding of dementia (Cantley, 2001, p.27). Only four of the perspectives are discussed below, as they are most relevant to this study.

### **2.4.1 The neuropsychological perspective**

A better understanding of the nature of cognitive difficulties the person with dementia is experiencing can lead to a better understanding of the individual. Dementia is often characterized by the loss of short-term and long-term memory. People with Alzheimer's disease find it difficult to add new information into long-term memory and any new information received is easily lost. It is important to consider that difficulties with memory can be related to problems with language and with the meaning of words. Furthermore, challenges with the retention of new information can be due to attention and concentration problems, and not "pure memory difficulty". A sound understanding of the neuropsychology of memory could assist caregivers and staff in providing suitable interventions for people with



dementia. Calendars and reality orientation boards are useful tools that can assist those with memory problems (Cantley, 2001, p. 27 – 28).

The language function can be affected in people with dementia. Expressive problems are likely to be seen in the early stages of the disease and people often experience difficulties in naming. Receptive problems are more common in the later stages. Problems with expression or finding the right words for objects can cause frustration in a person with dementia. Care staff can alleviate these feelings by assessing expressive language and suggesting ways to overcome this problem. Circumlocution has been found to be a useful tool for certain individuals with dementia. Increased care staff knowledge about the language disorders brought about by dementia can aid care staff in their work with people affected by the disease (Cantley, 2001, p. 28).

#### **2.4.2 The behavioral perspective**

The behavioral perspective is concerned with how a person responds to others and their environment. This perspective regards the behavior to be a response to triggers in the environment. The neuropathological changes of dementia and the impact of this on the individual, their personality, life history and the surrounding environment can explain certain behaviors in people with dementia. At the same time, it is crucial not to assume that neuropathological changes are solely responsible for “challenging behaviors”. Therapeutic approaches should consider background factors and consider for example, that a certain behavior could be connected to the person’s previous occupation. “Challenging behavior” is often an interaction between the person’s physical and social environment and consideration of both the physical and psychological aspects of the individual are crucial. Knowing the life history and background of the person with dementia is therefore paramount when adopting interventions that respect and promote individuality (Cantley, 2001, p. 32 - 33).

#### **2.4.3 The psychodynamic perspective**

Psychodynamic psychotherapy among the elderly has long been neglected as its benefits have not been fully appreciated in the past. However, the importance of psychotherapy in dementia care is now being recognized. The key components in psychodynamic perspective are centered around establishing relationships with people with dementia, where the person feels cared about, can express their feelings and enhance their self-esteem. This perspective

empathizes the importance of maintaining identity and highlights the transition the person with dementia might go through from being a “valued and respected” member of society to that of “patient” or someone who is dependent on others for help. Care staff can assist the person with dementia by taking the time to listen to their “stories”. These can be stories about their former lives – previous jobs and roles in the society, or stories about concerns or losses they have experienced. (Cantley, 2001, p. 34 – 35).

#### **2.4.4 The systemic perspective**

One way of gaining a better understanding of dementia is to explore its relation to the organization or system of care. Systematic perspectives can be valuable when considering changes that need to occur within an organization. Assumptions or “working myths” adopted by care staff about dementia and people with dementia can have detrimental consequences on care delivery and the well-being of the residents. Work with care-staff should involve debunking myths and exploration of assumptions to improve care and promote person-centered care.

### **3 Method**

Little is known about the implementation of psychosocial interventions in care homes and how they are linked to the QOL for residents with dementia (Vernooij et al., 2010). The research question for this study is to investigate the link between psychosocial interventions and improved QOL for people with dementia living in care homes. To obtain as much research material as possible, this review aimed to include studies with different designs and methods. A scoping review with a structured search and quality assessment was an appropriate method to use. A systematic approach was used to identify and include or exclude articles. The inclusion and exclusion criteria are discussed in greater depth further on in this thesis. A conscious decision to use the broad term “psychosocial intervention” and not a specific intervention (like music therapy) was made to encompass as many relevant articles as possible. Broad research questions in scoping studies allow for a wider range of generated literature (Arksey & O’Malley, 2005).

#### **3.1 Background for choosing the scoping review**

Arksey and O’Malley’s (2005, p.6) framework propose four common reasons that a scoping review might be used. These are as follows:

1. “To examine the extent, range and nature of research activity”. The authors state that this might be useful when the amount of material available in a field of study is difficult to visualize. The rapid review identifies existing research
2. “To determine the value of undertaking a full systematic review”. The preliminary mapping of literature helps to determine if a full systematic review is relevant or possible
3. “To summarize and disseminate research findings”. This scoping study is used when detailed descriptions of the findings are desired. Research findings are summarized and disseminated, and made available to consumers, practitioners, researchers or policy makers
4. “To identify research gaps in the existing literature”. This type of scoping study summarizes, disseminates and draws conclusions from the research findings. It is especially useful where there is a gap in knowledge or where little research exists.

According to Arksey & O'Malley (2005), the first two types of scoping studies are likely to be used as a part of a review that is already in process and can be used as precursors for conducting a full systematic review. The scoping studies described in points 3 and 4 can be perceived as standalone methods that lead to the publication of new research findings. The authors go on to state that the aims of the study determine the type of study used (Arksey & O'Malley, 2005). The reasons for choosing a scoping review for this study was twofold. This review aimed to find out if psychosocial interventions played a role in the quality of life of residents in care homes, and the point was to offer an overview of the research already available and identify potential gaps in knowledge. The second reason was to make recommendations for Norwegian care homes based on which psychosocial interventions had the strongest evidence base. Scoping reviews are effective ways of providing a general overview of the existing knowledge and find gaps in the evidence base that can prove useful to clinicians and consumer (Grant & Booth, 2009; McKinstry et al., (2014). While developing the research question, I discovered that there was a surprising paucity in literature on studies investigating QOL as a measurable outcome for residents with dementia in care homes. Therefore, a wide search or approach was needed to uncover as much research literature as possible. Scoping reviews are broad and creative in nature and allow for the use of a wide range of literature, including but not limited to policy documents, opinion pieces, and ongoing research. They also allow for the inclusion of all types of research material and study designs (Grant & Booth, 2009; McKinstry et al., 2014; Arksey & O'Malley, 2005). Anderson, Allen, Peckham & Goodwin (2008) point out that scoping studies can be advantageous when one wishes to identify available services for vulnerable groups. Elderly people with dementia is one such group. In addition, it was important for me to try and include the views of the person with dementia in this study. As previously pointed out, the disease process of dementia, coupled with the attitudes and actions of those around the person with dementia, can threaten an individual's identity and self-worth (Brooker & Latham, 2016; Mjørud et al., 2017). The perspective of people with dementia living in a care home is often neglected (Engedal & Haugen, 2018, p.300). That is why it was necessary to try and include qualitative studies, as these would provide useful subjective information that cannot be obtained from numbers and statistics. To ensure for an adequate study sample, I decided that a scoping review would be most appropriate. In addition, I was a novice to the world of scoping reviews and realized that this was a chance to learn and familiarize myself with this type of research design.

### **3.2 Scoping review**

According to Arksey & O'Malley (2005) the purpose of a scoping review is to present an overview of the research field and present key information from the included studies in a descriptive form. McKinstry et al., (2014) state that scoping reviews are efficient and effective methods of reviewing the evidence base on a given topic. They are useful in identifying the current state of understanding and for determining what is or is not known about the research topic (Anderson, Allen, Peckham & Goodwin, 2008). Scoping reviews allow for more creativity as a wide range of research and non-research material can be used to provide more clarity about a topic (Grant & Booth, 2009). Scoping reviews are like systematic reviews in that they have a methodological framework that is rigorous, consistent and transparent. This allows for replication of the review and readers can evaluate results for relevance and accuracy (Arksey & O'Malley, 2005; McKinstry et al., 2014). However, some distinct differences exist. Arksey & O'Malley (2005) state that systematic reviews tend to have a well-defined question with study designs that can be identified in advance. Scoping studies on the other hand, have a broader aspect and allow for the inclusion of a range of study designs and methodologies. Another clear distinction between these two types of studies is the quality assessment of articles. Quality assessment is an integral part of systematic reviews, whereas this process is omitted in scoping reviews. Scoping reviews are mainly concerned with "quantity", not "quality", and emphasize the coverage of all available material as opposed to in-depth analyses and appraisals of fewer studies (Arksey & O'Malley, 2005). However, scoping reviews are "indicative and suggestive" and not "definitive and prescriptive" according to Anderson et al., (2008), and it is important that researchers conduct the study as they deem appropriate. Therefore, quality assessments were performed on the selected articles in this review. This is discussed in greater detail further on in the paper.

According to Bettany-Saltikov & McSherry (2016), when conducting a review, it is important to use the "best research evidence". This means that in evidence-based practice, it is preferable to use research designs that rank high on the hierarchy of research evidence. This ranking system places systematic reviews, randomized controlled studies (RCTs) and cohort studies in the top half of the ranking system, while qualitative studies and opinion papers are ranked last.

### **3.2.1 The scoping review framework**

Arksey & O'Malley (2005) proposed how a researcher might conduct a scoping review in their "scoping review framework". This is a five staged process and includes the following steps:

- Identifying the research question
- Identifying the relevant studies
- Study selection
- Charting the data
- Collating, summarizing and reporting the results
- Framework Optional Stage: Consultation Exercise. This is an optional stage and is not part of this scoping review.

### **3.2.2 Stage 1. Identifying the research question**

This stage involves identifying the research question and guides the search strategy process. This stage is like that in a systematic review and includes the identification of the study population, interventions or outcomes (Arksey & O'Malley, 2005). The component parts in a research question are identified as the population (P), the intervention or exposure (I), comparative intervention (if available) (C), and the outcome (O) by Bettany-Saltikov & McSherry (2016). PICO is the acronym used to refer to this. The research question is:

**What is known about the link between psychosocial interventions and improved quality of life in care homes for people with dementia?**

The component parts are presented in table 1.

**Table 1**

<b>RESEARCH QUESTION WITH KEY PICO COMPONENTS</b>			
<b>P</b> <b>POPULATION</b>	<b>I</b> <b>INTERVENTION</b>	<b>C</b> <b>COMPARATIVE INTERVENTION</b>	<b>O</b> <b>OUTCOME</b>
People with dementia aged 65 years and older living in care homes	Psychosocial or non-pharmacological interventions	Psychotropic drug use.  No intervention	Quality of Life  Subjective or quantitative (measured by validated assessment tools)

### **3.2.3 Stage 2. Identifying relevant studies**

This stage involves identifying published and unpublished works by performing a comprehensive search using different sources. Like other reviews, scoping reviews require that practical decisions like cost and language are considered (McKinstry et al. 2014; Arksey & O'Malley, 2005). Given the limited time and resources I had to conduct this study, I decided to include only published works and those studies that satisfied my inclusion criteria. Table 2 lists the inclusion and exclusion criteria.

**Table 2**

<b>PICO TEMPLATE FOR INCLUSION and EXCLUSION CRITERIA</b>		
	<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
<b>Population</b>	People with dementia, with a formal diagnosis, or clearly stated by the authors; 65 years or older and living in care homes.	<p>People with dementia living at home /community dwelling</p> <p>People with dementia in hospitals</p> <p>Young people with dementia or people with dementia under 65 years</p>
<b>Intervention</b>	Use of psychosocial or non-pharmacological interventions, clearly stated	<p>Use of Psychotropic medications or any form of medication.</p> <p>No form of intervention</p>
<b>Outcome</b>	Primary measure outcome is Quality of Life – qualitative experiences or as measured / validated by standardized assessment tools like QUALID or QOL-AD	<p>Impact on Quality of Care</p> <p>No mention of impact on Quality of life</p> <p>QOL of caregivers</p>
<b>Type of Studies</b>	<p>Qualitative and Quantitative studies</p> <p>Free full text</p> <p>Abstract available</p> <p>Publication within the last 10 years</p> <p>Dissertations</p> <p>Books</p> <p>English language</p>	<p>Publication older than 10years</p> <p>Studies not in English</p>



According to Bettany-Saltikov (2012), stating inclusion and exclusion criteria is an important step for identifying primary research papers. This section describes the criteria that was used to include studies in the review. In this way, only papers that were relevant to answering my research question were included. As mentioned earlier, scoping reviews tend to be very broad in nature and encompass a wide range of research literature. In addition, the term “psychosocial intervention” is not specific, and embraces a plethora of interventions. Therefore, it was crucial that the inclusion criteria were very precise and clear, and only articles that adhered to these criteria were analyzed.

### **3.2.4 Stage 3. The search process**

In the initial phase of my literature search, I conducted a comprehensive search of published material in the electronic databases CINAHL, Scopus, PubMed, and Ovid, and organization networks like World Health Organization (WHO), United Nations (UN) and Alzheimer’s association. This is important as it ensures that all relevant studies are found and considered to provide an unbiased sample of papers. In addition, it gives a general idea of what research material is available and what is already known about this topic (Bettany-Saltikov, 2012). According to Khan, Kunz, Kleijnen & Antes (2005), the search for relevant studies should be extensive and include both computerized and printed resources. As expected, this produced a large amount of literature, but most of it was irrelevant to answering my research question. A trial search was done in CINAHL using the PICO terms including synonyms of “dementia”, “psychosocial interventions”, “psychotropic drugs” and “quality of life”. This resulted in only two hits of which one study was relevant (Ballard et al., 2018). A search in PubMed and Ovid using all the PICO components yielded similar results. Therefore, the term “psychotropic drugs” including variations was omitted from the process. This resulted in a wider range of potential articles. In addition, to further widen the search, the population component was separated into two terms. In other words, instead of searching for synonyms of “people with dementia in care homes,” the search was conducted using dementia and care homes with their respective synonyms as independent terms. Conducting a systematic literature search requires expertise and experience, therefore I sought the assistance of the librarians at VID vitenskapelig høgskole. From November 25<sup>th</sup> to January 15, 2019, database searches were conducted in Scopus, CINAHL, Ovid MEDLINE and PubMed. Truncations and wild cards were used in the databases to identify possible abbreviation and spelling variations. The truncation symbol \$ was used in Ovid Medline, and the symbol \* was used in the databases

CINAHL and Scopus. Double quotes (“ ”) were enclosed around “quality of life” in the database Scopus in order to search for the approximate phrase. The “?” is a wild card symbol and was used to find alternative spellings in all the databases. Table 3 below shows the synonyms of keywords and phrases used in the final searches.

The initial stage of the search involved a comprehensive search in the databases mentioned above and included a wide range of studies.

**Table 3 Search terms used in the final search process**

<b>POPULATION (WHO)</b>	<b>POPULATION (WHERE)</b>	<b>INTERVENTION</b>	<b>OUTCOME</b>
Dementia	Care homes	Psychosocial intervention	Quality of life
Alzheimer's	Long term care facility	Non-pharmaceutical intervention	
People with dementia	Nursing home	Person centered? intervention	
Elderly with dementia	Residential home	Non-pharmacological intervention	
Residents with dementia		Cognitive therapy	
Older people with dementia		Cognitive intervention	
		Behavioral? therapy	
		Behavioral? intervention	
		Cognitive behavioral? therapy	
		Emotional intervention	

The various keywords and phrases were then combined using the Boolean operators OR and AND. Table 4 shows the search term strategy list conducted in the database CINAHL. Searches were performed in a similar manner in the remaining three databases.

**Table 4**

<b>The search term strategy list in CINAHL</b>		
1. Dementia*	13. Psychosocial intervention*	24. Quality of life (26 434 hits)
2. Alzheimer's		
3. People with dementia*	14. Non-pharmaceutical intervention*	25. 7 AND 12 AND 23 AND 24 (73 potential articles limited to free full text, abstract available, 2008-2019)
4. Elderly with dementia*	15. Person-centere? intervention *	
5. Residents with dementia*		
6. Older people with dementia*	16. Non-pharmacological intervention*	
7. 1 OR 2 OR 3 OR 4 OR 5 OR 6 (6919 hits)	17. Cognitive therapy*	
8. Ca*e home	18. Cognitive intervention*	
9. Long-term care facility*	19. Behaviora? therapy*	
10. Nursing home*	20. Behaviora? intervention*	
11. Residential homes*	21. Cognitive behaviora? therapy*	
12. 8 OR 9 OR 10 OR 11 (9015 hits)	22. Emotional intervention*	
	23. 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 (218 326 hits)	

Table 5 shows the number of articles the different databases produced according the terms searched. All articles were limited to English language, free full text, abstract available and published from 2008 to 2019.

**Table 5**

<b>Search terms and total hits in databases</b>				
<b>SEARCH TERMS</b>	<b>SCOPUS Number of articles</b>	<b>CINAHL Number of articles</b>	<b>OVID (Medline EMBASE, PsycINFO) Number of articles</b>	<b>PubMED Number of articles</b>
<b>PEOPLE with DEMENTIA plus synonyms</b>	<b>173 754</b>	<b>4910</b>	<b>5474</b>	<b>48 455</b>
<b>PSYCHOSOCIAL INTERVENTIONS plus synonyms</b>	<b>312 644</b>	<b>123 925</b>	<b>6987</b>	<b>17 945</b>
<b>CARE HOMES plus synonyms</b>	<b>473 614</b>	<b>6881</b>	<b>4247</b>	<b>5451</b>
<b>QUALITY of LIFE plus synonyms</b>	<b>461 299</b>	<b>15 454</b>	<b>18 186</b>	<b>89 191</b>
<b>COMBINED with AND</b>	<b>170</b>	<b>73</b>	<b>20</b>	<b>50</b>
<b>ARTICLES REMAINING BASED ON TITLE</b>	<b>10</b>	<b>19</b>	<b>6</b>	<b>10</b>

<b>ARTICLES REMAINING BASED ON ABSTRACT</b>	<b>5</b>	<b>9</b>	<b>1</b>	<b>5</b>
<b>ARTICLES REMAINING AFTER FULL TEXT READ</b>	<b>2</b>	<b>4</b>	<b>0</b>	<b>2</b>

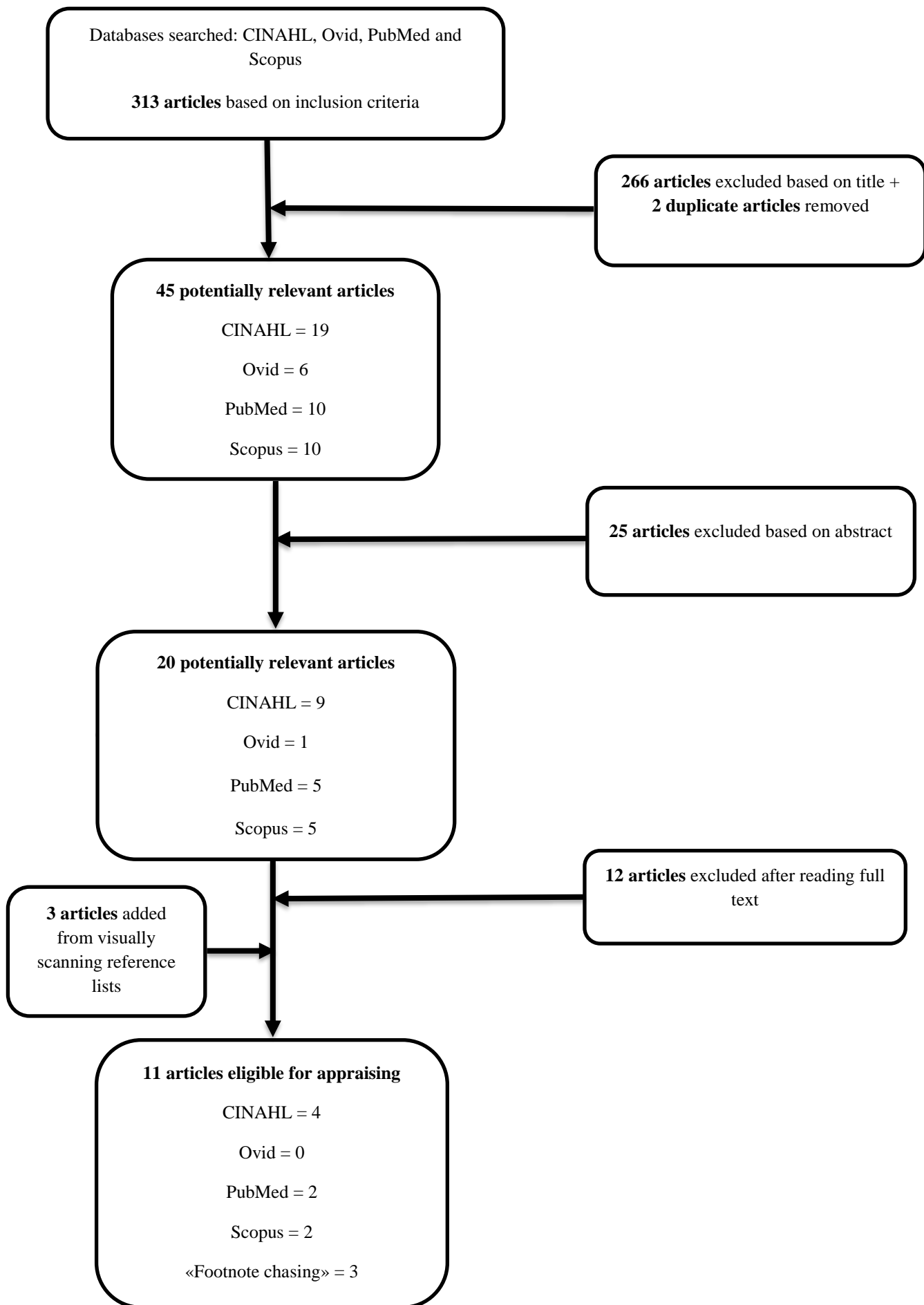
A search of the 4 databases resulted in 313 hits that satisfied the inclusion criteria. 293 were then excluded based on the title. Duplicate studies were also removed. This left 45 articles whose abstract was read. Of these, 25 were eliminated for not adhering fully to the inclusion criteria. This resulted in 20 articles, 9 in CINAHL, 1 in Ovid, 5 in PubMed, and 5 in Scopus. These were then read in their entirety in stage 5 of the scoping review framework to determine eligibility.

### **3.2.5 Stage 5. Study selection**

This stage involves reading the selected 20 articles in full to judge if they are eligible for appraisal (Arksey & O'Malley, 2005). The following studies were excluded in the CINAHL database: a study by Adam & Shahar (2016) did not mention a dementia diagnosis; three studies did not have QOL as the main measure outcome (Brooker et al., 2011; Folkerts et al., 2017; Ridder et al., 2013); while the intervention used was unclear in the study by Beerens et al., (2013). The remaining Ovid article failed to clearly state the effect of the intervention on QOL (Phillips & Pak, 2010). The Scopus studies by Husebo et al., (2015) and Weise et al., (2018) proved to be ongoing trials, while the study by O'Shea et al., (2011) focused more on the care staff than people with dementia. Of the potential five PubMed studies, two were ongoing trials (Weijenberg et al., 2013; Weise et al., 2018), while the participants in the study by Arrieta et al., (2018) did not require a dementia diagnosis. One PubMed qualitative study, (Moyle, Venturto, Griffiths, Grimbeek, McAllister & Murfield, 2011) did not specifically mention the intervention(s) used and did not fully adhere to the inclusion criteria. However, as this was the only qualitative study that had satisfied most of the inclusion criteria, and given that I wished to obtain perspectives of the people with dementia, this study was included in the final selection. This resulted in a total of 8 articles that were found eligible for this review. "Footnote chasing" is a technique that involves visually scanning the reference list of the

eligible articles to find additional potential studies. (Sandelowski & Barroso, 2007). Three additional studies Lin, Yang, Cheng & Wang (2018), Kårefjaard & Nordgren (2018), and Smit, de Lange, Willemse, Twisk & Pot (2016) were found this way. Documentation of the search process used is important as it ensures transparency and enables readers to replicate the process. The reader can then judge the merit and quality of the results (McKinstry, 2014). Figure 1 is the flow chart showing the selection process.

**Figure 1. Assessment flow chart**





### **3.2.6 Stage 4. Charting the data**

This stage involves identifying the key findings obtained from the selected articles. The articles are typically categorized under specific headings that provide general information about the study. These headings usually include details about the author, year of publication, study location, the study population, the type of intervention, the outcome measure and key findings (Arksey & O'Malley, 2005). The authors go on to state that this data should be presented in table or spreadsheet in a manner that is consistent and useful to the reader. In a systematic review this phase is called "data extraction". The point of this step in the research process is to summarize and present a short description of the central points in the study (Lerdal, 2009). A literature template assists the reader in identifying the dominant themes of the study, including the research question, the research design and method used, and what the results of the study revealed. The author points out that filling out a template for each article will provide a better understanding of the purpose of the studies, making it easier to see the comparisons and discrepancies.

The data charting for the eleven articles used in this study are presented below in table 6. The information in the charts include the author(s) of the article and the year of publication; the purpose of the study; the number of participants including demographic data; the country the study was conducted in; the method design used; a description of the intervention(s) used; key findings and central themes.

**Table 6**

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central Themes
<p>Ballard, C., Corbett, A., Orrell, M., Williams, G., Moniz-Cook, E., Romeo, R., . . . Fossey, J. (2018). Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial. <i>PLoS Med</i>, 15(2), e1002500. doi:10.1371/journal.pmed.1002500</p>	<p>To evaluate the impact of the WHELD intervention (Improving Wellbeing and Health for People with Dementia) on QOL, agitation, and antipsychotic use in people with dementia living in care homes, including determining cost.</p>	<p>553 people living with dementia in 69 UK care homes. Majority of participants were women</p> <p>9 month long randomized controlled cluster trial</p> <p>Intervention focused on promoting tailor-centered activities and social activities, including training of staff in patient-centered care. 404 residents were randomly assigned to receive the intervention, while 443 received “treatment as usual” (TAU).</p>	<p>1. Significant improvements in QOL, agitation, NPS and positive care interactions. Benefits for all people with dementia, not just those experiencing NPS.</p> <p>2. Intervention did not reduce antipsychotic drug use</p> <p>3. WHELD program is cost-effective</p>	<p>Training staff to give person-centered care and promoting pleasant activities involving social interaction was associated with improved QOL.</p> <p>The WHELD program was easy to implement and was cost effective.</p> <p>QOL assessed by caregiver. Subjective perspective absent</p> <p>Participants had mild, moderate and severe dementia. Majority women</p>

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central themes
<p>Cho, H. K. (2018). The Effects of Music Therapy-Singing Group on Quality of Life and Affect of Persons With Dementia: A Randomized Controlled Trial.(Report). <i>Frontiers in Medicine</i>, 5. doi:10.3389/fmed.2018.00279</p>	<p>Compare possible effects a music therapy-singing group on the QOL of people with dementia living in a care home with those of a music medicine listening group and a control-TV group</p>	<p>37 residents with dementia from a Veterans' Home in upstate New York. Majority of participants were men</p> <p>Randomized control trial</p> <p>Residents were randomly assigned to one of three groups; a music therapy-singing group, a music medicine-listening group, or a control-TV group</p>	<p>1.All three groups experienced improvements in QOL even though changes in the music listening and TV group were not significant; the music therapy-singing group had the largest effect on QOL.</p>	<p>Participation in meaningful activity and the physical and social benefits associated with this can improve QOL</p> <p>Lack of real active interaction on behalf of the participants can negatively affect QOL</p> <p>Individualized / person-centered interventions are important</p> <p>QOL measure outcome subjective and directly from the people with dementia</p> <p>Participants had mild, moderate and severe dementia.</p>

Article	Purpose of study	Population / Design / Intervention	Key findings	Central themes
<p>Edvardsson, D., Petersson, L., Sjogren, K., Lindkvist, M., &amp; Sandman, P. O. (2014). Everyday activities for people with dementia in residential aged care: associations with person-centredness and quality of life. <i>Int J Older People Nurs</i>, 9(4), 269-276. doi:10.1111/opn.12030</p>	<p>To explore point-prevalence in of participation in everyday activities for residents with dementia and to explore if residents participating in everyday activities experienced higher QOL and / or lived in person-centered units</p>	<p>1266 residents with dementia living in residential aged care units across Sweden. Majority of participants were women (70%).</p> <p>Cross-sectional design</p> <p>Participation in everyday activities such as making coffee, cleaning or outdoor walks</p>	<p>1.Residents that participated in everyday activities and excursions experienced higher QOL and had better cognitive capacity</p> <p>2. Only a small percentage of residents participated in activities</p>	<p>Participation in everyday activities can improve QOL</p> <p>Everyday activities can be turned into meaningful therapeutic opportunities</p> <p>Care staff lacked knowledge</p> <p>Improved relationships between residents, staff and family</p> <p>Proxy ratings used to measure QOL. Subjective perspective absent</p> <p>Participants had mild, moderate and severe dementia</p>

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central themes
<p>Henskens, M., Nauta, I. M., Drost, K. T., &amp; Scherder, E. J. A. (2018). The effects of movement stimulation on activities of daily living performance and quality of life in nursing home residents with dementia: A randomized controlled trial. <i>Clinical interventions in aging, 13</i>, 805-817. doi:10.2147/CIA.S160031</p>	<p>To evaluate the effect of 1) ADL training, 2) a multicomponent exercise training (aerobic and strength), 3) a combined ADL and exercise training on QOL and ADL performance among nursing home residents with dementia</p>	<p>87 residents with dementia from eleven locations of a long-term care organization in the Netherlands. More than 60% were women.</p> <p>A 6-month double parallel randomized controlled trial</p> <p>Participants were randomly allocated to an exercise or social activity (control) intervention resulting in the following four groups - PADL: physical activity and ADL training (n=22); SADL: social activity and ADL training (n=21); PCO: physical activity and care-as-usual (n=22); SCO: social activity and care as usual (n=22)</p>	<p>1. ADL training positively affected QOL</p> <p>2. Exercise training did not improve QOL or ADL performance</p> <p>3. No additional benefits from a combined ADL and exercise intervention</p>	<p>Residents that received ADL training showed less signs of worthlessness and improved QOL</p> <p>ADL training encouraged participation in domestic chores and self-care; residents experienced more control and autonomy</p> <p>Care staff lacked knowledge</p> <p>Improved care relationships</p> <p>ADL training can be easily implemented into daily clinical practice</p> <p>QUALIDEM completed by caregivers. Subjective perspective absent</p> <p>Residents had mild, moderate and severe dementia</p>

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central themes
<p>Kårefjård, A., &amp; Nordgren, L. (2018).  Effects of dog-assisted intervention on quality of life in nursing home residents with dementia.  <i>Scandinavian Journal of Occupational Therapy</i>, 26(6), 1-8.  doi:10.1080/11038128.2018.1467486</p>	<p>To investigate the effects of a dog-assisted intervention (DAI) on the quality of life of care home residents with dementia</p>	<p>59 residents from 3 nursing homes in Sweden. Around 50% were female</p> <p>A one-group, pretest post-test study</p> <p>Various dog-assisted activities such as playing with the dog, grooming or petting the dog. Sessions were usually 10 one-on-one sessions twice a week or sometimes only once a week, lasting 20-45 minutes (dependent on residents' health and needs).</p>	<p>1.DAI improved the QOL for residents</p> <p>2. Agitation was reduced, leading to calmer, more positive and more communicative residents</p> <p>3. No significant differences in total scores for gender, age or diagnosis</p> <p>4.DAIs improve communication between the person with dementia, family and staff</p> <p>5. Long term benefits of DAIs on QOL unclear</p>	<p>Meaningful activities, stimulation, social activity and comfort improve QOL</p> <p>Important to engage the person with dementia.</p> <p>Better care relationships</p> <p>Individually tailored interventions with person-centered perspectives important</p> <p>QUALID completed by caregiver. Subjective perspective absent</p> <p>Participants with mild to severe dementia</p>

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central themes
<p>Lin, H. C., Yang, Y. P., Cheng, W. Y., &amp; Wang, J. J. (2018). Distinctive effects between cognitive stimulation and reminiscence therapy on cognitive function and quality of life for different types of behavioural problems in dementia. <i>Scandinavian Journal of Caring Sciences</i>, 32(2), 594-602. doi:10.1111/scs.12484</p>	<p>To investigate the effects of cognitive stimulation therapy (CST) and reminiscence therapy (RT) on cognitive function and quality of life for people with dementia with disperse, return and dissociate types of behavioral problems</p>	<p>90 elderly people with dementia from 10 long-term care institutions in Taiwan. 62,9% were female</p> <p>Quasi-experimental design</p> <p>23 residents were assigned to the CST group. Activities included physical activities, sound, words association and team quiz. 40 people in the RT group participated in activities such as childhood experience sharing, my job and my hometown. Both CST and RT interventions were 50 minutes long, once a week, for 10 continuous weeks. The remaining 27 residents took part in regular activities.</p>	<p>1.CST and RT interventions improved QOL and cognitive function</p>	<p>Interventions must be tailored for the individual, dependent on the type of behavioral challenge they are experiencing</p> <p>CST and RT interventions encourage people with dementia to be active and social</p> <p>QOL-AD completed by the researcher and caregivers. Subjective perspective absent</p> <p>Participants had mild to moderate dementia. Perspective of people with advanced dementia absent</p>

Article	Purpose of study	Population / Design / Intervention	Key findings	Central themes
<p>Moyle, W., Venturto, L., Griffiths, S., Grimbeek, P., McAllister, M., Oxlade, D., &amp; Murfield, J. (2011). Factors influencing quality of life for people with dementia: A qualitative perspective. <i>Aging &amp; Mental Health, 15</i>(8), 970-977. doi:10.1080/13607863.2011.583620</p>	<p>To understand factors that influenced QOL and feelings of being valued for people with dementia living in care homes</p>	<p>32 people with dementia living in care homes in two Australian states. 22 were female  In-depth interviews</p>	<p>The three factors associated with a positive QOL were:</p> <ol style="list-style-type: none"> <li>1. Relationship with family and other people</li> <li>2. “Things”, described as being in control of their lives</li> <li>3. A need to contribute to the community</li> </ol>	<p>Poor QOL was connected to limited control over environment, relationships and social activities</p> <p>Residents expressed a desire to be treated as individuals; go outdoors, be involved in the community, and have meaningful conversations. Desires and needs no different from people without dementia</p> <p>Residents needs for social and intellectual stimulation largely ignored by staff.</p> <p>Lack of staff knowledge led to missed opportunities for residents</p> <p>Perspective of people with advanced dementia absent</p>



Article	Purpose of study	Population / Design / Intervention	Key findings	Central themes
<p>Smit, D., de Lange, J., Willemse, B., Twisk, J., &amp; Pot, A. M. (2016). Activity involvement and quality of life of people at different stages of dementia in long term care facilities. <i>Aging &amp; Mental Health</i>, 20(1), 100-109. doi:10.1080/13607863.2015.1049116</p>	<p>The aim of the study was to provide insight into the value of activity involvement and quality of life for care home residents with varying degrees of dementia</p>	<p>1144 people with dementia from 144 care homes in the Netherlands. Majority of the participants were women</p> <p>Cross-sectional study – the 'Living Arrangements for people with Dementia study' (LAD-study) consisting of qualitative and quantitative research</p> <p>A maximum of 12 residents were randomly selected to participate in the following 17 activities: playing cards, games and puzzles, using the computer, talking or making a phone call, handwork or art, dancing, exercise or sports, gardening,</p>	<p>1. Sole contribution of activity involvement resulted in relatively small benefits in QOL</p> <p>2. Activity involvement was beneficial in terms of care relationships, positive affect, restlessness, social relations and having something to do.</p> <p>3. High activity involvement was related to lower positive self-image</p> <p>4. More severely impaired residents less likely to be involved in activities</p> <p>5. Staff seemed unable to discriminate between passive and active</p>	<p>Although improvements in QOL were minimal, the activity involvement positively impacted several domains of QOL</p> <p>Individual needs and preferences should be assessed to avoid negative effects of activity involvement</p> <p>Deficit in staff knowledge. Training staff on how to actively engage people with dementia in activities is necessary</p> <p>Intervention implemented by nursing care staff</p>

		<p>taking care of plants, helping others, music or singing, reading, writing, cross-word puzzles, spiritual or religious activities, cooking, pets, domestic tasks, conversation groups, “Snoezelen” or sensory stimulation, beauty activities, excursions and walks outside. Duration of the intervention was 3 days</p>	<p>activity – staff perceived that putting on the TV or radio constituted active activity</p>	<p>Qualidem measure for QOL completed by both participants and caregivers</p> <p>Participants had mild-moderate-severe dementia</p>
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Article	Purpose of study	Population / Design / Intervention	Findings	Central themes
<p>Subramaniam, P., Woods, B., &amp; Whitaker, C. (2014). Life review and life story books for people with mild to moderate dementia: a randomised controlled trial. <i>Aging &amp; Mental Health, 18</i>(3), 363-375. doi:10.1080/13607863.2013.837144</p>	<p>To evaluate various methods of developing a life story book (LSB) for people with dementia. Primary aims of the study was to explore how a life review intervention which resulted in a life storybook, and a life story book developed by a life review process affected residents' QOL</p>	<p>23 residents with dementia from care homes in North Wales. 16 were women</p> <p>Randomized, single blind controlled trial</p> <p>12 participants were allocated to the life review group and actively took part in the writing of their life book. People in the "gift" group received their life book as a gift from relatives who wrote the book over a 12-week period</p>	<ol style="list-style-type: none"> <li>1. Receiving a life story book was associated with increased QOL, whether received as a gift or produced through a life review process</li> <li>2. There was no difference in QOL between the two groups, and both groups experienced improvement in QOL</li> <li>3. There was no difference in the depression and memory tests for both groups after 6 weeks</li> <li>4. Quality of relationships was the same for both groups</li> <li>5. Staff knowledge and attitudes showed improvements at the final assessment</li> </ol>	<p>LSBs associated with improved QOL</p> <p>LSB can assist relatives in re-establishing contact with the person with dementia, resulting in more meaningful conversations and improved relationships</p> <p>Improved staff attitudes and knowledge. Gives potential for individualized, person-centered care</p> <p>Intervention requires supervision or training</p> <p>QOL-AD participant version was used.</p> <p>Participants had mild to moderate dementia. Perspective of people with advanced dementia absent</p>

Article	Purpose of study	Population / Design / Intervention	Findings	Central themes
<p>Telenius, E. W., Engedal, K., &amp; Bergland, A. (2013). Physical performance and quality of life of nursing-home residents with mild and moderate dementia. <i>International journal of environmental research and public health</i>, 10(12), 6672-6686. doi:10.3390/ijerph10126672</p>	<p>Examine the relationship between QOL and levels of balance, mobility, muscle strength and daily life activity</p>	<p>170 residents with dementia from 18 nursing homes in Oslo. 73.5% were women</p> <p>Cross sectional study from 2012 -2013</p> <p>A balance test; a six-meter walking test; muscle strength test using the “30-s chair stands” test; Activities of Daily Living (ADL) performance test.</p>	<p>1. Poor balance and lower extremity strength are linked to poorer QOL in people with dementia</p> <p>2. No significant association between degree of cognitive impairment and QOL</p>	<p>Interventions in care homes that increase balance and muscle strength can increase QOL in people with dementia</p> <p>Preventative strategies should be implemented before residents show decline in balance and muscle strength</p> <p>Implementation in other settings possible</p> <p>QOL measured by QUALID; subjective perspective absent</p> <p>Residents with severe dementia excluded</p>

Article	Purpose of study	Sample / Design / Intervention	Key findings	Central themes
<p>Yamanaka, K., Kawano, Y., Noguchi, D., Nakaaki, S., Watanabe, N., Amano, T., &amp; Spector, A. (2013). Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial. <i>Aging &amp; Mental Health</i>, 17(5), 579-586. doi:10.1080/13607863.2013.777395</p>	<p>To examine the effects of the Japanese version of group CST (CST-J) on cognitive function and QOL on residents with dementia in long-term residential care settings</p>	<p>56 residents with mild to moderate dementia in residential homes and a care home in Tokyo. Majority was women.</p> <p>Single-blind, controlled clinical trial</p> <p>Japanese version of group CST which consisted, among other things quizzes, word and number games and being creative. 14 sessions were administered to a treatment group (n=26) twice a week for 7 days. 30 residents were assigned to the control group</p>	<p>1. CST-J improved proxy-rated QOL, cognitive function and mood;</p> <p>2. Self-rated QOL did not improve – likely due to cultural factors</p>	<p>Social group activities involving fun stimulate the individual’s intact abilities – improving cognitive function and QOL</p> <p>Individualization of activities important, especially for those that cannot participate in group activities</p> <p>CST interventions applicable in a variety of settings</p> <p>Self-rated and proxy-rated QOL</p> <p>Participants had mild to moderate dementia. Perspective of people with advanced dementia absent</p>

### **3.2.7 Collating, summarizing and reporting the reports**

Arksey & O'Malley (2005) state that this stage of the scoping review aims to provide an overview of the articles. The information is presented in a framework or categorized in themes that emerged from charting the data. Arksey & O'Malley (2004) emphasize that scoping reviews make no attempt to synthesize or aggregate the results, nor do they assess the quality of the results. This is because scoping studies review many articles and strive to present an overview of *all* the material. Therefore, the focus is not on the quality of the results, but on how best to present these results. However, this does not mean that critical appraisals have no place in scoping reviews. Arksey & O'Malley (2005) point out that their scoping study framework is a guideline and not the sole way of conducting a scoping review. Anderson et al., (2008, p. 10) state that there are various forms of scoping studies and that scoping studies are “indicative and suggestive” rather than “definitive and prescriptive”. It is important that researchers conduct the study in the manner they think will best answer the research question and prove beneficial to the reader. The eleven articles in this study were assessed for quality as the sample was relatively small, therefore this was feasible. Critically appraising articles important as it increases the trustworthiness and relevance of the study (Khan et al., 2003).

### **3.3 Critical appraisal of selected articles**

The framework developed by Caldwell, Henshaw & Taylor (2011) was used to appraise the quality of articles. This framework combines both quantitative and qualitative appraisal questions and is ideal for a scoping review study. Appraising the chosen papers is an important step as it assesses the quality of the studies and addresses any potential biases and the impact they could have on the results. It also allows for the interpretation of findings and helps to identify how they can be useful in practice (Khan et al., 2003). Bettany-Saltikov & McSherry (2016) suggest assigning a numerical value to assess the quality of the paper. The Caldwell framework has a total of 18 questions and each question has three possible answers. The answers with their numerical value are as follows; no = 0 points, partly = 1 point, and yes = 2 for a maximum value of 36 points. A high point sum indicates that the paper is of good quality. The authors point out that it could be advisable to have a cut-off point, as this ensures that only papers of good quality are included in the study. A cut-off point of 26 was given for this review, and studies that scored 26 or lower were considered of poor quality and further analyzed to see if these studies affected the overall results of my scoping review. Appendix 1

is an example of the framework by Caldwell et al., (2011) and is attached at the end of this review. Appendix 2 shows an example of how the critical appraisal was conducted for one of the articles in this study. The process was repeated for the remaining ten articles. The appraisal scores for the studies in this scoping review ranged from 28/36 (Cho, 2018) to 33/36 (Ballard et al., 2018; Henskens et al., 2018; Kårefjaard & Nordgren, 2018). All were of high quality and did not warrant further analysis.

## **4 Ethical considerations**

According to Johannessen, Christoffersen, Tufte(Moyle et al., 2011), (2017, p.83) ethics in research studies are concerned with ensuring that research is conducted in an ethical and acceptable way and that rules and guidelines are followed according to research ethical committees. Ethics are based on relationships between people and raises questions about what we can and cannot do to each other. This also includes peoples' actions, and how they can directly or indirectly affect another's life. Ethical problems in research can arise when studies have a direct influence on people. Examples are through the mismanagement of sensitive information like names or national identification numbers; or when research results have an unfavorable impact on the participant's life (Johannessen et al., 2017, p. 83-84). According to Johannessen et al., (2017, p. 84 – 85), ethical consideration requires that a researcher asks themselves how justifiable and beneficial the study will be to an individual, groups of people or the society before conducting it. This is especially the case when working with vulnerable groups like children or with people that cannot, for whatever reason, give their full informed consent to participate in the study.

Ten articles in this study, excluding the study by Smit et al. (2016), included an ethical section, with a detailed description of how informed consent was obtained and how other ethical considerations were accounted for. The study by Smit et al., (2016) was a continuation of an earlier study, the Living Arrangements for people with Dementia (LAD) that was run from January to June 2011 (Willemse, Smit, de Lange & Pot, 2011). This first study provided a detailed ethical section. Ethical consideration is an indicator of reliability and validity as it shows that the researchers sought the appropriate approval from ethical committees and complied with ethical rules and standards (Johannessen et al., 2017). In line with ethical research considerations, this scoping review did not falsify, alter material, or take credit for work that the researcher (myself) did not do. All relevant findings were mentioned, including those that did not support the research question.



## 5 Results

### 5.1 Demographic characteristics

Out of the eleven reviewed articles, ten of them had a female majority population. The only study with most male participants was that by Cho (2018), with a percentage of over 60%. Participants in the studies by Lin, Cheng & Wang, (2018) and Yamanaka et al., (2013) included residents with mild-to-moderate dementia. Four studies included residents with mild-to-severe dementia (Kårefjaard & Nordgren, 2017; Moyle et al., 2011; Subramaniam, Woods & Whitaker, 2014; Telenius, Engedal & Bergland, 2013). People with mild-moderate-severe dementia were represented in the four studies by Ballard et al., (2018), Cho (2018), Henskens, Drost & Scherder, (2018) and Smit, de Lange, Willemse, Twisk & Pot, (2016). The last study by Edvardsson, Peterson, Sjogren, Lindkvist & Sandman, (2014) does not state the degree of dementia. The studies with the largest sample groups were the RCT conducted by Ballard et al., (2018) which had 553 participants, the cross-sectional design study by Edvardsson et al., (2014) with 1266 participants, and the cross-sectional study by Smit et al., (2016) with 1144 individuals. The remaining eight studies had relatively small sample sizes, ranging from 24 individuals (Subramaniam et al., 2013) to 170 in the study by Telenius et al., (2013).

The studies in this review were conducted in the UK, the USA, Sweden, the Netherlands, Japan, Australia, North Wales and Norway and were published from 2011 to 2018. Four of the studies were randomized controlled studies, three were cross-sectional, and the remaining four were a pretest-post-test study, a quasi-experimental study, a qualitative study, and a controlled clinical trial. All the studies focused on the importance of “engaging” the person with dementia, with emphasis made on the social and physical aspects of activities, meaningful activities, sense of control and belonging, and relationships. The role of staff with respect to knowledge, perceptions and implementation of interventions was identified in 7 of the studies; while 6 studies discussed cost and feasibility issues. The following three themes were identified after reviewing the articles:

1. Engaging the person with dementia
2. Staff competence
3. Practicalities of the intervention and other considerations

These main themes were then further divided into subthemes as represented in Table 7.

**Table 7**

Themes	Subthemes
<b>Engagement</b>	<ul style="list-style-type: none"> <li>• Social and physical aspects, meaningful activities</li> <li>• Sense of control and belonging</li> <li>• Relationships</li> </ul>
<b>Staff</b>	<ul style="list-style-type: none"> <li>• Knowledge, attitude, perceptions</li> <li>• Person-centered care and individualized interventions</li> </ul>
<b>Practicalities and other considerations</b>	<ul style="list-style-type: none"> <li>• Cost, training and implementation</li> <li>• Cultural considerations</li> </ul>

## **5.2 Engaging the person with dementia**

The aim of this study was to investigate the relationship between psychosocial interventions and improved quality of life for people with dementia living in care homes. The eleven articles reviewed in this study confirmed that residents with dementia who engaged in some form of psychosocial activity experienced improvements in QOL (Ballard et al., 2018; Cho, 2018; Edvardsson et al., 2014; Henskens et al., 2018; Kårefjaard & Nordgren, 2018; Lin et al., 2018; Moyle et al., 2011; Smit et al., 2016; Subramaniam et al., 2014; Telenius et al., 2013; Yamanaka et al., 2013). Additional threads were noted under this central theme “engagement” and they were: social and physical aspects, meaningful activities, sense of control and belonging, and relationships.

### **5.2.2 Social and physical aspects, meaningful activities**

Ballard et al., (2018) state that the WHELD program is largely verbally based as it aims to increase the amount of social interaction for people with dementia living in care homes. It promotes among other things, activities that promote social interaction for elderly and includes staff taking a cup of tea with a resident. Results from this study showed beneficial effects of the intervention on QOL. Life story books created either through a life review process or by relatives improved communication, social activity and QOL for the elderly in care homes, as this enabled family members and care staff to have meaningful conversations with the person with dementia (Subramaniam et al., 2014). Cho (2018) found that active group singing in care homes provided people with dementia an opportunity to interact with other residents and be socially engaged, resulting in improvements in QOL. Individuals in the same study that only participated in music listening or TV watching also experienced improvements in QOL, but these improvements were marginal. People with dementia that participated in social activities such as parlor games, outdoor walks and church activities scored significantly lower on the QUALID scale, indicating a higher QOL (Edvardsson, 2014). Cognitive stimulation therapy (CST) and reminiscence therapy (RT) produced only slight improvements in the short-term effect on QOL for residents in the quasi-experimental study by Lin, Yang, Cheng & Wang (2017). Individuals with the dispute type behavioral problem experienced the greatest improvement in QOL. The study by Yamanaka et al., (2013) adapted the original UK group CST to a culturally appropriate Japanese framework. This was a group activity and the themes were modified to something fun and familiar that the residents could do together. The proxy-rated QOL-AD in the Japanese version of the CST, (CST-J) showed a positive trend, whereas the self-rated QOL-AD did not. The authors point to possible cultural factors as a reason for this. Kårefjaard & Nordgren (2018) deduced in their work with dog-assisted interventions (DAIs) in care homes that this intervention provided people with dementia a means of comfort, meaningful activity and social interaction, contributing to positive effects on QOL for the residents. The individuals in this study were stimulated both socially and physically by interacting with the dogs in various ways, like going on walks with the dogs or talking to them.

Edvardsson et al., (2014) revealed that those residents who participated in some form of physical activity such as clearing or setting the table and making coffee exhibited significantly better quality of life. In addition, outside walks, excursions and parlor games were associated

with improved QOL. Similarly, Telenius, Engedal & Bergland (2013) found that physical function (higher scores on the 30-2 sit-to-stand and Berg Balance Scale) positively affected QOL for care home residents with dementia. Individuals that had better balance and lower extremity strength fared better on the QUALID test, indicating better QOL. The findings by Telenius et al. (2013) however, discovered no significant improvements in QOL for care home residents with dementia regarding ADL or walking speed. Similarly, combined ADL training and exercise training failed to benefit QOL or ADL performance for residents with dementia in the randomized controlled trial by Henskens et al., (2018). Furthermore, physical activity in the form of multicomponent exercise did not appear to show any benefits in QOL for people with dementia in. The multicomponent exercise intervention focused on strength and aerobic exercises. The strength exercises targeted the torso and the upper and lower extremities. Aerobic exercise comprised of outdoor walks. However, Henskens et al., (2018) showed that improvements in QOL were promising for the healthy residents, and the elderly that participated in physical activities such as domestic chores and self-care showed improvements in QOL. In contrast to these findings was the study by Smit et al., (2016). The researchers found no significant improvements in QOL with activity involvement as the sole contributor.

### **5.2.3 Sense of control and sense of belonging**

People with dementia expressed a need for having a sense of control over their lives and situations, and this was clearly obvious in the three studies by Henskens et al., (2018); Cho (2018), and Moyle et al., (2011). The participants in the study by Moyle et al., (2011) expressed frustration over the lack of control over their surroundings and inability to do the things they desired, like visit family and friends. They felt activities were restricted and largely controlled by the staff. Cho (2018) discovered that of the three groups in their study, the residents in the music listening group and the control-TV group had the least improvements in QOL. The participants in the latter group were given no choice or control over the TV programs they watched. A significant factor that Cho (2018) attributed to marginal improvements in QOL. Cho (2018), pointed out that the process of active singing could possibly have contributed to a sense of accomplishment and of belonging, thus improvements in quality of life for people with dementia in long-term care. In the study by Henskens et al., (2018), residents that performed domestic chores that were familiar to them from their previous life at home experienced a sense of autonomy and control, factors that

contributed to increased QOL. When residents were encouraged to perform these chores and do as much of their self-care as possible, it improved their sense of “feeling at home”, and they felt useful, resulting in better quality of life (Henskens et al., 2018).

#### **5.2.4 Relationships**

Eight of the eleven studies clearly established the significance of “relationships” in the QOL of people with dementia living in care homes (Ballard et al., 2018; Cho, 2018, Edvardsson et al., 2014; Henskens et al., 2018; Kårefjaard & Nordgren, 2018; Moyle et al., 2011; Smit et al., 2016; Subramanian et al., 2014). These relationships focused on the caring staff and the family. Implementation of the WHELD intervention resulted in a 19,7% increase in improvements of positive care interactions between the caring staff and people with dementia and resulted in improvements in QOL (Ballard et al., 2018). Fewer conflicts with the care staff and other residents, and improved care relationships were reported by Smit et al., (2016). These were aspects of their activity involvement intervention and they showed benefits to QOL for the residents (Smit et al., 2016). Active group singing was linked to increased social interaction and interpersonal interactions with fellow residents, which in turn led to a sense of belonging and improvements in QOL (Cho, 2018). Providing people with dementia opportunities to participate in everyday activities that are often construed as nursing tasks, can provide chances for improved communication and relations for the care home staff and residents, according to Edvardsson et al., (2014). Henskens et al., (2018) pointed out that ADL training for people with dementia in care homes can improve care relationships and provide people with dementia more control and autonomy. Influencing factors on QOL for the residents in the study by Moyle et al., (2011) were identified as relationships with family, staff and fellow residents. Participants expressed how they anticipated and longed for visits from family and friends, and the disappointment they felt when visits were not realized. They then looked to the staff to fill this void, staff were described as often being too busy for lengthy conversations. Forming relationships with other residents was stated as challenging, due mainly to the “frailty” of the other residents, or due to the lack of individuals with similar interests. These relationships, or lack of them, were associated with poorer QOL. Dog-assisted interventions provided family and nursing staff chances to have positive, relaxed and meaningful conversations. This was linked to improved QOL for the people with dementia (Kårefjaard & Nordgren, 2018). Improvements in relationships were reported by the relatives of residents with dementia in the development of life story books (Subramaniam et al., 2014).

Relatives expressed greater engagement and contact, and conversations were more fulfilling. However, people with dementia reported improvements in relationships with their family only after they received the life story book, but not while it was being produced.

### **5.3 Staff**

Several of the articles mentioned how the nursing staffs' knowledge, attitudes and perceptions played a significant role in the implementation of psychosocial interventions and QOL for people with dementia.

#### **5.3.1 Staff knowledge, attitudes and perceptions**

Residents with dementia in the qualitative study by Moyle et al., (2011) spoke of the “little things” that staff and fellow residents did that made them feel worthless and belittled. An example given was when staff disregarded their views and opinions because they had dementia. Another resident mentioned how certain activities, like walks outside, were controlled and restricted by the staff because of fear that the person with dementia would get lost. These “little things” were associated with a poorer QOL for the person with dementia. Edvardsson et al., (2013) stated that staff attitudes and lack of knowledge about the capabilities of people with dementia could explain why only a small percentage of residents participated in everyday activities. Findings in the studies by Edvardsson et al., (2013) and Moyle et al., (2011) confirmed that care staff were less likely to include residents that had lower cognitive capacity in activities. Furthermore, Moyle et al., (2011) found that care staff frequently offered meaningless activities based on their own perceptions of what was appropriate for people with dementia. Although ADL training had a positive impact on the QOL for residents with dementia, some care staff failed to comply with the intervention, according to Henskens et al., (2018). Some of the reasons given was lack of knowledge about the importance of the intervention, and uncertainty about how to stimulate ADL (Henskens et al., 2018). This was echoed in the findings by Smit et al., (2016). There appeared to be general misunderstanding among the care staff about the differences between active and passive activity. Some care staff perceived simply turning on the TV as a form of actively involving the resident in activity (Smit et al., 2016).

Staff acquired better knowledge and attitudes after the implementation of the psychosocial interventions in some of the studies. One of the aims of the WHELD intervention was to

increase care staff knowledge about people with dementia by “developing ways to understand the individual needs of people who are distressed”. Results at the end of the study showed a large increase in the Quality of Interactions Scale (QUIS), revealing a greater number of positive care interactions between care staff and the residents with dementia (Ballard et al., 2018). The care staff in the article by Subramaniam et al., (2014) were asked to fill out the “approaches to dementia questionnaire” (ADQ) at different intervals during the study. This questionnaire measured how well staff knew the resident. The final total scores, hopeful attitudes and person-centered attitudes showed significant improvements from baseline at the end of the study. This increased biographical knowledge about the resident paved the way for individualized, person-centered care.

### **5.3.2 Person-centered care and individualized interventions**

Person-centered care (PCC) was attributed to higher QOL in four of the eleven reviewed articles (Ballard et al., 2018; Edvardsson et al., 2014; Henskens et al., 2018; Kårefjaard & Nordgren, 2018). Helping care staff understand and implement PCC was one of the major aims in the WHELD intervention conducted by Ballard et al., (2018). At the end of the 9-month trial, the researchers found that PCC, coupled with evidence-based non-pharmacological interventions greatly improved the QOL of people with dementia in care homes. Residents that participated in everyday activities, went on outdoor walks, attended parlor games and church visits scored higher on the Person-centered Care Assessment Tool (P-CAT) and experienced higher quality of life, according to Edvardsson et al., (2014). The residents with dementia in the ADL training group were encouraged to perform as much of their own self-care as possible during the day in the research work by Henskens et al., (2018). This intervention positively affected QOL for the residents by promoting personhood through activities that increased autonomy, control and self-worth (Henskens et al., 2018). The dog-assisted intervention (DAI) in the study by Kårefjaard & Nordgren (2018) was planned and performed from a person-centered perspective, resulting in significant improvements in total QUALID scores after the study.

The importance of interventions that were tailored and individualized to the person with dementia was an important factor that was identified in many of the studies (Ballard et al., 2018; Cho, 2018; Edvardsson et al., 2014; Henskens et al., 2018; Kårefjaard & Nordgren, 2018; Moyle et al., 2011). These individualized interventions were linked to a better QOL in

all the studies except one. The social activities in the WHELD intervention were aimed to promote the abilities and interests of the person with dementia. Results from the study showed significant benefits in QOL (Ballard et al., 2018). The participants in the music therapy group had the largest improvement in QOL in the study performed by Cho (2018). The songs in this group were chosen by the participants. The music therapist adjusted the intervention based on individual responses and strived to promote individual strengths and potentials. The music-listening and TV group interventions were not individualized and were conducted in a group format. Although these two groups experienced an increase in QOL, the change was marginal. The TV group also had the highest dropout rate, with only eight of the original 17 residents completing the study (Cho, 2018). Participants in the qualitative study by Moyle et al., (2011) did not wish to take part in activities that were pointless and chosen for them by the care staff. Residents felt the lack of individualized interventions negatively impacted their QOL. In slight contrast, interventions described in the study by Edvardsson et al., (2014) were everyday activities like cleaning and making coffee, watering plants and going on excursions, and they were chosen by the care staff. However, residents that participated in these activities lived on person-centered units, therefore interventions were likely tailored to their strengths and preferences. The daily care tasks that residents performed in the study by Henskens et al., (2018) were based on individual health care plans and encouraged the individuals to perform chores and tasks that were familiar to them. The DAI was individually tailored (Kårefjaard & Nordgren, 2018).

## **5.4 Practicalities and other considerations**

### **5.4.1 Cost, training and implementation**

The WHELD intervention was a large RCT that included 553 participants and involved 62 UK care homes. The researchers, Ballard et al., (2018) calculated that the intervention costs £8,627 more per home and expenses incurred per resident per month are just £130. A music therapist was used in the active singing group in the study by Cho (2018). For this intervention to take place in the care home, the author recommends the training of professionals and family members. The activities mentioned in the studies by Edvardsson et al., (2014), Henskens et al., (2018), and Moyle et al., (2011) are activities that are already occurring in most care homes, like domestic chores, self-care and access outdoors and are easy to implement according to the authors. The CST programs in the two studies by Lin et



al., (2017) and Yamanaka et al., (2013) were both conducted by professionals with previous knowledge of the therapies. However, neither study mentions the need for a professional. Yamanaka et al., (2013) state that the flexible framework of CST programs allows for individual resident preferences and opinions to be considered. The low dropout rate from both studies supports this fact. The dog handler in the study by Kårefjaard & Nordgren (2017) was an experienced trainer who had previously worked with dog-assisted interventions. In addition, the dogs used were certified and experienced. Trained physiotherapists were used in the study by Telenius et al., (2013). The activities listed by the Activity Pursuit Patterns were carried out by care staff in the study by Smit et al., (2016). Activities mentioned by residents in the study by Moyle et a., (2011) were simple tasks that did not require special training or extra costs.

#### **5.4.2 Cultural considerations**

Apart from gender and age, the studies in this review do not mention the cultural background of the participants. Two exceptions are the studies conducted by Lin et al., (2017) in Taiwan and by Yamanaka et al., (2013) in Tokyo. The authors mention that the Chinese (Lin et al., 2017) and Japanese (Yamanaka et al., 2013) versions of the interventions were used and activities culturally adapted to make them relatable to the participants. Therefore, it is safe to assume that the sample populations in these studies consisted of Chinese (Lin et al., 2017) and Japanese (Yamanaka et al., 2013) residents.

## **6 Discussion**

The purpose of this scoping review was to explore what was known about the link between psychosocial interventions and improved quality of life for people with dementia living in care homes. The findings in all eleven articles revealed that psychosocial interventions do improve the QOL for elderly residents with dementia in care homes. These results are in accordance with earlier studies that have shown better QOL with use of psychosocial interventions for people with dementia (Vernooij-Dassen et al., 2010). In addition, the findings from this scoping review discovered that the term “psychosocial interventions” encompasses a plethora of interventions that vary widely in their composition and implementation. These interventions include domestic, everyday chores that typically might not be considered as psychosocial interventions by some care staff. Furthermore QOL, as pointed out in chapter one, is a broad concept, involving several different aspects that include social and physical aspects (Crespo et al., 2011). The results from the three central themes identified in chapter 5 are discussed in greater detail in the following section.

### **6.1 Engaging the person with dementia**

The social benefits associated with psychosocial interventions were clearly apparent in eight of the eleven studies (Ballard et al., 2018; Cho, 2018; Edvardsson et al., 2014; Kårefjaard & Nordgren, 2018; Lin et al., 2017; Moyle et al., 2011; Subramaniam et al., 2014; Yamanaka et al., 2013). The social aspect of these interventions was largely responsible for the improvements in QOL. These findings are supported by previous studies which investigated QOL for care home residents. Kehyayan, Hirdes, Tyas & Stolee (2015) discovered that self-reported ratings of QOL were lower for residents that did not engage in meaningful social activities; while a systematic review by Jing, Willis & Feng (2016) found that participation in social activities and maintenance of social connections with family, friends and the community related to higher QOL. What most of the interventions in this scoping study had in common was that they encouraged the person with dementia to talk or interact socially with the people around them. As noted earlier in chapter one, residents in care homes spend large parts of their day in passive states, with little stimulation and activity (Mjørud et al., 2017). Residents in the study by Moyle et al., (2011) confirmed this by stating “how boring” it was in the care home, and how they “would just be sitting there until tea time” (p.974). Therefore, it is not surprising that the interventions that promoted social activity in this review, also

improved QOL. The need for social inclusion was also apparent in the study by Cho (2018). The author attributed the improvement in QOL in the music listening group and the control-TV group to participants being engaged in a social activity and being included in a group. This was different from their daily routine of solitude and inactivity. Kitwood (1997b, p.19) described how people are a “social species,” and how attachment is a psychosocial need that is crucial for all human beings, especially vulnerable groups like people with dementia.

A few of the interventions examined in this review were carried out in group settings (Cho, 2018; Lin et al., 2017; Telenius et al., 2013) and it appears that being in a “group” could have something to say about the QOL for the residents. As discussed in the theory section, language and speech impairments often accompany dementia and people with dementia are in danger of being excluded from society (Kitwood, 1997b). Kitwood (1997b) goes on to say that people with dementia often do not have a group to belong to, further increasing the chances of isolation and retreatment. If the need for inclusion is met, the person with dementia is likely to emerge from this reclusive state and experience improved well-being (Kitwood, 1997b). Findings from this study support this, as all interventions that occurred in a group setting positively influenced QOL. It appears that simply involving the residents in some form of activity made them feel included and that they belonged to a “community”. However, findings from this review found that care staff tend to interact less with residents with cognitive impairment, focusing rather on the physical aspect of care (Moyle et al., 2011; Smit et al., 2016). Earlier studies confirmed these results (Clare, Rowlands, Bruce, Surr & Downs, 2008). The more severe the cognitive impairment, the less likely they were to be included in activities (Smit et al., 2016). Six of the studies in this scoping review included people with varying degrees of dementia, implying that people with severe dementia can be engaged in some form of activity that has the potential to better their QOL (Ballard et al., 2018; Cho, 2018; Edvardsson et al., 2014; Henskens et al., 2018; Kårefjaard & Nordgren, 2018; Smit et al., 2016). Heavy workloads and staff time constraints could explain why some of the more cognitively impaired residents were excluded from activities according to Edvardsson et al., (2014). Animal interventions like the dog-assisted intervention (DAI) can play a crucial role in meeting the inclusion need of people with dementia. Engedal & Haugen (2018) point out that animal therapy can be an effective way to manage feelings of apathy commonly seen in people with dementia. Feelings of apathy are associated with lower QOL (Hoe, Hancock, Livingston & Orrell, 2006). The Need-Driven Dementia-Compromised Behavior Model (NDB) discussed in chapter 2 points out how NPS are often the result of an unmet need and

activities that promote activity and socialization tend to improve symptoms. In this review, the dog-assisted intervention reduced symptoms of sadness and discomfort, and improved quality of life in the study by Kårefjaard & Nordgren, (2018). A social void was filled as participants formed relationships with the dogs and the trainer. Their study included participants with mild to severe dementia implying that this intervention is an ideal way to involve residents with severe dementia in activities.

Engaging people with dementia in some form of physical activity appeared to benefit QOL (Edvardsson et al., 2013; Telenius et al., 2013). It is not unreasonable to assume that physical activity, whether in the form of clearing a table or doing sit-to-stand exercises provided the residents with something meaningful to do. In other words, physical activity fulfilled their need for occupation by providing them with activities that were personally significant and that alleviated feelings of boredom and apathy. However, exercise training and activity involvement failed to affect QOL in the studies by Henskens et al., (2018) and Smit et al., (2016). Smit et al., (2016) points out that the reason for this could lie in the residents being asked to perform tasks that were beyond their capabilities, thus emphasizing their shortcomings. Daatland & Solem (2011) state that some older people can experience feelings of despair when faced with situations they are unable to master. Some people can choose to solve this problem by isolating themselves. The Progressively Lowered Stress Threshold Model (PLST) mentioned earlier highlights the importance of simplifying tasks for the person with dementia to avoid triggering stress and to increase feelings of accomplishment. Kitwood (1997b) pointed out how important it was for people with dementia to take part in activities that empowered them and made them feel like they were contributing in a significant and meaningful way.

Findings from this study indicate that interventions that promoted a sense of control and meaningful contribution had a large impact on QOL (Edvardsson et al., 2014; Henskens et al., 2018; Moyle et al., 2011). This is in accordance with earlier research done by Clare et al., (2008), who mentioned how lack of control over one's life and surroundings had a negative impact on the QOL for the participants with dementia. Residents expressed despair over the inability to make meaningful contributions or control situations in their lives. This led to feelings of dislocation, fear, isolation and unhappiness (Clare et al., 2008). These feelings are linked to poor QOL for people with dementia (Jing, Willis & Feng, 2016; Mjørud et al., 2013; Wyller, 2018). Autonomy was a significant determinant in improving QOL for people with

dementia in care homes in the research work by Crespo et al., (2011), and Jing et al., (2016). Looking at the results from this review, the participants in the music therapy-singing group were provided with the opportunity to pick the songs they wanted to sing, and this group experienced the largest improvements in QOL (Cho, 2018). The individuals in the ADL training group were encouraged to perform as much of their own self-care as possible and did the tasks they could best master in the study by Henskens et al., (2018). This group also experienced significant improvements in QOL. It is not unreasonable to think that the positive effects seen with these interventions are due to people with dementia being given control over what activity they would like to perform, and control over how to execute the act. Some people with dementia can have difficulties asserting which activities they would like to participate in (Moyle et al., 2011). For care staff to meet this need, the individual's interests and abilities must be accounted for (Edvardsson et al., 2014). Therefore, care staff have a unique opportunity to provide meaningful tailored interventions that aim to promote the QOL of residents with dementia (Clare et al., 2008; Moyle et al., 2011).

The residents in the study by Moyle et al., (2011) expressed how engaging in meaningful conversations formed better relationships with family, staff and fellow residents, and gave them a sense of belonging and connection to the community. Better relationships between the person with dementia and care staff and family were also found in the studies that involved reminiscing (Lin et al., 2017; Subramanian et al., 2014). Previous studies have shown that interventions that involve reminiscing can have a positive impression on the QOL of people with dementia by providing the individuals with opportunities to relive pleasant memories (Clare et al., 2008). These interventions enable people with dementia to recant lived experiences and share their lives with others (Lawrence et al., 2012). "Identity" is one of the five great psychosocial needs for people with dementia (Kitwood, 1997b). The identity of the individual involves a "narrative" - a personal story told by the individual about his or her life experiences and its preservation is largely dependent on what those around the person with dementia provide. Promoting the identity (personhood) of the person with dementia leads to enhanced self-worth and well-being (Kitwood, 1997b, p.20). Life story books and reminiscence therapy are ways of promoting the identity and QOL for the elderly with dementia in care homes, as shown by the findings in this study. The participants in the study by Subramaniam et al., (2014) derived pleasure from recalling memories and experiences, as evidenced by the improvements in QOL. Life story books not only improved the QOL for people with dementia, they also improved relationships with relatives and care staff, *and*

enhanced staff knowledge. Relatives felt they could have meaningful conversations with their loved one, while increased knowledge about the individual improved care delivery (Subramaniam et al., 2014). Reminiscence therapy (RT) slightly improved QOL in the study by Lin et al., (2017), with the lowest improvements in the “return type” sample group. This was a surprising find given that people with return type behavioral problem have difficulty accepting life in the present time, and often seek comfort in the past. A high pretest score was a possible explanation for this finding according to the authors. However, Lin et al., (2017) do point out that this finding in their study is not supported by previous research, indicating the need for further research. Although reminiscence therapy in the study by Lin et al., (2017) did not display any significant improvements in QOL, previous studies have shown favorable effects of the intervention for people with dementia (Engedal & Haugen, 2018). One study found that reminiscence intervention using a life-story approach improved the QOL for people with dementia (Daniel Jorge Luis Serrani, 2012). Kitwood (1997b) mentioned how the lives of people with dementia are filled with uncertainties and worries. Successful promotion of personhood relies heavily on interventions that are centered around the life history and interests of the individual. The Utilization of Self-identity is one of the evidence-based models discussed earlier in chapter 2. The interventions stated in this model encourage social contact and the stimulation of memory through social contact and recollection of former jobs, hobbies and interests. Results from this scoping review support this theory, as they confirm that life story books and reminiscence therapy promote the self-identity and quality of life for the residents, and lead to better relationships.

## **6.2 Care staff**

The systemic perspective mentioned in chapter 2 discusses the importance of exposing “working myths” and assumptions about dementia and people with dementia adopted by care staff, as these can affect the wellbeing of residents and increase chances of MSP.

Misconceptions and a general lack of knowledge about dementia and people with dementia was apparent in four of these studies (Edvardsson et al., 2014; Henskens et al., 2018; Moyle et al., 2011; Subramaniam et al., 2014). There appeared to be an underlying sense of “fear”. “Fear” of doing the wrong thing, “fear” of the extra work involved, “fear” of the person with dementia. The results from this review suggest that care staff are uncertain about how to work with people with dementia. The abilities of the participants are often undermined as revealed by the studies by Edvardsson et al., (2014) and Henskens et al., (2018) and Moyle et al.

(2011). Residents in the study by Moyle et al., (2011) expressed their frustration when staff minimized their abilities, with one resident stating, “we’re not allowed to get out of here in case we get lost” (p.975). Other factors mentioned in this scoping review were fear of agitating the person, the extra work involved and insufficient knowledge about the intervention (Edvardsson et al., 2014; Henskens et al., 2018; Moyle et al., 2011; Subramaniam et al., 2014). Findings from four in-depth, ethnographic case studies by Backhouse, Killelt, Penhale & Gray (2016) confirmed that lack of knowledge about non-pharmacological interventions, NPS and fear of making errors were common reasons that care staff failed to use these interventions when working with people with dementia. Their study however, did not have QOL as a measure outcome. In this scoping review, the studies by Ballard et al., (2018) and Subramaniam et al., (2014) showed that care staff appeared to appreciate the benefits of the knowledge gained from implementing the interventions. The care staff developed a better understanding of the person behind the disease, while recognizing their own perceptions and biases that could negatively impact the QOL for the resident with dementia. Contrary to these results were the findings made by Livingston et al., (2014) in their systematic review of randomized controlled trials. The researchers concluded that training care-home staff without supervision in communication skills and person-centered care was an ineffective intervention. However, the outcome measure in this review was agitation, not quality of life. Enhanced staff knowledge and attitudes in the studies reviewed in this scoping study were associated with improved care relations, a better understanding of the person with dementia and increased knowledge about the implementation and purpose of the intervention (Ballard et al., 2018; Edvardsson et al., 2014; Henskens et al., 2018; Moyle et al., 2011; Subramaniam et al., 2014).

In this review, Henskens et al., (2018) mentioned how uncertainty about psychosocial interventions among the care staff led to their underuse. Part of the reason could be the unnecessary use of complicated terms. For example, reminiscence therapy involves discussing past events and experiences. As a nurse, reminiscing or talking with the residents about the past is something I do every day. It is often unplanned and occurs naturally without any effort on my part. When I asked a few colleagues about their thoughts on reminiscence therapy, they were skeptical and hesitant to try it as it was perceived as an extra task in an already busy schedule. However, when the term was explained, and it was made clear that it simply involved engaging the resident in conversation about past experiences, they became more

receptive. It appeared that the term “reminiscence therapy” created unnecessary confusion and resistance.

The psychological perspectives mentioned before aim to promote personhood by encouraging and respecting the individuality of the person with dementia by using tailored interventions. A common, and perhaps the most significant thread among all the reviewed studies was the importance of tailoring the psychosocial intervention to the individual. The interventions examined in this scoping review included both group and individual activities. Results offered strong support for the use of individualized interventions in working with people with dementia. Findings revealed that group-based activities (like TV-watching and CST) reported only marginal gains in QOL, while significant improvements were observed with those interventions that considered the preferences and abilities of the participant (life-story books and performance of familiar daily chores). Results from this study were in accordance with earlier research. A systematic review by McDermott et al., (2018) showed that individually tailored activity interventions had the largest effect on QOL for people with dementia. However, participants in their study included people in both community and care home settings. One study by Ridder, Stige, Qvale & Gold (2013) contradicted the findings from this scoping review. The authors found insignificant differences in QOL with individualized music therapy for residents with dementia. There was however, substantial improvements in the primary outcome measure which was agitation disruptiveness. Despite this, there appears to be firm support for the use of interventions that put the person with dementia at the center and respects their opinions and choices. The Psychodynamic perspective mentioned how challenging it could be for some people with dementia to transition from a “valued” member of society to being dependent on others for help. This perspective encourages care staff to form a relationship with the person with dementia, to take the time to listen to the life story of the individual, and to respect their feelings and choices. This was clear in the interviews conducted by Moyle et al., (2011) in their qualitative study. Some participants in the study described staff that were controlling and restrictive, with one resident referring to some care staff as “all high official as if they own the place” (p.974). The residents felt their lives had no meaning and they did not contribute to society in any way. They wished to be involved in decision making and felt disempowered and of little value when their views were not considered. “I don’t think I contribute much here,” stated one of the participants in the study (p. 974). Residents wanted to be included in decisions about which activities were most meaningful and interesting for them. Residents felt they “lost” their identity because of the



dementia diagnosis and their input was not respected (Moyle et al. 2011, p. 974). Kitwood referred to this “loss of identity” during his work with people with dementia (Kitwood, 1997b). He stated that dementia takes away many sources of the person’s identity and dementia care should prioritize maintaining identity or personhood. Attempts should be made to involve the person with dementia in activities that are personally significant and consider the individual’s interests and life history (Kitwood, 1997b). The models (theories) of dementia care mentioned earlier in this study suggest the promotion of interventions that are meaningful for the person with dementia and include activities like music, discussing family photos, activity and cooking projects. The results of this study showed that similar interventions, life story-books (Subramaniam et al., 2014), cooking and tending to plants (Smit et al., 2016) improved the quality of life for residents. The psychological perspectives aim to promote personhood by encouraging and respecting the individuality of the person with dementia through tailored interventions. The significance of tailoring activities to the capabilities of the person is particularly evident in the study by Smit et al., (2016). According to the authors, high activity involvement was associated with a lower positive self-image. This was likely due to the person with dementia being confronted with their own limitations (Smit et al., 2016) and not being offered activities that they personally chose or felt they could do. The Resource Model focuses on how older people can maintain a sense of control and achievement by avoiding situations or activities that can potentially result in failure (Daatland & Solem, 2011). They can remain active and involved by participating in those activities that they master. Although the Resource Model as described by Daatland & Solem (2011) refers to the elderly population in general, the need to excel at something and feel useful is a universal need. Results from this review show that people with dementia struggle to get this need met and rely heavily on those around them to take the initiative. Yet, as discussed earlier, life in care homes for many residents with dementia is devoid of any meaningful activity and care staff are still struggling to implement psychosocial interventions in everyday practice (Clare et al., 2008).

### **6.3 Other considerations**

One of the aims of this study was to identify which psychosocial interventions had the strongest evidence base and make recommendations for how to implement them in Norwegian care homes. A positive effect on QOL was seen in all the interventions investigated in this scoping review, implying that any one of these interventions can be used in Norwegian care

homes. For an intervention to succeed, it is essential that it is accepted by the participants, the care staff, and the stake holders (Sidan & Braden, 2009). “Acceptability”, according to the authors, refers to the appropriateness and feasibility of the intervention. The importance of acceptability was apparent in the study by Husebø (2019). The multicomponent intervention (COSMOS) used in this RCT aimed to investigate the QOL of care home residents with and without dementia in thirty-three Norwegian nursing homes. A temporary decrease in QOL was observed in the intervention group during the active phase of the trial. The authors hypothesized that the work intensity of the intervention led to staff feeling overwhelmed, resulting in suboptimal use of the intervention and consequent decline in QOL for the residents. However, positive effects in QOL were seen at the end of the nine-month trial indicating that despite its complexity, the intervention could have a positive influence on residents’ QOL. Chu, Puts, Brooks, Parry & McGilton, (2018) state that for an intervention to work, all parties involved must find it feasible and beneficial. Findings from this scoping review concur. The WHELD intervention conducted by Ballard et al., (2018) involved extensive staff training and guidance on antipsychotic medications. Although complex, this intervention was widely accepted by the care staff and resulted in positive outcomes for both the staff and the residents with dementia. Findings from this review show that interventions do not need to be complex and expensive. Engaging people with dementia in simple activities like making coffee and cleaning the table and self-care (Edvardsson et al., 2013; Henskens et al., 2018) can be beneficial to the QOL for people with dementia. As Edvardsson et al., (2014) pointed out, many of the psychosocial interventions that can potentially improve the quality of life for people in care homes are everyday nursing tasks and activities that can be reformed into therapeutic opportunities.

Six of the reviewed studies used professionals to carry out the intervention, with two studies strongly recommending the use of trained therapists (Subramaniam et al., 2014; Kårefjaard & Nordgren, 2019). Although simple enough in theory, these requirements involve investments in time and money – factors that some care homes might not be interested in considering. As Kitwood (1997a) pointed out, people with dementia rely heavily on others to maintain and promote their personhood. This responsibility falls on care staff in the care home setting and it is reasonable to assume that the complexity and cost of an intervention could determine its overall success. Most of the psychosocial interventions in this review did not require special training, reinforcing the notion that most psychosocial interventions can easily be incorporated into everyday nursing care. Cognitive stimulation therapies stimulate thinking

and memory and include a wide range of activities that can be individually tailored to promote the person's abilities and interests (Yamanaka et al., 2013; Lin et al., 2017). Results from this study indicate that CSTs are easy and cost-effective ways to improve the QOL for people in care homes Yamanaka et al., (2013); Lin et al., (2017). Earlier research confirms this finding. Cognitive stimulation therapy was found to be an effective and affordable way to improve the quality of life for people with dementia in UK care homes and community services (Orrell et al., 2014). Reminiscence therapy involves discussing past events, experiences and activities (Lin et al., 2017). It can help people with dementia maintain their identity, while giving care staff a better understanding of who the individual is, leading to enhanced personhood and better care relationships. Life story books are a form of reminiscence therapy (Subramaniam et al., 2014) and both reminiscence therapy and life story books were connected to improved QOL in this review. Even though these interventions were carried out by trained therapists, the authors point out that care staff without training can perform these interventions, although caution must be exercised. Wyller (2018) states that reminiscence therapy can be conducted by care staff and does not necessarily require expert training. Reminiscence therapy contribute to reducing feelings of anxiety and depression in people with dementia (Wyller, 2018), feelings that have been shown to negatively affect QOL for care home residents with dementia (Hoe et al., 2006). It appears that reminiscence therapy is a feasible and effective way to improve the QOL for residents with dementia in care homes, as evidenced by the results from this review.

Women constituted the larger part of participants in ten of the eleven studies reviewed in this study. Taking this into consideration, it could be argued that the interventions used in the studies favored the female gender and gave a biased account of the effect of the psychosocial interventions on QOL. However, given that the interventions were varied, and included everything from domestic chores (Edvardsson et al., 2014; Henskens et al., 2018) to strength training (Smit et al., 2018; Telenius et al., 2013), it is unlikely that this was the case. Results from this study confirm that the nature of the intervention, although significant, is not the most important determinant of QOL for the participants. Rather, it is how personalized the task is to the interests and abilities of the person that makes the most impact.

Results from this review indicate that care staff should consider the role of culture in their work with people with dementia. Participants in the study by Yamanaka et al., (2013) experienced insignificant improvements in self-rated QOL-AD. The possible reasons for this

as offered by the authors, is that self-criticism and careful expression of emotions is typical in the Japanese culture and changing the wellbeing in these individuals could require more time and investment. Given that there are over 800 000 people in Norway with a foreign background (Statistisk sentralbyrå (SSB), 2019), care home staff can expect to encounter elderly with different cultural backgrounds in the years to come. Naess & Moen (2015) found that despite popular belief, many immigrants in Norway did not have extensive families that could provide care, making care home admission an inevitable reality. Rosendahl, Sooderman & Mazaheri (2016) found that the main concern for relatives when their loved one moved into a care home was availability of activities. In their exploratory study, the authors found that the immigrant residents did not socialize much with the staff or other residents on the unit and preferred music and television programs in their native language. Immigrants with dementia are at added risk for isolation because communication difficulties become more pronounced when they move into care home, with many forgetting how to speak the host language despite having lived in the country for several years (Rosendahl et al., 2016). Being familiar with the person's culture and life history is therefore paramount if care staff are to prevent social isolation and deliver individualized interventions. The Self-Identity Roles for Designing Interventions model mentioned in chapter 2 stresses the importance of *knowing* the person with dementia – their likes, hobbies and previous jobs, in order to promote personhood and meet their psychosocial needs. This becomes especially important when working with residents with an unfamiliar cultural background, as needs are grounded in our evolutionary past and closely connected to a person's culture, meaning and past, as stated by Kitwood (1997b, p.19). Social isolation can be reduced by using interventions in the form of animal therapy like the dog-assisted intervention, encouraging the resident to perform household chores like setting the table, or by performing exercises that increase muscle strength and balance. These interventions, as discussed earlier, were linked to improved QOL in people with dementia in this study.

## **6.4 Limitations**

This review has limitations. Firstly, only studies written in English were included and many primary papers in other languages, that could have been pertinent in this review, were not regarded. Therefore, a publication bias must be acknowledged. Methodology shortcomings in some of the primary articles could have compromised the overall outcomes of this review. Three of the studies used cross-sectional data (Edvardsson et al., 2014; Smit et al., 2016;

Telenius et al., 2013) making it difficult to make any conclusions about causality. For example, the negligible improvements seen in the study by Smit et al. (2016) could have been noticeably larger had a different study design been used. This review sought to obtain the subjective perspective of the person with dementia, but due to the precise inclusion criteria only one qualitative study was eligible for analysis (Moyle et al., 2011). This is unfortunate given that research had shown that some people with dementia are able to communicate their feelings and identify the factors that can impact their quality of life (Moyle, Engedal, Røsvik & Kirkevold, 2017). This fact was further supported by Moyle et al. (2011) in this scoping review. A common thread through this scoping review was the importance of identity-promoting interventions. This is another reason it would have been preferable to include more studies that emphasized the subjective views of the person with dementia. Another weakness identified in this study was the missing subjective perspective of the person with dementia in measurement of the outcome measure. Six of the eleven reviewed studies used proxy ratings by staff to determine evaluate quality of life. Although the reliability and validity of proxy ratings has been established by earlier research (Ettema et al., 2007; Chua et al., 2016), most research supports self-rating of QOL as the gold standard (Crespo et al., 2012; Logsdon et al., 2002; Kehyayan et al., 2015).

Despite these limitations, this review did have some strengths. This study enabled the inclusion of a wide range of psychosocial interventions that differed greatly in their degree of complexity but resulted ultimately in improved QOL. Another strength is that the study population appeared to be representative of care home residents in respect to age and gender. According to Engedal & Haugen (2018), approximately 90% of people with dementia are at least 65 years old. Given that the incidence of dementia is greatest among the female population, it is probable that a greater percentage of residents with dementia in care homes are women (Engedal & Haugen 2018). The percentage of women aged 71 years and older with Alzheimer's disease and dementia is 16%, compared to 11% of men (Alzheimer's and Dementia, 2016). As discussed earlier, care staff are less likely to involve people with advanced dementia in activities, therefore, it was important to assess the QOL of people with dementia in the varying phases of the disease. This review managed to do that by including studies that enrolled participants with mild-moderate dementia, moderate-severe dementia, and mild-moderate-severe dementia. The quality of the study was accounted for by critically appraising all the articles using the framework developed by Caldwell et al., (2011). The total scores ranged from 28/36 (Chu, 2018) to 33/36 (Ballard et al., 2018) indicating acceptable

quality of the primary papers and an insignificant amount of bias among the studies. The studies included in this review were conducted in the UK, the USA, Netherlands, Sweden, Australian, North Wales, Tokyo and Norway. These countries have a political and cultural structure like Norway, making the generalization of findings possible. There was good representation of countries in this study, implying that several countries recognize the importance of assessing QOL for people with dementia in care homes. This implies that QOL for people in care homes is an important global issue, with many countries trying to find solutions on how to incorporate psychosocial interventions into the lives of people with dementia in care homes.

## 7 Conclusion

This review shows that the use of psychosocial interventions in care homes is linked to improved quality of life for people with dementia. This link is based on sound research as evidenced by the quality of research evidence. Findings from this review have clearly shown that psychosocial interventions are composed of a wide range of interventions, all of which have the potential to improve the quality of life for people with dementia living in care homes. The psychosocial interventions involved in the reviewed studies vary widely; from simple chores like making coffee and talking to a dog (Edvardsson et al., 2014; Kårefjaard et al., 2018), to more demanding tasks like 30s sit-to-stand tests, chair crunches and dancing (Smit et al., 2016; Telenius et al., 2013). Nonetheless, all interventions resulted in improved QOL suggesting that involving the person with dementia in any kind of activity is better than not engaging them at all. Results from this study highlight that small and unpretentious tasks like cooking coffee and watering plants are psychosocial interventions that can improve the QOL for the elderly in care homes. However, they are often overlooked by care staff. This study shows that psychosocial interventions do not need to be complicated, labor intensive or time consuming. A Norwegian study conducted by Bratt & Gautun (2015) in 2014 found that understaffing in care homes was common, and discrepancies were found between planned staffing and the actual number of staff on the unit. As a care home nurse, I know the lack of staff is still a problem, therefore, the benefits of promoting the use of “simpler” psychosocial interventions in care homes are obvious. Assisting residents with dementia to take over as much of their own self-care as possible, as well as assisting them to perform simple duties and nursing tasks not only improves the quality of life for the residents, it can also “free” care staff to perform more complicated duties. Other interventions investigated in this review like reminiscence therapy, life story books and cognitive stimulation therapy improved residents’ QOL and can be easily implemented in Norwegian care homes, at no extra cost or organizational restructuring.

This review shows that insufficient care staff knowledge and misconceptions about dementia are major contributing factors in the suboptimal use of psychosocial interventions in care homes. This study emphasizes the need for staff education and the need to rethink the delivery of nursing care, as the successful implementation of psychosocial interventions is dependent on this (Edvardsson et al., 2014).

In conclusion, it is apparent from this scoping review that psychosocial interventions that put the person with dementia in the center have the most significant impact on the quality of life for the resident. It does, however, require nursing staff to be more creative and reconsider current nursing practices. Kitwood (1997b p. 20) pointed out that fulfilling the psychosocial needs of people with dementia “requires a great deal of skill and imagination”. Therefore, a lack of imagination could be the only limiting factor in the use of psychosocial interventions in care homes. Kitwood (1997b) stated that fulfilling one of the five major psychosocial needs of a person with dementia could result in the satisfaction of the other needs as well. Findings from this review suggest that the psychosocial interventions used can improve quality of life for care home residents by *including* them in activities, enhancing feelings of *comfort* and *attachment*, keeping them *occupied* and maintaining their *identity*.

## **7.1 Implications for future practice**

Results from this review reveal that care staff lack general knowledge about dementia and the needs of the person with dementia. Care staff were often unsure about how to incorporate psychosocial interventions into everyday nursing care (Edvardsson et al., 2014; Henskens et al., 2018) resulting in little or no activity for the residents. However, added knowledge was welcomed by the care staff (Ballard et al., 2018; Yamanaka et al., 2013). This indicates that future research should focus on how organizations can educate care staff on the importance of promoting and maintaining personhood by implementation of various psychosocial interventions. Most the studies in this review had a small sample size, making the generalization of results difficult. Studies in the future should aim for a larger population. This however, might be challenging given the vulnerable health status of the elderly with dementia in care homes (Engedal & Haugen, 2018). Lastly, the rise in transnational migration calls for studies that investigate the subjective psychological experience of immigrant residents with dementia in care homes.



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# Appendix 1. Example of framework and guideline from Caldwell et al., (2011). From Bettany-Saltikov, 2012, p. 88

## SELECTING, APPRAISING AND EXTRACTING DATA 93

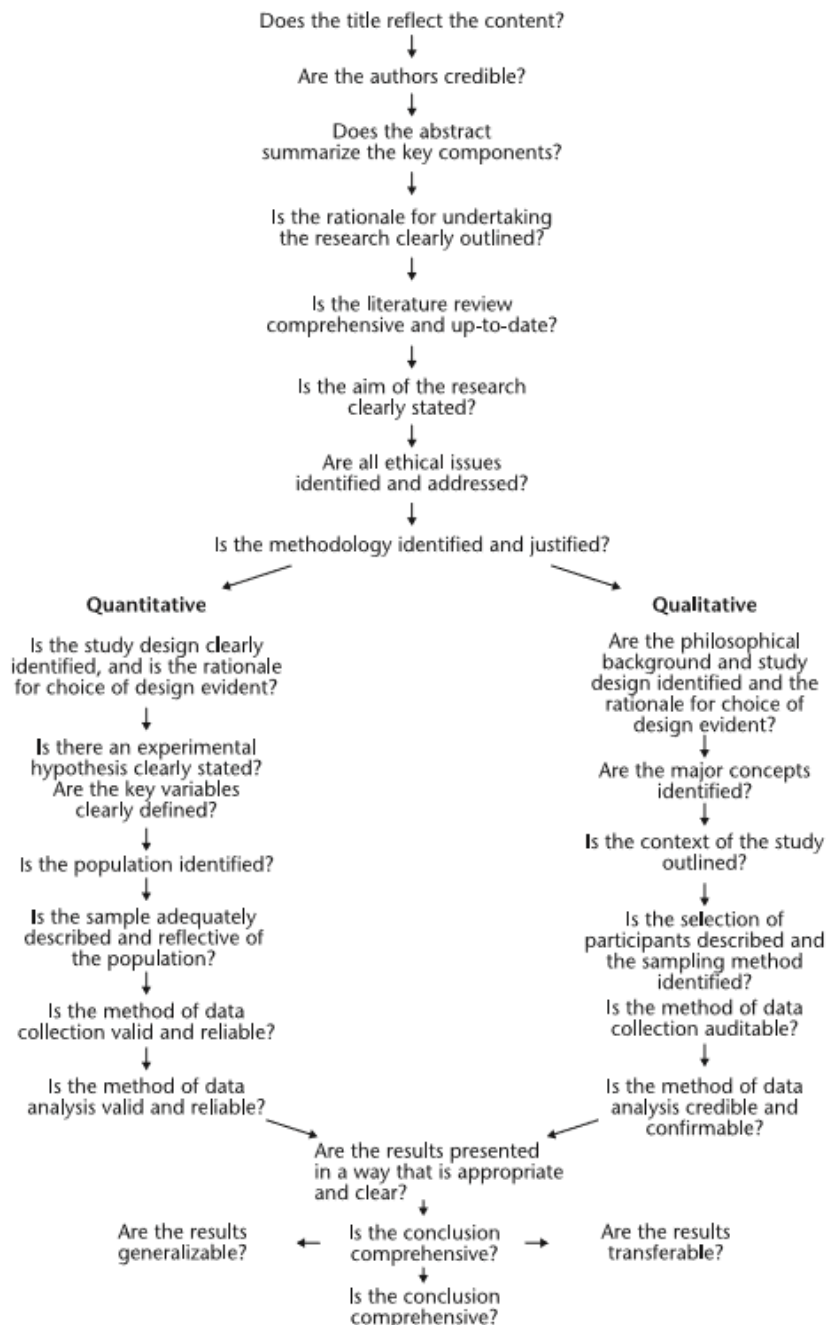


Figure 6.1 Framework and guidelines by Caldwell et al. (2011).

Source: Reprinted from Caldwell, K., Henshaw, L. and Taylor, G. (2011) Developing a framework for critiquing health research: An early evaluation. *Nurse Education Today* 21 (8): e1-7, with permission from Elsevier.

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## Appendix 2 Example of the critical appraisal of an article using the framework by Caldwell et al. (2011)

	Score
<p><b>Article</b></p> <p>Cho, H. K. (2018). The Effects of Music Therapy-Singing Group on Quality of Life and Affect of Persons With Dementia: A Randomized Controlled Trial</p>	
<p><b>Does the title reflect the content?</b></p> <p>Partly. The title is informative and states the population, the intervention used, the research design used, and the desired outcomes. However, it is not clear from the title if the population was people with dementia living in the community or in care homes. In addition, the comparative intervention(s) is not mentioned.</p>	2
<p><b>Are the authors credible</b></p> <p>Partly. There is no mention of the author's academic qualifications or professional title. There are two addresses provided; one from where the study was conducted and another from the Department of Music Therapy, Temple University. There is no mention of what the author's position is within this department. The credibility of the author could be favorably argued for as the article was submitted to Geriatric Medicine, which is a section in the Frontiers in Medicine journal. However, this is just speculation.</p>	1
<p><b>Does the abstract summarize the key components?</b></p> <p>Yes. The abstract is well detailed and mentions the aims and relevance of the study. The methodology, including results are clearly mentioned. The abstract mentioned all the inclusion criteria and it was clear this article was relevant for this study.</p>	2
<p><b>Is the rationale for undertaking the research clearly outlined?</b></p> <p>Partly. The author mentions that music therapy and singing has been widely used as therapeutic interventions when working with people with dementia and existing</p>	1

<p>literature supports this. Fewer studies have investigated the relationship between the effects of singing with those of listening. The author further states that there is a gap in knowledge about possible differences that can arise from using a music professional as opposed to professional caregivers, and this warrants further investigation.</p>	
<p><b>Is the literature review comprehensive and up to date?</b></p> <p>The current state of knowledge is well stated and previous studies in this area are mentioned. However, many of the articles used in this study are over 15 years old. This is surprising as the author has previously mentioned that music interventions and music therapy are widely used in long-term care facilities and the literature is not lacking. It would have been preferable if the author had found literature that was up-to-date</p>	<b>1</b>
<p><b>Is the aim of the study clearly stated?</b></p> <p>Yes. The purpose of the study is clearly stated both in the abstract and the introduction section</p>	<b>2</b>
<p><b>Are all the ethical issues identified and addressed?</b></p> <p>Yes. The study was reviewed and approved by Temple University's Institutional Review Board (IRB). Invitation letters, explanations of the study and consent forms were obtained from the participants or legal custodian</p>	<b>2</b>
<p><b>Is the methodology identified and addressed?</b></p> <p>Partly. The study was a randomized controlled trial, but the rationale is lacking. The key variables (music medicine-listening group and control-TV group) are clearly defined. The population was identified and the sample (n=37, gender, age and race specified) was adequately described. Procedure, intervention, outcome measures and training were identified and addressed. Results are presented appropriately and clearly.</p>	<b>2</b>
<p><b>Is the design clearly identified and a rationale provided?</b></p>	<b>1</b>



<p>Partly. The research design is a randomized control trial but no clear reason for this choice is stated</p>	
<p><b>Is there an experimental hypothesis clearly stated and are the key variables identified?</b></p> <p>Partly. No experimental hypothesis is mentioned, but the aim of the study including variable are well stated. The key variables were a music medicine-listening group and a control-TV group</p>	<p><b>1</b></p>
<p><b>Is the population identified?</b></p> <p>Yes. The population consisted of 37 residents with dementia from a Veteran’s Home in upstate New York, aged between 65 and 100 years, with no significant hearing impairments, and able to sit in a chair or wheelchair for a minimum of 1 hour.</p>	<p><b>2</b></p>
<p><b>Is the sample adequately described and reflective of the population?</b></p> <p>Partly. The method of sampling was clearly described, but the sample (n=37) was not large enough to eliminate bias. The author mentions age and vulnerable state as possible reasons. Although both genders were represented in the study, males dominated significantly. 52 residents agreed to participate, and of these 43 were men.</p>	<p><b>1</b></p>
<p><b>Is the method of data collection valid and reliable?</b></p> <p>Yes. Data was collected by specially trained staff at the beginning of the session and at the end, and additional training was given on how to use the measurement tools QOL-AD and PANAS.</p>	<p><b>2</b></p>
<p><b>Is the method of data analysis valid and reliable?</b></p> <p>Partly. Data was analyzed using the Statistical Package for the Social Sciences (SPSS) version 22.0 and a repeated-measures analysis of variance (ANOVA). Positive and negative affect was analyzed separately using the PASNAS Questionnaire. The QOL-AD was used analyze QOL. As mentioned earlier, this</p>	<p><b>1</b></p>

self-reporting questions the accuracy and validity of these results. This could have been avoided by considering the views of the professional caregiver by using the proxy assessment of the QOL-AD instrument.	
<b>Are the results presented in a way that is appropriate and clear?</b>  Yes. The author utilized charts, tables and graphs to present the results.	<b>2</b>
<b>Is the discussion comprehensive?</b>  Yes. The discussion was thorough and engaging and included strengths and weakness of the study	<b>2</b>
<b>Is the conclusion comprehensive?</b>  Yes. The conclusion, albeit short, answered the research question and suggested possible areas for future research. The author did not summarize the main findings of the study in this section, but these were mentioned earlier in the discussion section, together with limitations of the study, and implications for clinical practice and future research	<b>2</b>
<b>Are the results generalizable?</b>  Partly. Although the sample size is small and somewhat homogenous in terms of demographics, this sample is largely indicative of the general population in care homes. This study was conducted in upstate New York and results are possibly generalizable to many countries in Europe, including Norway. Secondly, use of the QOL-AD raises concerns about accuracy and validity, as discussed earlier.	<b>1</b>
<b>TOTAL</b>	<b>28/36</b>