

# **Factors that improve communication between caregivers and persons with dementia**

**A literature review**

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Abstract  <p>The number of people living with dementia worldwide in 2010 was estimated at 35.6 million and is expected to rise to 81 million in 2040. Dementia influences many factors, such as memory, orientation, comprehension, language, behaviour, and the ability to perform the activities of daily living.</p> <p>The aim of the study was to conduct a literature review on what factors improve communication between caregivers and persons with dementia. The purpose was to provide information about communication with persons with dementia to allow possibilities for better care.</p> <p>The study was implemented as a literature review. The data was collected from four information databases: Cinahl, Science-Direct, Pubmed and Google Scholar. Base on predefined inclusion and exclusion criteria, eight peer reviews empirical studies conducted in English between 2008-July 2018 were analysed using content analysis.</p> <p>The analysis and synthesis yielded four main categories: communication training for caregivers, communication methods and utilities for caregivers, and leisure activities for persons with dementia. These factors increase communication skills for caregivers and persons with dementia.</p> <p>This study can be utilized by health care professionals and family caregivers when caring for persons with dementia to enhance communication and to improve quality of life for persons with dementia. Further research is needed to increase quantity and quality of methods and utilities for communication that would benefit persons with dementia and their caregivers.</p>		
Keywords/tags dementia, communication, caregiver		
Miscellaneous		

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## 1 Introduction

Dementia is one of the major causes of disability and dependency among older people worldwide: the number of people living with dementia worldwide in 2010 was estimated at 35.6 million (WHO 2012, 2), and is expected to rise to 81 million in 2040. (Downs & Bowers, 2008, 1.) The challenges of governments to respond to the growing numbers of people with dementia are substantial (WHO 2012, 2), and organizing care for demented patients will be one of the biggest therapeutic and economical challenges in elderly care. (Erkinjuntti, Alhainen, Rinne & Soininen 2006, 40.) People with dementia generally require high levels of care (Brodaty & Donkin 2009, 217). Most of this support is provided by informal or family caregivers (Brodaty & Donkin 2009, 217), who can be relatives, partners, friends, or neighbors who provide assistance for a person with a chronic or disabling condition. There are also formal caregivers, who are paid workers or volunteers. (Definitions 2014.)

Persons who suffer from dementia may present symptoms of agitation and confusion when being treated in primary care or even in familiar home surroundings, and these can be intimidating even for health care professionals if they are not experienced in caring for these kinds of individuals, or if they have not been provided with specialized training. (Elkins 2011, 16.) The several difficulties that are a part of dementia, including cognitive, behavioural, and language challenges, affect interactions with caregivers, and there are multiple barriers to communicating with older adults who suffer from dementia. When dementia is severe, the majority are institutionalized, thus making communication and dementia a significant issue for nursing. (Perry, Galloway, Bottorff & Nixon 2005, 44.)

As little of the literature related to communication with older adults who have dementia is supported by research (Perry et. al. 2005, 44), the aim of the thesis is to produce a synthesis on what factors improve communication between caregivers and persons with dementia, thus allowing information for further research and better care.

## 2 Dementia

### 2.1 Definition of dementia

To work successfully with people with dementia, it is vital to have a profound understanding of the condition they are living with (Perrin, May, Anderson & Brooker 2008, 1). Studies suggests that defining dementia simply in terms of organic brain disease and relating the process to ageing may not be as straightforward as was once thought (Jootun et. al 2011). The concept of dementia is defined in various ways.

According to the World Health Organization (WHO), dementia is a syndrome, which is usually chronic and progressive. It influences many factors, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. (WHO 2017.) Dementia can also influence behaviour and the ability to perform daily activities (Alzheimer's Disease International 2012, 6).

Interference with social functioning seems to be a dominating factor when defining dementia. Huttunen (2016) defines dementia as a state where a person's intellectual functions and brain functions have weakened, thus limiting a person's social coping. According to Downs and Bowers (2008, 11), dementia is a group of syndromes which are characterized by a gradual decline in cognition which interferes with social and/or occupational functioning. Cantley (2001, 8) also describes dementia to have a significant decline in personal and social functioning.

Perrin et. al. (2008, 2) make an important notion related to the definition of dementia: dementia is an umbrella term which covers many different forms of disease and damage to the brain, making it not a specific disease, but a symptom of another condition. The World Health Organization (2017) and Alzheimer's Disease International (2012, 6) also describe dementia as a syndrome, not as a distinct disease.

## 2.2 History of dementia research

Aulus Cornelius Celsus, a Roman historian of medicine in the first century, in his writing *De Medicina*, was the first to use the term dementia. Celsus gave dementia the Latin term *demens*, which stands for the English definitions away (= de) and mind (= mens). (Erkinjuntti et. al. 2006, 16–17.) The Latin term was eventually used to derive the English translation (Cantley 2001, 8).

Despite the development in defining dementia, it was until the end of the 19<sup>th</sup> century, when the reasons and etiological divisions of dementia were tapped into (Erkinjuntti et al. 2016, 18–19). Medical usage of the definition *dementia* developed slowly from the early 19th century. By the beginning of the 20th century, clinical scientists had started to examine brain tissue of demented patients at post-mortem. (Cantley 2001, 8.)

Dementia research culminated in 1907, when Dr Alois Alzheimer described abnormal lesions in the brain of a patient (Cantley 2001, 8), which was the first description of Alzheimer's dementia in history (Barker & Board 2012, 106). Alzheimer's disease was considered as an academic rarity until the end of the 1960s, when it was found that aged and demented patients commonly had changes in the brain similar to Dr Alzheimer's descriptions. Eventually in the 1990s, the first medications were developed for the symptoms of Alzheimer's disease. (Erkinjuntti et. al. 2006, 20–21.) It is now known that Alzheimer's disease is the most common cause of dementia (Cantley 2001, 8). In the late 20<sup>th</sup> century, also cortical Lewy's bodies were, for the first time, linked to dementia. Dementia with Lewy bodies has in a short time proved to be one of the most common dementing diseases. (Erkinjuntti et. al. 2006, 21.)

### 2.3 Subtypes of dementia

Subtypes of dementia can be classified as follows: Alzheimer's disease, vascular dementia, mixed dementia, Lewy-body dementia, Fronto-temporal dementia, Parkinson's dementia and other dementias (Alzheimer's Society's view on demography 2018). Even though these diseases are different, all the subtypes have similar features by affecting memory, reasoning, communication, and mood (Barker & Board 2012, 9). The percentages of each type of dementia is shown in figure 1 (Alzheimer's Society's view on demography 2018, adapted).

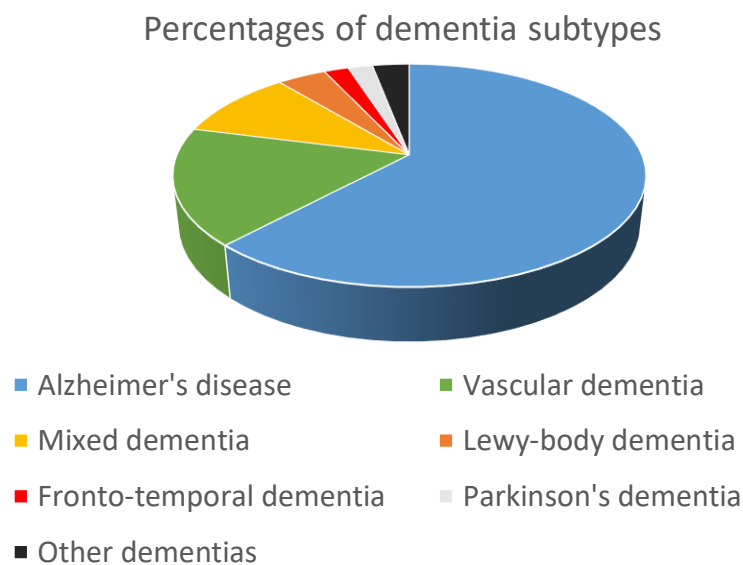


Figure 1. Percentages of dementia subtypes

Alzheimer's disease is the most common form of dementia, accounting about 62% of all dementias (Barker & Board 2012, 9). In Alzheimer's disease, brain cells are progressively dying due to changes of the brain and affecting the memory and the ability to process information (Juva 2015). The disease is typically diagnosed in patients by examining a patient's history of memory loss and eliminating other possible causes (Canadian Nursing Home 2010, 28).



Second most common form of dementia is vascular dementia (Barker & Board 2012, 9). Vascular dementia is caused by problems with blood supply to the brain (Perrin et. al. 2008, 3), leading to lack of oxygen in the brain cells (Barker & Board 2012, 9). Disorders in blood circulation can cause clogs or frequent haemorrhage in areas of the brain important to memory and other higher functions (Heimonen & Tervonen 2004, 46). Vascular dementia is typically associated with cerebrovascular and cardiovascular diseases (Chang, Liu, Billinski, Xu, Steiner, Seto & Bensoussan 2016, 1).

Mixed dementia covers 10% of all dementias (Alzheimer's Society's view on demography 2018). In mixed dementia, a person has two or more kinds of dementia combined (What is mixed dementia 2017). Other significant causes of dementia are dementia with Lewy bodies and Fronto-temporal dementia (Barker & Board 2012, 9), which both are similar to Alzheimer's disease, where brain cells are progressively dying because of the changes in the brain (Perrin et. al. 2008, 3), and also Parkinson's dementia, which may develop for those who have suffered from Parkinson's disease (Dementia 2011).

## 2.4 Risk factors of dementia

The statistics related to dementia may deceive a casual observer to believe that dementia is a disease of old age. However, this is incorrect. (Barker & Board 2002, 4.) Age is in fact the biggest risk factor of dementia (Heimonen & Tervonen 2004, 48), however it is not the cause (Barker & Board 2002, 4).

Besides old age, there are many risk factors that increase the possibility of dementia. Risk factors for Alzheimer's disease specifically include inheritance, Down's syndrome, and low level of physical and intellectual activity. Typical causes for vascular dementia include diseases of blood vessels and stroke. (Erkinjuntti et. al. 2006, 147.) Other risk factors for dementia include hypertension, high cholesterol

levels, sugar metabolism disturbances, obesity, smoking, low level of education, brain injuries, and depression (Heimonen & Tervonen 2004, 48).

## 2.5 Epidemiology of dementia

Dementia is an issue that concerns globally, in both developed and developing nations (Downs & Bowers, 2008, 1). Dementia is one of the major causes of disability and dependency among older people worldwide. The number of people living with dementia worldwide in 2010 was estimated at 35.6 million. (WHO 2012, 2.) The number of people with dementia is expected to double every 20 years and is expected to reach approximately an amount of 81 million people by 2040. Dementia is most prevalent in those over 80 years old, but a significant minority also develop the condition before they turn 65. (Downs & Bowers, 2008, 1.) In Europe there are annually 600 000 people who develop diseases related to dementia, which adds up to more people than those developing stroke, diabetes, or breast cancer (Erkinjuntti et. al. 2006, 23).

In Finland, the annual cost of dementia care for one demented person has been estimated to be 24 000 € (Erkinjuntti et. al. 2006, 40). The estimated worldwide costs of dementia in 2010 were US\$ 604 billion (WHO 2012, 2). In Great Britain, diseases related to dementia are evaluated to be the biggest disease group on a national-economical role, before cardiovascular diseases and cancer.

## 3 Communication

### 3.1 Definition of communication

Communication is a central part of human identity and part of everyday life and it has a variety of forms: spoken, written, and signed (Downs & Bowers 2008, 212; Mittal 2018, 243). Arnold and Underman Boggs (2015, 7) state that all behaviour is

communication and it is impossible to avoid communication entirely. Besides interacting with language, we use non-verbal communication which includes facial expressions, gestures, postures, eye contact and touch (Ali 2018a; Downs & Bowers 2008, 212; Kourkouta & Papathanasiou 2014; Mittal 2018, 243). Communication requires a sender, a message, and a receiver. A sender is the source of the message, a message is a combination of verbal or nonverbal expression of thoughts and feelings and a receiver is the who receives the message and interprets its meaning (Arnold & Underman Boggs 2015, 7–8).

Humans can also express themselves by different forms of creativity, such as painting, drama, and dancing (Downs & Bowers 2008, 212). In addition, silence is also a model of communication (Arnold & Underman Boggs 2015, 7). Every person can communicate, since it is an intrinsic characteristic of human nature (Kourkouta & Papathanasiou 2014).

Communication is essential part of our relationships, as it helps us to express our needs, desires, perceptions, knowledge, and feelings (Alzheimer's Association 2016). The purpose of communication is to share information and ideas using the combination of verbal and non-verbal communication (Arnold & Underman Boggs 2011, 164). Communication also includes sharing and exchanging information and ideas, thoughts and feelings among people using speech or other means of communication (Kourkouta & Papathanasiou 2014; Stevenson & Waite 2011, 289). According to Alzheimer's Association (2016), communication is more about listening than talking. Listening is a necessary part of communication (Kourkouta & Papathanasiou (2014), and effective listening also involves observation of the body language of the sender (Ali 2018b).

### 3.2 Verbal and nonverbal communication

**Verbal** communication is what we speak and write, and how we say things; tone, volume, pitch, pauses, fluency, and speed of speech add further meanings to words (Ali 2018a). **Non-verbal** communication on the other hand refers to communication without words (O'Toole 2012, 173). Large amount of all communication is nonverbal (Cherry 2018). Nonverbal communication is primarily about body language; it supports spoken words and can help people to understand each other's real feelings. The effect of nonverbal communication is individual to each situation (Ali 2018a). People tend to pay more attention to nonverbal communication instead of words when they are not harmonious with each other (Arnold & Underman Boggs 2015, 7).

Facial expressions are responsible for a large amount of nonverbal communication (Cherry 2018). A person's face is usually the first thing we see and from the expression we can already guess what the person has to say: Even a smile, frown or raised eyebrows give messages (Cherry 2018; Ali 2018a). Non-verbal communication and behaviour vary between cultures, but facial expressions for happiness, anger, sadness, and fear are similar worldwide (Cherry 2018).

### 3.3 Barriers to effective communication

Communication is a complex process where anything can go wrong. There can be many reasons for failure in communication and these reasons are referred to as "barriers to communication" (Mittal 2018, 243). A vital element for interactions to be effective is for meanings to be shared and understood (Bach & Grant 2015, 86; Mittal 2018, 243). In positive and successful communication, the receiver must understand the message that the sender has meant (Dailey 2017; Mittal 2018, 243). Bach & Grant (2015, 86) state that awareness should be created for factors blocking effective communication, which may arise from individual differences, such as language, ability and disability, power, authority, personality, background, gender, age, race, and socioeconomic group. According to Dimbleby & Burton, barriers of

communication should be recognized to be able to improve it. These barriers are factors which interfere with free and full communication (Dimbleby & Burton 1998, 78).

Communication might be blocked by physical or environmental barriers which are present in the area surrounding the sender and receiver (Dailey 2017; Mittal 2018, 243). Noise, bad lighting, and unstable temperature are interferences which can affect the context of communication between individuals (Ali 2017; Arnold & Underman Boggs 2015, 8; Dailey 2017; Dimbleby & Burton 1998, 79; Mittal 2018, 243). Noise is the most common barrier to communication, and it can occur, for instance, as an interruption of another person or a phone call. Something as simple, as the distance of the sender and the receiver can act as a physical barrier and disturb the process of communication. (Mittal 2018, 243.)

One of the greatest barriers in communication is the inability to create understandable language between the sender and the receiver (Dailey 2017). Ideal situation is where the sender and a receiver speak the same language, but quite often the level of language is not equal, creating a barrier to communication (Mittal 2018, 243–244). In addition to language, also usage of words, context of speech, time used and assumption-making about meaning of words affect the ability of communication between individuals (O'Toole 2012, 233). When not sharing a common language, it is easier to be misunderstood by the receiver (Dailey 2017). If words are not used correctly and don't have the intended meaning, the risk of misunderstandings becomes larger (Dimbleby & Burton 1998, 79). The sender can also use terminology that is not understood by the receiver, creating a barrier to communication. In addition to these, emotions also disturb the flow of communication. Any mental state, such as anxiety or fear, can become a barrier to communication. (Mittal 2018, 243–244.)

Languages often have words with multiple meanings and a word can convey different meanings between the sender and the receiver (Mittal 2018, 243). According to Dimbleby & Burton (1998, 80), these meanings exist only in our mind, and not in the words themselves. Even in the same culture, the different age groups may have different meanings to the same word (Arnold & Underman Boggs 2011, 172). When individuals can communicate with a common language, and when meanings are the same for specific words between the individuals, mutual understanding is enhanced (O'Toole 2012, 234). According to Dimbleby & Burton (1998, 80), there is a barrier to communication if we cannot attach meaning to a sign.

## **4 Aim & Purpose**

The aim of this literature review is to produce a synthesis of what factors improve communication between caregivers and persons with dementia. Our purpose is to provide information about communication with dementia patients to allow possibilities for better care.

Research question:

- What factors improve communication between caregivers and persons with dementia?

## **5 Methodology**

### **5.1 Literature review**

The study was conducted as a literature review. This method was chosen to develop insights on what factors improve communication between caregivers and persons with dementia. The objective of this literature review is to summarize the most recent information, thus to distil the existing literature (Rowley & Slack 2004, 31) and to allow to form a general view on what factors improve communication between

caregivers and persons with dementia. (Stolt, Axelin, Suhonen 2016, 7). This also allows identifying of areas in which further research would be beneficial (Rowley & Slack 2004, 31).

The constructor of a literature review needs to be sufficiently familiar of the area of study, to allow filtering of only appropriate and topic-related information. Only with expertise the review can be formed so that common, loosely related studies are explained only in general, and studies that create a background for a new research, are analysed adequately in detail. (Hirsjärvi, Remes & Sajavaara 2007, 253.)

As a literature review, this thesis has two key elements. First, it concisely summarizes the findings or claims that have emerged from prior research efforts related to communication with persons with dementia. (Knopf 2006, 127.) It seeks to summarize the literature that is available on the topic (Aveyard 2014, 4). Second, it reaches a conclusion about how accurate and complete that knowledge is (Knopf 2006, 127). It presents an analysis of the available literature and makes sense of the body of the research. This will allow the reader to not need to access individual reports about communication with persons with dementia. (Aveyard 2014, 4.)

Hart (n.d., 1) states that conducting literature reviews is important, because without one, it would not be possible to acquire understanding of the topic, its previous research, and the key issues. Stolt et. al. also emphasize the significance of literature reviews as a research tool: it is unquestionable. This literature review can be regarded as a special systematic research method, which is based on process-related and scientific functioning. (Stolt, et. al. 2016, 7.) For the students, the literature review permitted an excellent learning opportunity, as they had a chance to show that they are able to filter the main points, build the foundation for their study and to justify their research. (Hirsjärvi et. al. 2007, 253.)

## 5.2 Data collection

The data for this literature review was collected from the databases CINAHL, PubMed, Science Direct and Google Scholar. Additionally, manual search from the university library and the World Wide Web have been conducted in an effort to retrieve all relevant data. Different combinations of keywords were used during the data search process. Best results were gathered using the words dementia, nurs\*, and communicat\*. Search results are seen in the table 1 for each database.

The process of selecting studies for a literature review consist of two phases. The first phase involves going through the titles and abstracts to find studies that meet the inclusion criteria. The second phase involves reading full text of each article. (Bettany–Saltikov 2012, 84.) The obtained data were examined by the heading, and the abstracts read. Relevant articles were chosen based on the predetermined research question and inclusion criteria. The inclusion criteria included studies which were published between 2008-2018, were in English language, had full text access, were peer-reviewed, and answered the research question.



Table 1. Results of the literature search

Database	Search terms	Results	Chosen based on title and abstract	Relevant studies
Cinahl	Communicat* AND Dementia OR Alzheimer's OR "Cognitive impairment" OR "memory loss" AND Nurs*	1231	10	5
Science-Direct	Dementia, communication, nurse, nursing, Alzheimer's, Cognitive impairment	512	1	0
Pubmed	Nurses communication with dementia patients	30	4	1
Google Scholar	Dementia, communication, nurse, nursing, Alzheimer's, Cognitive impairment	21900	4 from first page	0
Manual search		-	-	2
Total		1777	15	8

### 5.3 Data analysis

The selected data was analysed by using **content analysis**. Content analysis is a basic analysis method, which can be used to analyse different materials and to describe them. The objective of a content analysis is to present a phenomenon widely but densely. Some of the strengths of a content analysis include sensitivity of the content and flexibility of the research setting. (Kankkunen & Vehviläinen-Julkunen 2009, 134.)

A content analysis can be done inductively or deductively. (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs 2014, 1; Kankkunen & Vehviläinen-Julkunen 2009, 135.) In **inductive** analysis, categories are conducted from the materials and are directed by the research problems. The theoretical totality is strived to be gathered from the research material so that earlier findings, information, or theories don't lead the analysis. Inductive analysis should be used if there is not information of the subject or the earlier information is scattered. The basis of a **deductive** content analysis is theories, theoretical concepts, and their appearing in practice. The researcher is usually using an analysis structure or a form, in which the theoretical baseline is operationalized according to the direction of earlier knowledge and research. (Kankkunen & Vehviläinen–Julkunen 2009, 135.)

This study will use an inductive content analysis method for purposes of data analysis. The researchers chose this method based on their notions that the earlier information on the subject is scattered, to be able to describe the phenomenon widely but densely and based on their findings that little of the literature related to communicating with people with dementia is supported by research (Perry et. al. 2005, 44).

Inductive content analysis has three phases: preparation, organizing and reporting. **Preparation** consists of collecting suitable data and making sense of it. (Elo et. al. 2014, 1–2.) According to Elo et. al., Elo & Kyngäs (2008) state that the **organizing** phase involves open coding, creating categories and abstraction. The final phase, **reporting**, includes describing the results by the content of the categories describing the phenomenon. (Elo et. al. 2014, 1–2.)

## 6 Results

The results are presented in three main categories: communication training for caregivers, communication methods & utilities for caregivers, and leisure activities for persons with dementia. The themes and subthemes of the results are presented in table 2 described below.

Table 2. Categories and subcategories of the factors that improve communication among caregivers and persons with dementia

Research question	Themes	Sub-themes
Factors that improve communication between caregivers and persons with dementia	Communication training for caregivers	Validation method training
		VIPS communication tool training
	Communication methods & utilities for caregivers	Communication sessions
		Memory aids
		Music Therapeutic Caregiving
	Leisure activities for persons with dementia	Technology-supported games
		Creative therapy

### 6.1 Communication training for caregivers

The results of this research indicate that communication training could be beneficial considering communication between persons with dementia and caregivers (Egan, Bérubé, Racine, Leonard & Rochon 2010, 5; Söderlund, Cronqvist, Norberg, Ternstedt & Hansebo 2016, 37; Eggenberger, Heimerl & Bennett 2012, 12; Passalacqua & Harwood 2012, 425). Communication training was found to have

positive effects on nurse-patient co-operation (Vasse, Vernooij-Dassen, Spijker, Olde Rikkert & Koopmans 2010, 193), to increase quality of life and wellbeing of people with dementia, and to have a clear benefit considering positive behaviour and satisfying interactions (Eggenberger et. al. 2012, 11–12). It is possible that having conversations as a planned activity for persons with dementia could contribute to their overall wellbeing (Söderlund et. al. 2016, 45). When used in daily care, communication training programs have positive effects on communication among care workers and persons with dementia (Vasse et. al. 2010, 198.)

Brooker's (2004) **VIPS** principles (Valuing people, Individualized care, Personal perspectives, and Social environment) appear to help to facilitate ways of consistent communication. *"Smooth execution of the workshops, positive evaluations from participants, and promising trends in outcome measures indicate the feasibility and usefulness of the program."* Caregivers reported using more communication strategies known to be effective with persons with dementia and exploring new ways of communicating in a person-centred approach to dementia care. (Passalacqua & Harwood 2012, 425, 440–443.)

Communication training programmes could also lead to nurses becoming more aware of the remaining abilities of communication for persons with dementia. It is likely that the persons with dementia can benefit from **Validation Method** programme which aims to facilitate communication and help to use the remaining communication abilities. *"It is possible that at the end of the programme, the nurses had developed their communication skills, which gave the persons opportunities to communicate what was on their mind at the time."* (Söderlund et. al. 2016, 37, 45.)

After training, persons with dementia had the opportunity to use their remaining communication abilities (Söderlund et. al. 2016, 37), and it also resulted in reduction in caregiver depersonalization and an increase in empathy and hope for persons with dementia (Passalacqua & Harwood 2012, 425). Communication skills training

enhanced awareness of the viewpoint of the person with dementia and built understanding of the challenges and opportunities in communicating with people with dementia (Eggenberger et. al. 2012, 12).

Education in communication ultimately increased caregivers' communication skills, competencies, and knowledge (Eggenberger et. al. 2012, 12; Söderlund et. al. 2016, 45). Post-training, caregivers used more gestures and humour, which suggests substantive attempts to explore routes to mutual understanding. Yes/no questions and giving choices between two options were also used more, which according to Passalacqua & Harwood (2012, 441), Rodin & Langer (1977) describe to be approaches to enhance resident choice and thus control. (Passalacqua & Harwood 2012, 438, 441.) Caregivers found the communication techniques and tips useful and valuable (ibid., 439–440) and reported a greater feeling of control, and to be enjoying the opportunity to learn more about the patients they cared for. (Eggenberger et. al. 2012, 12.)

## 6.2 The use of communication methods & utilities for caregivers

The use of certain communication methods and aids were found to be beneficial considering communication between persons with dementia and their caregivers (Egan et. al. 2010, 8; Vasse et. al. 2010, 189; Marmstål Hammar, Emami, Engström & Götell 2011, 167). Positive effects were found with communication methods such as Music Therapeutic Caregiving (Marmstål Hammar et. al. 2011, 167) and using structured and communicative sessions, such as life-review or one-on-one conversation (Vasse et. al. 2010, 189). Memory aids, such as biographical information, simple images, brief phrases, and pictures of family members, were also found to be useful in communication between caregivers and persons with dementia (Egan et. al. 2010, 8; Vasse et. al. 2010, 193, 196).

**Music Therapeutic Caregiving**, which involved singing during care situations with persons with dementia increased communication and evoked co-operation: caregivers and persons with dementia connected during their encounter, and persons with dementia were more active in communicating and during the care situation. Singing during care situations seemed to be a useful method to promote communication between caregivers and persons with dementia. (Marmstål Hammar et. al. 2011, 166–167.)

*“The caregiver stopped her [caregiver’s] singing, and the person with dementia continued where she had left off. One person with dementia made up her own lyrics to a song, and another one that normally spoke with single words began singing. The caregiver seemed surprised and started to cry, apparently overcome with positive emotions. Another caregiver seemed overwhelmed and forgot the lyrics when the person with dementia started to sing.”* (Marmstål Hammar et. al. 2011, 165.)

The use of **memory aids** combined with caregiver training was also found to be beneficial for communicating with persons with dementia. In their research, Egan et. al. concluded that memory aids incorporated with caregiver training resulted in highest level of support for communication between persons with Alzheimer’s disease and their caregivers. Memory aids were able to address verbal attention and help individuals focus their thoughts, and they demonstrated most definite effectiveness in improving communication. (Egan et. al. 2010, 8.)

### 6.3 Leisure activities for persons with dementia

Leisure activities, such as creative therapy and technology-supported games, were found to stimulate and improve communication among persons with dementia (Nijhof, van Hoofb, van Rijnc & van Gemert-Pijnen 2013, 263; Rylatt 2012, 42).

**Creative therapy** resulted in improvements in general engagement, communication, and creative self-expression, and it showed to have significant effects on wellbeing of

persons with dementia. (Rylatt 2012, 42.) **Technology-supported games** also led to similar results: a higher occurrence was seen on social behaviour, stimulated communication, and empathy among persons with dementia (Nijhof et. al. 2013, 271).

## 7 Discussion

### 7.1 Discussion of key findings

All reviewed articles pointed out the fact that people with dementia have problems expressing themselves and produce understandable language. Similarly, WHO (2017) conclude that dementia as a progressive syndrome influences thinking, language, comprehension and ability to learn, therefore overtime it will limit person's social coping and functioning. It is obvious that people with dementia need support in their daily life and assistance to maintain their ability to communicate. Eggenberger et. al. (2012), Passalacqua & Harwood (2012) and Söderlund et. al. (2016) therefore propose communication training for caregivers. It was proved to be effective way to help the people with dementia to use their remaining communication abilities (Söderlund et. al. 2016, 37). Egan et. al. (2010) combined communication training for caregivers and aids for people with dementia. Few articles introduced more innovative solutions to improve the communication between caregivers and people with dementia.

The current review indicates that persons with dementia often have trouble comprehending and producing messages, which might lead to inadequate interactions between caregivers and persons with dementia (Egan et. al. 2010; Passalacqua & Harwood 2012, 427–428; Vasse et. al. 2010, 199). This is in line with Dailey (2017) who concluded that one of the greatest barriers to communication is the inability to create understandable language leading to higher risk of misunderstandings. To minimize this, Bach & Grant (2015), propose that when the

factors blocking effective communication are recognized there is possibility to make improvement. To avoid the problematic interactions, communication-skills training has been proposed to improve the quality of care and helps the caregivers to support persons with dementia (Egan et. al. 2010; Passalacqua & Harwood 2012, 427–428; Vasse et. al. 2010, 199). The results further show that communication training for caregivers might improve the abilities of people with dementia to communicate (Egan et. al. 2010, 5; Söderlund et. al. 2016, 37; Eggenberger et. al. 2012, 12; Passalacqua & Harwood 2012, 425). Communication training for the caregivers was found to be one of the most effective ways to improve communication. Therefore opportunities for communication training should be made available for caregivers, for instance as an additional training programme.

Humans can use different means expressing themselves, such as painting, drama, and dancing (Downs & Bowers 2008, 212). Communication is a central part of human identity and an essential part of our relationships helping to express our needs, desires, perceptions, knowledge, and feelings (Downs & Bowers 2008; Alzheimer's Association 2016), therefore it seems that the ability to communicate should remain sufficient. The results of this study suggest that alongside with communication training and memory aids, different kind of leisure activities might help persons with dementia to use their remaining abilities to communicate (Egan et. al. 2010, 8; Nijhof et. al. 2013, 271; Rylatt 2012, 42). It was found that use of music, drama, dance and other activities offered people with dementia an opportunity for self-expression, which led to improved communication and feel of pleasure and enjoyment (Rylatt 2012, 47). Furthermore, games, such as question games and technology-supported games were also found to possibly stimulate communication and increase social behavior (Nijhof et. al. 2013, 271–272). The best results came when communication training for caregivers was combined with memory aids and leisure activities (Egan et. Al. 2010; Nijhof et. al. 2013). Moreover, the results indicated that persons with dementia spent more time on leisure activities after communication interventions were performed (e.g. workshops for caregivers and evaluation of the results) (Passalacqua & Harwood 2012, 440–441).



## 7.2 Ethical considerations

It is important to adhere to ethical norms in research. Ethical norms promote the aims of research, which include knowledge, truth, and avoidance of error. Norms also promote values essential to collaborative work, e.g. fairness, accountability, and respect, as research often involves cooperation and coordination between people. Many ethical norms ensure that researchers can be held accountable to the public, and they also promote other moral and social values, such as human rights, public health, and safety. (Resnik 2011.)

The conductors of this research applied principles of honesty to avoid **plagiarism**, which refers to representing others' work as one's own (Price 2014, 46), and **fabrication**, which means presenting invented information (Finnish Advisory Board on Research Integrity 2012, 32). All evidence and scientific information were gathered and presented carefully to ensure correct presentation of knowledge and to credit authors, whose material has been used for the purposes of the thesis. An effort has been made also to not apply **falsification**, which is modification or selection of research results. (Finnish Advisory Board on Research Integrity 2012, 33.) Results have been filtered only to answer the research question, and the conductors of this research have not had any personal interests giving reason to modify or select certain results.

For this literature review, the gathered literature answering the research question originated from six countries: Austria, Canada, The Netherlands, The United Kingdom, The United States of America, and Sweden. According to Huntington (1996, 26–27, 54–55), all of these countries represent western cultures (western culture is defined as Euro-American or North-American culture). As all of the results are from similar cultures, it reduces the ability to generalize the results of this research to areas of other cultures.

The authors of this research were nursing students in a university of applied sciences. For acquiring information, the authors had access to the school library, certain information databases, such as Cinahl and Pubmed, and data that was free and accessible in the World Wide Web. The research was not funded in any matter. Considering these factors, it is important to take into consideration the possibility of availability bias, as results were gathered with material found from sources accessible to university students and which were public on the internet. With funding and access to more databases and information, there could have been more and/or different kind of results for the research question.

The topic for this thesis was chosen based on the interest of the authors. The thesis was not assigned to the authors by any organization or individual person. The authors did not conduct the thesis in sight of any personal advantages, except for advancing in their curriculum.

### 7.3 Conclusions and recommendations

In this literature review, there were many factors that were found to improve communication between caregivers and persons with dementia: communication training programmes for caregivers, communication utilities and methods for caregivers, such as memory aids and communication sessions, and leisure activities for persons with dementia, such as creative therapy and technology-supported games. These factors helped persons with dementia and also caregivers gain vast improvements in their ability to communicate with each other. Communication training for caregivers was found to improve quality of life and wellbeing for persons with dementia, and to increase positive behaviour and satisfying interactions.

This study can be utilized by health care professionals and other caregivers when caring and communicating with persons with dementia. The utilities and techniques

that emerged in this study can be used to enhance communication with persons with dementia and to improve their quality of life. Further research is needed to increase quantity and quality of methods and utilities for communication that would benefit persons with dementia.

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## Appendices

Appendix 1. Summary of research articles included in the study in alphabetical order

Author(s), year, country	Aim	Research method	Sample	Main results
Eggenberger et al. 2012, Austria.	To evaluate interventions designed to enhance communication or interaction in dementia care.	Systematic review	831 persons with dementia, 519 professional caregivers, 162 family caregivers.	Communication skills training improves wellbeing of persons with dementia, increases positive interactions, and has a significant impact on caregivers' communication skills.
Egan et al. 2010. Canada.	To investigate the efficacy of methods used to improve communication between individuals with Alzheimer's disease and their caregivers.	Systematic review		Caregivers indicated the highest level of support for the use of memory aids combined with caregiver training.
Marmstål Hammar, et al. 2011, Sweden	To describe how persons with dementia and their caregivers communicate during morning care situations with and without music therapeutic caregiving (MTC).	Qualitative analysis	6 caregivers, 10 persons with dementia	MTC increased communication and evoked co-operation between persons with dementia and their caregivers.
Nijhof et. Al. 2013, Netherlands	To explore the impact of technology-supported leisure activities on the wellbeing of persons with	A mixed-method design	21 persons with dementia	A technology-supported game may encourage communication and social behaviour among persons with

	dementia.			dementia.
Passalacqua & Harwood 2012. USA.	To test the practicability of VIPS: a communication skills intervention	Pre- and post-test design	50 caregivers	After communication skills training, caregivers were exploring new ways of communicating that reflected a person-centred approach to dementia care.
Rylatt 2012. United Kingdom.	To evaluate use of creative therapy for persons with dementia.	-	37 persons with dementia	Creative therapy provides opportunities for enhanced communication and general engagement for persons with dementia
Söderlund et al. 2016, Sweden	To highlight the actions and reactions of persons with dementia in conversations with caregivers during communication training.	Qualitative analysis	4 persons with dementia, 4 nurses	Persons with dementia had opportunities to use their remaining communication abilities.
Vasse, E. et. Al. 2010. Netherlands.	To study the effects of nonpharmacological interventions on communication between persons with dementia and caregivers.	Systematic review		Care staff can improve their communication with residents with dementia when strategies are embedded in daily care activities.