# OF PEOPLE WITH MAJOR NEUROCOGNITIVE DISORDER (DEMENTIA) IN RESIDENTIAL LONG-TERM CARE: A SYSTEMATIC REVIEW

## Submitted by

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A research project submitted in partial fulfilment of the requirements for the degree of Master of Nursing

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## **ACKNOWLEDGEMENTS**

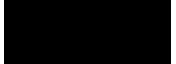
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#### **DECLARATION**

I, Kyoung Mi Cho hereby declare that the work presented in this thesis for a Master of Nursing degree has not been presented either wholly or in part, for any other degree and is not being currently submitted for any other degree. To the best of my knowledge, the thesis contains no material previously published or written by any other person, except where due reference is made in the text of the thesis.



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#### **ABSTRACT**

**Background:** Dementia is a syndrome that indicates progressive decline in a person's cognition and functioning. The goal of dementia care needs to focus on living well with dementia, which can be measured through assessing quality of life as there is currently no cure for dementia.

**Objectives:** The aim of this systematic review was to identify which interventions had the best outcomes to improve the quality of life of people with dementia living in residential long-term care facilities.

Method: Studies that examined effects of interventions on quality of life of residents with dementia in long-term care were explored. Studies with outcomes of interventions measured using valid quality of life measurement instruments were considered eligible for this review. Published and unpublished literature from 1995 to 2014 in English was searched through electronic databases. The methodological quality of eligible studies was assessed and data of included studies were extracted by two independent reviewers using the Joanna Briggs Institute instruments. All findings were summarised in narrative form. Where the data of comparable studies lacked statistical difference, statistical pooling was used for meta-analysis with the software developed by the Joanna Briggs Institute.

**Result:** After a comprehensive search throughout relevant databases and quality appraisal of eligible studies, 19 studies were identified for this review. Interventions were categorised into six types according to features of interventions: reminiscence, staff training, cognitive stimulation therapy, physical exercise, pharmacology-related treatment, and other interventions. The data from studies with respect to reminiscence,

staff training and cognitive stimulation therapy were pooled for meta-analysis, but the pooled results did not show significant effects of intervention of interest.

Conclusion: The review showed that reminiscence, staff training, physical exercise, cognitive stimulation therapy, music, companion-robot, and aromatherapy may have benefit in improving the QOL or wellbeing of people with dementia in residential long-term care, however, the evidence is of low to moderate grade. Recommendations include further research in this field and a person-centred approach to interventions and monitoring of quality of life of people in residential long-term care.

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#### **GLOSSARY**

Dementia: A syndrome of progressive cognitive and functional deterioration which is incurable and irreversible (Alzheimer's Association, 2013)

Major Neurocognitive disorder: The category of dementia in the fourth edition of
Diagnostic and Statistical Manual of Mental Disorders (DSM-4) has been
replaced with the category of 'major neurocognitive disorder' in the fifth
edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5)
released by the American Psychiatric Association (Alzheimer's Association,
2013)

Quality of life: "An individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, and standards and concerns" (World Health Organization Quality of Life Group, 1995, p. 1405)

Residential long term care: Residential facilities where dependent clients reside in a substitute surrounding permanently or during a long-term period, and are given shelter and long-term care (Van Malderen, Mets, & Gorus, 2012)

#### **ABBREVIATIONS**

AD-RQL - Alzheimer's Disease-Related Quality of Life

BCCs - Behaviour Category Codes

CST - Cognitive Stimulation Therapy

DCM - Dementia Care Mapping

DQOL - Dementia Quality of Life

EQ-5D - Euro Quality of Life-Five Dimensions

JBI - Joanna Briggs Institute

LTC - Long-Term Care

MAStARI - Meta-Analysis of Statistics Assessment and Review Instrument

MMSE - Mini Mental Sate Examination

MOHW - Ministry of Health and Welfare in South Korea

N/A - Not Applicable

OAS - Observed Affect Scale

PGCMS - Philadelphia Geriatric Center Morale Scale

QOL - Quality of Life

QOL-AD - Quality of Life - Alzheimer Disease

QUALID - Quality of Life in Late-Stage Dementia

RCT - Randomised Controlled Trial

SD - Standard Deviation

SE - Standard Error

SMD - Standardised Mean Difference

SRQoL - Self-Report Quality of Life Scale

UK - United Kingdom

USA - United States of America

WHO - World Health Organization

WIB - Well and Ill-Being

#### **CHAPTER 1: INTRODUCTION**

The main objective of this project was to determine the most effective intervention(s) for improving the quality of life (QOL) of people with dementia in residential long-term care (LTC). This study employed a systematic review method in order to synthesise the results that have been reported in various studies and thus lead to the evaluation of effectiveness of interventions. An overall delineation of this study in terms of objectives, methods of the systematic review, criteria for inclusion or exclusion of studies, and approaches of data extraction and synthesis has been shown in the protocol of this study (Appendix I), which has been peer reviewed and for publication in the Joanne Briggs Library.

In this chapter the position of the author, background about current issues related to dementia, and purpose of this study are explained.

## 1.1 Positioning of the Author

Recently, the South Korean Government established a Dementia Management Act consistent with increasing awareness of the importance of treatment, care, research and policy associated with Dementia. Currently, Korean people with dementia who need help for daily living receive LTC benefits under the LTC insurance system which is operated by the National Health Insurance Service, a single national insurer in South Korea (Kim & Choi, 2013). Roles of the National Health Insurance Service in LTC insurance scheme include setting and imposing contributions, managing finances, assessing potential beneficiaries, assuring and improving care quality, and evaluating and auditing LTC facilities (Chon, 2012).

As a manager working for the National Health Insurance Service, which has

continuously endeavoured to ensure and improve quality of LTC, the author has recognised the increasing need to improve the quality of dementia care and to diversify South Korean care services to make them person-centred and evidence-based (Cho & Ko, 2012). Accordingly, in order to explore and introduce feasible and effective interventions for people with dementia, this systematic review was conducted. Because of the author's work history, the background of this review is set in both an international context, and a local Korean context.

### 1.2 Background

Dementia is a group of symptoms that indicate progressive decline in a person's cognition and functioning (World Health Organization [WHO] & Alzheimer's Disease International [ADI], 2012). In the fifth edition of Diagnostic and Statistical Manual of Mental Disorders (DSM-5) released by the American Psychiatric Association (American Psychiatric Association, 2013) the category of 'dementia' has been replaced with the category of 'major neurocognitive disorder'. However, given that this current systematic review includes studies undertaken prior to this change; the term 'dementia' is used throughout this paper. In addition, although the incidence of reversible dementia has been reported, resulting from potential causes such as depression, delirium, abuse of alcohol, or side effects of medication (Alzheimer's Association, 2013; Clarfield, 1988, 2003; Tripathi & Vibha, 2009; Weytingh, Bossuyt, & van Crevel, 1995), the focus of this systematic review is on degenerative and irreversible dementia, which accounts for a larger proportion of dementia prevalence and is devastating for those who suffer it.

#### 1.2.1 The Incidence of Dementia in Korea and Internationally

Dementia is perceived as a major and growing health problem due to its increasing prevalence and impact on affected people and their families (Park, Eum, Bold, & Cheong, 2013; Terada et al., 2013; WHO & ADI, 2012). According to a WHO report (WHO & ADI, 2012) it was estimated that about 35.6 million people globally suffered from dementia in 2011 and the number of people worldwide with dementia is estimated to double every 20 years, increasing to 65.7 million by 2030 and to 115.4 million by 2050. Likewise, the proportion of people with dementia is also rapidly increasing in Korea. According to a report by the Korean Ministry of Health and Welfare [MOHW], 9.18% of the 5.8 million people are aged 65 and over in South Korea in 2012, with 1 out of 11 elders living with dementia (Cho & Ko, 2012; MOHW, 2013). The number of elderly with dementia is estimated to grow to more than 2.1 million in 2050, accounting for 13.2% of an estimated 16.1 million elderly people (MOHW, 2009). Dementia is an illness that threatens the QOL and autonomy of affected people, and no one is assured that dementia will not be diagnosed in one's later stages of life.

#### 1.2.2 The Cost of Dementia

Alzheimer's Disease International (2010) anticipated that the worldwide cost of dementia care was around US\$ 604 billion, corresponding with about 1% of global gross domestic product (GDP), highlighting that dementia has a huge impact on the global socioeconomic state. The increasing number of people with dementia also has a great impact on patients' families and the community in terms of financial and psychological aspects. According to a study conducted by the Alzheimer's Association (2013), in the United States of America (USA), approximately 17.5 billion hours are spent providing affected people with care by over 15 million unpaid caregivers, which was appraised at

over \$ 216 billion. It also reported that Medicare expenditures for beneficiaries aged 65 years and over with dementia are 3 times greater than expenditure for beneficiaries without dementia, and that Medicaid expenditures are 19 times greater in 2013.

In South Korea, the total socioeconomic cost of dementia was estimated to range from US\$ 3 billion to US\$ 7 billion in 2004, accounting for 0.446 to 1.040% of gross domestic product, valued at US\$ 673.1 billion (Kim et al., 2009). The socioeconomic burden of dementia care is expected to rise together with the increase in the elderly population with dementia. Furthermore, many studies show that caring for people with dementia may be demanding and contribute to depression and anxiety amongst carers, potentially leading to a lower QOL (Joling et al., 2012; Kim & Min, 2006; MOHW, 2009).

#### 1.2.3 Prognosis of Dementia

There is no known cure for dementia and no known methods to slow the development of this illness (WHO, 2014). The symptoms of dementia can be diverse and depend on subtypes of dementia such as Alzheimer's disease or vascular dementia (ADI, 2013). As dementia advances, it causes irreversible cognitive loss that leads to the impairment of daily functioning and eventual death for an individual affected (Murray & Boyd, 2009). Dementia is devastating for affected people as it develops, and can also be overwhelming for families who take care of people with dementia. Compared to other chronic diseases, dementia makes those affected increasingly more dependent on others for help with activities of daily living, due to eroding mental abilities and later somatic functions (Murray & Boyd, 2009; Nygaard & Ruths, 2003).

#### 1.2.4 Barriers to Diagnosing Dementia

Diagnosing dementia is also challenging due to the varied characteristics of dementia. A systematic review by Koch and Iliffe (2010) determined several hindrances regarding the delay of diagnosis and management for people with dementia in primary care, which are categorised into three factors; patient or societal factors, doctor factors and system factors. For instance, the former can be caused by negative recognition about dementia as a shameful and stigmatised illness, contributing to social isolation and avoidance, which can lead to a delay in receiving a proper diagnosis and support at an appropriate time (Koch & Iliffe, 2010). The authors also stated that patients and carers did not recognise the symptoms of dementia or regarded the symptoms as a normal part of ageing. Doctor factors can be due to insufficient knowledge or experience (Koch & Iliffe, 2010). Lastly, systemic factors delaying the diagnosis of dementia include barriers such as the lack of a decisive diagnostic testing, financial and time limitations for medical staff and caregivers (Koch & Iliffe, 2010). These barriers appear to contribute to inappropriate care provision for and treatment for affected people. Likewise, South Koreans with dementia tend to be improperly treated, as there is a general unawareness of the public and communities toward dementia (Cho & Ko, 2012). Koreans tend to regard dementia as a process of normal ageing, and this may be the main challenge impacting upon the detection and treatment of dementia in Korea.

Acknowledging that dementia tends to be delayed in diagnosis and recognition of its incidence (Australian Institute of Health and Welfare [AIHW], 2012), it is expected that the real size of the population of people with dementia is much larger (Cho & Ko, 2012) with those yet to be properly diagnosed being improperly managed.

#### 1.2.5 The Management of Dementia

The goal of dementia care focuses on 'living well with dementia', which can be maintained through QOL (ADI, 2013; Logsdon, McCurry, & Teri, 2007). Although various new treatments are being examined in clinical trials, and there is currently no cure for dementia, treatment is aimed at supporting and improving the lives of people with dementia and their families (WHO & ADI, 2012). This means that the interventions and treatment for people with dementia should aim to improve their QOL, and can be monitored and measured. Furthermore, along with growing interest in how care affects patients as distinct from how care is delivered (Hubbard, Downs, & Tester, 2003), there is a movement toward assuring quality and monitoring outcomes of care in LTC and dementia research, through QOL and its assessment (ADI, 2013; Moyle et al., 2011; Sheard, 2011; Sloane et al., 2005; Smith, 2008). This shift appears to have resulted from insight about the ultimate goal of dementia care in LTC settings.

Moreover, the QOL of people with dementia in residential LTC needs to be a priority (Edelman, Fulton, Kuhn, & Chang, 2005). This is because people with dementia are unlikely to have their QOL and autonomy assured due to their declining cognitive abilities such as recall and thinking. They are perceived as vulnerable to abuse and neglect (Murray & Boyd, 2009; National Collaborating Centre for Mental Health UK, 2007) and those with dementia in residential LTC facilities are likely to experience a reduced QOL (Kane, 2001; Robichaud, Durand, Bedard, & Ouellet, 2006). A study conducted in 2000 in the USA identified the effects of three different types of housing on QOL of older people. It showed that residents in nursing homes constantly reported the lowest QOL compared to people living in specialised housing and personal dwellings. Therefore,

assuring and improving QOL of people with dementia in residential LTC is essential (Crist, 2000).

#### 1.2.6 Public Policy in Korea related to Care of People with Dementia

In Korean society the value of filial piety has been influential over the centuries (Chon, 2012) with children expected to care for their dependent parents by themselves in their own home (Kim, 2009). However, recently, the capability of family members to care for the affected person has decreased as socio-cultural changes, such as family nuclearisation, a hectic modern lifestyle and employment obligations have led to a considerable reduction in the number of family carers for elderly parents (Kong, Cho, & Song, 2009). These societal changes have resulted in the need for managing dementia with a nationally systematic approach.

To deal with this challenge, the South Korean government has developed the LTC insurance (LTCI) scheme, which exercises filial duty in a social context (Lee, 2013). Since 2008, the LTC Insurance Act was executed to care for the elderly who need help for the daily activities of living, including people with dementia. LTCI services are financed by public funding, taxes, and recipient payments (Kim & Choi, 2013). LTCI services consist of in-kind and cash benefits, but cash benefits are very limited to extraordinary cases in which, for example, formal services are not available in remote regions (Kim & Choi, 2013). In-kind benefits are provided to people, mainly the elderly, who are rated grade I, II or III based on the extent of their dependency and the need for help according to the assessment system of the LTCI law. These include home-care services and residential facility care. Home-care services are perceived as more desirable than using residential facilities and are encouraged to be used as those, who need help for daily living, can maintain relationships with their families (Kim & Choi, 2013; Korean Government, 2011).

However, as symptoms of dementia become increasingly complicated and severe, affected people are likely to be more dependent, overwhelming family care capabilities, and eventually require admission to residential LTC facilities (ADI, 2013; Organisation for Economic Co-operation and Development [OECD], 2005).

#### 1.3 Statement of the Problem

In residential LTC facilities, a higher proportion of residents are expected to have dementia. The estimated dementia proportion varies among studies, from 40% to 80% (Alzheimer's Association, 2013; ADI, 2013; AIHW, 2012; Bernstein & Remsburg, 2007; Möhler, Renom, Renom, & Meyer, 2012; Nygaard & Ruths, 2003). For those with dementia, indications are that they have a lower QOL than those without dementia (Cooper, Bebbington, Katona, & Livingston, 2009). In South Korea, family caregivers want diverse and professional services for dementia care (MHW, 2009) and several reports and studies have suggested that the dementia care services should be enhanced in current Korean LTC settings, pointing out the lack of dementia-specific care delivery (Cho & Ko, 2012; Han, Lee, Cho, & Kim, 2012; Lee, Park, Han, & Seo, 2012).

## 1.4 Purpose of this Systematic Review

In spite of increasing literature regarding interventions and/or QOL for people with dementia, there has been no widely accepted position about the effectiveness of interventions on QOL of *people with dementia in residential LTC*. Previously conducted reviews focused on people with dementia in comprehensive settings including individual homes or day care centres (Cooper et al., 2012; Cooper et al., 2013) or residents of LTC facilities who may or may not have dementia (Van Malderen et al., 2012). The objective

of this systematic review is to identify which interventions have the best outcomes to improve QOL or wellbeing of people with dementia in residential LTC.

The results of this study will equip healthcare providers with valuable information to aid decision-making concerning the application and improvement of practical interventions consistent with their resources, competencies and residents' needs.

Furthermore, the results of this review may be used to develop guidelines regarding interventions to improve QOL in residential LTC facilities.

#### **CHAPTER 2: LITERATURE REVIEW**

The purpose of this literature review is to introduce and define related terms and to clarify the terms being used in the context of this systematic review (Ridley, 2012). In particular, the theories and notions relevant to QOL which underpin this systematic review are mainly discussed and explored. Studies which were associated with interventions aimed at improving the QOL of people with dementia or of residents in LTC are discussed, thus underlining the significance of QOL-focused interventions.

#### 2.1 Long-Term Care

Until now there has been no worldwide standard for 'long-term care' (OECD, 2005), and no explicit definition on 'long-term' (ADI, 2013). LTC includes health and social care services such as long-term nursing care, supporting basic or instrumental activities of daily living, palliative care, care delivered in residential care or assisted living facilities (ADI, 2013). LTC services could be provided to all age groups of people with long-term physical or psychological infirmities, who need other's support for basic activities of daily living, but elderly are expected to be the main users (OECD, 2005).

## 2.2 Residential Long-Term Care

Residential LTC facilities are described differently in different countries (Van Malderen et al., 2012). For example, the term 'residential aged care' is used in Australia (Chenoweth & Jeon, 2007), 'care homes' in the UK (Subramaniam, Woods, & Whitaker, 2014), 'long-stay units' in Ireland (O'Shea et al., 2014), and 'nursing home' in the USA, Argentina and Hong Kong (Azcurra, 2012; Chibnall, Tait, Harman, & Luebbert, 2005; Lai, Chi, & Kayser-Jones, 2004). In this systematic review, residential LTC is considered a residential facility where dependent clients reside in a substitute surrounding

permanently or for a long period, and are given shelter and LTC (Van Malderen et al., 2012).

There is significant international literature to indicate that health and social care for older people is primarily medically oriented and the quality of care is evaluated using health-related outcome measures (Kane, 2003; Vaarama, Pieper, & Sixsmith, 2007). This reflects a traditional medical approach focused on aetiology, mechanisms of disease, symptoms and clinical results (Dugan et al., 1998). In addition, many researchers have recognised that good care can be delivered to residents without affecting the resident's wellbeing (Forder & Caiels, 2011; Kane, 2001; Sloane et al., 2005). Thus the resident's own experience and perspective, and therefore, their QOL should be considered (Kane, 2003). In accordance with this awareness, QOL is receiving increasing attention as a medical outcome measure for the growing number of the elderly living with chronic health problems including dementia in residential LTC (Hoe, Hancock, Livingston, & Orrell, 2006; Kane, 2003; Kane et al., 2003; Sloane et al., 2005; Van Malderen et al., 2012)

## 2.3 Quality of Life

Although concern regarding QOL has a long history, it was not until the 1960s that QOL research appeared in sociology with diverse labels including satisfaction and wellbeing (Bowling, 2001; Schuessler & Fisher, 1985). Publications on QOL can be found in diverse disciplines but still the definition of QOL is not consistent. Different interests and perspectives lead to different approaches to QOL (Logsdon, Gibbons, McCurry, & Teri, 2002) across a range of areas such as philosophy, sociology, psychology, medical science, health economics, and political science (Bowling, 2001; Hyde, Wiggins, Higgs, & Blane,

2003; Schuessler & Fisher, 1985). This reflects a broad and multidimensional understanding of QOL (Jonker, Gerritsen, Bosboom, & Van der Steen, 2004).

Quality of life represents the description as well as the evaluation of one's QOL (Hyde et al., 2003; Schuessler & Fisher, 1985; Vaarama et al., 2007). QOL researchers have tried to develop indicators that can quantify what is generally accepted to comprise QOL and to evaluate whether the indicators are valid and reliable to measure QOL in various contexts (Møller & Huschka, 2008).

#### 2.3.1 Broader Quality of Life

There is a plethora of definitions of QOL. Until recently, there has been a lack of agreement concerning the definition of QOL and compositions of it (Moyle, Venturto, et al., 2011), but, some agreement is that QOL is multidimensional and may mean more than the sum of compositions of QOL (Burgener & Twigg, 2002).

It is generally agreed that a broad assessment of QOL consists of both objective and subjective domains (Bowling, 2001; Brod, Stewart, Sands, & Walton, 1999; Schuessler & Fisher, 1985). In social science, indicators of objective domains include physical environment such as income and housing while subjective indicators include feelings such as satisfaction or happiness (Bowling, 2001; Schuessler & Fisher, 1985). The WHO (1995, p. 1405) defined QOL as "an individual's perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, and standards and concerns". The concept of QOL is affected by various factors such as physical health, psychological state, a level of independence, social relationships, spirituality and environment (Min et al., 2002). Based on WHO's definition,

QOL is multifaceted and dynamic, and an individual's QOL may change along with one's life experiences as perception and value may change over time.

#### 2.3.2 Health-Related QOL

Health-related QOL seems to be often unclearly described in research studies (Bowling, 2001) and yet health-related QOL as an outcome measure has become significant in measuring the impact of chronic illness (Hoe, 2006) and outcomes of treatment (Ok, 2012). Disease-specific QOL as a term, is often used in the literature and it seems similar to health-related QOL, but more concerned about a specific disease or specific therapy (Jonker et al., 2004; Sloane et al., 2005). The notional framework of health-related QOL rests on a broad and multifaceted viewpoint of health, which reflects the WHO's perspective of health as a "state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" (WHO, 1948, as cited in Bowling, 2001, p. 6). Interestingly, this definition of health appears to be similar to the concept of QOL in terms of multifaceted features including physical and mental wellbeing, social functioning and overall wellbeing.

This multidimensional aspect of health and QOL appears to lead to conceptual confusion in health-related research (Bowling, 2001). Measuring broader health status seems to be increasingly regarded as assessing QOL. Many researchers have used measures of comprehensive health status to evaluate health-related QOL (Bowling, 2005; Bruyere et al., 2005; Jonker et al., 2004; Teri et al., 2003). For example, the abbreviation of 36-item Short Form Health Survey (SF-36) was originally developed to measure the broader notion of health status associated with physical, emotional, and social wellbeing amongst a generic adult population (Meng, King-Kallimanis, Gum, & Wamsley, 2013).

Now SF-36 appears generally accepted for measuring health-related QOL in the nursing field (Ok, 2012).

Although there is no consistently established definition of health-related QOL (Bowling, 2005; Kane, 2003), generally agreed domains of health-related QOL in adults include "physical health and functioning, emotional health, cognitive functioning, role performance and work productivity, sexual functioning, and life satisfaction and emotional health, physical and cognitive functioning" (Kane, 2003, p. 30). Health-related QOL to some extent differs from broader QOL which also includes adequacy of housing, revenue, and perspective of immediate surroundings (Bowling, 2001). The concept of health-related QOL restricts the general notion of QOL to aspects of QOL that are affected by diseases, the patient's condition or healthcare interventions (Bowling, 2001; Kane, 2003; Sloane et al., 2005).

## 2.4 Quality of Life in Dementia

The improvement and assessment of QOL in dementia has gained increasing attention in the context of ageing populations, person-centred approaches, and the administrative concern of reducing public expenditure (Sloane et al., 2005; Vaarama et al., 2007). Although definitions of QOL are diverse, Lawton's (1994) model has been the most prevalent and influential conceptualisation of QOL in dementia (Jonker et al., 2004; Moyle, Gracia, Murfield, Griffiths, & Venturato, 2011). Lawton (1994) explained that QOL is composed by four sectors which are overlapped: (1) psychological wellbeing, including individual's positive and negative affects (2) perceived QOL, the individual's own evaluation of one's environment (3) behavioural competence, including activities of daily living, cognitive performance, and social behaviour; and (4) the environment, including

physical environment and architectural structures. Each sector is interlinked to other sectors and it is regarded as essential to the notion of QOL. Accordingly, understanding the QOL of an individual with dementia may require integrated evaluations regarding subjective and objective aspects and their interactions.

#### 2.4.1 Quality of Life of People with Dementia in Long-Term Care

Recent research in the area of dementia in LTC has clearly presented that QOL is an important and meaningful outcome indicator of care (Beerens, Zwakhalen, Verbeek, Ruwaard, & Hamers, 2013; Clare et al., 2013; Edelman et al., 2005; Sloane et al., 2005). As LTC care services can significantly affect the QOL for residents with dementia living in LTC facilities who need support in everyday life, (Vaarama et al., 2007), assessment of QOL of people with dementia may have many advantages for affected people and staff (Edelman et al., 2005). Firstly, the action of asking about residents' QOL may help to clarify resident's perspectives on their own life and satisfaction with LTC services they receive (Vaarama et al., 2007). Additionally, LTC service providers may also identify the appropriateness or effectiveness of interventions they provide for residents through QOL assessment (Edelman et al., 2005).

#### 2.4.2 Factors of Quality of Life of People with Dementia in Long-Term Care

There are many factors related to QOL for people with dementia in residential LTC. They include emotional wellbeing (Jonker et al., 2004), mood (Hoe et al., 2006), individual characteristics, social support (Brod et al., 1999), physical environment, social dimension (Vaarama et al., 2007) and cognition and function (Chenoweth & Jeon, 2007; Cordner, Blass, Rabins, & Black, 2010; Edelman et al., 2005). A recently conducted systematic review, including 13 studies, investigating factors related to QOL of people with dementia

in LTC facilities, also supports the notion that QOL is affected by diverse factors such as socio-demographic features, symptoms of depression, anxiety, behavioural disturbance, the level of dependency, cognition, severity of dementia, and medication (Beerens et al., 2013). It seems that multiple domains of life do have a significant role in QOL of people with dementia, as in QOL of people without dementia (Jonker et al., 2004). Consequently, it is important to find interventions which impact QOL positively, together with consideration regarding most contributable factors or domains of QOL of an individual with dementia (Jonker et al., 2004). A small but effective change might lead to improvement in QOL.

#### 2.4.3 Dementia-Specific Quality of Life Measurement

The interest regarding QOL as an outcome measurement for people with dementia reflects the awareness that affected individuals can experience pleasure, a sense of achievement, and satisfaction through involvement in activities, despite their impairment (Vaarama et al., 2007). Dementia-specific QOL has been described as similar to health-related QOL but focuses more on dementia and its impact (Jonker et al., 2004; Sloane et al., 2005). Dementia-specific QOL instruments appear to distinguish more sensitively between the changes in people with dementia and to therefore more sensitively detect the outcome of a specific therapy. A plethora of dementia-specific QOL measures have been developed and found across a range of literature (Logsdon, Gibbons, McCurry, & Teri, 1999; Sloane et al., 2005). Most of them are valid, reliable and appropriate for measuring QOL of people with dementia. However, some literature appears to operationalise the meaning of QOL in accordance with the studies' purposes and use, such as, a behavioural symptom measure or a combination of several measures to measure QOL with non-standardised methods (Bowling, 2005; Duff & Nightingale, 2006;

Wong & Lantz, 2009). There is no gold standard of assessing of QOL in dementia (Cooke & Chaudhury, 2013; Lawton, 1997; Sloane et al., 2005), yet, it seems that subjective and objective aspects seems to need to be taken into account in assessing QOL in order to enhance understanding QOL (Lawton, 1997; Sloane et al., 2005).

However, there seems to lack agreement towards how the QOL of residents with dementia is assessed. As illustrated above, some scholars support the notion that QOL includes more diverse aspects including psychological, physical, environmental, and social factors, which are beyond a medical model (Vaarama et al., 2007). Others support that the QOL of people with dementia in LTC should be measured and conceptualised on the basis of residents' subjective evaluation of QOL (Beerens et al., 2013; Brod et al., 1999).

#### 2.4.4 Psychological Wellbeing Measurement

The term 'psychological wellbeing' has been used interchangeably with life satisfaction, morale, subjective wellbeing or QOL in many research studies (Conradsson, Littbrand, Lindelöf, Gustafson, & Rosendahl, 2010; Pinar & Oz, 2011). Although there are inconsistent perspectives regarding the individual's ability to respond and the reliability of the results in persons with cognitive impairment (Jonker et al., 2004; Logsdon et al., 1999; Moyle, Gracia, et al., 2011), there is an accord that individual experience should be centred in measures of QOL (Jonker et al., 2004; Pinar & Oz, 2011). Brod et al., (1999) maintain that the subjective perceptions are the real features of QOL and other aspects, such as surrounding, function, and social behaviour are elements of this subjective wellbeing (Sloane et al., 2005). It has been considered that psychological wellbeing of people with mild-to-moderate dementia can be assessed directly through an administered approach (Brod et al., 1999; Moyle, Gracia, Murfield, Griffiths, & Venturato,

2012). In many dementia studies, measuring psychological wellbeing is regarded as being equivalent to assessment of an individual's general QOL (Brod et al., 1999; Jonker et al., 2004; Wu, 2009).

#### 2.4.5 Methods of Measuring Quality of Life in Dementia

Traditionally, evaluation of wellbeing has been measured through self-report such as survey or interview (Perrin, 1997). However, as the cognitive ability of people with dementia changes as their illness progresses, other appropriate approaches are needed.

Aside from self-report approaches, QOL of people with dementia can also be measured by proxy-report by a family member of primary caregiver, or by direct observation (Logsdon et al., 2002). Findings by Edelman and associates (2005), showing different QOL in the three approaches, indicate that each approach is unique and independent to some degree and reflects different perspectives and factors (Clare et al., 2013), with both benefits and drawbacks.

#### Self-reported QOL

Self-report QOL measures include the evaluation of individuals with dementia in relation to their experience and life. Given the fact that subjective domains are mainly weighted in QOL in people with dementia (Brod et al., 1999; Conradsson et al., 2010; Moyle et al., 2012) and the principles of person-centred care (Spector & Orrell, 2006), the individuals with dementia themselves appear to be the best informers (Moyle, Gracia, et al., 2011; Spector & Orrell, 2006). Although it is often assumed that people with dementia are unable to report on their QOL due to cognitive and recall impairment, those in the early stage of dementia can often consistently express their own QOL (Brod et al., 1999; Jonker et al., 2004; Logsdon et al., 1999; Moyle, Gracia, et al., 2011). Even individuals with

severe dementia can consistently report their QOL to a degree (Moyle, Gracia, et al., 2011; Spector & Orrell, 2006; Thorgrimsen et al., 2003). Many studies have shown that self-report scales for QOL of people with mild to moderate dementia showed acceptable test-retest reliability ranging from 0.60 to 0.90, implying that people with dementia are able to deliver a subjective evaluation of their own QOL. (Brod et al., 1999; Jonker et al., 2004; Logsdon et al., 1999; Thorgrimsen et al., 2003).

Therefore, in dementia care and LTC settings, hearing the opinions of care recipients appears to be important to reflect and develop the care (O'Shea et al., 2014) that closely affects the QOL of residents. However, this is not always possible because self-reported measures can become challenges for people with severe dementia, including those with severe impairment of understanding, language and cognition (Moyle, Gracia, et al., 2011). These challenges have resulted in dementia-related studies, excluding the voice of people with dementia opting instead for proxy-rated QOL measures (Moyle, Gracia, et al., 2011).

#### **Proxy-reported QOL**

Proxy-reports are commonly obtained from a family member or primary caregiver of the individual with dementia (Logsdon et al., 2002). This approach can be used throughout the progression of the dementia illness, bypassing the problems of cognitive limitation on self-reported QOL.

However, proxy-reports can have biases as they may reflect the perspective or belief of proxies (Logsdon et al., 2002). A number of studies have shown that the evaluation of QOL between self-report and proxy-report are inconsistent (Logsdon et al., 1999; Logsdon et al., 2002; Spector & Orrell, 2006). For example, a study comparing the

QOL of residents with dementia and care staff in nine residential homes showed that increased hope in staff was correlated with higher resident QOL (Spector & Orrell, 2006). Yet another study by Logsdon (1999) reported that proxy ratings of QOL were lower than self-rated QOL by people with dementia. Proxy ratings may be affected by some individual factors of proxies such as expectation, belief systems, connection with the individual being rated, depression or stress (Logsdon et al., 2002; Spector & Orrell, 2006). Accordingly, it is significant to understand and recognise the biases of proxy-reported QOL when decisions are made about the extent of treatments or the effectiveness of interventions based on proxy rated QOL (Logsdon et al., 2002).

Furthermore, Spector and Orrell (2006) concluded that proxy rated QOL measures are an undesirable guide, based on their study result showing very poor correlations between self-reported QOL and proxy-rated QOL. The basis of their argument was only that the individuals with dementia are appropriate raters of their QOL. However, like Logsdon et al. 's (2002) explanation, there is no gold standard for QOL, and the dissimilarities between self-reported QOL and proxy-reported QOL are more likely to reveal existent differences in the way proxies observe the QOL of people with dementia rather than incorrectness of the proxy-ratings.

#### **Direct Observation**

The direct observation approach is used by trained raters. This approach is to directly observe behaviours which are regarded as being related to QOL of people with dementia (Logsdon et al., 2002). This can be a more objective QOL rating method as QOL related behaviours are predefined and thus consistency of rating can be maintained. Further, this may be the most appropriate alternative in severe dementia (Perrin, 1997).

The drawbacks of this method, however, include vagueness of whether observed behaviours truly show what the affected individual regards to be significant components of QOL (Logsdon et al., 2002; Perrin, 1997). This approach is also likely to have bias similar to that which occurs in proxy-rated QOL measures and to have variances between raters. Some raters may be sensitive to changes in behaviour while others may not (Logsdon et al., 2002). Therefore, when the direct observation approach is used, inter-rater reliability needs be considered (Cooke & Chaudhury, 2013; Logsdon et al., 2002).

#### 2.4.6 Quality of Life Measurement Instruments in Dementia

There are a number of QOL measurement instruments for people with dementia, which have been detected through the process of this systematic review. The most commonly used QOL measurement scales across dementia studies were QOL-AD, Dementia Care Mapping (DCM), AD-RQL, DQOL, PGCMS, QUALID, and Qualidem. They are described in terms of content, administration and scoring, and validity and reliability below.

#### Quality of Life - Alzheimer Disease (QOL-AD)

The QOL-AD is a questionnaire with two versions. One is a self-report measure and the other is a a caregiver proxy version to measure the QOL of the client with dementia (Logsdon et al., 1999). The QOL-AD self-report questionnaire is recommended for people with mild to moderate dementia (MMSE= 10 to 28) (Logsdon et al., 2002; Selai, Vaughan, Harvey, & Logsdon, 2001). It consists of 13 items including physical condition, mental health, relationships, money, and an overall QOL. Each item is rated as poor, fair, good, or excellent and uses simple language (Logsdon et al., 2002). Items are calculated and the sum of each score runs from 13 to 52, meaning that a higher score is a higher level of QOL.

Each version of the QOL-AD can be used separately, or both the scores from the self-report measure and the caregiver proxy-report can be pooled into an amalgamated QOL score with different weight.

The QOL-AD was developed based on Lawton's concepts of QOL in older people and reviews of people with dementia, caregivers and experts in the area of gerontology and geriatrics in the USA (Logsdon et al., 2002). The QOL-AD has a high internal reliability of patient and caregiver reports ( $\alpha$  = 0.88-0.89), and test-retest reliability (intra-class correlations are 0.76 in patient report and 0.92 in caregiver reports (Logsdon et al., 1999). Validity has correlated with levels of depression, functioning, activity, and cognition (Logsdon et al., 2002). Furthermore, the QOL-AD has been reported as a reliable and valid instrument in diverse countries including the UK, Brazil, France and China (Novelli, Nitrini, & Caramelli, 2010; Selai et al., 2001; Thorgrimsen et al., 2003; Wolak et al., 2009; Yu, He, Ai, Liang, & Zhou, 2013).

### Dementia Care Mapping (DCM)

The DCM tool comprises a measure of well and ill-being (WIB) and the behaviour category codes (BCCs) that assesses behaviours through an observational approach every 5 minutes in consecutive time frames (Kuhn, Ortigara, & Kasayka, 2000). The BCCs are composed of 24 domains such as direct social involvement, social withdrawal, eating and drinking, and personal care. The BCCs can be quantified and analysed regarding the frequency of the 24 BCCs and more diverse engaged activities of people with dementia are regarded as desirable (Chibnall et al., 2005; Kuhn et al., 2000). With each behaviour observed for each 5-minute frame, a numerical score is assigned to evaluate wellbeing (e.g. +1, +3, +5) and ill-being (e.g. -1, -3, -5). The WIB score is calculated by dividing the

sum of all scores assigned by the number of the observed time frames. Higher scores indicate a higher wellbeing status. DCM is reliable and valid for examining the QOL of a client with dementia and in people with dementia in residential LTC settings (Fossey, Lee, & Ballard, 2002). It requires mappers to be trained and qualified as inter-rater reliability of DCM can be affected by the skill of mappers. Thus it is important for mappers to achieve appropriate concordance coefficients for inter-rater reliability (i.e., greater than 0.8) before the DCM appraisals are commenced (Cooke & Chaudhury, 2013; Fossey et al., 2002).

Originally, DCM was developed based on the social-psychological theory of personhood in dementia in the UK, and aimed at providing a person-centred intervention (Cooke & Chaudhury, 2013; Kuhn et al., 2000; van de Ven et al., 2013). As it has developed, DCM has been used as a means of promoting quality of care, a tool for evaluating QOL and a research tool in various countries (Cooke & Chaudhury, 2013).

### Alzheimer's Disease-Related Quality of Life scale (AD-RQL)

Alzheimer's Disease-Related Quality of Life scale (AD-RQL) is a 47-item questionnaire rated by a family caregiver, which is administered by a qualified interviewer or researcher (Sloane et al., 2005). It consists of five domains which are social interaction, awareness of self, feeling and mood, enjoyment of activities, and response to one's surroundings. Each item is assigned with weighted score varying from 9.15 to 13.51. Then, the scores of all items are totalled and calculated to yield the final score. Higher scores mean better QOL. The AD-RQL was developed for evaluating health-related QOL in Alzheimer disease through the Delphi method of focus groups meetings involving family caregivers, expert panels, and health professionals in the USA (Rabins, Kasper, Kleinman,

Black, & Patrick, 1999). It has satisfactory reliability (internal consistency varies from 0.77 to 0.91), and content and convergent validity (Hoe, 2006).

### Dementia Quality of Life (DQOL)

The DQOL is a 29-item, self-report questionnaire administered by a researcher, which assesses subjective QOL (Brod et al., 1999). It has a single item rating general QOL and five domains including positive affect, negative affect, feelings of belonging, self-esteem, and sense of aesthetics. Each item is rated with 5-point scales to evaluate the QOL of people with dementia. Each domain has a mean score of constituent items and higher scores reflect better QOL status. The DQOL was developed based on a review of the literature and through focus groups involving family caregivers, healthcare professionals, and people with dementia in the USA (Hoe, 2006). The DQOL has been reported as a reliable instrument with internal consistency ranging from 0.62 to 0.89 and with test-retest ranging from 0.64 to 0.94 (Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Sloane et al., 2005). Convergent validity was supported by correlations with the geriatric depression scale (Hoe, 2006). This scale does not contain a proxy perspective of QOL of individuals with dementia.

### Philadelphia Geriatric Center Morale Scale (PGCMS)

The PGCMS was developed by Lawton and has been used for assessing morale, satisfaction, subjective or psychological wellbeing (Pinar & Oz, 2011). Lawton (1972) described that "high morale is a basic sense of satisfaction with oneself, a feeling that there is a place in the environment for oneself, and a certain acceptance of what cannot be changed" (p. 148). Morale is regarded as multidimensional and as equivalent to general wellbeing (Bowling, 2005; Lawton, 1975). This scale, including 17 items, is

perceived to be suitable for the elderly population in the community or in residential facilities, and for people with memory loss to complete it. The scale does not also cause respondent tiredness (Bowling, 2005; Conradsson et al., 2010; Pinar & Oz, 2011). The 17-item scale, which is self-reported and can be administered by a researcher, comprises three subsets that are agitation (six items), attitude toward own ageing (five items) and lonely-dissatisfaction (six items) (Lawton, 1975). Most items are rated dichotomously. The total score ranges from 0 to 17. Higher scores indicate greater morale, that is, higher level of QOL. The scale has been reported to have acceptable reliability (internal consistency: 0.8, test-retest reliability: 0.75 – 0.91) and discriminant validity supported by correlation with satisfaction regarding interaction with others. It is generally perceived to be superior in measuring morale and life satisfaction (Bowling, 2005).

#### Ouality of Life in Late-Stage Dementia scale (OUALID)

The QUALID is an 11-item questionnaire to measure QOL of people with severe dementia (Martin-Cook, Hynan, Rice-Koch, Svetlik, & Weiner, 2005; Weiner et al., 2000). It is administered by a primary caregiver and rated according to observed individual behaviours reflecting subjective and affective status, such as comfort, calmness, discomfort, or sadness, which are regarded to be suggestive of an individual's QOL. The observation focuses on basic daily activities in order to reduce the effect resulting from confounding factors such as cognitive impairment, education and culture. Each item is rated by a 5-point Likert scale, and the sum of all items rated ranges from 11 to 55. Lower scores reflect a better QOL state. This scale was developed in the USA through consensus conferences involving multidisciplinary clinicians. The QUALID scale has satisfactory reliability supported through test-retest reliability (0.807), inter-rater reliability (0.826), and internal consistency (0.769). Furthermore, convergent validity was supported

through correlations with other scales including the Pain-Visual Analogue Scale, the MMSE and the Neuropsychiatric Inventory-Nursing Home scale (Josep et al., 2010).

### **Qualidem**

The Qualidem is a professional caregiver-rating QOL scale for people with mild-to-severe dementia in residential facilities (Bouman et al., 2011; Ettema, Droes, de Lange, Mellenbergh, & Ribbe, 2007a). It consists of 37 items in subscale groups consisting of care relationship, positive affect, negative affect, restless tense behaviour, positive self-image, social relations, social isolation, feeling at home, and having something to do. Each item is rated using four response choices and higher scores indicate a better QOL status. The Qualidem has been reported as a reliable (Bouman et al., 2011; Ettema, Droes, De Lange, Mellenbergh, & Ribbe, 2007b) and valid tool (Dichter et al., 2011; Ettema et al., 2007a). The reliability coefficient ρ ranged from modest (0.60) to very acceptable (0.90) for the mild-to-severe dementia subscales. The validity of Qualidem was established through convergent and discriminant validity along with the content validity using the method of construction (Dichter et al., 2011; Ettema et al., 2007a).

# 2.5 Interventions Aiming to Improve Quality of Life

There are a number of studies regarding the effectiveness of diverse interventions which aim to improve physical function, psychological symptoms and cognitive function or to reduce disruptive behaviours for people with dementia in residential LTC facilities (Christofoletti et al., 2011; Stevens & Killeen, 2006; Tappen, Roach, Applegate, & Stowell, 2000). Although most of them elucidate their intentions by illustrating that, for example, the study's aim is to improve QOL through intervention delivery of their interest, outcomes relevant to QOL are rarely reported and quantified. Most of these studies seem

to assume that that good care processes will result in good outcomes, in terms of the comprehensive wellbeing of the client which include physical, psychological and social wellbeing (Vaarama et al., 2007).

Numerous studies show that there was no significant change in the level of QOL after interventions were applied although the functions or disruptive behaviours of people with dementia improved as a result of those (Orrell et al., 2005; Ridder et al., 2013). This may be interpreted that good care interventions which may improve function or disruptive behaviours, may happen regardless of the improvement of QOL. Therefore, as mentioned earlier, the QOL of residents with dementia needs to be a high priority (Edelman et al., 2005).

Currently, the types of interventions designed to improve QOL appear to be not sufficiently diverse to deal with multidimensional nature of life and to improve QOL. A systematic review, including 35 studies, identified interventions delivered aimed at improving the QOL of older LTC residents who may or may not have had dementia (Van Malderen et al., 2012). The authors concluded that the highest proportion of interventions, whose outcomes were measured through valid QOL instruments, tended to account for physical and psychological interventions. This study implies that multidimensional interventions are required to impact QOL. Studies related to dementia appear to have to include the QOL measurement because QOL can be an important indicator showing the general impact of interventions for those with dementia (Logsdon et al., 2007) and their general wellbeing in the individual level.

#### 2.6 Conclusion

Residential LTC is considered a residential facility where dependent clients with long-term physical or psychological infirmities reside in a substitute surrounding permanently or for a long period, and are given shelter. Recent research in the area of dementia in LTC has clearly presented that QOL is an important and meaningful outcome indicator of care. There is a plethora of definitions of QOL. Until recently, there has been a lack of agreement concerning the definition of QOL and compositions of it. Some scholars account for subjective and objective aspects in assessing QOL in order to enhance understanding QOL while others regard psychological wellbeing as being equivalent to assessment of an individual's general QOL. Nonetheless, QOL is multidimensional and impacted by many factors. There are a number of QOL measurement instruments along with the numerous definitions of QOL. Studies related to dementia appear to have to include the QOL measurement because QOL can be an important indicator showing the general impact of interventions for an individual with dementia and the person's general wellbeing. The next chapter will deliberate the methodology used in this systematic review.

### **CHAPTER 3: METHODS**

This systematic literature review aimed to find evidence related to effective interventions to improve QOL of people with dementia in residential LTC. This chapter explains the study methods undertaken to achieve the aim of this review. It starts with an explanation regarding the general conception of this systematic review, and then the methods which were used to conduct this systematic review are described.

### 3.1 Systematic Review

In nursing and healthcare fields, evidence-based practice has been a pervasive paradigm, in which the best available evidence transforms healthcare provision and interventions (Jolley, 2013; Stevens, 2013). Evidence-based practice intends to employ properly evaluated practices and to take away unscientific practices originated from tradition and experience (Jolley, 2013). Nurses and other health professionals are encouraged to use research evidence for establishing sound grounds for their practices (Stevens, 2013). There is an abundance of evidence including healthcare research aligned with improvement of the current medical technologies, pharmacology, and treatments (Aromataris & Pearson, 2014). This abundance of information can challenge healthcare providers, researchers, and policy makers to identify, appraise and conclude the best available evidence due to a lack of time, skills or resources (Aromataris & Pearson, 2014; Higgins & Green, 2011).

A systematic review is considered a research method of a comprehensive and balanced synthesis of research evidence on a specific research topic (Aromataris & Pearson, 2014; Holly, Salmond, & Saimbert, 2012). Systematic reviews help nurses and clinicians to introduce up-to-date evidence to guide clinical practice and decision-making

(Aromataris & Pearson, 2014). For policy makers, it can assist to develop health policies that contribute to positive outcomes in accordance with available resources. Systematic reviews also provide researchers with a summary of existing evidence and insights, with which future research outlines may be defined (Holly et al., 2012). A good systematic review is explicitly conducted with a systematic approach and methodological rigour (Holly et al., 2012). Thus, the significant features of a systematic review generally include (1) pre-planned protocol (Appendix 1) with eligible criteria based on a specific research question, (2) transparency by showing a reproducible methodology including systematic search strategies, (3) a quality appraisal of all individual studies relevant to a research question, and (4) a systematic presentation of findings derived from included studies (Higgins & Green, 2011; Holly et al., 2012).

# 3.2 The Methods of a Joanna Briggs Institute Systematic Review

Joanna Briggs Institute (JBI) is recognised as a global leader in evidence-based healthcare, having been constructed to make evidence-based healthcare rational and effective (Pearson, Wiechula, Court, & Lockwood, 2005). This current study is a systematic review of primary quantitative research studies using a JBI systematic review approach (JBI, 2014b). Traditionally, systematic reviews are used to find clinical effectiveness but as health professionals increasingly search for evidence to validate the value of interventions and alternative care delivery they provide, types of evidence can be different in accordance with the nature of clinical interventions and their purpose (Pearson et al., 2005; JBI, 2014b). The JBI has recently released new levels of evidence with four categorisations of evidence; effectiveness, diagnosis, prognosis, and economic

evaluations. The levels of evidence can provide reviewers with information on the most suitable study design when asking a research question (JBI, 2014c).

The JBI levels of evidence also help to rank study findings along with the approach of the GRADE (Grading of Recommendations Assessment, Development and Evaluation). The GRADE working group has developed grading systems for quality of evidence and strength of recommendations. The approach of the GRADE facilitates consistent judgement (GRADE Working Group, 2004), which has been acknowledged by many evidence-based healthcare organisations including Cochrane, WHO, AHRQ and others (JBI, 2014c). The approach of GRADE allows findings to be classified based not only study design, but also other factors such as risk of bias, inconsistency, imprecision of evidence, effect size, and confounders (JBI, 2014c). The GRADE approach provides a systematic technique of appraising whether evidence, which is a body of evidence generated from individual studies, should be upgraded or downgraded (refer to Table 2) (Dijkers, 2013). This approach supports reviewers to make a primary judgement on the methodological rigorousness and quality of research evidence together with the JBI levels of evidence. Therefore, both the JBI levels of evidence and the GRADE approach (Balshem et al., 2011) were applied to this study.

This review aims to evaluate the effectiveness of interventions on the QOL of people with major neurocognitive disorder (dementia) in residential LTC. The levels of evidence *for effectiveness* (Table 1) amongst the JBI levels of evidence were considered when study types were determined. The GRADE approach was also reflected in evaluating the quality of a body of evidence (Table 2) (Balshem et al., 2011).

Table 1: Joanna Briggs Institute Levels of Evidence for Effectiveness

14.516 2110411114 211000 111041	tate Levels of Evidence for Effectiveness			
Level 1	Level 1.a – Systematic review of Randomized Controlled			
Experimental Designs	Trials (RCTs)			
	Level 1.b – Systematic review of RCTs & other study designs			
	Level 1.c – RCT			
	Level 1.d – Pseudo-RCTs			
Level 2	Level 2.a – Systematic review of quasi-experimental studies			
Quasi-experimental	Level 2.b – Systematic review of quasi-experimental & other			
Designs	lower study designs			
	Level 2.c – Quasi-experimental prospectively controlled study			
	Level 2.d – Pre-test – post-test or historic/retrospective			
	control group study			
Level 3	Level 3.a – Systematic review of comparable cohort studies			
Observational/Analytic	Level 3.b – Systematic review of comparable cohort & other			
Designs	lower study designs			
	Level 3.c – Cohort study with control group			
	Level 3.d – Case – controlled study			
	Level 3.e – Observational study without a control group			
Level 4	Level 4.a – Systematic review of descriptive studies			
Observational/Descriptive	Level 4.b – Cross-sectional study			
Studies	Level 4.c – Case series			
	Level 4.d – Case study			
Level 5	Level 5.a – Systematic review of expert opinion			
Expert Opinion and Bench	Level 5.b – Expert consensus			
Research	Level 5.c – Bench research/ single expert opinion			

Source: JBI (2014a, para. 2)

Table 2: Summary of GRADE's Approach to Rating Quality of Evidence

Study	Initial Quality of	Lower If	Higher If	Quality of a Body
Design	Body of Evidence			of Evidence
Randomised	High	Risk of Bias	Large effect	High (4 plus:
Trials		-1 serious	+1 Large	++++)
		-2 very serious	+2 Very large	
		Inconsistency	Dose response	Moderate (3
Observational	Low	-1 serious	+1 Evidence of a	plus: +++)
Studies		-2 very serious	gradient	
		Indirectness	All plausible residual	Low (2 plus: ++)
		-1 serious	confounding	Vamilani/1
		-2 very serious	+1 Would reduce a	Very low (1 plus: +)
		Imprecision	demonstrated	pius. +)
		-1 serious	effect	
		-2 very serious	+1 Would suggest	
		Publication bias	a spurious effect if	
		-1 likely	no effect was	
		-2 very likely	observed	

Source: Balshem et al. (2011, p. 404)

# 3.3 Review Question

A clearly defined question guides a review in finding answers to the specific question from the available literature (Stern, Jordan, & McArthur, 2014). The current review question is 'which interventions have the best outcomes to improve QOL for people with dementia in residential LTC?' This review aimed to summarise all existing evidence dealing with effective intervention(s) which improved QOL of the population. The detailed objectives were to (1) identify interventions which improve QOL of people with dementia in residential LTC; (2) evaluate the effectiveness of these identified interventions. To deal with these objectives, a JBI quantitative systematic review approach was applied (JBI, 2014b).

In order to ensure that the relevant studies meet the aim of the review and irrelevant ones are excluded, eligibility criteria should be thoroughly and clearly reported before the systematic review starts (Bettany-Saltikov, 2010; Holly et al., 2012).

### 3.4 Inclusion Criteria

The inclusion criteria help to decide which studies should be included or excluded in order to search for evidence and answers to the research question. By defining inclusion criteria in advance of commencing of the review, the study search process can be rigorously and transparently conducted (Bettany-Saltikov, 2010; Holly et al., 2012). The criteria can help to reduce selection bias that may be caused by investigators, by being strictly applied to all relevant studies (Aromataris & Pearson, 2014; Bettany-Saltikov, 2010).

The PICOS approach was used to clarify the characteristics of studies for inclusion in this review. The acronym PICOS means population, intervention, comparison, outcome and study design (Aromataris & Pearson, 2014). Identified PICOS components focusing on the research question provide an organised approach to identify eligible criteria explicitly.

### 3.4.1 Types of Participants

This review included studies dealing with people with dementia of any type, duration, and stage in LTC facilities. Participants for inclusion should have a clinical diagnosis of dementia according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as well as the International Classification of Diseases (ICD-10), and National Institute of Neurological Communication Disorders and Stroke-Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA). Initially, the protocol of this review indicated that people having received a medical diagnosis of major neurocognitive disorder according to DSM-V or dementia according to DSM-IV, but ICD-10 and NINCDS-ADRDA have been widely used for dementia criteria in many studies, having been acknowledged as valid dementia diagnostic systems (Bennett, 2000; Hoe, 2006) so these additional diagnosis were also used for inclusion. The Functional Assessment Staging Test (FAST), Global Deterioration Scale (GDS), or Clinical Dementia Rating (CDR) is a clinical dementia staging instrument with reliability and validity (Olde Rikkert et al., 2011). If a study was found in which the diagnosis of dementia was not clearly articulated, but where participants were identified as having CDR 1 or greater (Morris, 1993), FAST 4 or greater (Sclan & Reisberg, 1992), or GDS 4 or greater (Auer & Reisberg, 1997; Reisberg, Ferris, De Leon, & Crook, 1982), indicating mild-to-severe dementia stages, the study was included for this review. Where a study stated that people had medical diagnosis of dementia but no further explanation was provided regarding dementia criteria, the study

was included with the inference that medical diagnosis undertaken in a country with sophisticated health systems would be undertaken according to DSM-IV or V criteria. Furthermore, as the nature of dementia is inclined to be unrecognised in its initial stage and diagnosed more accurately in its advanced stage (AIHW, 2012), the length of dementia diagnosis is not considered in this review.

### 3.4.2 Types of Interventions(s)

Studies were included if they reported an intervention aiming at improving QOL with outcomes measured through one of a number of standardised QOL instruments.

More specifically, interventions included physical activity, psychological and independence-oriented interventions, social relationship interventions, environment-oriented interventions, spiritually oriented interventions, medication treatment, care provider/staff-oriented interventions (e.g. staff education), and multidisciplinary team applications. Interventions of any length and frequency were included, aiming to improve QOL, wellbeing or satisfaction of people with dementia.

### 3.4.3 Types of Outcomes

The outcome of interest was the QOL as measured by QOL instruments which are generally accepted as reliable and valid QOL measurement scales. The scales can be sorted into three types according to QOL measurement methods; self-rating scale, proxyrating scale, or direct observation-based scale. These measurement methods were considered to produce profiles of the QOL of the affected people as there is no gold standard to measure QOL. More specially, any instruments aiming to measure QOL of people with any stage of dementia were considered as follows: ADROL, WIB, DCM, DQOL, Lawton Observed Affect Scale, Lawton's conceptualisation of psychological wellbeing,

PGCMS, Psychosocial Impact of Assistive Devices Scale (PIADS), QOL-AD, Qualidem, QUALID, EuroQOL 5D, and Self-Reported Quality of Life (SRQoL).

### 3.4.4 Types of Studies

Studies included randomised or non-randomised controlled trials, before and after studies including comparison group, and quasi-experimental trials including the control group, in order to evaluate the effect of currently available interventions on the QOL of the people with dementia. In addition, studies published in English since 1995 were considered. This is because it was around 1995 that the World Health Organization quality of life [WHOQOL] group developed a definition of QOL and its cross-cultural measurement instruments.

### 3.5 Exclusion Criteria

Studies which did not meet inclusion criteria were excluded as follows:

- Participants did not have a medical diagnosis of major neurocognitive disorder (dementia), who instead had another functional or mental health problem (e.g. delirium, depression, anxiety) or problematic behaviour;
- Studies presenting a dementia based on MMSE scores only without medical diagnosis of dementia, as a low score of MMSE does not always mean that an individual has dementia (Fox & Hodgkinson, 2013);
- Studies reporting people with dementia who lived in their own homes or other residences designed for individuals such as senior apartments or independent care, individuals with dementia using day care centres, or patients with dementia who were hospitalised;

- Data with mixed populations, which did not separate data for people with dementia;
- Studies, not including interventions, investigating factors or elements that influence QOL, or reporting no activity-based interventions (e.g. comparing small scale residential facilities with traditional facilities);
- Outcomes resulting from combining findings based on the author's operational definition of QOL, which did not include a valid and reliable QOL instrument, were excluded (e.g. combined outcomes of Global Deterioration Scale (GDS) and Mental Health Questionnaire (MHQ));
- Trials without parallel comparison group.

The criteria regarding studies which should be included or excluded for this current review are presented in Table 3, using the PICOS components.

Table 3: Inclusion and Exclusion Criteria

	Inclusion Criteria	Exclusion Criteria
Population	People with dementia living in	People without dementia or those
	residential LTC facilities	living in their homes or acute settings
Intervention	Any form of activity-based	Interventions irrelevant to improve
	interventions, aiming at improving	QOL
	QOL	Studies comparing small scale
		residential facility with traditional
		facility
Comparative	None	None
Intervention		
Outcomes	Quantitative QOL scales measured	Qualitative outcomes
	by validated QOL instruments	Scales measured by unauthorised
		QOL instruments
Type of	RCTs	Observational trials
Studies	Quasi-experimental trials with	Case studies
	parallel control group(s)	Qualitative studies

### 3.6 Search Strategy

Searching literature for a systematic review aims to identify as many studies relevant to the research question as possible, with a comprehensive and organised search strategy (Aromataris & Pearson, 2014). In this review a three-phase search strategy was utilised in accordance with the JBI Reviewers' Manual (JBI, 2014b). A preliminary limited search of CINAHL Plus and MEDLINE was undertaken to identify keywords in the title, abstract, or index terms to describe studies. Key words, synonyms and spelling variations were considered when building search strategies. A second search applying search strategies was then undertaken across databases including CINAHL Plus, MEDLINE, Cochrane, EMBASE, and PsycInfo in consultation with a librarian. The search for unpublished studies included Google Scholar, ProQuest (dissertations and theses databases), National and International Alzheimer's associations' websites, WHO, and AIHW, and Organisation for Economic Co-operation and Development [OECD]. Search keywords were: ("people", "person", "patients", "patient", "client", "clients", "residents" ("dementia", "Alzheimer", OR "resident") AND "Alzheimer's", "cognitive impairment", "Lewy Body disease" OR "major neurocognitive disorder") AND ("long term care", "long-term care", "longer term care", "facility care", "residential", "institutional care", "nursing home" OR "nursing homes") AND ("quality of life", "life qualities", "life quality", "satisfaction", "wellbeing", OR "well-being"). Thirdly, the reference lists of relevant papers were hand searched for additional studies. Studies published in English between 1995 and March 2014 were searched. An example of search results is presented in Appendix IV.

### 3.7 Critical Appraisal of Methodological Quality

Quality appraisal of all identified studies is a significant part of the systematic review process (Holly et al., 2012). The benefit of the critical appraisal is to improve the opportunity to ensure that high quality studies are included in the process integrating research findings of a systematic review and that each study satisfied the inclusion criteria (JBI, 2014b). The quality appraisal ensures that the reliability and validity of a study are assessed by defining whether the approaches used throughout the study address possible biases (JBI, 2014b).

In this review, two independent reviewers assessed studies for methodological validity prior to data extraction and analysis, using a standardised critical appraisal instrument from the JBI Meta-Analysis of Statistics Assessment and Review Instrument (JBI MAStARI). As study types for this review were limited to RCTs and quasi-experimental, the MAStARI critical appraisal tool for randomised control/pseudo-randomised trial was used (Appendix II).

The JBI MAStARI critical appraisal tool comprising ten questions is a specific and validated tool for assessing risk of bias in each eligible study. For each study, the appraisal tool was used and each of the ten assessment questions was marked as 'yes' (Y), 'no' (N), 'unclear' (U), or 'not applicable' (N/A). Recoding (Y) for a question means that the study clearly addressed the question. A (N) response indicates that the question was not adequately satisfied by the particular study. A (U) response was recorded when there was no clear account or vague information in the study when tested with the assessment question. Lastly, (N/A) was marked when the criteria was not applicable to the study.

The first question (Q1) is regarding selection bias related to true randomisation.

True randomisation is regarded as desirable, by which every participant has a truly equal chance to be allocated in any group involved in the trial (JBI, 2014b). If it was not clear in a study how participants were randomised and was just simply presented such as 'participants were randomised', it was marked as 'unclear' (U). (Y) was recorded where true randomisation was clearly articulated in the method, such as simple randomisation, coin-tossing or computer generated random number list (Higgins & Green, 2011). A (N) was recorded where the randomisation method was not mentioned or quasi-randomisation methods, such as alternate allocation or allocation using unconcealed procedure, were used.

The second question (Q2) is about the risk of performance bias which results from the awareness of the allocated treatments of participants (Higgins & Green, 2011).

Performance bias may lead to an influence of the study's outcomes. If blinding of participants was completed, (Y) was assigned, but if it was not completed, a (N) was recorded. Where the statement related to blinding of participants was unclear, a (U) was assigned.

The third question (Q3) is related to selection bias, which may be caused when an allocator is unconcealed and thus possibly have an influence on the particular treatment arm. If the study reported that investigators could not anticipate assignments due to a properly concealed allocation method such as pharmacy-controlled allocation or distribution by personnel unrelated to a study, (Y) was marked. If investigators could forecast assignments due to unconcealed methods such as allocation using alternation or date of birth, (N) was rated.

The fourth question (Q4) is related to attrition bias which was caused by missing outcome data. Intention-to-treat analysis may minimise bias resulting from participant withdrawal. If a study illustrated intention-to-treat analysis and the outcomes of participants who dropped out, (Y) was rated; otherwise, (N) was rated. The fifth question (Q5) is associated with the risk of detection bias which may be caused due to awareness of the allocated treatments by outcome raters. If the study reported that assessors were blinded to treatment allocation (Y) was rated; otherwise, (N) was assigned.

The sixth question (Q6) related to comparability of the intervention and control groups at baseline in a trial. If a study described comparable characteristics of participants in both groups at entry and heterogeneity of two groups was not likely to have an effect on outcomes, (Y) was rated; otherwise, (N) was assigned. The seventh question (Q7) is about whether the groups are treated equally except for the treatment of interest. If a trial treats groups equally in similar settings and conditions, (Y) was rated; otherwise, differences were detected which may lead to influence on outcomes then (N) was rated. The eighth question (Q8) is about whether outcomes were measured in the same way for all groups. If outcomes were measured using the same scales and methods for all groups by reliable assessors, (Y) was recorded; otherwise, (N) was recorded. The ninth question (Q9) is related to a form of the risk of detection. If the instruments for outcome measures were proved as valid and reliable, and the quality of presentation of findings is satisfactory, (Y) was rated; otherwise, (N) was rated. The last question (Q10) is whether proper statistical analysis is used. If the analysis methods were widely accepted and appropriate, then (Y) was assigned; otherwise, (N) was recorded.

If seven or more questions were marked as (Y) in a specific study of 10 questions, the study was regarded as a high-quality study and was included for data extraction in the review. If the number of questions marked as (Y) was six and under in a study, the study was excluded in the data synthesis.

These assessment criteria on the MAStARI instrument were discussed before the primary and secondary reviewer conducted their independent appraisal in order to maintain consistency in the quality appraisal (JBI, 2014b). Following independent appraisal by the two reviewers, discrepancies in judgment on each question or on whether a study should be included, were solved in the final review stage in which the both reviewers discussed together or a third reviewer was further involved to reach agreement.

### 3.8 Data Extraction

Data extraction is the process to identify and draw relevant findings from included research studies in the systematic review (JBI, 2014b). In this review, quantitative data were extracted from all included studies using the standardised data extraction tool from JBI MAStARI (Appendix III) by two independent reviewers. This tool was used to reduce the risk of error when pulling out data from an individual study included. The data extracted from each study included study method, setting, participants, attrition, interventions, and outcomes. They were extracted in accordance with the review question and specific objectives.

# 3.9 Data Synthesis and Meta-Analysis

Data synthesis provides the summary of outcomes from all included studies with a general evaluation of the effectiveness of an intervention (Holly et al., 2012). After

identifying interventions across included studies, analogous interventions were congregated according to the nature of intervention, in order to assess the effectiveness of different types of interventions on the QOL of people with dementia in residential LTC.

Furthermore, this systematic review included a meta-analysis (Holly et al., 2012). Meta-analysis has been regarded as an influential method by allowing estimation of the effect size of an intervention. Meta-analyses not only combine results of an intervention, but also assist decision-making and evidence-based practice (Borenstein, Hedges, Higgins, & Rothstein, 2009). If two or more distinct studies were appropriately analogous in features relevant to the review question, the results of these studies were pooled, which could produce statistically combined estimates of effect (Holly et al., 2012).

Heterogeneity in several aspects such as the population, intervention, or outcome across studies may hinder studies from being statistically combined. It has been recommended that if heterogeneity is too severe across the studies, a meta-analysis should not be used (Borenstein et al., 2009; Schmidt & Hunter, 2015). However, this does not mean that all studies included in meta-analysis need to be identical in their nature which is designed to answer the same question using the same population and intervention. Meta-analysis addresses comprehensive questions rather than specific questions of separate studies (Schmidt & Hunter, 2015). For example, if the question is about whether a specific intervention could have an advantage on a specific population, then the population and intervention need to be homogenous. However, the question is about whether an intervention will be beneficial overall, and then the model of meta-analysis allows studies to be heterogeneous in their study design and populations.

Therefore, before conducting meta-analysis for this review the extent of similarity and

difference across studies and where the data lacked statistical difference, statistical pooling was used.

In this review, quantitative data extracted from comparable groups of studies were collected in a statistical meta-analysis using the JBI MAStARI (JBI, 2014b). Overall effect size was expressed as standardised mean differences (SMD) or weighted mean differences (WMD) and 95% confidence intervals were calculated for each study reported in the meta-analysis. The difference in means of each study was measured using WMD when QOL of people with dementia was measured using the same scale. SMD calculated on the overall difference in means between intervention groups for all studies, which is comparable to the effect size, based on a weighted average of all studies, which is associated to the standard deviation (JBI, 2014b). In MAStARI, WMD is calculated for fixed effects models with the inverse variance method and for the random effects models with the DerSimonian and Laird method (JBI, 2014b). On the other hand, when studies measured QOL of people with dementia using different QOL scales, the data from these studies were pooled in a meta-analysis incorporating SMD (JBI, 2014b). Where the QOL scales operated in the same direction, which means that an increase in the level of QOL was measured as an increase in all scales across included studies, then SMD was used without further adjustment.

When QOL measurement scales drove in a different direction, the mean data from one scale were reversed by multiplying the data by -1. In this case, standard deviation did not need to be changed. MAStARI uses Cohen's SMD or Hedges' SMD to calculate the SMD for fixed effects and DerSimonian and Laird method (1986, as cited in Higgins & Green, 2011) to calculate the SMD for random effect models. The meta-analysis using

random-effects method admits heterogeneous but related intervention effects with an assumption that data of the control and intervention group is normally distributed (Higgins & Green, 2011). The data used in this review were processed with DerSimonian and Laird SMD and random effect models in order to address the different scales of QOL and heterogeneous intervention approaches across studies (JBI, 2014b). Basically, intention-to-treat data were used where provided, otherwise the data for participants who completed trials were used, which is known as per-protocol analysis (Higgins & Green, 2011). In addition, heterogeneity between combined studies in the meta-analysis was assessed using the standard chi-square test. Meanwhile, when statistical combining of quantitative data was not possible due to very severe heterogeneity in study design, study methods, interventions and data, the findings were presented in narrative summary (Munn, Tufanaru, & Aromataris, 2014).

### 3.10 Conclusion

The JBI systematic review approach was adopted to this systematic review. This led to an organised and comprehensive search of published and grey literature with predefined inclusion and exclusion criteria which were formed based on the question of this systematic review. The JBI approach was also used to evaluate the quality of eligible studies and to extract and synthesise data retrieved from included studies. The GRADE approach was used in evaluating the overall quality of a body of evidence in the discussion section of this review (Chapter 5). In the next chapter, the results of the JBI systematic review approach will be shown.

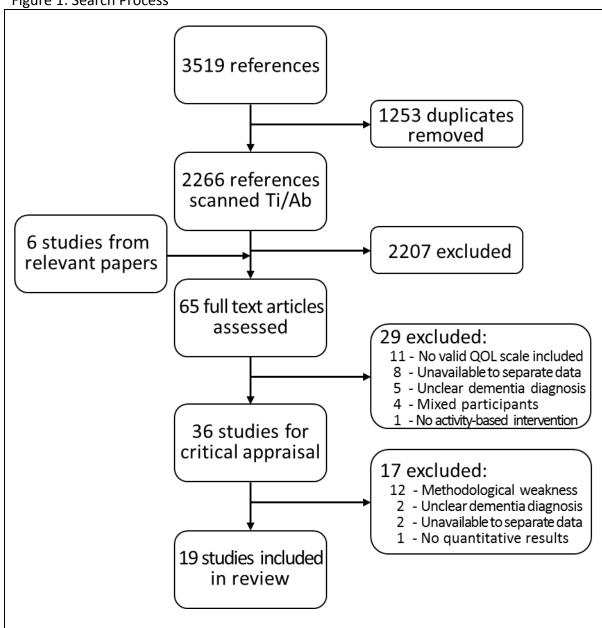
### **CHAPTER 4: RESULTS**

In this results section the findings created over the systematic review process are summarised. This review aimed to define the most effective interventions to improve QOL of people with dementia in residential LTC. The results of the study search explained in the previous chapter, study quality appraisal, and data extraction and synthesis are described.

### 4.1 Results of Search Strategies and Eligible Studies

The initial search yielded 3519 studies. These were then exported into the bibliographic software (Endnote<sup>™</sup>X7). After removing duplicated entries, the titles and abstracts for 2266 papers were scanned for relevance to the inclusion criteria and thus 2207 papers were excluded by the primary researcher. With six additional papers searched after reviewing reference lists of relevant studies, 65 full papers were evaluated for eligibility by two independent researchers based on inclusion and exclusion criteria. This yielded 36 studies for quality appraisal, resulting in the exclusion of 29 studies due to no QOL outcomes measured by a valid QOL scale (11 studies), unavailable data for residents with dementia (eight studies), unclear dementia diagnosis criteria (five studies), mixed settings such as individual home or day care centre (four studies), and a study comparing traditional nursing home and a group living home. The search process of this review is shown in Figure 1.

Figure 1: Search Process



# 4.2 Result of Study Selection after Quality Appraisal

The study quality appraisal was a process not only to assess the quality of each study, but also to ensure that each study met the predefined inclusion criteria of this review (JBI, 2014b). Quality appraisal of the studies was undertaken in order to establish the validity of studies being searched and to minimise risk of bias. This quality appraisal was a significant process to detect poor quality studies which may lead to over-or under-

estimates of effectiveness. It was also an important procedure to find the strength of each study. Of the 36 studies selected for quality appraisal, 25 studies were experimental designs including RCTs, pseudo-RCTs, cluster RCT, cross-over RCT and 11 studies were quasi-experimental designs. As described in Section 3.7, the 36 studies were critically assessed to determine methodological quality by two independent researchers using the JBI MAStARI critical appraisal tool for randomised control/pseudo-randomised trial (Appendix II).

#### 4.2.1 Included Studies

The results of the quality appraisal and the level of evidence of each study are presented in Table 4. Nineteen of the 36 eligible studies were accepted for inclusion by both reviewers, being assessed as having appropriate methodological quality (refer to section 3.7) and satisfying the inclusion criteria (refer to section 3.4). In addition, each included study was categorised by 'the JBI Levels of Evidence for Effectiveness' in order to determine the quality of a body of evidence across studies (section 5). Amongst the 19 studies, 16 studies were RCTs, two were quasi-RCTs, and one study was a quasi-experiment. Except for the study using a quasi-experimental prospectively controlled design (Williams & Tappen, 2007) which was rated as level two, all studies were included in level one according to the JBI Levels of Evidence, indicating the potential high-level of evidence (Balshem et al., 2011; JBI, 2014a).

Table 4: Quality Appraisal Result and the JBI Levels of Evidence

	Quality Appraisal Nesult and the 3BI Levels of Evidence												
Authors & Year	Q 1	Q 2	Q 3	Q 4	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10	Sum	Study Design	JBI Level
Azcurra, 2012	Υ	Υ	U	N	Υ	Υ	Υ	Υ	Υ	Υ	8	RCT	1C
Ballard et al., 2002	Υ	Υ	U	N	N	Υ	Υ	Υ	Υ	Υ	7	RCT	1C
Ballard et al., 2004	U	Υ	Υ	N	U	Υ	Υ	Υ	Υ	Υ	7	RCT	1C
Bergh et al., 2012	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	Υ	Υ	9	RCT	1C
Chenoweth et al, 2009	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	10	Cluster- RCT	1C
Chibnall et al., 2005	U	Υ	Υ	Υ	Υ	N/ A	Υ	Υ	Υ	Υ	8	Cross-over RCT	1D
Clare et al., 2013	Υ	Υ	Υ	Υ	Υ	N	Ν	Υ	Υ	Υ	8	Cluster- RCT	1D
Conradsson et al., 2010	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	10	Cluster- RCT	1D
Cooke et al., 2010	Υ	N	Υ	Υ	Υ	Υ	Υ	Υ	Υ	Υ	9	Cross-over RCT	1D
Lai & Kayser- Jones, 2004	Υ	U	U	Υ	Υ	Υ	Υ	Υ	Υ	Υ	8	RCT	1C
Moyle et al., 2013	Υ	U	Υ	N	Υ	Υ	Υ	Υ	Υ	Υ	8	Cross-over RCT	1C
Orrell et al., 2005	N	Υ	Υ	U	Υ	Υ	Υ	Υ	Υ	Υ	8	Quasi-RCT	1D
Orrell et al., 2007	Υ	Υ	Υ	Υ	Υ	N	Υ	Υ	Υ	Υ	9	RCT	1C
O'Shea et al., 2014	Υ	N	Υ	Υ	Υ	Υ	Y	Υ	Υ	Υ	9	Cluster- RCT	1D
Politis et al., 2004	Υ	Υ	U	N/ A	Υ	Ν	Υ	Υ	Υ	Υ	7	RCT	1C
Subramaniam et al., 2014	Υ	N	N	N	Υ	Υ	Υ	Υ	Υ	Υ	7	RCT	1C
van de Ven et al., 2013	Υ	N	Y	Υ	N	Υ	Y	N	Υ	Υ	7	Cluster- RCT	1D
Williams & Tappen., 2007	U	Υ	U	N	Υ	Υ	Υ	Υ	Υ	Υ	7	Quasi- experiment	2C
Yamanaka et al., 2013	N	Υ	Υ	Υ	N	Y	U	Υ	Υ	Υ	7	Quasi-RCT	1D

#### 4.2.2 Excluded Studies

After critical appraisal, 17 studies were excluded as they did not meet the predefined inclusion criteria. Common reasons were methodological weakness (12 studies), unclear criteria related to dementia diagnosis (two studies), unavailable data extraction due to mixed participants (two studies), and quantitative data not reported (one study). For example, the study by Spector et al. (2003) was a well designed trial, but included data with participants with and without dementia. The latter factor made it impossible to separate the data for people with dementia for this review. A subsequent study by Orrell et al. (2005), testing the long-term effects of cognitive stimulation therapy (CST), was developed following participation in the RCT by Spector et al. (2003). Orrell et al.'s (2005) study reported the available data for people with dementia. Consequently, Spector et al.'s (2003) paper was excluded from this systematic review while the study by Orrell et al. (2005) was included. The details of other exclusion reasons are described in Appendix V.

### 4.3 Results of Data Extraction

Data extraction from all 19 studies was conducted using the standardised JBI MAStARI data extraction tool by two independent reviewers (JBI, 2014b). The data extracted from each study included study method, the number of participants, interventions, and outcome measures, and results and author's conclusion. An overview of each study is presented in Appendix VI.

### 4.3.1 Outcome Measures of Included Studies

There were 10 types of QOL measurement tools across 19 studies. Three studies employed two kinds of QOL measurement tools (Azcurra, 2012; van de Ven et al., 2013;

Yamanaka et al., 2013). The other 16 studies used one type of QOL measurement tool. In terms of incidence of usage across all the 19 studies, QOL-AD was the most prevalent instrument, used in seven studies. It is followed by DCM used in five studies while QUALID and EuroQoL five dimensions (EQ-5D) were used in two studies respectively. The other six scales, including AD-RQL, DQOL, Lawton's Observed Affect Scale (OAS), PGCMS, QUALIDEM, and SRQoL were used once across the 19 studies. With the exception of three scales, which are DQOL, Lawton OAS, and PGCMS, measuring subjective QOL only, all other scales assessed both subjective and objective aspects of QOL. In general, self-reporting or proxy-reporting QOL scales were used for people with mild-to-moderate dementia, direct observation scales of QOL were used for people with severe dementia.

Table 5 shows the QOL scales used in included studies and data sources. It also offers a summary of the domains of QOL, data source, and the level of target cognition which were addressed by each QOL scale.

Table 5: QOL Scales and Features

Measure	Domains of QOL	Study	Data Source	Target Cognition
QOL-AD	Physical condition, mental health, relationships, money, overall QOL	Yamanaka et al. (2013); Subramaniam et al. (2014); Orrell et al. (2007); Orrell et al. (2005); O'Shea et al. (2014); Moyle et al. (2013); Bergh et al. (2012)	Resident and/or care provider	Mild to moderate dementia
DCM	Well and ill-being, and 24 behavioural category codes	Ballard et al. (2004); Lai et al. (2004); Azcurra (2012); Ballard et al. (2002); Chibnall et al. (2005)	Mapper (Observation approach)	All consecutive levels of dementia
EQ-5D	Mobility, self-care, usual activities, pain/discomfort, and anxiety/depression	Yamanaka et al. (2013); van de Ven et al. (2013)	Resident and/or care provider	Mild to moderate dementia
AD-RQL	Social interaction, awareness of self, feeling and mood, enjoyment of activities, response to surrounding	Politis et al. (2004)	Care provider	Mild to moderate dementia
DQOL	Positive affect (6 items), negative affect (11 items), feelings of belonging (2 items), self-esteem (4 items), sense of aesthetics (5 items) and a global QoL rating	Cooke et al. (2010)	Resident	Mild to moderate dementia
Lawton- Observed Affect Scales	Pleasure, anger, anxiety, sadness, interest, contentment	Williams and Tappen (2007)	Care provider	All consecutive levels of dementia
PGCMS	Agitation, attitude toward own ageing, lonely- dissatisfaction	Conradsson et al. (2010)	Resident	Normal to mild dementia
QUALID	Observation of both the affective state (Smiling, sadness, crying, discomfort, irritability, calmness), and behavioural signs of engagement (Eating and engaging)	Clare et al. (2013); Chenoweth et al. (2009)	Care provider (Observation approach)	Late stage of dementia
Qualidem	Observational behaviours (Care relationship, positive affect, negative affect, restless tense behaviour, positive selfimage, social relations, social isolation, feeling at home, having something to do)	van de Ven et al. (2013)	Care provider (Observation approach)	Mild to very severe dementia
SRQoL	Comfort, security, meaningful activities, relationships, functional competence, enjoyment, privacy, dignity, autonomy, individuality and spiritual wellbeing	Azcurra (2012)	Resident	Mild to moderate dementia

### 4.3.2 Interventions of Included Studies

There were diverse interventions across the 19 included studies. Along with the characteristics of interventions, there were eight different types of interventions; reminiscence, physical exercise, CST, pharmacology-related intervention, staff training, music, emotion-oriented intervention, and aromatherapy (Table 6). Reminiscence was the most prevalent intervention, being used in 5 of the 19 studies included, which was followed by staff training with four studies and then pharmacology-related intervention with three studies. Physical exercise and CST interventions were the focus for two studies while there was a single study for music intervention, aromatherapy, and emotion-oriented interventions.

Table 6: Intervention Category

Туре	Interventions	Reference		
	Life review	Subramaniam et al. (2014)		
	Life story approach	Lai et al. (2004),		
Reminiscence		Azcurra (2012)		
	A kit-based activity	Politis et al. (2004)		
	Staff care involving reminiscence sessions	O'Shea et al. (2014)		
	Neuroleptic discontinuation	Ballard et al. (2004)		
Pharmacology	Acetaminophen	Chibnall et al. (2005)		
	Discontinue antidepressant treatment	Bergh et al. (2012)		
Physical	Comprehensive exercise	Williams and Tappen (2007)		
Exercise	High intensity exercise program	Conradsson et al. (2010)		
CST	Maintenance CST	Orrell et al. (2005)		
C31	CST Japanese version	Yamanaka et al. (2013)		
Music	Music	Cooke et al. (2010)		
Emotion	Companion robot	Moyle et al. (2013)		
	DCM	van de Ven et al. (2013)		
Staff Training	Awareness based approach	Clare et al. (2013)		
	Resident-centred care practices	Orrell et al. (2007)		
	DCM and person-centred care	Chenoweth et al. (2009)		
Aromatherapy	Melissa essential oil	Ballard et al. (2002)		

## 4.4. Result of Data Synthesis

The results of data synthesis were discussed in accordance with the types of different interventions. Broadly, six categories of interventions were synthesised; reminiscence, physical exercise, CST, pharmacology, staff training, and others. Each category of intervention was narratively summarised, and statistical pooling was used where the data lacked statistical difference. In addition, the description regarding QOL scales used in each study was presented, referring where necessary to use QOL scales illustrated earlier in chapter two within this review (section 2.4.6).

#### **4.4.1 Reminiscence Intervention**

Reminiscence therapy includes the conversation of past occasions, experiences, and activities, often including triggers such as pictures, life story books, or records (Woods, Spector, Jones, Orrell, & Davies, 2005). Five studies used the reminiscence approach (Azcurra, 2012; Lai et al., 2004; O'Shea et al., 2014; Politis et al., 2004; Subramaniam et al., 2014) and reported QOL outcomes using different measurement scales. The details of the five studies using reminiscence intervention are presented in Table 7 and Table 8. Table 7 shows information concerning the research questions, outcomes and author's conclusion for each of the studies. Table 8 presents the features of each study with respect to study design, participants, diagnosis, setting, sample size, reminiscence contents and activity, frequency and duration of intervention, and outcome measures. The description of each study intervention is presented to show how each individual study reported results that were relevant to this current review.

In all five reminiscence studies, the assessors were blinded to the treatment allocation. Four of the studies were RCTs and one study used a cluster RCT. All studies

used individualised intervention approach, and compared a reminiscence approach and usual care, or reminiscence therapy and unstructured conversation. Two studies showed a statistically significant improvement of QOL in the reminiscence intervention groups compared to the control groups (O'Shea et al., 2014; Subramaniam et al., 2014). Two other studies reported a statistical significance in improved QOL within the reminiscence intervention groups over time (Azcurra, 2012; Lai et al., 2004). Only one study showed there was no difference of QOL over time and between treatment groups (Politis et al., 2004).

The study by Subramaniam and associates (2014) reported on the effect of different pathways for developing a life story book in 24 people with dementia over 18 weeks. Regarding these different pathways, the intervention group attended 12 sessions of life review including developing a life story book, across 12 weeks. The control group received usual care over a 12-week period while relatives of these participants were developing the residents' life story books. Both intervention and control groups received a life story book at the 12-week phase after life review sessions were completed. The QOL-AD self-report measure was used to evaluate the level of QOL at baseline, at 12 weeks, and finally at 18 weeks. There was no difference in QOL between the intervention and control groups at the 18-week test, but there was a significant improvement of QOL-AD in the intervention group (life review), compared to the control group at the 12-week test (F (1, 20) = 5.11, p= 0.035). Furthermore, within the control group, there was an increased score of QOL between the 12-week test following usual care and the 18-week test following the receipt of a life story book through the longitudinal analysis (p = 0.024).

Politis and colleagues (2004) reported on reminiscence therapy using the Geriatrics Network Kit (the kit), a standardised activity aiming to offer mental stimulation and one-on-one control treatment over 4 weeks, including 37 participants. The Intervention group was involved in structured conversation based on the kit, reflecting an individual's interests for twelve 30-minute sessions over 4 weeks. The control group had unstructured interaction including conversations about the participant's past and interests for 30 minutes. The AD-RQL was used to evaluate QOL at the baseline and post-test at 4 weeks immediately after the intervention. The results indicated that there was no clear effect of the reminiscence-based intervention on QOL. However, within control groups the mean score of AD-RQL was increased at the post-intervention test, compared to that at baseline (p=0.030).

A study by O'Shea et al. (2014) reported on a reminiscence-based education programme for care staff, who were consequently involved in individualised reminiscence with residents in LTC. Although O'Shea et al.'s (2014) study involved staff education, it was decided that this study would be included in the reminiscence category with the consideration that participants received reminiscence-based treatment and the impact of reminiscence-based interventions on the QOL of residents with dementia was able to be explored. The study was conducted over 18 to 22 weeks, including 304 residents and 90 staff using reminiscence strategies in care. The staff members in the intervention group were trained through a structured education program over 3 days by experienced nurse educators, and used reminiscence with residents in the intervention group in at least four sessions per week. The control group received usual care. Both the self-rating version and proxy-rating version of QOL-AD scale were used to evaluate the QOL of residents with

dementia at baseline and at 18-22 weeks. Intention-to-treat analysis of data indicated that the interventions had no effect on QOL. While in per-protocol analysis, the proxyrated (caregiver) QOL-AD scores were not significantly different between the treatment groups, there was a statistically significant improvement of self-rated QOL-AD scores in the intervention group, compared to the control group (p=0.04).

Lai et al. (2004) compared the effects of a specific reminiscence program in the intervention group, social contacts in the comparison group, and usual care in the control group, including 101 participants. The participants in the reminiscence intervention had conversations using triggers approximating an individual's life history for 30 minutes a week over 6 weeks. The comparison group discussed several themes such as diet, health, and social security for older people, not life experiences. Aside from the content, the protocol's design was the same for both the intervention and comparison groups whilst the control group received usual care. QOL was measured using the WIB scale of the DCM (not BCCs) at baseline, post-test at 6 weeks after the immediate intervention, and at 12 weeks from baseline. The results showed that there was no difference between the three groups over time, but in intention-to-treat analysis within intervention groups the WIB score at the 6-week post-test was significantly improved, compared to that at the baseline test (p = 0.014).

Azcurra (2012) investigated the effect of the reminiscence program with 135 participants using a life-story approach, compared to counselling and unstructured social contact. The reminiscence intervention group attended directed conversation sessions in which memory triggers such as photographs or recordings were used to support individual memories for 1 hour, twice a week over 12 weeks. The control group was

involved in counselling and informal social interactions and the comparison group participated in unstructured social contact, for 1 hour, bi-weekly over a 12 week duration. QOL was measured using the self-report QOL scale and the WIB scale of DCM at the baseline, 12 weeks and 6 months. The resident SRQoL includes 11 domains of QOL, which are regarded to be associated with an individual's experience (Kane et al., 2003). Higher scores reflect a better QOL state. This scale was reported as having acceptable internal consistency reliability (α: 0.78-0.85) (Azcurra, 2012) and validity supported by confirmatory factor analysis (Kane et al., 2003). The WIB scale was illustrated in the literature review chapter of this review (refer to section 2.4.6). The results showed a significant improvement in the SRQoL scores of the intervention group between the baseline test and the 12-week test (effect size: 0.267), and between the 12-week test and the 6-month test (effect size: 0.450). Yet, there was no statistically significant difference in WIB scores.

Table 7: Summary of Reminiscence Studies

Characteristic	Subramaniam et al. (2014)	Politis et al.	O'Shea et al. (2014)	Lai and Kayser-Jones	Azcurra (2012)
		(2004)		(2004)	
Objective	To evaluate the effect of	To evaluate the	To evaluate the	To investigate the	To investigate
	different pathways for	efficacy of a kit-	effectiveness of a	effect of a specific	whether a specific
	developing a life story	based activity	structured education-	reminiscence	reminiscence
	book (LSB) for people with	compared to	based reminiscence	program on the	program is
	dementia	control group	programme (the dementia	psychosocial	associated with
		involved in one-	education programme	wellbeing, compared	higher levels of QOL
		on-one meetings	incorporating	with the social	in nursing home
			reminiscence for staff) for	contact group and	residents with
			people with dementia	the usual care group	dementia
Measurements	Baseline (T0), post-test	Baseline (T0) and	Baseline (T0) and post-test	Baseline (T0), post-	Baseline (T0), post-
	(T1) at 12weeks after	post- test (T1) at	(T1) at 18-22 weeks	test (T1) at 6 weeks	test (T1) at 12 weeks
	immediate life review	4 weeks after		after immediate	after immediate
	intervention. After T1, life	immediate		intervention, and	intervention, and
	story books were given	intervention		follow-up (T2) at 6	follow up (T2) at 6
	and further test (T2) at 18			weeks after	months after
	weeks after baseline			intervention	intervention
Results	No difference in QOL	There was a	Intention-to-treat analysis:	Improved wellbeing	Improved QOL in the
	between the intervention	greater within	no difference in QOL	in the intervention	intervention group
	and control groups at T2.	group	between the intervention	group between T0	between T0 (23.3)
	Yet, at T1, QOL had	improvement in	and control groups.	and T1 in intention-	and T1 (27.1)
	improved in both groups	QOL ratings in the	Per-protocol analysis:	to-treat analysis	(intervention effect
	and there was a significant	control group	improved self-rated QOL		size=0.267) and T1
	between-group difference	(p=0.03)	in the intervention group		and T2 (34.6)
	in favour of the life review		compared to the control		(intervention effect
	intervention group		group (P=0.04).		size=0.450)

Characteristic	Subramaniam et al. (2014)	Politis et al. (2004)	O'Shea et al. (2014)	Lai and Kayser-Jones (2004)	Azcurra (2012)
Conclusion	The life review process and the creation of life story books have benefits for people with dementia, relatives and staff in care homes.	No clear advantage to the reminiscence- based intervention over the time and attention, one- on-one control intervention	Reminiscence may be an effective care option for people with dementia in long-stay settings with potential to impact positively on the QOL of residents	The intervention did not lead to significant differences between the three groups over time, there was a significant improvement in psychosocial wellbeing in the intervention group.	Improved QOL within the intervention group
Recommendation	Undertaking a life review requires training and supervision.	More research is needed to develop specific behavioural interventions	More work, including economic evaluation, is required to find positive and sustained effects in dementia populations in other care settings and care regimes	Reminiscence using a life story approach showed some promising effects on the wellbeing of people with dementia. More research is needed.	More focused research is needed to determine the effectiveness of features of reminiscence
Reviewers Comments	Advantage of life review and life story book	No clear advantage of the reminiscence- based intervention	Advantageous in reminiscence using recalling pleasant memory	Advantageous in reminiscence using life story. Cautious interpretation needed	Advantageous in reminiscence using life story

Table 8: Characteristics of Reminiscence Studies

Characteristic	Subramaniam et al. (2014)	Politis et al. (2004)	O'Shea et al. (2014)	Lai and Kayser-Jones (2004)	Azcurra (2012)
Study Design	RCT	RCT	Cluster RCT	RCT	RCT
Country	UK	USA	Ireland	Hong Kong	Argentina
Setting	Care home	LTC residential facility	Long-stay units	Nursing home	Nursing home
Total Participants (n)	24	37	304	101	135
Participants in Reminiscence Condition (n)	12	18	153	36	44
Participants in Control/Comparative Group (n)	11	18	151	30/35	44/44
Treatment Type of Intervention Group	12 weeks Life review and then 6 weeks life story book	The geriatric network kit	Reminiscence sessions by care staff in daily care context	Life story approach	Life story approach
Treatment Type of Control /Comparative Group	12 weeks usual care and then 6 weeks life story book	One-on-one (unstructured social contact)	Usual care	Usual care/ Discussion (structured social contacts)	Administered counselling (informal social contact) / Unstructured social contact
Intervention Facilitators	Qualified clinical psychologist	Trained activity therapist	Nursing and healthcare assistant staff receiving a structured education reminiscence-based programme over 3 days	Research assistants: three social workers and one occupational therapist	Psychologists

Characteristic	Subramaniam et al., 2014	Politis et al., 2004	O'Shea et al., 2014	Lai & Kayser-Jones, 2004	Azcurra, 2012
Mean Age (SD)	86.48 (6.48)	83.95 (4.7)	85.4 (7.1)	85.7 (7.0)	85.7 (4.8)
Baseline MMSE (SD) /CDR Score	CDR: mild to moderate	MMSE: 9.5 (5.6)	MMSE: 12.34 (5.5)	MMSE: 9.3 (5.4)	MMSE: 13.9 (1.4)
Reminiscence Intervention Content	Individual life review on childhood, adolescence, adulthood and summary based on Haight's Life Review model and Life Review Experiencing Form	Individually treated, Structured conversation based on the kit, reflecting an individual's interests	Individually treated, the deliberate use of prompts including photographs, smells, music and questioning, to promote the recall of pleasant memories	Individually treated, discussion about individual life experiences	Individually treated, memory triggers, such as photographs, recordings and newspaper clippings were used to promote personal and shared memories in the context of guided conversations
Session Time, Frequency	1 hours/1 session × 1 session/week	30 min/1 session × 3 sessions/week	At least four sessions incorporating care planning	30 min/1 session × 1 session/week	1 hour/1 session × 2 sessions/week
Length of Intervention (the Number of Sessions)	12 weeks (12 sessions)	4 weeks (12 sessions)	18-22 weeks	6 weeks (6 sessions)	12 weeks (24 sessions)
Outcome	QOL	QOL	QOL	QOL	QOL
Outcome Measurement Scales	Proxy-rated QOL-AD version	AD-RQL	Self-rated and proxy- rated QOL-AD scales	DCM (WIB)	SRQoL, DCM (WIB)
Outcome Score (SD) of Intervention	36.9 (6.9) at T1	73.7 (16.0) at T1	Self-rated QOL: 35.22 (4.29) at T1 Proxy-rated QOL: 30.42 (6.31)	1.41 (0.24) at T1	SRQoL:27.1 (8.7) at T1 WIB: 1.2 (0.5) at T1

Characteristic	Subramaniam et al., 2014	Politis et al., 2004	O'Shea et al., 2014	Lai & Kayser-Jones, 2004	Azcurra, 2012
Outcome Score (SD) of Control/Comparison	35.5 (4.7) at T1	74.9 (14.5) at T1	Self-rated QOL: 31.77 (6.55) at T1 Proxy-rated QOL: 29.09 (6.02)	1.44 (0.32) at T1/ 1.42 (0.27)	SRQoL: 23.6 (5.8) / 23.9 (3.7) at T1, WIB: 1.5 (0.3) / 1.3 (0.9)
Outcome Scale	Higher scores indicate	Higher scores	Higher scores indicate	Higher scores indicate	Higher scores indicate
Direction	higher QOL	indicate higher QOL	higher QOL	higher QOL	higher QOL
Outcome Collection	By Interviewing	By Interviewing	Self-rated QOL and	By observing	Self-reported QOL
Method	participants	primary caregiver	caregiver-rated QOL	participants	and observation
Assessor or Rater	Single blinded	Partially-masked	Single blinded assessor	Single blinded raters	Single blinded raters
Blind to Allocation	assessor	rater			
Type of Randomisation	A sequential individual-based randomisation using a dynamic stratification algorithm	A table of random numbers, in blocks of four	Random allocation sequence using a computer generated random number list	Fixed allocation (computer created random numbers)	A fixed and equal allocation
Respondent Withdrawal	One participant from the intervention group died in week 7	One participant dropped out before randomisation	25 participants from intervention and 27 from control group	Six from intervention, three from control (no-intervention), and six from comparison group	Missing data 2.5%
Intention-to-Treat Analysis	No	N/A	Yes	Yes	No

## **Meta-analysis**

Meta-analysis was conducted to compute an estimate of effect size and to explore the extent of differences in effects of the intervention between included studies (JBI, 2014b). The extracted data from these studies were those measured right after the intervention was completed. Outcome measurements for defining the impact of an intervention in dementia need to be oriented to 'here and now' because of the deteriorating nature of dementia over time, which is likely to cover potential benefits from the intervention (Giroux, Robichaud, & Paradis, 2010; van de Ven et al., 2013). The data from 517 subjects retrieved from the included studies were entered for meta-analysis. Proxy-rated QOL data were entered in common, with the exception for the data from the study by Subramaniam et al. which reported administered self-rated QOL only.

Meta-analysis was performed including the use of SMD (see section 3.9) due to usages of different QOL scales across five studies. The random effect model was adapted in order to adjust for heterogeneity of trials regarding intervention contents and duration (refer to section 3.9). Statistical heterogeneity amongst studies was not high (p = 0.51). The direction of estimated effects in included studies showed subtle differences, but confidence intervals for each study lay across the value of no effect. The combined results from all studies did not show a significant effect of the reminiscence intervention (SMD= 0.09, 95% CI 0.08 to 0.27, p = 0.28) (Figure 2).

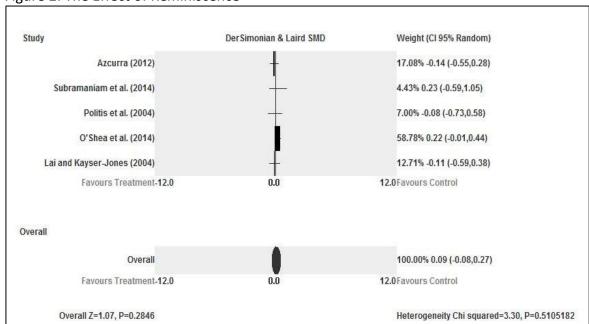


Figure 2: The Effect of Reminiscence

#### 4.4.2 Staff Training and Person-Centred Care Practice

Four studies regarding staff training involving person-centred care practice were cluster-RCTs. The staff training consisted of DCM, an awareness-based approach, a need-based practice, and person-centred care. They aimed to lead to person-centred care planning and practice. The summary of the four studies is presented in Table 9 and Table 10.

A study by van de Ven and colleagues (2013) investigated the effect of DCM on resident QOL, compared to usual care. DCM was used as a QOL measurement scale as well as a person-centred intervention. The DCM method as an intervention consisted of three components: observation, feedback, and action plans (Kuhn et al., 2000). During the observation period, trained staff quantified individual activities and interactions in residents with dementia, using the DCM observational tool. In the feedback phase, results gained from analysis of data collected from the DCM tool, were deliberated with

all care staff members. Then insight and feedback regarding the care setting were provided to support staff's care capacities for improvement of the resident's wellbeing and behaviours, followed by the staff's care plans reflecting the feedback. The study included 192 residents. QOL was measured using Qualidem and EQ-5D at the baseline and two follow-up times at 4-month intermissions. The findings indicated that there was no statistically significant effect of DCM on QOL.

Chenoweth et al. (2009) investigated the effects of the DCM treatment, personcentred care, and usual care on QOL of residents with dementia. The care staff trained to use DCM assisted their colleagues to practice person-centred care with the feedback of DCM data for 4 months. The staff in the person-centred care group attended a 2-day person-centred care training session, which included understanding, recognising and acknowledging behaviours or feeling of an individual resident. After training, care staff delivered person-centred care for a 4-month period, and this care practice had been supported through visits and telephone contact by a researcher. The QOL of residents in the treatment groups was measured by the QUALID scale at baseline, 4 months, and 8 months. There was no statistical improvement of QOL in both DCM and person-centred care groups.

Clare et al. (2013) carried out a cluster RCT comparing awareness-based staff training intervention with usual care, including 65 participants. Staff received awareness-based training incorporating identifying behavioural signs of residents with severe dementia into their daily practice, using the AwareCare observational measure. This was expected to be more likely to empower the trained staff to respond to the needs of the resident with severe dementia (Clare et al., 2012). QOL was measured by family and care

staff using QUALID at the baseline and follow-up. Analysis of covariance showed that there was a significant increase in family-rated QUALID scores in the intervention group at follow-up (F (1, 29) = 5.88, p = 0.022, effect size Cohen's d = 0.72) while there was no change in the staff rated QUALID scores (F (1, 57) = 0.31, p = 0.58).

Orrell and associates (2007) compared the intervention aiming to reduce residents' unmet needs with usual care in control groups. The intervention procedure involved researchers visiting residential care homes for 2 hours per fortnight for a 20-week period to discuss general observations and provide feedback or recommendations which helped to refine each resident's care plan. A resident's QOL was measured by both self-rated and proxy-rated QOL-AD scales at the baseline and at 20 weeks immediately after the intervention was completed. The results showed that there were no significant changes on QOL-AD scores in both the self-and proxy rated versions in the intervention group as compared to the usual care group.

Table 9: Summary of Staff Training and Person-Centred Care Studies

rable 31 Garminar	y or starr framming arrain erson ex			
Characteristic	van de Ven et al. (2013)	Chenoweth et al. (2009)	Clare et al. (2013)	Orrell et al. (2007)
Objective	To investigate the	To investigate the	To establish whether	To reduce unmet needs in
	effectiveness of DCM on	effectiveness of person-	training care staff to observe	older people with dementia
	resident and staff outcomes	centred care and DCM	and identify signs of	in residential care compared
		compared with each other	awareness in residents with	to a 'care as usual' control
		and with conventional	severe dementia resulted in	group
		dementia care	improved QOL for residents	
Measurements	Baseline (T0), test 1 (T1)	Baseline (T0), test 1 (T1)	Baseline (T0), and follow-up	Baseline (T0) and follow-up
	after first DCM cycle, and	directly after the 4 months	test (T1)	test (T1) at 20 weeks
	test 2 (T2) after second DCM	of intervention, and follow-		
	cycle	up test (T2) at 8 months		
Results	There was no statistically	There was no significant	Residents in the	There was no significant
	significant result of DCM on	difference in QOL in the	intervention group had	differences in either unmet
	QOL.	intervention groups	significantly better QOL as	needs or QOL
			rated by family members	
			than those in the control	
			groups, but care staff ratings	
			of QOL did not differ	
Canalysian	There was no confirmed	There were no statistically	Doloti, so of vocidonts in the	The weet the did not indicate
Conclusion	There was no confirmed effect of DCM on the QOL.	There were no statistically	Relatives of residents in the intervention homes	The results did not indicate that the intervention
	,	significant results for QOL as		
	Perhaps the variability of the	measured by QUALID	perceived an improvement	reduced unmet needs or
	extent of implementation of		in their QOL	improved QOL at follow-up
	DCM may explain the lack of			
De se se se se de t	effect.	Nieuwani in atuu waa auta ay ala aa	F. with an averagination is	Frontle and a constant in the second and
Recommendat	In order to inform daily	Newer instruments, such as	Further examination is	Further research is needed to show if increased
ion	practice, it is needed to	the DEMQOL, might be more	needed to improve	
	explore the relationship	apt for future studies as the	perceived QOL for people	intensity or duration of an
	between the extent of the	items of QUALID are more	with severe dementia in	intervention would be
	implementation and the	subtle experiences that	residential care settings	effective
D - '-	effectiveness of DCM	make judgement difficult	Daniel Communication of the Co	No december 5
Reviewers	No clear advantage of DCM	No clear advantage of	Benefit of awareness-based	No clear advantage of
Comments	intervention	intervention	staff straining	intervention

Table 10: Characteristics of Staff Training and Person-Centred Care Studies

Characteristic	van de Ven et al. (2013)	Chenoweth et al. (2009)	Clare et al. (2013)	Orrell et al. (2007)
Study Design	Cluster RCT	Cluster RCT	Pilot cluster RCT	Cluster RCT
Country	Netherlands	Australia	UK	UK
Setting	Care home	Nursing home	Care home	Care home
Total	192	289	65	238
Participants (n)				
Participants in	73	101/ 88	32	92
Intervention (n)				
Participants in	119	70	32	100
Control (n)				
Treatment Type	Two cycles of the 4-	DCM-intervention/ Person-	Awareness-based staff	Intervention to reduce
of Intervention	months DCM-intervention	centred care	training and person-	unmet needs and person-
Group	and person-centred care		centred care	centred care
Treatment Type	Usual care	Usual care	Usual care	Usual care
of Control				
Group				
Mean Age (SD)	84.7 (6.3)	83.9 (6.9)	83.5 (8.0)	86.4 (7.4)
Baseline MMSE	Not reported	Not reported	Severe dementia FAST	CDR: 2.0 (0.8), Severe
(SD) /CDR Score			stage 6 or 7	dementia
Staff Training	Phase 1: training in DCM	DCM was carried out by the	Week 1 and 2: two 90-	Researchers visited care
and Person-	Phase 2: organisational	authors and care staff and then	mintue training sessions	homes to discuss the unmet
Centred Care	briefing day for DCM	developed person-centred care	Week 3 to 8: six 10-	needs of residents and
Intervention	Phase 3: two DCM cycles	plans with nursing home staff	minute observation per	provided feedback on the
Content	of observations-feedback-	for residents/ Person-centred	week (total 36	care plans
	action plan	care including a 2-day training	observations)	
		session, two visits, and regular		
		telephone contact during the 4-		
		month intervention period		

Characteristic	van de Ven et al. (2013)	Chenoweth et al. (2009)	Clare et al. (2013)	Orrell et al. (2007)
Length of Intervention	About 8 months	4 months	Over 8 weeks	2 hours every fortnight for 20 weeks (10 times)
Outcome Measurement Scales	Qualidem, EQ-5D	QUALID rated by direct care staff	QUALID rated by family members and by care staff	QOL-AD self-report and staff-report
Outcome Score (SD) of Intervention	Qualidem (SE): 61.88 (2.10) EQ-5D Mean score (SE): 0.34 (0.03)	DMC intervention: QUALID: 23.4 (1.6) PCC: QUALID 21.5 (2.2)	QUALID family report: 19.00 (4.59) n=18 QUALID staff report: 23.28 (5.71) n=32	Self-rated QOL-AD: 30.4 (7.6), n=40 Proxy-rated QOL-AD: 27.2 (6.1)
Outcome Score (SD) of Control	Qualidem (SE): 63.72 (1.81) EQ-5D Mean score (SE): 0.41 (0.02)	QUALID: 23.7 (1.7)	QUALID family report: 22.11 (7.84) n=18 QUALID staff report: 22.03 (5.95) n=32	Self-rated QOL-AD: 33.7 (6.3), n=50 Proxy-rated QOL-AD: 29.9 (6.5)
Outcome Scale Direction	Higher scores indicate better QOL	Lower scores indicate better QOL	Lower scores indicate better QOL	Higher scores indicate better QOL
Outcome Collection Method	Care staff report in both Qualidem and EQ-5D	Proxy rating	Family report and staff report	Resident and staff report
Assessor Blind to Allocation	Assessor not blinded (van de Ven et al., 2012)	Assessor blinded	Assessor blinded	Assessor blinded
Type of Randomisation	Minimisation method	Balanced incomplete-block, complete-block randomisations	Paired block randomisation	Block randomisation
Respondent Withdrawal	28 lost to attrition and 34 newly included during the study period in the intervention group, 29 lost to attrition and 19 newly included in the control group	14 lost in the DCM group, 21 lost in the person-centred care group, and 18 lost in the Usual care group	One enrolled resident died before baseline members	26 lost in the intervention group while 20 lost in the control group
Intention-to- Treat Analysis	Yes	Yes	Yes	No

## **Meta-analysis**

Four cluster RCTs evaluated the effect of staff training which lead to personcentred care practice in common, thus they were appropriate for meta-analysis. Data from 298 participants in the combined intervention group and 321 participants in the combined control group were analysed. The random effect model was used due to heterogeneity of the trials, and SMD was adapted as different QOL scales were used. While all data were entered without any adjustment, the data of the QUALID were adjusted by multiplying by -1 due to a different QOL measurement direction where the lower scores of QUALID implied higher QOL. The SMD was – 0.17 with a 95% confidence of interval -0.39 to 0.06, indicating that the effect of the staff training intervention was not significantly different between the intervention group and the control group (Figure 3). The study by Orrell et al. (2007) did not include the value of no effect, indicating a statistically significant effect in the intervention group.

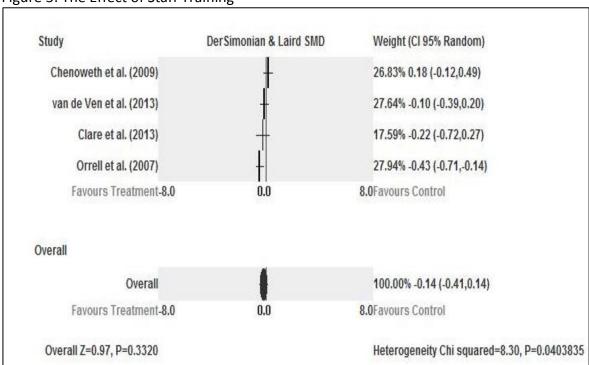


Figure 3: The Effect of Staff Training

## 4.4.3 Cognitive Stimulation Therapy

CST involves diverse activities such as word games, orientation, and current affairs, which are intended to enhance general cognitive functioning (Spector et al., 2003; Yamanaka et al., 2013). Only two studies using CST were identified as measuring QOL with valid scales. The summary of each study is presented in Table 11 and Table 12.

Yamanaka and associates (2013) examined the effect of the Japanese version of group CST on people with dementia compared to usual care with 56 participants. The Japanese version was developed from a group CST program established by Spector et al. (2003) and was administered in accordance with Japanese culture. Residents in the group CST were involved in small group-based activities such as physical activity, clapping hands to music, describing childhood memories and food, discussing current affairs, quizzes, word associations, and orientation for about 45 minutes twice a week for seven weeks. The QOL of residents was measured through resident-rated and staff-rated versions in both EQ-5D and QOL-AD at the baseline and at seven weeks. The two versions of QOL-AD scale were valid and reliable as previously illustrated (refer to section 2.4.6). The EQ-5D is an instrument measuring health-related, non-disease-specific QOL (Gerritsen et al., 2011). The results showed that the staff-rated EQ-5D scores significantly improved within the intervention group at the 7-week test compared to that at baseline (p = 0.019). Yet, there were no significant changes in self-rated EQ-5D and self-rated QOL-AD scales, and the staff-rated QOL-AD scales.

The study conducted by Orrell and colleagues (2005) examined the effect of maintenance cognitive stimulation therapy (MCST) for people with dementia with 35 participants. This MCST study was intended to identify the long-term benefits of CST,

following on from the previous CST study (refer to section 4.2.2). This study compared three different treatments; MCST group, CST only group, and no CST group. Participants in the MCST group attended weekly sessions of MCST for 16 weeks. The CST only group received usual care after finishing the 7 weeks of the CST program in the previous study, and the no CST group received usual care from the baseline of the previous study as a control group. The QOL of residents was measured using the self-rated QOL-AD scale at baseline of the previous CST program, at 7 weeks after the initial CST program, and at 23 weeks from the baseline after MCST. The findings showed that there were no effects of MSCT on QOL of people with dementia.

Table 11: Summary of Cognitive Stimulation Therapy Studies

Characteristic	Yamanaka et al. (2013)	Orrell et al. (2005)
Objective	To examine the effects of cognitive stimulation therapy Japanese version (CST-J) on cognitive function, QOL and mood in people with mild-to-moderate dementia	To investigate whether the benefits in cognition and QOL could be maintained through participation in 16 further weekly sessions, in comparison with a group of people who participated in the initial CST programme but did not receive maintenance CST
Measurements	Baseline (T0) and post-test (T1) at 7 weeks after immediate intervention	Baseline (T0), post-test (T1) at 7 weeks after initial CST program, and post-test (T2) at 23 weeks from baseline after MCST
Results	Staff-rated EQ-5D was a significant improvement within the intervention group over the study period (p=0.019), and the staff-rated QOL-AD showed a positive trend (p=0.06), although not when rated by the participants themselves	There were no effects on QOL following maintenance sessions
Conclusion	The CST-J showed promising improvements in cognition, mood, and aspect of QOL for people with dementia in Japanese care settings	Benefits in QOL, as found following CST, were not maintained, suggesting that weekly sessions might not be sufficient to impact on QOL
Recommendation	A large RCT is needed	A large-scale, multi-centre maintenance CST trial is required to clarify potential longer-term benefits of maintenance CST for dementia
Reviewers Comments	Benefit of CST	Potential benefit of maintenance-CST

Table 12: Characteristics of Cognitive Stimulation Therapy Studies

Characteristic	Yamanaka et al. (2013)	Orrell et al. (2005)
Study design	A single-blind controlled clinical trial	Pilot pseudo-RCT
Country	Japan	UK
Setting	Residential home and nursing home	Residential home
Total Participants (n)	56	35
Participants in	26	8
Intervention (n)		
Participants in	30	12/15
Control/Comparative		
Group (n)		
Treatment Type of	CST Japanese version	Maintenance-CST
Intervention Group		
Treatment Type of Control	Usual care	Only CST/ Usual care
/Comparative Group		
Intervention Facilitators	Researcher	Researcher (therapist; although unclearly stated, based
		on the previous CST study report)
Mean Age (SD)	83.91( 5.98)	84.2
Diagnosis	Dementia	Dementia
Baseline MMSE (SD) /CDR	CDR: 1.28 (0.57)	MMSE: 13.2 (3.6)
Score		
<b>CST Intervention Content</b>	Small group-based, physical games, sound,	Childhood, current affairs, number game, quiz, music
	childhood, food, current affairs, recognition of	session, physical games, categorising things, using
	faces, word associations, being creative,	objects, useful tips, golden expressions cards, opinions,
	categorizing objects, orientation, using money,	famous faces, word completion
	number games, word games, team quiz	
Session Time, Frequency	About 45 minutes/session × 2 sessions/week	1 session/week
Length of Intervention	7 weeks (14 sessions)	16 weeks (16 sessions)
(the Number of Sessions)		

Characteristic	Yamanaka et al. (2013)	Orrell et al. (2005)
Outcome	QOL	QOL
Outcome Measurement	Self-rated and proxy-rated QOL-AD scales, and self-	Self-rated QOL-AD
Scales	rated and proxy-rated EQ-5D scales	
Outcome Score (SE or SD)	Self-rated QOL-AD: 28.59 (1.19)	Self-rated QOL-AD 35.67 (3.83) at T2
of Intervention	Self-rated EQ-5D: 0.74 (0.05)	
	Proxy-rated QOL-AD: 28.65 (1.02)	
	Proxy-rated EQ-5D: 0.65 (0.04)	
Outcome Score (SE or SD)	Self-rated QOL-AD: 28.19 (1.20)	Self-rated QOL-AD: 29.25 (5.12) / 34.33 (7.97) at T2
of Control/Comparison	Self-rated EQ-5D: 0.80 (0.05)	
	Proxy rated QOL-AD: 28.13 (0.94)	
	Proxy rated EQ-5D: 0.54 (0.04)	
Outcome Scale Direction	Higher scores mean higher QOL	Higher scores mean higher QOL
Outcome Collection	Self-report and care worker-report	Self-report
Method		
Assessor or Rater Blind to	Raters (care workers) were not blinded	Not clearly stated, but assumed that the assessor blinded
Allocation		in a basis of the previous study (Spector et al., 2003)
Type of Randomisation	Alternative allocation (as 'quasi-random')	Voluntary participations for MCST, randomisation was not
		clearly presented, but randomisation completed in the
		previous study
Respondent Withdrawal	One intervention participant dropped and two	One person had dropped out from both original CST
	treatment participants refused post-intervention	groups
	assessment. Six participants in the control group	
	refused post-intervention assessment	
Intention-to-Treat Analysis	Yes	Not mentioned, but may be yes based on the inference
		that the previous study used intention-to-treat analysis

## **Meta-analysis**

Data from the two CST studies were pooled for meta-analysis. The features of the population, such as age and severity of dementia were similar to some extent and both studies tested the effects of CST and usual care. Both studies reported quantitative outcomes, which allowed analysis exploring the level of differences in effects of CST between the two studies. Meta-analysis was conducted using the random effect model due to the heterogeneity of the trials, and weighted mean differences were used as both studies reported the same self-rated QOL-AD scales. Outcome data measured right after the interventions were used for the meta-analysis. The computed results showed WMD of 0.7 and a 95% confidence interval was -2.03 to 3.43 (p = 0.62), indicating that there was no significant difference between the CST group and the usual care group (Figure 4). The estimate of effect of treatment was more favourable in the usual care group than the CST while the results did not show any statistical significance.

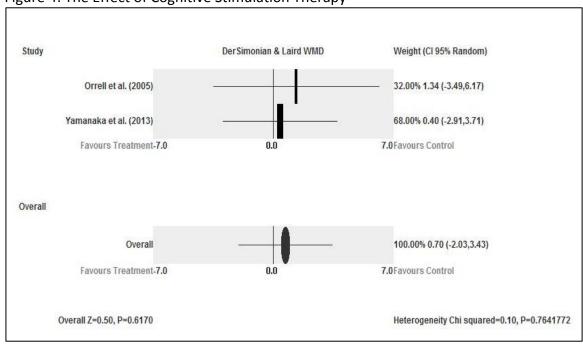


Figure 4: The Effect of Cognitive Stimulation Therapy

## **4.4.4 Physical Exercise Intervention**

Two studies using a physical exercise intervention were identified. Table 13 and Table 14 show the summary of each study.

The study conducted by Williams and Tappen (2007) examined the effect of three types of behavioural interventions on affect and mood in nursing homes, using a pre-post design, including 90 participants with dementia. The three types of treatments were comprehensive exercise, supervised walking, and social conversation. All treatments were provided individually for about 15-30 minutes per session, five sessions per week, over 16 weeks, yielding a total of 80 sessions. Participants in the comprehensive exercise group undertook strength, balance, and flexibility exercises for 10 minutes, followed by 20-mintues of walking. The supervised walking group walked at their own pace in accordance with their abilities for up to 30 minutes. The social conversation group was involved in casual conversation in each participant's room for about 30 minutes. Although the authors used the Lawton's Observed Affect Scale to measure the affect status of each participant, the scale has been also regarded as a valid QOL scale (Lawton, 1997; Sloane et al., 2005).

The Observed Affect Scale developed by using 6 of the 10 items from the Philadelphia Geriatric Center Positive and Negative Affect Rating Scales, consists of six adjectives presenting positive and negative affect states: pleasure, interest, contentment, sadness, anxiety and anger (Lawton, VanHaitsma, & Klapper, 1996). An observer rates the occurrence of observed affect using a 5-point score during a 10-minute period and also scores the participant over the previous 2 weeks. In positive affect states, higher scores mean a better wellbeing state while in negative affect states higher scores mean a poorer

affect state. This scale has an acceptable inter-rater reliability coefficient ranging from 0.76 to 0.89. Discriminant and convergent validity was proved by correlation with the status indicators of residents with Alzheimer disease in LTC facilities (Lawton et al., 1996). The outcome measurement was taken at the baseline and at 16 weeks immediately after the provision of the intervention. The results showed that participants receiving comprehensive exercise presented higher positive and lower negative affect and mood scores. Two subscales of the Lawton observed affect four subscales demonstrated significant changes between treatment groups. With the 10-minute observed negative affect scale, the comprehensive exercise group revealed a significantly lower negative affect score, compared to the social conversation (p = 0.0343) and the walking group (p=0.0502). However, the 10-minute observed positive affect scores were not significantly different between treatment groups. In terms of the 2-week observed positive affect scores, the score of the comprehensive exercise group was significantly higher than either the conversation group (p = 0.0065) or the supervised walking group (p = 0.0101). Yet, the 2-week observed negative affect scores had no significant differences between groups.

Conradsson and associates (2010) evaluated the effects of a high-intensity functional exercise program on psychological wellbeing in older persons with and without dementia, using a cluster-RCT. This study reported separate data for people with dementia. Participants received a high-intensity functional exercise program and practiced functional tasks that are usual in daily life as well as performing weight-bearing exercises. This program was intended to improve lower-limb power, balance and walk ability. Control activity included sitting, watching films, singing, and conversation. Both

treatments were implemented for 45 minutes five times over 2 weeks, repeated for 3 months. Psychological wellbeing was measured using PGCMS at the baseline and at 3 months after immediate intervention and also at 6 months. The findings showed that there was a significantly higher PGCMS score in the exercise group than the control group (the between-group mean difference = 1.12, 95% CI = 0.09 to 2.16, p = 0.03) at 3 months.

## Inappropriateness for meta-analysis

These two studies were considered as unsuitable for meta-analysis due to severe heterogeneity and incompatible results. While Conradsson et al. (2010) employed a well-designed cluster RCT, the study by Williams and Tappen (2007) was not clear in randomisation and allocation concealment, which may have led to overestimate or underestimate treatment effect (Glasziou & Sanders, 2002). Furthermore, QOL outcomes reported by Williams and Tappen (2007) included inconsistent and separate subscale scores of QOL, which did not allow combining the results for meta-analysis.

Table 13: Summary of Physical Exercise Intervention Studies

Characteristic	Williams and Tappen (2007)	Conradsson et al. (2010)
Objective	To examine the change over 16 weeks in affect and mood in nursing home residents with AD who participated in a comprehensive exercise program or a supervised walking program, and compare their outcomes to those receiving an attention control intervention.	To evaluate the effects of a high-intensity functional exercise programme on depressive symptoms and psychological wellbeing among older people dependent in activities of daily living (ADL) and living in residential care facilities
Measurements	Baseline (T0) and Post-test (T1) at 16 weeks after immediate intervention	Baseline (T0), post-test (T1) at 3 months after immediate intervention and further test (T2) at 6 months after baselines
Results	At post-test, participants receiving comprehensive exercise exhibited higher positive and lower negative affect and mood. The social conversation group exhibited the lease positive and most negative mood and affect.	Among people with dementia, there was a between-group difference at 3 months in PGCMS scores in favour of the exercise group.
Conclusion	Exercise programs may be emphasized in LTC, particularly whole-body involvement rather than walking alone	An exercise programmes as a single intervention may have a short-term effect on wellbeing among people with dementia
Recommendation	Potential physiological responses to the interventions and measures of disturbed behaviour should be investigated in future studies.	Exercise alone may not be the optimal treatment. A combination of individualised interventions may also be needed
Reviewers Comments	Advantage of exercise	Advantage of exercise

Table 14: Characteristics of Physical Exercise Intervention Studies

Characteristic	Williams and Tappen (2007)	Conradsson et al. (2010)
Study Design	Pre-post design	A cluster-RCT
Country	US	Sweden
Setting	LTC facility	Residential care facility
Total Participants (n)	90	100
Participants in Exercise (n)	30	47
Participants in	29/31	53
Control/Comparative Group (n)		
Treatment Type of	Comprehensive exercise	High intensity exercise program
Intervention Group		
Treatment Type of Control	Social conversation/Supervised walking	Control activity
/Comparative Group		
Intervention Facilitators	Graduate nursing and physical therapy students	Physiotherapists (PTs)
	trained and supervised by the investigators	
Mean Age (SD)	88 (6.32)	Mixed data 84.7 (6.5)
Diagnosis	AD	Dementia
Baseline MMSE (SD) /CDR	MMSE: 10.37 (7.60), range 0-28	Mixed data having people with or without dementia,
Score		17.8 (5.1), range 10-30
Exercise	10 minutes of strength, balance, and flexibility	High-intensity functional weight-bearing exercise:
Intervention Content	exercises followed by about 20-minute walking.	Lower-limb strength, balance and gait ability
Session time, Frequency	Individually,	45mins/session × 5 sessions/ 2 weeks
	15-30mins/session × 5 sessions/week	
Length of intervention (the	16 weeks (80 sessions)	3 months (29 sessions)
Number of Sessions)		
Outcome	Subjective wellbeing	Subjective wellbeing
Outcome Measurement Scales	Lawton's OAS	PGCMS

Characteristic	Williams and Tappen (2007)	Conradsson et al. (2010)	
Outcome Score (SE) of	Lawton OAS 10-minute negative: 2.55	11.72 (0.38) at T1	
Intervention	Lawton OAS 2-week positive: 11.11		
Outcome Score (SE) of	Lawton OAS 10-minute negative: 4.78/4.11	10.60 (0.35) at T1	
Control/Comparison	Lawton OAS 2-week positive: 9.14/9.65		
Outcome Scale Direction	In positive subscales higher scores indicate greater positive affect.  In negative subscales higher scores indicate greater		
	negative affect.		
Outcome Collection Method	By family rating affect frequency scales over 10-minute observation By researcher rating affect rating scale over 2 weeks based on direct behaviour observation (Lawton, 1996; 1997)	By interviewing participants (Interviewer-administered)	
Assessor or Rater Blind to Allocation	Blinded rater	Blinded assessor	
Type of Randomisation	Unclear	Randomisation using lots in sealed non-transparent envelopes	
Respondent Withdrawal	19 dropped out prior to pretesting and 26 unable to complete the study after pretesting. Not precisely described.	Not reported for dementia group	
Intention-to-Treat Analysis	No	Yes	

## 4.4.5 Pharmacology-Related Treatment

There were two studies examining medication withdrawal and one study testing the effect of an analgesic on QOL of people with dementia in residential aged care. Table 15 and Table 16 show the summary of included studies. Discontinuation of medication is expected to improve QOL without symptom deterioration by reducing the side effects of the medication and those of combined drug effects (polypharmacy) (Ballard et al., 2004; Bergh et al., 2012), however, two included studies for this review failed to show the effectiveness of medication discontinuation on QOL. The other study reporting the effect of acetaminophen showed an increase in positive social and physical activities but failed to show improvement in emotional wellbeing.

Ballard and colleagues (2004) conducted a double-blinded RCT, including 100 participants, to investigate the effect of a 3-month neuroleptic withdrawal on QOL of people with mild-to-severe dementia. Participants who had been taking neuroleptics for 3 months and over, were randomised to neuroleptic or placebo treatment groups, and treatment was sustained for a 3-month period. QOL was measured using the WIB scale of DCM. Inter-rater reliability in DCM raters of this study was kappa values of more than 0.8, indicating an acceptable reliability of the WIB scale being used. The results indicated that there was no significant difference in QOL improvement between the neuroleptic withdrawal group and the placebo group (z = 0.77, p = 0.44).

A double-blinded RCT by Bergh et al. (2012) tested the effect of antidepressant withdrawal in 128 participants with mild-to-severe dementia and neuropsychiatric symptoms. There were 63 patients in the antidepressant discontinuation group and 65 patients in the continuation group. QOL was measured by self-rated and proxy-rated

QOL-AD scales at the baseline, 4, 7, 13 and 25 weeks. The results indicated that there was no difference of the level of QOL between the intervention group and control group (p = 0.314).

Chibnall et al.'s (2005) double-blinded cross-over RCT evaluated the effect of analgesic medication, acetaminophen, on the emotional wellbeing of people with moderate-to-severe dementia in nursing homes. Participants in the intervention group received acetaminophen for 4 weeks while those in the placebo group received a placebo for 4 weeks. Emotional wellbeing was measured using WIB and BCCs of DCM. The BCCs were quantified into time spent in accordance with 26 domains of behaviours. The results showed that there was no difference between the intervention and placebo groups in WIB scores (p = 0.80). However, when participants received acetaminophen they were more involved in activities such as media engagement (F (1, 22) = 7.4, p = 0.01), work-like activity (F (1, 23) = 4.0, p = 0.06), direct social interaction (F (1, 23) = 4.1, p = 0.05), passive social involvement (F (1, 22) = 9.1, p = 0.06) and talking to themselves/imaginary others (F (1, 23) = 5.7, p = 0.03). Furthermore the participants spent less time in independent self-care activity (F (1, 23) = 6.2, p = 0.02), in their rooms (F (1, 23) = 4.9, p = 0.04) and less time removed from the nursing home unit (F (1, 24) = 4.4, p = 0.047) when they received acetaminophen.

## Inappropriateness for meta-analysis

The three included medication-related trials were not suitable for meta-analysis due to heterogeneous features of the medication included. Two studies investigating medication discontinuation included antipsychotics and antidepressants, which were not

similar enough to be pooled for meta-analysis (Ballard et al., 2004; Bergh et al., 2012).

The other study tested an analgesic (Chibnall et al., 2005).

Table 15: Summary of Pharmacology-Related Studies

Characteristic	Ballard et al. (2004)	Bergh et al. (2012)	Chibnall et al. (2005)
Objective	To examine the impact of neuroleptic withdrawal on QOL	To determine the effect of discontinuing antidepressant treatment in people with dementia and neuropsychiatric symptoms	To evaluate the effect of regularly scheduled administration of analgesic medication on behaviour, emotional wellbeing, and use of as-needed psychotropic medications in nursing home residents with moderate-to-severe dementia
Measurements	Baseline (T0), 1 month (T1), 3 months (T2)	Baseline (T0), 4 (T1), 7 (T2), 13 (T3), and 25 (T4) weeks	Crossover RCT, in a 4-week period of each study phase
Results	Although there was a 15% improvement in wellbeing in patients allocated to placebo compared with a slight deterioration for those continuing to receive neuroleptics, these differences were not statistically significant.	There was no difference in the level of QOL between the intervention group and control group.	Participants who took acetaminophen spent more time in social interaction, engaged with media, talking to themselves, engaged in work-like activity, and experiencing unattended distress when they received acetaminophen than they did when they received placebo. The participants also spent less time in their rooms, less time removed from the nursing home unit, and less time performing personal care activities when they received acetaminophen. There were no effects on emotional wellbeing.
Conclusion	There was no evidence that discontinuing neuroleptic treatment improves QOL	There were no statistically significant changes in QOL, activity of daily life function, or side effects	Routine analgesic caused higher levels of general activity in participants but did not improve emotional wellbeing.
Recommendati on	A standardised evaluation with an instrument such as the NPI may be a clinical indicator of which people with dementia are likely to benefit from discontinuation of neuroleptic treatment.	Antidepressants could be discontinued in most patients with dementia as 86% of the patients in the discontinuation group tolerated the discontinuation, but these patients should be monitored carefully to identify those with worsening depressive symptoms	Future studies must address whether similar patterns of findings would occur with different inclusion/exclusion criteria such as dementia severity
Reviewers Comments	Unclear benefit	Unclear benefit	Unclear benefit

Table 16: Characteristics of Pharmacology-Related Studies

Table 10. Characteristic	3 of Friatmacology Neiated Studies		
Characteristic	Ballard et al. (2004)	Bergh et al., 2012	Chibnall et al., 2005
Study Design	Double blinded RCT	Double blinded RCT	Double blinded crossover RCT
Country	UK	Norway	USA
Setting	Residential or nursing home facilities	Nursing home	Nursing home
Total Participants (n)	100	128	25
Intervention (n)	36	35	25
Control (n)	46	46	25
Treatment Type of	Placebo (Neuroleptics 3-month	Discontinue antidepressant treatment	Participants received 3 times a day for 4 weeks
Intervention Group	discontinuation)	(Placebo)	of Acetaminophen and 4 weeks of placebo
Treatment Type of	Neuroleptics	Antidepressant treatment	4 weeks of placebo and then 4 weeks of
Control Group			Acetaminophen
Mean Age (SD)	83.3 (8.1)	85.7 (7.4)	85.9 (7.4)
Baseline MMSE (SD)	MMSE:5.5 (6.6) / CDR: 2.5 (0.7)	CDR: 2.3	Not stated (Inclusion criteria: moderate-to-
/CDR Score	Range from mild to severe	Range from mild to severe	severe dementia)
Length of	3 months	Antidepressant discontinuation for over one	Intervention for 4 weeks and 1 week washout,
Intervention		week during a 25-week study period	then placebo for 4 weeks
Outcome	DCM	QOL-AD self-report, proxy-report (caregiver)	DCM Type 1 and 2 behaviour categories
Measurement Scales			WIB
Outcome Score (SD)	2.68 (1.72) at T1	QOL-AD self-report: 32.80 (7.12) n=26	DCM Type 1: 21.3 (2.2), DCM Type 2: 15.4 (1.7)
of Intervention		QOL-AD proxy-report: 29.89 (6.57)	WIB: 7.8 (0.5)
Outcome Score (SD)	2.35 (2.41) at T1	QOL-AD self-report: 35.87 (4.95) n=31	DCM Type 1: 20.7 (1.3)
of		QOL-AD proxy-report n=45: 29.11 (5.12)	DCM Type 2: 14.2 (1.8)
Control/Comparison			WIB: 7.8 (0.5)
Outcome Scale	Higher scores mean higher wellbeing	Higher scores mean higher QOL	Higher scores mean higher wellbeing
Direction			
Outcome Collection	Direct observation	Self-report and proxy-report	Direct observation
Method			
Respondent	At T1 point, 10 participants dropped	4 participants dropped out in the	One was removed in week 3 (intervention
Withdrawal	out in the neuroleptic withdrawal	antidepressant withdrawal group, and 7	phase), and the other dropped in week 4
	group and 8 participants in the	participants dropped out in the antidepressant	(placebo phase)
	neuroleptic continuation group	continuation group	
Intention-to-Treat	No	No	Yes

#### 4.4.6 Other Interventions

Three different studies reported effects of music, companion robot, and aromatherapy respectively. The summary of each study is presented in Table 17 and Table 18.

Cooke and associates (2010) undertook a double-blinded, cross-over RCT with a music intervention group and a reading control group. The intervention and control group treatments ran for 40 minutes, three times per week for 8 weeks with 47 participants. Subsequently, participants of each group crossed over into the other treatment and the procedure was repeated. A 5-week wash-out period was allowed between cross-over in order to lessen potential carry-over effects. Music intervention sessions consisted of a musician-led group activity for 30 minutes and pre-recorded instrumental music for 10 minutes. Participants in the music intervention group were encouraged to be actively involved through singing, playing musical instruments and, movement if appropriate. The reading control sessions included diverse reading and social activities such as reading local news stories, playing jokes and quiz activities. The specific outcome of QOL was measured using the DQOL at baseline, midpoint after the first 8-week treatment arm and post-intervention after the second 8-week treatment arm. The music intervention did not significantly affect levels of QOL in older persons with dementia in residential facilities. However, sub-analysis of participants showed that being presented in over 50% of music sessions demonstrated a significant improvement in DQOL self-esteem scores (F (2, 46) = 4.471, p < 0.05).

Moyle and associates (2013) conducted a pilot double-blinded, cross-over RCT with an intervention group providing companion robots called PARO and a reading control

group. Both treatments ran for 45 minutes, three times per week, for 5 weeks. Participants in each group then crossed over into the opposite treatment and the procedure was repeated. Between the cross-over a 3-week wash-out period existed in order to minimise the probable carry-over effects. PARO is a therapeutic companion robotic seal intended to evoke an emotional response and to develop the socialisation of persons with others through interaction with PARO. The PARO intervention group was encouraged to have a conversation about PARO and to touch PARO while the reading control group was facilitated by reading to participants who were encouraged to look at pictures and to engage in social contact by becoming involved in questions about the readings. QOL-AD was used to measure the level of QOL of each participant. The result showed that PARO treatment had a positive, clinically significant influence on the QOL-AD (d = 0.6 to 1.3), and with 4.48 on reliability change index (scores  $\geq 1.96$  are statistically significant).

Ballard and colleagues (2002) undertook a placebo-controlled trial, investigating the effectiveness of a Melissa oil aromatherapy intervention with 72 participants. Treatment procedures were delivered in the same way in both intervention and control groups except for an aromatherapy treatment. Melissa oil (the intervention) or sunflower oil (the placebo) was applied on each participants' face and both arms two times a day over 4 weeks. The time to complete the cream application to the skin took around 1 to 2 minutes. BCCs of DCM were used to measure participants' QOL. In the Melissa intervention group, a 5.6% decrease of time in socially withdrawn behaviour and a 6.2% increase of time in constructive activities were shown to be significant.

# Inappropriateness for meta-analysis

Three included trials had high heterogeneity with respect to interventions and cointerventions, which were music, companion-robot, and aromatherapy. It was not feasible to combine the data for meta-analysis.

Table 17: Summary of Other Interventions

Characteristic	Music	Emotion	Aromatherapy
	Cooke et al. (2010)	Moyle et al. (2013)	Ballard et al. (2002)
Objective	To investigate the effect of live music	To compare the effect of companion	To determine the value of
	on QOL and depression in 47 older	robots (PARO) with the effect of the	aromatherapy with essential oil of
	people with dementia	reading group on emotions in people	Melissa officinailis (lemon balm) for
		living with moderate-to-severe dementia	agitation in people with severe
		in residential care setting	dementia
Measurements	Baseline (T0), midpoint (T1), and post-	Baseline (T0), midpoint (T1), and post-	Baseline (T0), and post-intervention (T1)
	intervention (T2)	intervention (T2)	
Results	The control group reported higher	PARO was found to have a positive,	QOL indices improved significantly more
	midpoint feelings of belonging than	moderate to large influence on the QOL-	in people receiving Melissa essential
	the music group (F (1, 45) = 6.672,	AD (effect size=0. 6 to 1.3). The PARO	balm oil (Mann-Whitney U test;
	p<0.5). Sub-analyses of over 50%-	group had higher QOL-AD when	percentage of time spent socially
	music session attendance found	compared to the reading group.	withdrawn: Z=2.6, p=.005; percentage of
	improvements in self-esteem over		time engaged in constructive activities:
	time (F (2, 46) = 4.471, p <0.5)		Z=3.5, p=.001).
Conclusion	Music intervention did not	Finding suggest PARO may be useful as a	The finding that aromatherapy with
	significantly affect levels of QOL in	treatment option for people with	Melissa essential balm oil is a safe and
	older people with dementia, but the	dementia	effective treatment for clinically
	results suggested that both the music		significant agitation in people with
	and reading group activities offered		severe dementia.
	opportunities to improve sense of		
	belonging, self-esteem and depressive		
	symptoms in some older people with		
	dementia		
Recommendation	Further research is needed	A larger trial is needed	Further controlled trials are needed
Reviewers	Potential benefit of music	Benefit of companion robots	Possible benefit of Melissa balm oil
Comments	intervention		treatment

Table 18: Characteristics of Other Interventions

	NA	Facation	A
Characteristic	Music	Emotion	Aromatherapy
	Cooke et al. (2010)	Moyle et al. (2013)	Ballard et al. (2002)
Study Design	Double blinded cross-over RCT	A pilot double blinded cross-over RCT	Double blinded, controlled trial
Country	Australia	Australia	UK
Setting	Aged residential care facility	Residential care facility	Residential care facility
Total Participants (n)	47	18	72
Participants in	47	18	36
Intervention Condition (n)			
Participants in Control	47	18	36
Group (n)			
Treatment Type of	Music	Companion robots (PARO)	Melissa essential oil
Intervention Group			
Treatment Type of Control	Reading	Reading	Sunflower oil
Group			
Intervention Facilitators	Musician	Bachelor degree-educated activity	Staff
		therapist	
Mean Age (SD)	86.27	85.3 (8.4)	78.5 (8.1)
Baseline MMSE (SD) /CDR	MMSE: 16.5 (6.7)	MMSE: 7.4 (5.0)	Not reported, but CDR stage 3 was
Score			confirmed in the study screen stage
Intervention Content	30 mins of musician-led familiar	Discussion about and touching PARO	Melissa oil was applied topically to
	song singing and 10 mins of pre-	being passed around the intervention	the patient's face and both arms
	recorded instrumental music for	group	
	active listening		
Session Time, Frequency	40mins × 3 times/week	45 mins × 3 times/week	About 2 minutes × 2 times/day ×
	·		7days
Length of Intervention	8 weeks (24 times)	5 weeks (15 times)	4 weeks (42 times)
(the Number of Sessions)			
Outcome	QOL	QOL	QOL

Characteristic	Music	Emotion	Aromatherapy
	Cooke et al. (2010)	Moyle et al. (2013)	Ballard et al. (2002)
Outcome Measurement Scales	DQOL	Modified QOL-AD	DCM BCCs
Outcome Score (SD) of Intervention	DQOL feeling of belonging: 3.17 (95% CI: 2.92, 3.41)	37.2 (8.2)	5.6% reduced time spent socially withdrawn 6.2% increased time engaged in constructive activities
Outcome Score (SD) of Control	DQOL feeling of belonging: 3.61 (95% CI: 3.35, 3.87)	26.4 (16.8)	<ul><li>1.4% increased time spent socially withdrawn</li><li>9.4% decreased time engaged in constructive activities</li></ul>
Outcome Scale Direction	Higher scores reflect higher QOL	Higher scores reflect higher QOL	Not applicable
Outcome Collection Method	Resident-rated by interview	Trained research assistants measured QOL (unclearly state whether QOL was measured by a resident interview or a care provider interview)	Observation
Assessor or Rater Blind to Allocation	Assessor blinded	Assessor blinded	Assessor blinded (But, high possibility to be detected)
Type of Randomisation	Computer-generated program to conduct the randomisation process	Computer-generated program to determine the different ordering of treatments for each participant.	Using the toss of a coin
Respondent Withdrawal	3 participants withdrawal before midpoint and then 16 participants withdrawal before final data collection	Not reported	One participant in the intervention group decease during the study
Intention-to-Treat Analysis	Yes	No	No

### 4.5 Conclusion

This chapter has covered an explanation of eligible studies according to preestablished search strategies, the results after study quality appraisal and data extraction in included studies are presented. As a result, six categories of interventions were classified in accordance with the characteristics of interventions in 19 studies. The outcomes of each study were presented in a narrative way in order to provide summarised information regarding the effect of a particular intervention on QOL. Meta-analyses were conducted where the studies and data were homogenous or similar enough for meta-analysis. Accordingly, 11 studies including reminiscence, staff training, and CST were used for meta-analysis.

In the next chapter, in order to find the most effective intervention for improved QOL of residents with dementia in LTC, the overall effect of a particular category of intervention will be discussed. For this, the GRADE approach was used, which will be beneficial for decision makers using this review by providing information regarding both strengths and limitations of the detailed studies, and a comprehensive evaluation of the quality of a body of evidence.

### **CHAPTER 5: DISCUSSION**

This systematic review has explored the impact of six different categories of interventions on QOL of residents with dementia in LTC. The results of this review indicate that reminiscence, staff training, physical exercise, CST, music, companion-robot introduction, and aromatherapy may have potential benefit for an improved QOL or wellbeing of people with dementia in residential LTC. Seven of the included 19 studies reported a statistically significant improvement of QOL in the intervention groups compared to control groups (Ballard et al., 2002; Clare et al., 2013; Conradsson et al., 2010; Moyle et al., 2013; O'Shea et al., 2014; Subramaniam et al., 2014; Williams & Tappen, 2007). Three studies reported a statistically significant improvement of QOL in the intervention groups over time (Azcurra, 2012; Lai et al., 2004; Yamanaka et al., 2013). Six studies showed that there were no statistically significant differences to QOL between the intervention and control groups (Ballard et al., 2004; Bergh et al., 2012; Chenoweth et al., 2009; Orrell et al., 2007; Orrell et al., 2005; van de Ven et al., 2013). Two studies reported positive or inconsistent changes in several sub-items of QOL scales (Chibnall et al., 2005; Cooke et al., 2010). Only one study reported an improved QOL within the control groups over time (Politis et al., 2004).

All studies reporting positive outcomes of interventions on QOL had data measured immediately after interventions were completed. Except for four studies (Chenoweth et al., 2009; O'Shea et al., 2014; Orrell et al., 2007; van de Ven et al., 2013), all other studies did not have sufficiently large sample size, which led to imprecision of the evidence (GRADE Working Group, 2004). There was an insufficient effect size on meta-analysis to confidently assert that these interventions improve QOL. Furthermore, most QOL

outcomes of each of the studies were measured by different measurement scales with continuous data, which led to analysis challenges in comparing the effects of interventions.

It is important to consider the overall quality of evidence, based not only on the study design, but also on other factors such as consistency of evidence, precision of evidence, and confounders (GRADE Working Group, 2004). According to each intervention category, the overall effect of the intervention approach was discussed with consideration of the overall quality of the evidence using the GRADE approach as detailed earlier (refer to Table 2 in section 3.2).

## 5.1 Effect of Reminiscence Interventions on QOL

The five reminiscence trials all employed the individualised reminiscence approach, which intended to draw on early memories or realise a sense of self-esteem and reconciliation (Azcurra, 2012; Lai et al., 2004; O'Shea et al., 2014; Politis et al., 2004; Subramaniam et al., 2014). Although the meta-analysis results did not show a statistically significant effect for reminiscence therapy as an intervention, overall findings indicated that the individualised reminiscence therapy may improve QOL of LTC residents with dementia.

The initial quality of the body of evidence regarding reminiscence interventions was assessed as high as all five studies were well-designed RCTs or a cluster RCT (refer to Tables 1 and 2). However, the quality of evidence regarding reminiscence interventions was limited due to a high proportion of small trials showing a small number of events, which caused an imprecision of evidence. In other words, four of the five studies did not have large sample sizes with a total of 213, ranging from 23 to 96, which implies a small

number of the event showing the effectiveness of the intervention. This led to a downgrading of the quality of the evidence by one level. Although only a single study by O'Shea et al. reported a large sample size with 304 participants with the intervention delivered by 90 nursing and healthcare assistant staff receiving education; there might have been confounders such as interactions of care staff and participants. On the other hand, the reminiscence interventions in the other four small studies were facilitated by psychologists or therapists.

After study quality evaluation, it was determined that there was no serious risk of bias. It can be argued that investigators who were not blinded may treat groups unfairly; this issue was addressed and offset by assessors being blinded to treatment allocation. The participant dropout rate was low from 2.5% to 17.1% and distributed similarly between treatment groups. Accordingly, the limitations of these studies were evaluated as not serious (refer to Tables 2 and 4). In addition, there was no serious inconsistency in the effect of the reminiscence intervention. Only a single study by Politis et al. (2004) reported different results that the one-on-one control group's QOL scores significantly improved over the time whilst there was no improvement for the reminiscence intervention group. These results implied that social contact of the one-on-one control group is beneficial for the QOL improvement, but a kit-base reminiscence intervention may be impersonal to some extent according to the authors' interpretation. Thus, the result of the study was not seen as a serious inconsistency of the effect of a reminiscence intervention on QOL of residents with dementia.

Overall, the evidence of the reminiscence intervention was rated as moderate quality due to a downgrading one level resulting from an imprecision of evidence (refer

to Table 2), indicating that the true effect is likely to be adjacent to the effect estimate but substantial difference also possibly exists. Therefore, it can be concluded that the individualised reminiscence approaches may lead to improving QOL of residents with dementia in long-term care with moderate quality of evidence.

## 5.2 Effect of Staff Training and Person-Centred Care

There is scarce evidence from four cluster RCTs that staff training interventions leading to person-centred care plans improve QOL of residents with dementia in LTC. The pooled results in meta-analysis indicated no effect of the staff training interventions on QOL. Only a single study showed the benefit of staff training in improving QOL of residents with dementia in LTC, including small sample size (n=65) (Clare et al., 2013).

Particularly, the trial by Clare et al. (2013) reported a difference between family-rating QOL and staff-rating QOL. If there were no other detection biases, it may be interpreted that the difference between family and staff-rating QOL scores suggests that each method is somewhat unique and reflects different perspectives regarding QOL (Clare et al., 2013).

The initial quality of evidence of the staff training intervention category commenced with a high level because of the detailed studies using cluster-RCTs which indicate a high potential level of evidence. However, the study by van de Ven et al., (2013) had a high risk of bias due to a lack of blinding of outcome assessors, which led to lower the quality of evidence by one level. Other than this, severe inconsistency, indirectness, publication bias or imprecision of the evidence was not detected. Overall, the quality of evidence was rated as moderate (refer to Table 2), meaning that true effect is likely to be adjacent to the effect estimate but substantial difference can also possibly exist.

## **5.3 Effect of Cognitive Stimulation Therapy**

Two quasi-RCTs provided insufficient evidence of the capacity of CST to improve QOL in this review (Orrell et al., 2005; Yamanaka et al., 2013). However, the studies suggested that CST can be advantageous by showing improved scores within intervention groups over time (Yamanaka et al., 2013) and by describing the effectiveness of the previous study (Orrell et al., 2005). Despite the fact that in the previous study by Spector et al. (2003) CST showed benefits in improving QOL of people with dementia, maintaining CST sessions as presented by Orrell et al. (2005) might not be enough to influence on the level of QOL of residents with dementia in LTC. As illustrated earlier in the study selection results section (section 4.2.2), the previous study conducted by Spector et al., (2003) was not analysed for this review due to data mixed with participants with and without dementia, which made it impossible to separate the data for people with dementia. However, a previous systematic review concluded that group CST was the only effective intervention to improve QOL of persons with dementia in residential LTC facilities (Cooper et al. 2009). Their result was found on a reanalysis of a single RCT trial by Spector et al. (2003). The reanalysis appeared to be possible for the reason that the reviewers were in the same university with the researchers of the RCT trial, which allowed data to be obtained.

The quality of the evidence resulting from two studies (Orrell et al., 2005;

Yamanaka et al., 2013) was graded as very low due to the risk of bias and imprecision of the evidence. In terms of risk bias, Yamanaka et al.'s (2013) study used an alternative allocation method which may cause a high risk of selection bias, and outcome raters were not blinded to treatment allocations which can cause a high risk of detection bias. The

study by Orrell et al (2005) also included the risk of selection bias as residential facilities were selected voluntarily. Furthermore, two participants in poor health, who were not able to participate in MCST treatment, were included in CST only group, which might have led to bias in the context of the small sample size. This high risk of bias resulted in a downgrading one level of the quality of evidence (refer to Table 2). Furthermore, the study by Yamanaka et al. (2013) reported a significant improvement of QOL within the intervention groups over time based on the staff-rated EQ-5D. Although the EQ-5D scales are perceived as valid and reliable in general populations without dementia, as a tool measuring QOL of people with dementia, the inter-rater reliability of proxy-rated of EQ-5D has been reported as unsatisfactory (Councill, Bryan, & Bentham, 1999). However, other reliable scales including self-rating and proxy-rated QOL-AD scales did not show a significant difference in QOL between or within the treatment groups. Therefore, reporting bias due to selective outcome reporting based on an unreliable QOL tool led to a further downgrading of the quality of evidence level (refer to Table 2).

Furthermore, both included studies only have a small sample size of 79 participants and showed very large confidence intervals in meta-analysis (refer to Figure 4 in section 4.4.3), indicating the imprecision of the evidence. For these confounding factors, the overall quality of the evidence was rated as very low; indicating the estimate of effect is very unclear.

## 5.4 Effect of Physical Exercise Interventions on QOL

From the two included studies, it can be said that physical exercise regardless of the intensity can improve psychological wellbeing of residents with dementia in LTC facilities.

A well-designed cluster RCT showed the short-term benefit of high intensity exercise on

subjective wellbeing (Conradsson et al., 2010) and a quasi-experimental study reported benefits of a comprehensive exercise on subjective wellbeing (Williams & Tappen, 2007).

The initial quality of evidence rating started high to moderate based on study designs in both studies (Conradsson et al., 2010; Williams & Tappen, 2007). As a result, it was downgraded by one level due to a small sample size in both studies, which was related to the low events of the effectiveness of the interventions (GRADE Working Group, 2004). Furthermore, the study by Williams and Tappen (2007) was not clear in the randomisation of the study design and allocation concealment. This led to one-level downgrade further. Overall, the quality of evidence was graded as low to very low, indicating that the true effect may be considerably different from the effect estimate or that the estimate of effect is unclear.

# **5.5 Effect of Pharmacology-Related Treatment**

There is no clear evidence of the effects of either a discontinuation of medication intervention or a routine analgesic treatment on the QOL or emotional wellbeing of people with dementia. Although there were no statistically significant differences between treatment groups, there was a 15% improved wellbeing score in the neuroleptic discontinuation group compared with that in the neuroleptic continuation group (Ballard et al., 2004). This study implied that discontinuation of medication may improve QOL, but it is not enough to be confident with the effectiveness of neuroleptic discontinuation on QOL.

The trial regarding routine analgesic treatment also suggested that residents with dementia who took acetaminophen regularly were likely to have an increase in the level of positive activities such as increased social involvement (Chibnall et al., 2005). However,

spent in self-care activities and increased time in a distressed state. These inconsistent findings are helpful to support person-centred care, but they are not able to be the basis of statistically confident evidence that is associated with improved wellbeing or quality of life of people with dementia. Furthermore, the sample size was very small with 24 participants, which made generalisation of the study result hard. Although this study did not report the result of adverse events resulting from acetaminophen treatment, given the fact that acetaminophen may cause side effects such as liver injury and most LTC residents with dementia are relatively frail, the level of the evidence quality needed to be downgraded one further level to reflect the potential risk. Similarly, the study regarding discontinuation of antidepressants showed that discontinuation of medication led to increased depressive symptoms compared to participants who continued to take antidepressants (Bergh et al., 2012). Overall, the quality of evidence of pharmacology-related intervention was rated low, indicating the true effect may be significantly dissimilar from the effect estimate.

#### 5.6 Effect of Other Interventions

Music, emotion-based intervention, and aromatherapy were related to improved QOL. The quality of the evidence was rated low as each intervention was reported in only one study with a small sample size. This caused very serious imprecision of the evidence, which led to downgrading the quality of evidence by two levels each.

The evidence regarding music suggested that music activities may offer opportunities to improve self-esteem, sense of belonging, and reduce depressive

symptoms in some people with dementia. Yet, the optimistic effects of the music intervention were temporary and dissipated soon after the intervention sessions ended.

In terms of the evidence of emotion-based intervention, PARO robots introduction, there was a clinical significance in improved QOL of residents with dementia with the PARO intervention. This study had limitations due to not only a small sample size, but also a large amount of missing data. Furthermore, the economic aspects need to be considered when considering the introduction of PARO.

The evidence regarding aromatherapy intervention suggested that aromatherapy may improve QOL of people with dementia, but this study had a high risk of detection bias as raters were not blinded to treatment allocation as they could detect the treatments because of the smell of the oil. Although the authors reported blinded assessors, another study by the same authors reported raters used nose clips (Burns et al., 2011). This severe bias led to downgrading the quality of evidence further.

## **5.7 Implications**

### 5.7.1 Implications for Clinical Care

This review provides available evidence that reminiscence therapy, physical exercise, CST, staff training, music, companion-robot introduction, and aromatherapy may improve QOL or wellbeing of people with dementia in residential LTC. However, the quality of body of evidence was of low to medium grade. Nevertheless, this review also provides information regarding strengths and limitations in each category of interventions. With the results of this review, it may be useful for decision makers to decide appropriate interventions, which will lead to effective outcomes of QOL according to each facility's resources and conditions.

### Recommendation for clinical care

When interpreting the results of this review, an important aspect to be considered is that there are many different contributing factors to QOL across settings. Accordingly, individualised interventions should be provided, which are targeted towards specific factors that contribute to QOL of an individual with dementia, as they are more likely to lead to effective and positive outcomes on QOL for residents with dementia in LTC.

## **5.7.2 Implications for Nursing Research**

This review is the first which encompasses various interventions and provides a synthesis of results showing the effect of interventions on QOL of residents with dementia in LTC. Reviews previously conducted focused on a certain type of intervention such as reminiscence, exercise, or cognition therapy with several outcomes, including the changes in function or disruptive behaviours rather than QOL. This systematic review focused on the effect on a single outcome, QOL across diverse interventions, in accordance with the study's objective to find the most effective interventions on QOL of residents with dementia living

in LTC facilities. While other reviews have mostly studied the effect of interventions on QOL of people with dementia regardless of residential settings (Cooper et al., 2012; Cooper et al., 2013), this review has specifically focused on people with dementia in residential LTC.

### Recommendation for future systematic reviews and meta-analysis

This systematic review used a meta-analysis after methodological quality appraisal was assessed according to the JBI systematic review approach. This approach ensured that high quality studies were included, which can enable the result of this review to be valid.

On the other hand, some different meta-analysis approaches recommend to include all studies, regardless of the methodological quality of studies (Schmidt & Hunter, 2015). The basis of this assertion is that 'methodological deficiencies' are usually founded on a personal theory which is not empirically verified, furthermore, accord between researchers on inclusive methodological quality is usually fairly low. It is argued that the methodological issues can be managed to measure the deficiency and correct for it. Given that there is little agreement on methods of meta-analysis (JBI, Schmidt & Hunter, 2015), future researchers, who intend to pool data statistically from all studies relevant to a research question, may need to consider including all data for meta-analysis, including data from studies from apparently weaker methodology.

In a similar vein, the GRADE approach, designed for grading the quality of evidence for systematic reviews, does not rate every single study as a single item, rather it is feasible in assessing the quality of the related evidence which was retrieved across studies (Guyatt et al., 2011). In other words, the data from all studies satisfying the inclusion criteria (e.g. PICO) may be considered for systematic reviews. Methodological deficiencies of all studies are reflected in rating the quality of evidence by being modified downward or upward (Guyatt et al., 2011). Although this current systematic review attempted the application of

this approach, the overall JBI systematic approach was mainly followed and thus selective studies based on methodological quality were reviewed. Therefore, future reviewers need to consider incorporating all studies, identified with inclusion criteria, and conduct comprehensive meta-analysis of all study data relevant to the research question.

## Recommendations for research related to dementia

Dementia-related studies should consider several issues regarding QOL measures. It is desirable to consider diverse measurement methods of QOL measures such as resident-rating, proxy-rating or direct observation, in order to reflect complex aspects of QOL. The results can differ according to the method of the QOL measures that are used (O'Shea et al., 2014; Sloane et al., 2005). As the concept of QOL is multifaceted and dynamic, and there is no gold standard of measuring QOL, a collection of methods is likely to offer the most comprehensive demonstration of QOL of people with dementia (Sloane et al., 2005).

Moreover, it is appropriate to use valid and reliable QOL scales for people with dementia so that the QOL outcomes of residents with dementia are trustworthy.

With respect to dementia research aiming at developing interventions, multidimensional approaches which consist of diverse individualised interventions, are required to improve QOL including multidimensional aspects such as physical, psychological, emotional, and social aspects. Furthermore, high-quality studies using RCTs with adequate sample size are required, so that the clinical effectiveness of interventions on the QOL of people with dementia is determined. With consideration of the degenerative characteristics of dementia, it is preferable to focus on the short-term effectiveness of an intervention rather than the long-term influence. Lastly, all interventions related to a study population with dementia need to use QOL measures to test the effects of those interventions on the QOL of the affected people. QOL is particularly essential for this population, given that there

is no cure for dementia and functional or behavioural improvement only may not assure an improved QOL.

## **5.7.3 Implications for Nursing Practice**

This review found that there is no evidence to show the long-term effects of interventions on QOL of residents with dementia in LTC, except for one reminiscence study showing an association between life story approach and higher QOL state (Azcurra, 2012). This may mean that the outcomes of dementia-related interventions need to focus on 'here and now', rather than long-term effects. Furthermore, van de Ven et al.'s study (2013) reported that the levels of QOL of LTC residents with dementia tend to decline over time regardless of intervention. This implies that the potential effects of interventions can be attenuated over time due to association with the declining nature of dementia. From these, it can be inferred that interventions are needed to be integrated into daily nursing practice, rather than applying a special intervention program separately.

#### Recommendation for nursing practice

In order to integrate interventions into clinical nursing practice, staff education and support are needed. At the same time, the QOL assessment should be a continuous circular process to evaluate and monitor the QOL of people with dementia. By doing this, QOL can be assured for people with dementia living in LTC settings.

# 5.8 Limitations of the Study

This systematic review has several limitations which may lead to undermining the generalisability of the outcomes of this review. First, this review only considered studies written in English due to resource limitations. Hence, data that have been published in non-English languages were not included in the systematic review and meta-analysis.

Furthermore, this review excluded studies reporting an unclear dementia diagnosis or only MMSE scores. This may lead to missing many potential participants with dementia, and thus limit the outcomes of this systematic review and meta-analysis. However, this issue is not only limited in this review, but dementia related studies are prone to diagnostic difficulties (Lai et al., 2004). This is because there are not always standardised diagnoses of dementia in residential LTC settings. For example, an Irish study has reported insufficient official diagnosis of dementia (O'Shea et al., 2014). Many dementia-related systematic reviews tend to illustrate and include unclear dementia criteria.

Reporting bias means that positive-result data are prone to be published more than studies with insignificant results. Although this review attempted to include unpublished studies to avoid the bias, this review may not be free of this kind of limitation.

## 5.9 Conclusion

Ensuring QOL is particularly significant for people with dementia in residential LTC. QOL is an important indicator showing the general impact of interventions for those with dementia and their general wellbeing in the individual level. Through QOL measures it is desirable to check whether an intervention or care delivery contributes to QOL of residents with dementia as improvement of functions or problematic behaviours may not assure an improved QOL for people with dementia. The efforts to improve and ensure their QOL can help to deal with unmet needs of residents as well as to ensure the quality of care (Edelman et al., 2005; Moyle, Venturto, et al., 2011).

This review used a comprehensive approach regarding the identification of diverse interventions aimed at improving QOL of people with dementia in residential LTC. Although the findings in this review indicated that there was a lack of conclusive evidence of benefit from the identified interventions, this does not mean conclusively that there are no benefits

of those interventions. The results of this review indicate that reminiscence therapy, physical exercise, CST, staff training and person-centred care practice, music, companion-robot introduction, and aromatherapy may have potential benefits on improving QOL or wellbeing of people with dementia in residential LTC. There was no indication of harm related to these interventions on the population with dementia living in residential facilities.

Further research is required to develop and validate effective interventions with adequate sample size and thus to enhance and improve QOL of people with dementia in residential LTC. It would be desirable to diversify interventions in order to affect the multidimensional aspects of QOL as well as to measure the change of QOL in order to confirm whether the interventions affect the person with dementia's wellbeing in positive ways. This is likely to provide a higher confidence and probability that providing personcentred interventions in accordance with people's needs, facilities' resources, and various conditions will lead to a better QOL for residents with dementia in LTC.

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## **Appendix I: Systematic Review Protocol**

#### Review title

The effectiveness of interventions on the quality of life of people with major neurocognitive disorder (dementia) in residential long-term care: a systematic review protocol

#### Reviewers

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# Review question/objective

The objective of this review is to answer the following question:

Which interventions have the best outcomes related to improved quality of life of people with dementia in residential long-term care?

In addition, this review will also define the components of the effective interventions.

# **Background**

The recently revised Diagnostic and Statistical Manual of Mental Disorders (DSM-V)<sup>1</sup> utilizes the term "major neurocognitive disorder" to describe what has previously been known as dementia. However, given that this systematic review reflects previously published literature, the term "dementia" will be used.

In 2013, over 35 million people around the world, were estimated to have dementia. The number of people worldwide with dementia is projected to increase to 65.7 million in 2030 and 115.4 million in 2050, which is approximately a doubling of sufferers every 20 years. Dementia is a syndrome of progressive cognitive and functional deterioration which is incurable. There are diverse symptoms and various levels of impairment depended on affected brain regions and types of dementia. Typical symptoms in the early phase of illness include memory loss, affected mood and behavior, and indications of depression. In the intermediate phase, increased communication difficulties, behaviour changes such as wandering, agitation and aggression can appear. In the last phase of dementia illness, severe symptoms appear such as unawareness of time, place, inability to recognise familiar people, and severely limited mobility. The most common type of dementia is Alzheimer's disease which accounts for 60-70% of the incidence of dementia. The remainder include vascular dementia, dementia with Lewy bodies, frontotemporal dementia and so on. There is no known cure or treatment that alters the degenerative process of dementia. Having an irreversibly worsening

projection, dementia gradually makes affected people increasingly reliant on others for help with daily living, often leading to placement in residential long term care (LTC).<sup>4,5</sup>

Although there are different types and labels of LTC services across the world, <sup>5,6</sup> LTC services can be roughly categorized into both home-based services and residential facility-based services. <sup>5</sup> Many OECD countries encourage home-based care which enables clients to have more flexibility, independence and self-determination. <sup>5</sup> Nonetheless, as problematic behaviors occur and function declines, eventually, people with dementia are likely to require care in a residential LTC facility for ongoing care. <sup>7-9</sup> The prevalence of dementia is relatively high in people living in LTC facilities. Estimates of the incidence of dementia widely vary from 40% to 80% in residential LTC facilities. <sup>3,10-12</sup> Furthermore, residing in residential LTC tends to be related to a reduced quality of life (QOL) for residents, <sup>14,15</sup> and people with dementia have an increased likelihood to face challenges in relation to their human rights and QOL compared to other people, <sup>4</sup> as a consequence of decreased cognition, reduced language skills and introspection in people with dementia. Accordingly, improving and assuring QOL of LTC residents with dementia is imperative.

A number of studies concerning QOL have been undertaken with little consensus on the definition of QOL, because of its subjective qualities. The World Health Organization Quality of Life [WHOQOL] group involving 15 countries defined QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns". Furthermore, the WHOQOL group illustrated that contributors of QOL can include multiple features such as physical, psychological, spiritual, social, and environmental aspects. Hence the meaning of QOL is broad, with multiple facets.

Many studies suggest that diverse indicators are correlated to QOL of people living in LTC facilities. Khader investigated several factors influencing QOL of the residents in three nursing homes in Jordan. The results indicated that the levels of QOL were determined by numerous factors such as age, level of education, and marital status. For instance, in relation to length of stay, residents who had lived for eleven years or more had a decreased level of QOL in most domains as compared with those who had lived for eleven years and less. Robichaud and colleagues also explored QOL indicators in nursing homes from the perspective of residents and their families and identified that feelings of respect, involvement in relationships, professional competency, privacy, staff stability and so on. 15

Furthermore, the QOL of people with dementia is likely to be more complex compared to those without dementia. Cordner investigated measures of QOL in nursing home residents with advanced dementia. <sup>22</sup> This study indicated that higher cognitive function of residents and the application of pain medication lead to a higher QOL, while those with behavior problems had a lower QOL. Another study systematically reviewed 13 studies to investigate factors related to QOL of people with dementia in long-term care facilities. <sup>23</sup> This review identified that socio-demographic characteristics, depressive symptoms and anxiety, behavior, dependency in activities of daily living, cognition, severity of dementia and medication use all influence QOL. This review concluded that, particularly, depressive symptoms are reliable factors which are negatively correlated to QOL. From these findings, it may be implied that multifaceted approaches are needed when care services and interventions are applied in order to improve QOL of individuals with dementia living in long term care facilities.

As there is currently no known cure for dementia, many studies have been conducted focusing on interventions to improve QOL of people with dementia.<sup>24-27</sup> Diverse interventions such as physical activity, psychological therapy, behavioral care or education of staff/care givers are potentially beneficial to people with dementia by improving cognitive and functional capabilities, to postpone deterioration, as well as to reduce behavioral symptoms. Ultimately, the aim of these interventions is

to maintain or to improve QOL of individuals with dementia by reducing dementia-associated symptoms and incapacity. <sup>26,28-30</sup>

In recent years, there has been a gradual movement towards the evaluation of LTC services for residents with dementia through evidence of the outcomes of care. 4,31-33 This shift seems to be come from the realisation that the significant objective of care provision is to promote QOL of residents, not simply to improve quality of care delivery.<sup>32</sup> This suggests that quality of care should be monitored for improving residents' QOL. Similarly, a World Alzheimer Report<sup>4</sup> demonstrated that quality of care should be ascertained through QOL or satisfaction of residents in LTC facilities. Traditionally, there are diverse objective measures of resident outcome, such as level of independence, 34 cognitive function, 25,35 and reduced neuropsychiatric symptoms. 36,37 These measures have generally been accepted through their long-lasting use; however, functional improvement does not necessarily mean an enhancement of QOL. For instance, a pilot study of 35 residents with dementia showed that participants receiving cognitive stimulation therapy had a significant improvement in cognitive function but no effect on QOL.<sup>38</sup> Another randomized controlled trial including 42 participants with dementia also examined the effect of individual music therapy on agitation and other disruptive behaviors, QOL and medication.<sup>39</sup> The results indicated that music therapy reduced agitation, disruptive behavior and prevented medication increases, but music therapy made no difference to QOL. Taking into consideration that enhancing QOL is the significant objective of dementia care, 4 it is essential that QOL remains a primary outcome of interventions. In other words, evaluations of the effectiveness of interventions should contain QOL measurements for people with dementia. Accordingly, the application of QOL measurements to the outcome of healthcare interventions may help to define effective and efficient interventions in residential LTC settings.

In order to improve QOL, the efforts to find and integrate effective interventions in residential LTC settings should be ongoing. Although several reviews have contributed to identifying various interventions on QOL of residents in LTC facilities, or to evaluate the effect of diverse interventions on QOL of people with dementia, there is so far no overview of the effectiveness of the interventions on QOL of people with dementia in residential LTC facilities. For that reason, the aim of this systematic review is to identify interventions that improve the QOL of people with dementia in residential LTC and to evaluate the effectiveness of the interventions. This will assist healthcare providers in making decisions regarding the implementation of feasible interventions and the development of programs in accordance with their capabilities, resources and resident preferences.

### Inclusion criteria

#### Types of participants

This review will consider studies that include people with any type of dementia living in residential LTC facilities. Individuals with dementia are those who have received a medical diagnosis of major neurocognitive disorder according to DSM-V or dementia according to DSM-IV. As dementia tends to be unrecognized in its early stage and diagnosed in its later stage, 12 the length of dementia diagnosis is not relevant to this review. If participants are mixed (i.e. residents with and without dementia, or people with dementia in community and in residential LTC participating together), distinct QOL outcomes for people with dementia must be obtainable.

Exclusion criteria are studies that deal with people without medical diagnosis of major neurocognitive disorder (dementia), who instead may have another functional mental health problem (e.g. delirium, depression, anxiety) or problematic behavior. Studies that focus on people living in their own homes, other residences designed for individuals such as senior apartments or independent care, or patients with dementia being hospitalized will also be excluded.

#### Types of interventions

This review will include studies that evaluate physical activity, psychological and, independence-oriented interventions, social relationships, social relationship interventions, environment-oriented interventions, spirituality and spiritually oriented interventions, medications, care provider/staff-oriented interventions (e.g. staff education), and multidisciplinary team applications. In addition, interventions of any length and frequency will be included, providing they aim to improve QOL, well-being or satisfaction of people with dementia. Studies which did not involve interventions will be excluded (e.g. studies focusing on factors influencing QOL of people with dementia).

### Types of outcomes

This review will consider studies that include the following outcome measures:

Quantitative outcomes should be measured by explicit QOL instruments which are generally accepted as reliable and valid QOL measurement tools. Broadly, the instruments can be categorised into three types; observational based scale, proxy-rating scale or self-rating scale.<sup>32,42</sup> As there is no gold standard to measure QOL, it would be desirable to consider all perspectives to produce profiles of the QOL of affected people.<sup>32</sup> More specially, any instruments aiming to measure QOL of people with any stage of dementia will be considered as follow: Alzheimer's Disease-Related Quality of Life (ADROL), Well-being/Ill-being Scale (WIB), Dementia Care Mapping (DCM), Dementia Quality of Life (DEMQOL), Lawton observed Affect Scale, Lawton's conceptualisation of psychological well-being, Philadelphia Geriatric Centre Morale Scale (PGCMS), Psychosocial Impact of Assistive Devices Scale (PIADS), Quality of Life-Alzheimer's Disease (QOLAD), Qualidem, Quality of Life In Late-stage Dementia (QUALID), EuroQOL 5D, Self-Reported Quality of Life (SRQOL).

Exclusion criteria will be studies showing combined outcomes based on the author's operational definition of QOL, which do not include a valid QOL instrument (e.g. combined outcomes of Global Deterioration Scale (GDS) and Mental Health Questionnaire (MHQ), studies including data of results for people with dementia which are not available separately, or studies dealing with quantitative outcomes which do not measure QOL (e.g. symptom management, decreased problematic behaviors, measurements of behavioral disturbance or improvement of physical/emotional status), or qualitative studies.

#### Types of studies

This review will consider experimental study designs, including randomized controlled trials, non-

randomized controlled trials, quasi-experimental designs and before and after studies in order to investigate the effectiveness of interventions.

### Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of CINAHL and MEDLINE will be undertaken to identify relevant keywords in the title, abstract, or index terms to describe articles. A second search using all identified keywords and index terms will then be undertaken across all included databases which are CINAHL, MEDLINE, Cochrane, EMBASE, and PsycInfo. Thirdly, the reference list of all identified articles will be reviewed for additional studies. Studies published in English will be reviewed due to resource limitation and studies distributed after 1995 will be considered for inclusion in this review as the World Health Organization quality of life [WHOQOL] group developed conception of QOL around 1995.

The search for unpublished studies will include:

Google Scholar, ProQuest (dissertations and theses databases), National and International Alzheimer's associations' websites, World Health Organization [WHO], and Australian Institute of Health and Welfare [AIHW], Organisation for Economic Co-operation and Development [OECD] will also be searched.

Initial keywords to be used will be:

("people", "person", "patients", "patient", "client", "clients", "residents" OR "resident") AND ("dementia", "Alzheimer", "Alzheimer's", "cognitive impairment", "Lewy Body disease" OR "major neurocognitive disorder") AND ("long term care", "long-term care", "longer term care", "facility care", "residential", "institutional care", "nursing home" OR "nursing homes") AND ("quality of life", "life qualities", "life quality", "satisfaction", "wellbeing", OR "well-being").

## Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

### **Data collection**

Quantitative data will be extracted from papers included in the review by the two independent reviewers, using the standardized data extraction tool from JBI-MAStARI (Appendix II). The data extracted will include specific details about the interventions, populations, study methods and outcomes of significance to the review question and specific objectives. If primary studies include any missing data or clarification, efforts to will be made to contact the authors.

### **Data synthesis**

Quantitative data will, where possible, be pooled in statistical meta-analysis using JBI-MAStARI. All results will be subject to double data entry. Effect sizes will be expressed as weighted mean differences (for continuous data) or odds ratio (OR) for categorical data and their 95% confidence intervals will be calculated for analysis. Heterogeneity will be assessed statistically using the standard Chi-square. Statistical pooling will be used where the data lacks statistical difference. However, where statistical pooling is not possible the findings will be presented in narrative form including tables and figures to aid in data presentation where appropriate.

### **Conflicts of interest**

The authors declare there are no conflicts of interest.

### **Acknowledgements**

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## **Appendix II: JBI Appraisal Instruments**

# JBI Critical Appraisal Checklist for Randomised Control / Pseudo-randomised Trial

Rev	ewer	_ Date _			
Auth	nor	Year_	R	ecord Numb	oer
		Yes	No	Unclear	Not Applicable
1.	Was the assignment to treatment groups truly random?				
2.	Were participants blinded to treatment allocation?				
3.	Was allocation to treatment groups concealed from the allocator?				
4.	Were the outcomes of people who withdrew described and included in the analysis?				
5.	Were those assessing outcomes blind to the treatment allocation?				
6.	Were the control and treatment groups comparable at entry?				
7.	Were groups treated identically other than for the named interventions				
8.	Were outcomes measured in the same way for all groups?				
9.	Were outcomes measured in a reliable way?				
10.	Was appropriate statistical analysis used?				
Ove	erall appraisal: Include	Excl	ude 🗆	See	k further info.
Con	nments (Including reason for exclusion)				
_					

## **Appendix III: JBI Data Extraction Instruments**

### JBI Data Extraction Form for Experimental / Observational Studies

Reviewer		Date										
Author Year												
JournalRecord Number												
Study Method												
RCT		Quasi-RCT	Longitudinal									
Retrospective		Observational		Other								
Participants												
Setting												
Population												
Sample size												
Group A		Group B										
Interventions												
Intervention A												
Intervention B												
Authors Conclus	ilons:											
Reviewers Conc	lusions:											

### Study results

#### Dichotomous data

Outcome	Intervention ( ) number / total number	Intervention ( ) number / total number

#### Continuous data

Outcome	Intervention ( ) number / total number	Intervention ( ) number / total number		

## **Appendix IV: Example of Database Search Results (Medline)**

No	Searches	Results
1	People.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	225658
2	Person.mp.	70277
3	Patient.mp.	1751244
4	Patients.mp.	3728363
5	Client.mp.	17005
6	Clients.mp.	24229
7	Resident.mp.	38106
8	Residents.mp.	60517
9	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8	4796351
10	Dementia.mp.	82616
11	Major neurocognitive disorder	2
12	Cognitive impairment	25179
13	Lewy Body disease.mp	2597
14	Alzheimer's.mp.	70103
15	Alzheimer.mp.	71314
16	10 or 11 or 12 or 13 or 14 or 15	160953
17	Long term care.mp.	28412
18	Longer term care.mp.	19
19	Facility care.mp.	89
20	Residential.mp.	22171
21	Institutional care.mp.	1361
22	Nursing home.mp.	14882
23	Nursing homes.mp.	30758
24	17 or 18 or 19 or 20 or 21 or 22 or 23	78041
25	Quality of life.mp	177351
26	Life qualities.mp.	21
27	Life quality.mp.	3277
28	Well being.mp.	36178
29	Satisfaction.mp.	135633
30	25 or 26 or 27 or 28 or 29	321982
31	9 and 16 and 24 and 30	897

Search date: 5<sup>th</sup> April 2014

## **Appendix V: Excluded Studies**

Authors (Year of Publication)	Reason for Exclusion (MAStARI Assessment Score)
Bone et al. (2010)	Methodological low quality and no control group (3/10)
Charras and Gzil (2013)	Methodological low quality (6/10)
Chenoweth et al. (2014)	Unclear criteria of dementia diagnosis
Coen et al. (2011)	Methodological low quality (4/10)
Davidson and Fedele (2011)	Unable to separate the data for people with dementia
de Rooij et al. (2012)	Methodological low quality (4/10)
Finnema et al. (2005)	Methodological low quality (5/10)
Giroux et al. (2010)	Unclear criteria of dementia diagnosis
Martin-Cook et al. (2005)	Methodological low quality (4/10)
Spector et al. (2003)	Unable to separate the data for people with dementia
Ridder et al. (2013)	Methodological low quality (6/10)
Rokstad et al. (2013)	Methodological low quality (6/10)
Smit et al. (2014)	Quantitative data not reported
Te Boekhorst et al. (2009)	Methodological low quality (2/10)
Van De Ven-Vakhteeva et al. (2013)	Methodological low quality (6/10)
Verbeek et al. (2010)	Methodological low quality (4/10)
Visser et al. (2008)	Methodological low quality (1/10)

## **Appendix VI: Table of Included Studies**

No.	Title	Authors	Study Type	Number of	Intervention/	Outcome	Results
		(Year)		Participants	Comparison	Measure	
1	A 3-month, randomized,	Ballard et	RCT	100	Discontinuation	DCM	There was a 15%
	placebo-controlled,	al. (2004)			neuroleptics/		improvement in wellbeing in
	neuroleptic discontinuation				Continuation		patients allocated to placebo
	study in 100 people with				neuroleptics		compared with a slight
	dementia: The						deterioration for those
	neuropsychiatric inventory						continuing to receive
	median cutoff is a predictor						neuroleptics, but these
	of clinical outcome						differences were not
							statistically significant.
2	Effect of acetaminophen on	Chibnall et	Cross-over	25	Acetaminophen/	DCM	There were no effects on
	behavior, well-being, and	al. (2005)	RCT		Placebo		emotional wellbeing.
	psychotropic medication use						Participants who took
	in nursing home residents						acetaminophen increased
	with moderate-to-severe						social interaction, talking
	dementia						alone, and distress. They also
							spent less time in their room,
							less time removed from the
							nursing home unit, and
							decreased personal care
							activities.

No.	Title	Authors	Study Type	Number of	Intervention/	Outcome	Results
		(Year)		Participants	Comparison	Measure	
3	Discontinuation of	Bergh et	RCT	128	Discontinuation	QOL-AD	There was no difference in
	antidepressants in people	al. (2012)			antidepressant/		the level of QOL between
	with dementia and				Continuation		the intervention group
	neuropsychiatric symptoms				antidepressant		and control group.
	(DESEP study): Double blind,						
	randomised, parallel group,						
	placebo controlled trial						
4	Life review and life story	Subrama	RCT	24	12 weeks Life review	QOL-AD	At 12-week test, QOL had
	books for people with mild	niam et			and then life story		improved in both
	to moderate dementia: A	al. (2014)			book/		treatment groups and
	randomised controlled trial				12 weeks Usual care		there was a significant
					and then story book		between-group difference
							in favour of the life review
							intervention group.
5	A randomized, controlled,	Politis et	RCT	37	The geriatric network	AD-RQL	There was a greater within
	clinical trial of activity	al. (2004)			kit/		group improvement in
	therapy for apathy in				One-on-one		QOL ratings in the control
	patients with dementia						group.
	residing in long-term care						
6	The impact of reminiscence	O'Shea et	Cluster RCT	304	Reminiscence	QOL-AD	QOL improved in the
	on the quality of life of	al. (2014)			sessions by care		intervention group
	residents with dementia in				staff/ Usual care		compared to that in the
	long-stay care						control group.

No.	Title	Authors (Year)	Study Type	Number of Participants	Intervention/ Comparison	Outcome Measure	Results
7	A randomized controlled trial of a specific reminiscence approach to promote the well-being of nursing home residents with dementia	(16a1) Lai et al. (2004)	RCT	101	Life story approach/ Usual care/ Discussion group	DCM	Wellbeing improved in the intervention group between the baseline test and the post-test right after the intervention was
8	A reminiscence program intervention to improve the quality of life of long-term care residents with Alzheimer's disease: A randomized controlled trial	Azcurra (2012)	RCT	135	Life story approach/ Counselling/ Unstructured social contact	SRQoL, DCM	completed.  Within the intervention group, there were improved QOL over the time.
9	Effects of cognitive stimulation therapy Japanese version (CST-J) for people with dementia: a single-blind, controlled clinical trial	Yamanak a et al. (2013)	Controlled clinical trial	56	CST/ Usual care	QOL-AD, EQ-5D	Staff-rated EQ-5D was a significant improvement within the intervention group over the study period.
10	A pilot study examining the effectiveness of maintenance Cognitive Stimulation Therapy (MCST) for people with dementia	Orrell et al. (2005)	Pilot pseudo- RCT	35	Maintenance CST/ CST only/ Usual care	QOL-AD	There were no effects on quality of life following maintenance sessions.

No.	Title	Authors	Study Type	Number of	Intervention/	Outcome	Results
		(Year)		Participants	Comparison	Measure	
11	Effect of exercise on mood in	Williams	Pre-post	90	Comprehensive	Lawton's	Participants receiving
	nursing home residents with	and	design		exercise/ Social	OAS	comprehensive exercise
	Alzheimer's disease	Tappen			conversation/		exhibited higher positive
		(2007)			Supervised walking		and lower negative affect
							and mood
12	Effects of a high-intensity	Conradss	Cluster RCT	100	High intensity	PGCMS	Among people with
	functional exercise	on et al.			exercise program/		dementia, there was a
	programme on depressive	(2010)			Control activity		between group difference
	symptoms and psychological						in PGCMS scores in favour
	well-being among older						of the exercise group at
	people living in residential						post-test at 3 months right
	care facilities: A cluster-						after the intervention was
	randomized controlled trial						completed
13	Effects of Dementia-Care	van de	Cluster RCT	192	DCM/ Usual care	Qualidem,	There was no statistically
	Mapping on residents and	Ven et				EQ-5D	significant result on DCM
	staff of care homes: A	al. (2013)					on QOL.
	pragmatic cluster-						
	randomised controlled trial.						

No.	Title	Authors	Study Type	Number of	Intervention/	Outcome	Results
		(Year)		Participants	Comparison	Measure	
14	AwareCare: A pilot	Clare et	Pilot cluster	65	Awareness-based	QUALID	Residents in the
	randomized controlled trial	al. (2013)	RCT		staff training/ Usual		intervention group had
	of an awareness-based staff				care		significantly better quality
	training intervention to						of life as rated by family
	improve quality of life for						members than those in
	residents with severe						the control groups, but
	dementia in long-term care						care staff ratings of quality
	settings						of life did not differ.
15	A cluster randomised	Orrell et	Cluster RCT	238	Unmet needs	QOL-AD	There was no significant
	controlled trial to reduce the	al. (2007)			detection and care		difference of QOL
	unmet needs of people with				plan/ Usual care		between treatment
	dementia living in residential						groups.
	care						
16	Caring for Aged Dementia	Chenowe	Cluster RCT	289	DCM/ Person-	QUALID	There was no significant
	Care Resident Study	th et al.			centred care/ Usual		difference in QOL in the
	(CADRES) of person-centred	(2009)			care		intervention groups.
	care, dementia-care						
	mapping, and usual care in						
	dementia: A cluster-						
	randomised trial						

No.	Title	Authors	Study Type	Number of	Intervention/	Outcome	Results
		(Year)		Participants	Comparison	Measure	
17	A randomized controlled trial	Cooke et	Cross-over	47	Music/ Reading	DQOL	The control group reported
	exploring the effect of music	al. (2010)	RCT		group		higher midpoint feelings
	on quality of life and						of belonging than the
	depression in older people						music group. Sub-analyses
	with dementia						of more over 50% music
							session attendance found
							improvements in self-
							esteem over time.
18	Exploring the effect of	Moyle et	Cross-over	18	PARO-robots/	QOL-AD	PARO was found to have a
	companion robots on	al. (2013)	RCT		Reading group		positive moderate to large
	emotional expression in						influence on the QOL-AD.
	older adults with dementia:						The PARO group had
	a pilot randomized						higher QOLAD when
	controlled trial						compared to the reading
							group.
19	Aromatherapy as a safe and	Ballard et	Controlled	72	Melissa officinailis	DCM	In the intervention group,
	effective treatment for the	al. (2002)	trial		intervention/		social engagement
	management of agitation in				Placebo sunflower		activities increased and
	severe dementia: The results				oil		social withdrawal
	of a double-blind, placebo-						decreased.
	controlled trial with Melissa						