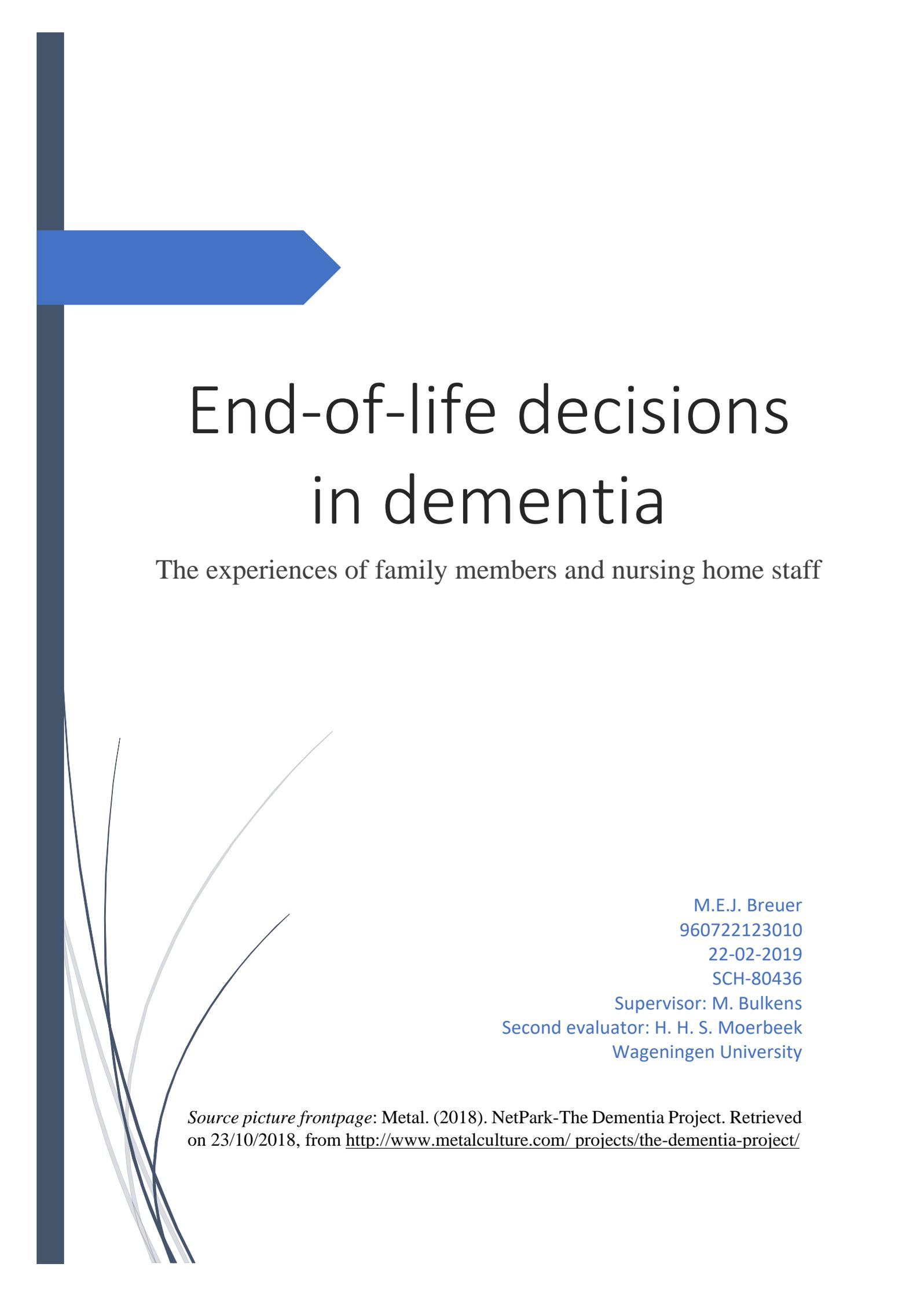


# End-of-life decisions in dementia

The experiences of family members and nursing home staff



M.E.J. Breuer



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## 1. Introduction

Dementia is the term for a combination of symptoms, a syndrome, in which the brain can no longer process information properly (Stapersma, 2015). It includes more than fifty diseases of which the most common one is Alzheimer's disease, followed by vascular dementia, frontotemporal dementia, and Lewy body dementia (Alzheimer Nederland, n.d.; Sampson, 2010).

Dementia concerns memory disorders in combination with one or more specific cognitive disorders (Vilans, 2014). Memory disorders are characterized by a reduced ability to learn new information and to remember previously learned information. Cognitive disorders are related to perception, language, memory, and thinking. The specific cognitive disorders are: aphasia (problems with expression in and understanding of spoken or written language), apraxia (problems with deliberate actions), agnosia (loss of ability to recognize things), and disorders in executive functions (Vilans, 2014). Next to memory and cognitive disorders, persons with dementia develop personality changes, and behavioural and psychological symptoms (e.g. depression, psychotic symptoms, wandering, and aggression) (Sampson, 2010).

As no cure is foreseen, dementia can be considered a chronic disease that progressively and irreversibly leads to death (Birch & Draper, 2008). Dutch persons with dementia live with the disease for an average of eight years, after which they often die of complications of dementia (e.g. pneumonia) (Alzheimer Nederland, n.d.). The course, duration, and prognosis of dementia differs depending on multiple factors, such as the area of the brain that is affected and the age of onset (Birch & Draper, 2008; Harris, 2007).

Due to the ageing population and the fact that dementia is an age-related disease, the worldwide prevalence of dementia is increasing (Alzheimer's Disease International, 2009; Hall, Petkova, Tsouros, Costantini, & Higginson, 2011; International WHO'sAsD, 2012). In 2010, the worldwide prevalence of dementia was almost 36 million out of 69 billion people. It is expected that this number will double every 20 years, resulting in a predicted prevalence of about 65 million out of 85 billion people by 2030 (Ryan, Gardiner, Bellamy, Gott, & Ingleton, 2012; Van der Steen et al., 2014) and 90.3 million out of 92 billion people by 2040 (Prince et al., 2013). Consequently, the number of people dying with or from dementia is increasing (Van der Steen, 2010). This makes dementia a major global health problem (e.g. Prince et al., 2013; Ryan et al., 2012; Van der Steen et al., 2014; Wimo, Jonsson, & Winblad, 2006; Wimo, Winblad, Aguero-Torres, & Von Strauss, 2003).

The Dutch Health Council (Gezondheidsraad) estimates that in 2020 approximately 230.000 out of 17 million persons in the Netherlands will suffer from dementia. An increase to 400.000 out of 18 million persons is expected by 2050 (Health Council of the Netherlands, 2002). With these numbers, dementia is rapidly becoming one of the most common conditions affecting older people (Diwan, Hougham, & Sachs, 2004).

In the Netherlands, more than 90% of people with dementia die in a nursing home (Houttekier et al., 2010). This makes the provision of end-of-life care in Dutch nursing homes crucial (Mitchell, Kiely, & Hamel, 2004a; Mitchell, Morris, Park, & Fries, 2004c). In this thesis, end-of-life care is defined as:

*“an approach that aims to provide patients who are considered to be in the last years of life and their families with the highest possible quality of life, by preventing and alleviating suffering through early signalling and careful assessment and treatment of problems of physical (e.g. pain), psychosocial (e.g. feelings of unsafety and discomfort), and spiritual nature (e.g. feelings of peace) and to help them to die with dignity”*

This definition is based on the WHO (2002) definition of palliative care, combined with the new view on palliative care as independent of prognosis (Murray, Kendall, Boyd, & Sheikh, 2005; National Council for palliative care, 2007; Zerzan, Stearns, & Hanson, 2000). Besides, elements of a definition of end-of-life care are incorporated (National Council for Palliative care, 2018). This resulted in a definition which includes a focus on patients and their families, quality of life, and dignity. By using this definition of end-of-life care, this thesis focuses on decisions that are often made in the last phase of the lives of persons with dementia (e.g. forgoing curative treatment and applying a dehydration policy). This way, this thesis excludes decisions to actively end the lives of persons with dementia (euthanasia). As literature on end-of-life care for persons with dementia is scarce, this thesis is largely based on literature that focuses on palliative care. By using the definition stated above, end-of-life care can include palliative care.

The end-of-life phase in persons with dementia is complex and characterized by various complicated choices (Wary, 2003). For 53% of Dutch nursing homes residents, a decision to forgo treatment is relevant prior to death (Muller, Kester, & Groenewoud, 1997). This percentage is estimated to be even higher for persons with dementia (Onwuteaka-Philipsen et al., 2001). As persons with advanced dementia often lack decisional capacity (Rabins, Hicks, & Black, 2011), they can become unable to make decisions about their own end-of-life

treatment (Carpenter & Flinders, 2004). This means that someone else must act on behalf of the person with dementia. In addition, the physician has to ask the representative of the person with dementia for permission for medical actions to be pursued (Rabins et al., 2011). It may happen that the representative of the person with dementia does not agree with the advice of the physician, or that there are different opinions within the family about the best way to proceed (Gjerberg, Førde, & Bjørndal, 2011). These two factors make that end-of-life decisions about the treatment of persons with dementia can be considered a challenge (Wary, 2003).

## 2. Background

This chapter provides background information on the end-of-life decision-making process in the context of dementia. It is important to have background knowledge on this process, as this has implications for research in this area. The end-of-life decision-making process in the context of dementia can be considered complex for two main reasons. Firstly, a representative of the dementia patient has to make decisions about end-of-life treatment on behalf of the patient (Rabins et al., 2011). The representative can be the patient's partner, child, brother, or sister. To be able to act in the interest of the dementia patient, the representative must be aware of the views of the patient and the treatment options. Therefore, the preferences of the patient can be documented in advance directives or communicated to family members (Van Soest-Poortvliet et al., 2013). An advance directive is a document in which a person gives instructions about his or her own wishes for end-of-life care (Robinson et al., 2011).

Secondly, the physician is responsible for the treatment decision made (Vilans, 2014). However, in the context of dementia, the physician cannot act without the consent of the representative of the patient. Therefore, the physician and the representative of the dementia patient have to come to an agreement about the decision to be taken. Yet, it may happen that the representative of the patient makes a choice that, according to the physician, is not in the patient's interest (Gjerberg et al., 2011). In this case, the physician has to choose between acting in the best interest of the patient or respecting family members' opinions. Besides, family members may have different opinions about the end-of-life decision. These different opinions may cause disagreement about the decision, which can further complicate the end-of-life decision-making process in the context of dementia (Gjerberg et al., 2011).

As the end-of-life decision-making process in the context of dementia is often characterized by a representative who acts on behalf of the dementia patient, early communication about patient wishes for future care is important (Stapersma, 2015). Early end-

of-life communication with a dementia patient can reduce stress experienced by family members during the end-of-life decision-making process (Vandervoort, Houttekier, Vander Stichele, Van der Steen, & Van den Block, 2014), hospital admissions that are undesired by patients, and health care costs (Robinson et al., 2011). An approach that can facilitate early end-of-life communication is the use of 'goals of care' (Fried & O'Leary, 2008; Gillick, Berkman, & Cullen, 1999; Van der Steen et al., 2014). A patient's goals of care can guide the start of decisions on new treatments or the withdrawal of ongoing treatments in the future (Fried & O'Leary, 2008; Gillick et al., 1999; Van der Steen et al., 2014).

In literature, three goals of care are distinguished: curative, palliative, and symptomatic care (Van Soest-Poortvliet et al., 2013). Curative care aims to cure the disease or influence it in such a way that the patient has a normal life expectancy (Van Soest-Poortvliet et al., 2013). Because no cure for dementia is available, in this case, curative care is aimed at problems that are often related to dementia (e.g. pneumonia). Palliative care and symptomatic care both aim to ensure optimal wellbeing and an acceptable quality of life. The difference between these two types of care is that life extension is accepted in palliative care but is undesirable in symptomatic care (Van Soest-Poortvliet et al., 2013). For example, in palliative care, life-sustaining treatments for other medical conditions related to dementia (such as pneumonia) are continued if discontinuation of treatment will result in premature death, unpleasant symptoms, or a lower quality of life (Thomas, Zubair, Hayes, & Ashby, 2014). In symptomatic care, life-sustaining treatments are stopped unless this causes suffering for the patient (Thomas et al., 2014). A symptomatic care goal is chosen when death is believed to be imminent and care should merely focus on providing comfort, quality of life, and dignity (Thomas et al., 2014).

### 3. State of the art

In the last 30 years, advanced dementia has become an upcoming topic of interest in scientific literature (Volicer, Rheaume, Brown, Fabiszewski, & Brady, 1986). However, dementia has only been seen as a terminal illness by many experts in the field since recent years (Di Giulio et al., 2008; Mitchell, et al., 2004a; Mitchell et al., 2012; Sachs, Shega, & Cox-Hayley, 2004). For this reason, there have been little research and initiatives executed to improve the quality of life of dementia patients at the end of their lives (Mitchell et al., 2012).

Since research started to focus on dementia, the number of studies on end-of-life in dementia patients has greatly increased (Van der Steen, 2010; Van der Steen & Goodman, 2015). However, there is still sparse evidence on the effects or effective elements of end-of-life

care in dementia. A few studies on the perceptions of family members of dementia patients on end-of-life care for their relative have been performed. A study by Hill, Mason, Poole, Vale, & Robinson (2017) showed that most family members of dementia patients like to be involved in decision-making. In addition, research by Lopez, Mazor, Mitchell, & Givens (2013) identified five themes that family members of nursing home residents with advanced dementia find important in end-of-life care: (1) providing basic care (including food, cleanliness, and comfort), (2) ensuring safety and security, (3) creating a sense of belonging and attachment (both between the residents and staff and between family members and staff), (4) fostering self-esteem and self-efficacy when making end-of-life decisions on behalf of someone else, and (5) accepting the final stage of life. However, the most appropriate approach to end-of-life decision-making differs per dementia patient and per family member (Hill et al., 2017).

Some evidence suggests that palliative care improves the satisfaction with care of family members (Cohen et al., 2012). However, the benefits of palliative care for patients are less clear (Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2008; Teno et al., 2011; Van Soest-Poortvliet, et al., 2015). Few studies on the efficacy of end-of-life care in the context of dementia are undertaken. In addition, studies showed mixed results (Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). Three studies that were included in a systematic review by Sampson et al. (2005) suggested that there were some benefits of the palliative approach, such as better symptom control and fewer unnecessary interventions. In contrast, a study by Ahronheim, Morrison, Morris, Baskin, & Meier (2000) did not show an effect of a palliative approach on the care that dementia patients received.

Despite conflicting results, consensus is reached that end-of-life care is valuable in advanced dementia (Van der Steen et al., 2014). The perception of dementia as a life-threatening illness is associated with better comfort in dementia patients in the last years of their lives (Van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, & Deliëns, 2013). This association is mediated by better quality of family-patient relationships as perceived by family and higher quality of end-of-life care (Van der Steen et al., 2013). In addition, some scholars suggested that only labelling dementia care as palliative care may already result in improved patient care, as the terminal nature of the disease becomes more recognized (Hughes, Jolley, Jordan & Sampson, 2007). Furthermore, the multidisciplinary basis of palliative care might help in anticipating, assessing, and managing the various problems associated with dementia (Van der Steen et al., 2014). The behavioural and psychological symptoms of dementia can be challenging for caregivers, patients, and family members. Integration of expertise from different

fields (e.g. geriatrics, psychology, and dementia care), which is an important element of the palliative care approach, is needed to deal with these symptoms (Van der Steen et al., 2014).

Literature on end-of-life in the context of dementia can be divided into two topics: determining the end-of-life phase in dementia, and the end-of-life decision-making process. Research on these two topics will be discussed in more detail below.

### 3.1 Determining end-of-life in dementia

The unpredictable prognosis of dementia leads to difficulties in determining the terminal phase of the disease. Although the CASCADE (Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life) study showed that advanced dementia is characterized by high mortality rates (Mitchell et al., 2006), research has not been successful in accurately estimating death in advanced dementia (Marsh, Prochoda, Pritchett, & Vojir, 2000; Mitchell et al., 2004b; Mitchell et al., 2010; Schonwetter et al., 2003; Van der Steen, Mitchell, Frijters, Kruse, & Ribbe, 2007).

Nevertheless, the Global Deterioration Scale may be helpful in determining the end-of-life phase in dementia patients. This scale describes the stages of clinical progression of dementia (Reisberg, Ferris, de Leon, & Crook, 1982). Stage 7 of this scale describes prognostic indicators of what is called advanced dementia, which can be considered the terminal phase of dementia. These indicators are: inability to recognize familiar faces, verbal abilities limited to less than five words, incontinence of urine and stool, total functional dependence, and inability to walk. Furthermore, the end-of-life phase of dementia is often characterized by frequent infections (Harris, 2007). In addition, non-specific symptoms, such as bowel incontinence, seem to be better predictors of death within six months than specific cognitive symptoms of dementia (Rabins et al., 2011).

Another widely used way of identifying dementia patients who are approaching the end of their life is asking the surprise question: “Would you be surprised if this patient were to die in the next 6-12 months” (Harris, 2007, p.363). However, this method is often not applied by general practitioners in the care for older people (Elliott & Nicholson, 2017). The reason for this is the subjective nature of the question (Elliott & Nicholson, 2017). Due to the subjective nature of the question, a physician can make an inaccurate estimation of when the palliative phase begins (Elliott & Nicholson, 2017). According to literature, prognostic indicators seem to be the best identifiers of dementia patients who are likely to be in the last year of life (Sachs et al., 2004). Therefore, contrary to what one would expect, the end-of-life phase of dementia patients is expressed in other determinants than time.

Looking at literature on the end-of-life phase in the context of dementia, it seems to be difficult to estimate death in dementia patients. Therefore, one of the challenges of end-of-life care in dementia concerns diagnosing the terminal phase. As the prognostication of dementia is uncertain and differs per patient, it is difficult to provide end-of-life care at the appropriate time (Birch & Draper, 2008). Despite the difficulty, it is important to identify the terminal phase of dementia, so that end-of-life care can be planned and provided and dementia patients, as well as family members, can be prepared for the terminal phase (Harris, 2007). In addition, the definition of end-of-life in dementia shows which dementia patients are considered suitable for palliative care. Therefore, how end-of-life is defined influences the end-of-life decision-making process (Lorenz et al., 2008).

### 3.2 End-of-life decisions

The end-of-life decision-making process is characterised by different choices. The choice between curative and palliative care in advanced dementia can be considered a challenge (Wary, 2003). Because no cure for dementia is available, curative care is aimed at problems that are related to dementia (e.g. behavioural and psychological problems). End-of-life decisions in dementia most often concern eating problems and infections (Givens, Kiely, Carey, & Mitchell, 2009). Eating problems can be treated by continued assisted oral feeding or tube feeding. Decisions about treatment of infections involve the choice between the use of antimicrobials or only supportive measures (Mitchell et al., 2012).

In literature, there is much discussion about the appropriateness of medical (curative) treatment for dementia patients (Birch & Draper, 2008). The reason for this is that there is considerable evidence that a medical approach is minimally effective for patients with dementia (Ahronheim, Morrison, Baskin, Morris, & Meier, 1996; Evers, Purohit, Perl, Khan, & Marin, 2002; Hinkka et al., 2002; Lloyd-Williams, 1996; Morrison & Siu, 2000; Volicer, 2001). Observational studies have not been able to show the benefits of tube feeding (Finucane, Christmas, & Travis, 1999; Meier, Ahronheim, Morris, Baskin-Lyons, & Morrison, 2001; Mitchell, Kiely, & Lipsitz, 1997), which led experts to argue against the use of this treatment in advanced dementia (Finucane et al., 1999; Gillick, 2000; Mitchell, 2007). Furthermore, it is unclear whether antimicrobials meaningfully extend life or improve comfort in advanced dementia patients (Morrison et al., 1998; Van der Steen, Ooms, Adèr, Ribbe, & Van der Wal, 2002; Van der Steen et al., 2006). Therefore, the use of medical treatment for dementia patients can be questioned.

Another frequently occurring and challenging end-of-life decision concerns hospitalization (Rabins et al., 2011). A study in Belgium showed that it is common to hospitalize nursing home residents with dementia in the last month of life (Houttekier et al., 2014). The most prevalent purposes of hospital admission of nursing home residents with dementia are treatment of infections and pneumonia (Dosa, 2006; Givens, Selby, Goldfeld, & Mitchell, 2012). The choice to hospitalize a person with dementia is challenging because transitions to the hospital can be burdensome for nursing home residents with dementia. Namely, hospital transitions lead to a higher risk of functional decline and mortality for dementia patients. Furthermore, transferred nursing home residents with dementia are at higher risk of anorexia, delirium, incontinence, and falls (Mitchell et al., 2009; Sampson, Blanchard, Jones, Tockman, & King, 2009). The decision to hospitalize a dementia patient is further complicated because the positive effects of hospitalization of dementia patients are unclear. Research has shown that hospitalized dementia patients with pneumonia have no better treatment outcomes than those who receive care in nursing homes (Dosa, 2006; Givens et al., 2012). Because appropriate care can also be offered in the nursing home, hospitalization is often avoidable (Givens et al., 2012; Ouslander et al., 2009). However, the treatment of a fracture is an exception, as it is often assumed that hospitalization is needed in this case.

### 3.3 Influences on the end-of-life decision-making process

Patients with advanced dementia often receive treatment that is inconsistent with their goals of care (Gozalo et al., 2011; Mitchell et al., 2004c). This can be a consequence of inadequacy in the end-of-life decision-making process. Multiple studies on the end-of-life decision-making process in the context of dementia have been executed in the USA. In these studies, a variety of influences on the end-of-life decision-making process in the context of dementia have been identified. These influences will be discussed in this section.

#### 3.3.1 Patient characteristics

Patient characteristics can influence the decision between curative and palliative treatment as well as the involvement of persons with dementia in the end-of-life decision-making process. Characteristics such as race, age, functional decline, and the presence of some chronic diseases play a role in the choice between curative and palliative treatment (Kelley et al., 2011; Kelley, Ettner, Morrison, Du, & Sarkisian, 2012; McKinley, Garrett, Evans, & Danis, 1996). A study by Tschirhart, Du, & Kelley (2014) showed that older patients (85 years and older) were less likely to undergo an intensive (curative) procedure in the last six months of life than younger

patients. On the other hand, black race was associated with twice the odds of an intensive procedure (Tschirhart et al., 2014). Furthermore, having Alzheimer's disease was associated with lower odds of undergoing an intensive procedure compared to other diseases (Tschirhart et al., 2014).

Besides, research on the end-of-life decision-making process specifically focussed on persons with dementia has shown that the involvement of persons with dementia in end-of-life decision-making varies considerably per patient (Smebye, Kirkevold, & Engedal, 2012). Various patient characteristics influence patient's involvement in end-of-life decisions. Firstly, the competence of the patient. Research by Smebye et al. (2012) showed that when patients were, because of the trajectory of dementia, no longer capable of being involved in decision-making, they were not given the opportunity to participate. Secondly, communication problems, such as difficulties with recall, interpretation of sensations, and verbal expression, may reduce the ability of the patient to indicate that pain or other symptoms are present (Hughes, Robinson, & Volicer, 2005). Thirdly, the person with dementia may have problems trusting his or her own reasoning abilities (Smebye et al., 2012), and therefore decide to not be involved in end-of-life decision-making.

Lastly, as the autonomy of dementia patients is often limited, they have to trust their family members when they make decisions on their behalf (Hansebo & Kihlgren, 2002). If trust is absent, dementia patients may show physical resistance towards certain treatments that family members chose (e.g. stop eating) (Chrisp, Tabberer, Thomas, & Goddard, 2012; Chrisp, Tabberer, & Thomas, 2013; Livingston et al., 2010; Wolfs et al., 2012).

### 3.3.2 The nature of the decision

The nature of the decision that has to be made also influences the decision-making process. Decision-makers find curative decisions to treat less difficult to make than palliative or symptomatic decisions to not treat (Rabins et al., 2011). In addition, research has shown that persons with dementia take more autonomous decisions when they have to decide about daily activities in comparison with decisions about medical treatment or moving residence (Smebye et al., 2012). Furthermore, when decisions have no serious consequences, the person with dementia will have an autonomous role in decision-making (Smebye et al., 2012).

A possible reason for this difference in patient involvement is that the dementia patient is perceived to be capable of making such decisions by nursing home staff and family members. Because of this, nursing home staff and family members facilitate patient's opportunity to

participate, by for example verbally and non-verbally explaining the options the patient can choose from (Smebye et al., 2012). In contrast, when major decisions have to be made, actors most often share responsibility (Smebye et al., 2012). Reasons for this can be that the dementia patient is not perceived as being capable of being fully involved in decision-making by nursing home staff and family members or that these actors did not provide the dementia patient with the opportunity to fully participate in decision-making (Smebye et al., 2012).

### 3.3.3 Involved actors

The end-of-life decision-making process in the context of dementia may be influenced by two other actors who are involved in this process, besides the dementia patient: nursing home staff and family members of the dementia patient. Firstly, health care professionals of nursing homes often start a conversation with family members about end-of-life decision-making (Caron, Griffith, & Arcand, 2005). Furthermore, a close relationship with health care professionals can provide support to family members in the context of complex end-of-life care decisions (Caron et al., 2005). Therefore, health care professionals influence the end-of-life decision-making process when they interact with family members.

In Dutch nursing homes, elderly care physicians are also on the staff. As they know the patient and the family well, they can significantly impact the end-of-life decision-making process (Helton, Cohen, Zimmerman, & Van der Steen, 2011; Helton, Van der Steen, Daaleman, Gamble, & Ribbe, 2006; Koopmans, Lavrijsen, Hoek, Went, & Schols, 2010). They can assist the progress of discussions on end-of-life care when the patient has an early stage of dementia (Hendriks, Smalbrugge, Hertogh, & Van der Steen, 2014; Hertogh, 2006). Therefore, they often have a strong and definite influence on end-of-life decision-making (Helton et al., 2006; Helton et al., 2011; Koopmans et al., 2010). Physicians may influence the decision in favour of a curative treatment for several reasons. Firstly, physicians often feel guilty if they choose palliative care over curative care (Birch & Draper, 2008). A reason for this could be that their practices are mostly focussed on prolonging life of patients. Secondly, the legal consequences of palliative end-of-life decisions are uncertain in the Netherlands (Mendelson & Jost, 2003). Consequently, physicians more often focus on reversible comorbidities of patients with dementia, as in this way they can avoid the terminal context (Campbell & Guzman, 2004; Hinkka et al., 2002).

Secondly, family members of the dementia patient can influence the end-of-life decision-making process. As dementia is characterized by cognitive and communicative deterioration, a representative of the dementia patient might have to make decisions about end-

of-life treatment on behalf of the patient (Rabins et al., 2011). The representative can be the patient's partner, child, brother, or sister. However, family members may find it difficult to understand end-of-life in dementia. Even though dementia has recently been recognized as a terminal illness by many experts in the field (Lloyd-Williams & Payne, 2002; Olson, 2003; Shuster, 2000), research shows that health professionals and family members still find it challenging to perceive dementia as a life-threatening illness (Hertogh, 2006; Morrison & Siu, 2000; Sachs et al., 2004). Consequently, they do not always find the palliative care approach appropriate for dementia and prefer curative care. Literature suggests that this probably results from families and physicians being unaware of the poor prognosis of dementia patients (Morrison & Siu, 2000) or from the long time period that passes between diagnosis and death (Albinsson & Strang, 2002).

Next to the influences of nursing home staff and family members separately, the relationship between these actors can also influence the end-of-life decision-making process in the context of dementia (Boogaard, Werner, Zisberg, & Van der Steen, 2017; Rosemond, Hanson, & Zimmerman, 2017). Family-health care professional trust relationships are important at the moment when family members have to become decision-makers on behalf of the dementia patient (Rosemond et al., 2017). A good relationship between family members and health care professionals can facilitate the end-of-life decision-making process on behalf of dementia patients (Gessert, Forbes, & Bern-Klug, 2001). For shared decision-making to effectively take place, it is important that, in their relationship, families feel equal to health care professionals (Elwyn et al., 2012). The knowledge of health care professionals puts them in the position to decide what is medically best for the patient (Smebye et al., 2012). This can make family members feel unequal to the health care professional. Trust may restore this feeling of inequality. Research by Rosemond et al. (2017) has shown that family members who experienced trust towards nursing home staff had a positive end-of-life experience of their relative with dementia, formed dynamic goals of care, and felt less need for formal goals of care discussions. Therefore, Rosemond et al. (2017) conclude that trust between family members and nursing home staff may moderate the effectiveness of efforts to improve decision-making on behalf of dementia patients.

Thirdly, depending on the severity of dementia, the patient can influence the end-of-life decision-making process. As the autonomy of the dementia patient is often limited, the dementia patient has to trust his or her family members when they make decisions on his or her behalf (Hansebo & Kihlgren, 2002). Therefore, the relationship between the dementia patient

and his or her family members can influence the end-of-life decision-making process. A study by Smebye et al. (2012) found that patient-family relationships characterized by affection and norms of reciprocity, or tensions and power-struggles influence the decision-making process. As dementia progresses, the distribution of power within relationships may change. Families may mix up the interests of the patient with their own interests (Hirschman, Joyce, James, Xie, & Karlawish, 2005). The presence of an advance directive may prevent this to a certain extent (Van Soest-Poortvliet et al., 2013). In addition, awareness of patient's goals of care can help family members in making end-of-life decisions on the start of new treatments or the withdrawal of ongoing treatments in the future (Fried & O'Leary, 2008; Gillick et al., 1999; Hendriks et al., 2017; Rosemond et al., 2017; Van der Steen et al., 2014).

### 3.4 Facilitators in end-of-life decision-making

In literature, various facilitators of end-of-life decision-making in the context of dementia are identified. In this thesis, a facilitator is defined as something that contributes to the end-of-life decision-making process in the context of dementia by making it easier. This section discusses various facilitators in the end-of-life decision-making process in the context of dementia, as identified in literature.

Firstly, a health care professional of the nursing home who is trusted by family members may consult family members in decision-making and advocate effectively (Walker & Dewar, 2001). Besides, when staff gets to know the dementia patient and his or her family, this provides them with insight in the experience of the patient, which can help in decision-making (Stapersma, 2015). In this way, the collaboration between nursing home staff and family members facilitates the decision-making process on behalf of dementia patients (Heinrich, Neufeld, & Harrison, 2003; Lord, Livingston, & Cooper, 2015; Walker & Dewar, 2001). In a study by Torke, Schwartz, Holtz, Montz, & Sachs, (2013), family carers of dementia patients expressed that the nursing home staff helped them with the decision-making process by starting discussions about various decisions and by being an expert with significant knowledge. Furthermore, a study by Ryan et al. (2012) showed that establishing relationships with important actors in the end-of-life phase of dementia patients over a long time period may facilitate end-of-life decision-making.

Secondly, a study by Livingston et al., 2010 showed that family carers often want to know the opinion of others when making decisions on behalf of the person with dementia. This creates a feeling of having permission and alleviated guilt (Livingston et al., 2010). Even after

the decision was made, many carers sought reassurance from others about their decision (Butcher, Holkup, Park, & Maas, 2001). Support from others once the decision is made facilitates future end-of-life decision-making (Butcher et al., 2001).

Lastly, triggers for conversation about end-of-life decision-making can be recognized as facilitators to end-of-life decision-making. For example, deterioration of the person with dementia often leads to conversations about decision-making (Lord et al., 2015). Furthermore, increased caring responsibilities trigger the decision-making process (Ducharme, Couture, & Lamontagne, 2012). Besides, changes in the living environment trigger end-of-life decision-making (Caron, Ducharme, & Griffith, 2006).

### 3.5 Barriers in end-of-life decision-making

In literature, various barriers of end-of-life decision-making in the context of dementia are identified. In this thesis, a barrier is defined as something that hampers the end-of-life decision-making process in the context of dementia by making it more difficult. This section discusses various barriers in the end-of-life decision-making process in the context of dementia, as defined in literature. Livingston et al. (2010) identified four difficulties in decision-making on behalf of a dementia patient experienced by family members. These included the responsibility of deciding for another adult, resistance by the person with dementia, denial of the terminal nature of dementia, and barriers to accessing information (Livingston et al., 2010).

Firstly, the responsibility of decision-making is experienced to be difficult by family members due to the emotional impact that is associated with end-of-life decision-making. Family carers expressed the desire to honour the wishes of the person with dementia (Elliott, Gessert, & Peden-McAlpine, 2009). However, this desire can function as a barrier to end-of-life decision-making if the patient's wishes are not known by family members. Furthermore, family members find it difficult to know when they have the 'right' to make decisions on behalf of the person with dementia because of the variation in and unpredictability of the dementia patient's cognitive status (Heinrich et al., 2003). In addition, families may feel directly responsible for the patient's dying if they decide to withhold treatment (Bern-Klug, 2006; Sachs et al., 2004; Thuné-Boyle et al., 2010). Family carers expressed feelings of guilt and failure after making end-of-life decisions (Butcher et al., 2001; Livingston et al., 2010). Anxiety for these feelings and anticipatory grief may hamper the end-of-life decision-making process (Küpper & Hughes, 2011). Furthermore, achieving family consensus on end-of-life decisions can be emotionally challenging for family members (Lord et al., 2015). Likewise, conflict on end-of-life decisions between family members and the physician can be emotionally

challenging (Gjerberg et al., 2011). Family members often choose to prolong life of the person with dementia in contrast to staff opinions (Gjerberg et al., 2011). Disagreement between those two actors can hamper end-of-life decision-making (Gjerberg et al., 2011).

Secondly, behaviour of the person with dementia is defined in literature as a possible barrier in end-of-life decision-making (Lord et al., 2015). For example, if the person with dementia refuses certain treatments that family members chose, decision-making may be hampered (Wolfs et al., 2012). Furthermore, resistance from the person with dementia towards end-of-life decisions can hinder decision-making (Chrisp et al., 2012; Chrisp et al., 2013; Livingston et al., 2010; Wolfs et al., 2012). This resistance might occur when the person with dementia does not feel involved in end-of-life decision-making (Tyrrell, Genin, & Myslinski, 2006).

Thirdly, the unpredictable prognosis of dementia can be considered a barrier to the end-of-life decision-making process (Chrisp et al., 2013). Dementia is an irreversible process and is often accompanied by very gradual deterioration with, occasionally, acute impairments (Birch & Draper, 2008). The deterioration of the person with dementia varies per person and per type of dementia. Therefore, the duration from time of diagnosis to death is difficult to predict (Birch & Draper, 2008). This makes it difficult to know when the end-of-life phase begins, and end-of-life decisions are to be made. Besides, the slow and gradual loss of cognitive decline makes that health care professionals, as well as family members, often have difficulty seeing someone with dementia as someone in the palliative phase (Stapersma, 2015). This is related to health care professionals and family members not seeing dementia as a terminal illness (Ryan et al., 2012; Sachs et al., 2004; Sampson et al., 2011). A failure to acknowledge this, combined with doubts about appropriate timing of end-of-life discussions, produces a barrier to end-of-life decision-making (Robinson et al., 2013).

Fourthly, family members of dementia patients expressed that they received inadequate quality, quantity, and timing of information about dementia after it was diagnosed (Livingston et al., 2010). Information on dementia is, however, crucial to end-of-life decision-making. Family members of dementia patients who live in Dutch nursing homes often feel unprepared and unsupported in making end-of-life decisions for their relatives (Forbes, Bern-Klug, & Gessert, 2000). Furthermore, family members of dementia patients often do not know what the most appropriate treatment decision is, and many family members do not want to think about their relative's death (Davies, Maio, Rait, & Iliffe, 2014; Peacock, 2013).

Fifthly, the health care system can be a barrier to end-of-life decision-making. Health care providers in dementia care are used to mainly carrying out medical care tasks (Stapersma, 2015). However, providing palliative care requires more than merely executing care tasks. Communication about palliative care demands for intensive coordination, not only medically, but also psychosocially, and spiritually (Stapersma, 2015). Thus, the end-of-life decision-making process may be hampered due to the fact that health care providers in dementia care are not trained for the intensive coordination that palliative care requires. Additionally, health care professionals find it difficult to talk about the end-of-life (Stapersma, 2015). They often lack confidence to initiate end-of-life discussions (Ersek, Kraybill, & Hansberry, 1999). This makes early communication about end-of-life wishes and decisions difficult. Furthermore, practical experience shows that the role- and task division between the various involved professionals (e.g. general practitioner, case manager dementia/palliative care) are unclear (Department of Health, 2009; Robinson et al., 2013; Stapersma, 2015). These uncertainties about end-of-life discussions can delay the end-of-life decision-making process (Robinson et al., 2013).

#### 4. Societal and scientific relevance

The ageing population leads to a worldwide increase in the prevalence of dementia (Alzheimer's Disease International, 2009; Hall et al., 2011; International WHOAsD, 2012). Consequently, more and more people will die with or from dementia (Van der Steen, 2010). Most of the people with dementia die in a residential long-term care setting, including nursing homes (92% in the Netherlands) (Houttekier et al., 2010). As no cure is foreseen, care for dementia patients in nursing homes focuses on end-of-life (Birch & Draper, 2008).

The choice between curative and palliative care in advanced dementia can be considered a challenge (Wary, 2003). Much research has studied facilitators and barriers to end-of-life decision-making in the context of dementia (e.g. Birch & Draper, 2008; Dickinson et al., 2013; Lord et al., 2015; Mitchell et al., 2004c; Ryan et al., 2012; Thuné-Boyle et al., 2010). In addition, the end-of-life decisions that family members have to make at the end-of-life of a relative with dementia (e.g. hospital transfer and infection treatment) have been researched multiple times (Hendriks et al., 2017; Rabins et al., 2011; Toscani et al., 2015). However, influences on the decision-making process and the final decisions, such as patient characteristics and relationships between different actors involved, are less often the main topic of interest (e.g. Tschirhart et al., 2014). More insight in these influences may stimulate the development of interventions aimed at lowering the experienced burden of end-of-life decision-

making in the context of dementia. Furthermore, this insight may influence the decision-making practice (e.g. the participation of actors in the decision-making process and their mutual relationships) in nursing homes with dementia patients.

One influence that can play an important role in end-of-life decisions is the definition of end-of-life. The challenge of diagnosing end-of-life in dementia is widely acknowledged in literature (Marsh et al., 2000; Mitchell et al., 2004b; Mitchell et al., 2010; Schonwetter et al., 2003; Van der Steen et al., 2007; Volicer, Hurley, Fabiszewski, Montgomery, & Volicer, 1993). Although there are indicators for determining the end-of-life phase in dementia (e.g. unable to recognize familiar faces, verbal abilities limited to less than five words, and incontinence of urine and stool), research on how various decision-makers in the end-of-life of dementia patients, such as family members and health care professionals, define end-of-life in dementia is scarce. I think this is because 'end-of-life' is a subjective concept that can be defined in many different ways. Insight in different definitions of end-of-life in dementia can help to better understand the end-of-life decisions people make. Furthermore, different opinions about the definition of end-of-life can cause conflict between actors involved in the end-of-life decision-making process. By gaining insight in the different definitions of end-of-life in dementia that actors use, conflict between actors may be preventable.

Next to this, most research on end-of-life decision-making in the context of dementia is conducted in the USA. However, the proportion of people with dementia who dies in a nursing home is larger in the Netherlands (66% in the United States and 92% in the Netherlands) (Cohen et al., 2012). This makes the Dutch nursing home setting an important research area. Research conducted in the United States cannot always be applied to the Dutch setting, as the Netherlands, compared to the USA, operates from a culture in which quality of life is considered to be important in end-of-life decisions and often outweighs life extension (Helton et al., 2006). Furthermore, the Netherlands differs from the USA in terms of legislation and regulations. Yet, no nationally representative data about the influences on end-of-life decisions of nursing home residents with dementia are available.

## 5. Research objective and research questions

As persons with advanced dementia often lack decisional capacity (Rabins et al., 2011), they might become unable to make decisions about their own end-of-life treatment (Carpenter & Flinders, 2004). This means that someone else must act on behalf of the patient, which makes the end-of-life decision-making process complex. The objective of this thesis is to explore

influences on the end-of-life decision-making process in the context of Dutch nursing home residents with dementia. Accordingly, the following research questions are formulated:

1. How do family members and health care professionals define end-of-life in dementia patients?
2. Which roles do family members of the dementia patient, health care professionals and the dementia patient have regarding the end-of-life decision-making process?
  - a. To what extent are previously expressed wishes by a now permanently incapacitated person overridden by family members and health care professionals and to what extent do they think this is acceptable?
3. Which other influences play a role in the end-of-life decision-making process?
4. How is dealt with disagreement and doubt when making end-of-life decisions?

## 6. Theoretical framework

This chapter provides insight into important concepts, models and theories that can help in answering the research questions. As this thesis focuses on the decision-making process in the context of advanced dementia, it is important to have a general idea about how this process occurs in practice. Therefore, a mapping of the decision-making process in dementia by Wolfs et al. (2012) is critically assessed. Furthermore, the trajectory of dementia makes that dementia patients may no longer be capable of being involved in decision-making (Hughes et al., 2005). In order to understand the role of the dementia patients in the decision-making process, a taxonomy of levels of involvement in the decision-making process by Thompson (2007) is provided.

Lastly, the concept of trust will be critically examined. Dementia patients may not be able to fully participate in the decision-making process when they are in the end of their lives (Rabins et al., 2011). Therefore, dementia patients are often dependent on family members and nursing home staff to make decisions concerning their end-of-life. They have to trust their family members and nursing home staff to act on behalf of their wishes and in their best interest. In this way, trust relations between the patient, family members, and nursing home staff are important for end-of-life decision-making in dementia to effectively take place. However, trust is a complex and multidimensional concept (Lewicki & Bunker, 1996; McAllister, 1995), which makes that there is no consensus on what trust means (Carter, 1989; Hall, Dugan, Zheng, & Mishra, 2001; Johns, 1996). To gain a better understanding of the concept of trust, various

definitions of the concept are examined and central elements to trust are identified in this chapter.

### 6.1. The decision-making process in dementia

Wolfs et al. (2012) mapped three elementary components of the decision-making process in dementia: identifying individual needs, exploring options, and making a choice (Figure 1). They state that the process of reviewing options for treatment and care is complex, dynamic, and emotional (Wolfs et al., 2012). Acknowledgement of the specific needs of patients and caregivers is the first component of the decision-making process. The second component, exploring options, differs per person. Some people prefer to have an overview of all care and treatment options, so that they can actively search and investigate the options and make independent choices. Other people also prefer an overview of all options, but they wish to be guided by health care professionals. The last group of people depends only on the competent decision of the health care professional. The ultimate choice is often emotional rather than rational (Wolfs et al., 2012).

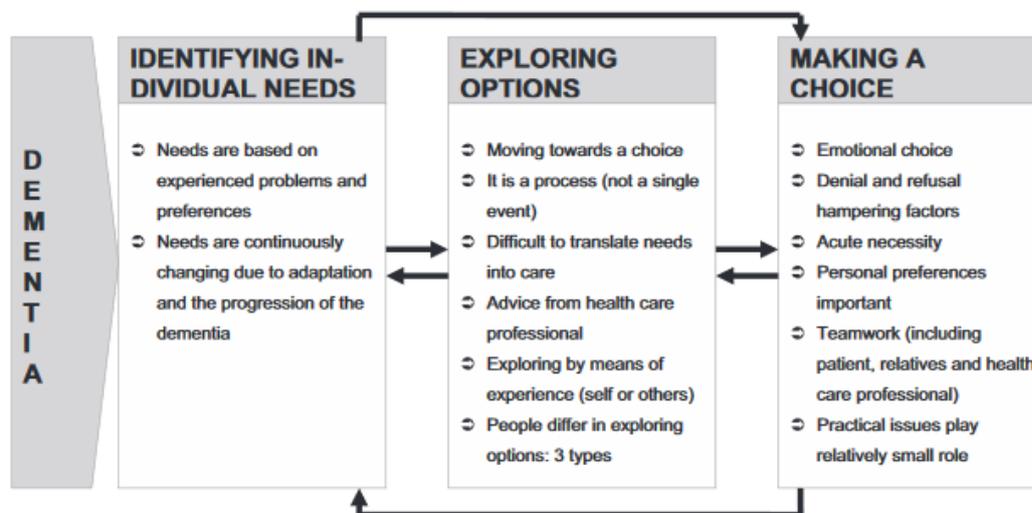


Figure 1: The decision-making process in dementia (retrieved from Wolfs et al., 2012, pp.45).

As the decision-making process in the context of dementia is complex, dynamic and emotional (Wary, 2003), various limitations can be attributed to the model described above. Firstly, the model by Wolfs et al. (2012) states that identifying the individual needs of the patients and caregivers is the starting point of the decision-making process. However, the individual needs of dementia patients and their caregivers may continuously change because the individuals adapt to the progressive nature of dementia. As the first step of the model by Wolfs et al. (2012), identifying the individual needs, keeps changing, the two steps that follow (exploring options

and making a choice) will continuously change as well. This makes the model difficult to apply in practice.

Secondly, a process that is as complex as the decision-making process in the context of dementia cannot be captured in one theoretical model. In practice, the decision-making process in the context of dementia differs per individuals involved and per situation (Hill et al., 2017). This complex practice cannot be adequately described in a simplified theoretical model.

Thirdly, the model that is described above is based on focus group interviews, in which group responses may keep individuals from expressing their opinions (Wolfs et al., 2012). Furthermore, the small sample size of the study on which the above model was based, makes that the generalisability of the results of this study may be questioned (Wolfs et al., 2012).

## 6.2 Thompson’s taxonomy for participating in decision-making

Thompson’s taxonomy for participating in decision-making in consultations, treatments, and continuing care identifies five levels of involvement: non-involvement, information-seeking/information receptive, information-giving/dialogue, shared decision making, and autonomous decision making (Thompson, 2007). Table 1 explains the different levels of involvement.

*Table 1: Description of different levels of involvement (Based on Thompson, 2007).*

<b>Level of involvement</b>	<b>Description</b>
Non-involvement	Patients are passive recipients of care and treatment
Information seeking/-receptive	Patients receive information required for taking part in decision-making
Information-giving/dialogue	Patients and clinicians exchange information
Shared decision making	Patients and clinicians cooperate to find solutions; the patients’ opinions are considered for decision-making
Autonomous decision making	Patients make independent decisions

In addition, Thompson (2007) identified three distinct contextual dimensions that influence the demand for involvement of patients in health care (Table 2). These dimensions are: need for health care, personal characteristics, and professional relationship.

Table 2: Contextual dimensions of involvement (Based on Thompson, 2007, pp. 1308).

	Reduced demand	Increased demand
<b>Need for health care</b>		
<b>Type of illness</b>	acute	chronic
<b>Seriousness</b>	high	low
<b>Personal characteristics</b>		
<b>Knowledge/experience</b>	(variable)	(variable)
<b>Personality</b>	passive	active
<b>Professional relationship</b>		
<b>Trust</b>	high	low

When critically examining Thompson’s taxonomy of participation levels, various limitations to this model can be identified. Firstly, the taxonomy is based on results from individual interviews and focus groups (Thompson, 2007), which can cause interviewer bias (Bowling & Ebrahim, 2005). Furthermore, the participants of Thompson’s study may not have been representative of the general public and may have been more in favour of involvement in decision-making (Thompson, 2007).

Secondly, the different levels of patient involvement in the context of dementia cannot be captured in a single model. Thompson’s taxonomy places different individuals into one single category of involvement. However, in practice, their involvement may differ depending on the situation, such as the complexity of the decision that has to be made. Furthermore, their involvement may change over time, because individuals may adapt to the progressive nature of dementia. Besides, the social and political contexts that influence patient involvement are not taken into account in this model. Therefore, this complex practice cannot be adequately described in a simplified taxonomy.

Lastly, Thompson’s taxonomy does not address analysis of patient involvement in specific conditions, such as dementia. Therefore, Smebye et al. (2012) updated Thompson’s taxonomy of participation levels by applying it to persons with dementia. Two new levels of involvement were identified: pseudo-autonomous decision making and delegated decision making (Smebye et al., 2012). Pseudo-autonomous decision-making is similar to autonomous decision-making, except the prerequisites for decision-making (e.g. explicit decisions, dialogue and informed patients) are not present. Delegated decision-making concerns patients actively authorizing others to decide on the behalf of them (Smebye et al., 2012).

### 6.3 Trust

As dementia is characterized by cognitive and communicative deterioration, patients may not be able to fully participate in the decision-making process between possible treatments when they are in the end of their lives (Rabins et al., 2011). This makes dementia patients dependent on other actors who may play a role in end-of-life decision-making (Rabins et al., 2011). As stated above, the end-of-life decision-making process in the context of dementia may be influenced by two other actors besides the dementia patient: nursing home staff and family members of the dementia patient. Trust relations between these three actors are important for end-of-life decision-making to effectively take place (Marx, Boakye, Jung, & Nauck, 2014). Furthermore, actors have to trust their own capabilities of end-of-life decision-making in the context of dementia (McCullough, 2016). The six trust relations that may be of importance in this process will be discussed below.

Firstly, the trust relation between family members of the dementia patient and the patient him- or herself may influence the end-of-life decision-making process (Smebye et al., 2012). Family members who trust in the competences of their relative with dementia may allow him or her to participate in end-of-life decision-making (Smebye et al., 2012). In contrast, family members who do not trust in the competences of their relative with dementia may exclude the dementia patient from the end-of-life decision-making process (Smebye et al., 2012). Furthermore, as the autonomy of the dementia patient is often limited, the dementia patient has to trust his or her family members when they make decisions on his or her behalf (Hansebo & Kihlgren, 2002). If this trust is absent, the dementia patient may refuse certain treatments that family members chose or show resistance towards end-of-life decisions (Chrisp et al., 2012; Chrisp et al., 2013; Livingston et al., 2010; Wolfs et al., 2012).

Secondly, the trust relation between nursing home staff and the dementia patient may present itself in the same way as the trust relation between family members and the dementia patient. Staff's trust in the competences of the dementia patient may influence his or her opportunities to be involved in the end-of-life decision-making process (Smebye et al., 2012) and the dementia patient has to trust the nursing home staff to make decisions on his or her behalf (Hansebo & Kihlgren, 2002).

Thirdly, the trust relation between family members of the dementia patient and nursing home staff is important when family members have to become decision-makers on behalf of the dementia patient (Rosemond et al., 2016). For shared decision-making to effectively take place, it is important that, in their relationship, families feel equal to health care professionals (Elwyn et al., 2012). However, this is often not the case because health care professionals have

more medical knowledge than family members (Smebye et al., 2012). If family members feel unequal towards health care professionals, trust may restore this feeling of inequality.

Lastly, each of the three actors who play a role in the end-of-life decision-making process in the context of dementia have to trust their own abilities to participate in this process. For example, if the person with dementia has problems with trusting his or her own reasoning abilities, he or she may decide to not be involved in end-of-life decision-making (Smebye et al., 2012). Besides, family members may not always know the patient's wishes, which may hinder trust in their own abilities to honour the wishes of the dementia patient (Elliott et al., 2009). Additionally, trust between family members is important during the end-of-life decision-making process as family members may have different opinions about the end-of-life decisions that have to be made (Gjerberg et al., 2011). They have to trust each of the family members to make decisions based on what they think is best for the patient. Furthermore, the trust that nursing home staff has in their own abilities may influence their participation in the end-of-life decision-making process in the context of dementia. As health care providers in dementia care often are not trained for the intensive coordination that palliative care requires, they find it difficult to talk about the end-of-life (Stapersma, 2015) and they often lack confidence to initiate end-of-life discussions (Ersek et al., 1999). This may indicate that nursing home staff does not trust their own abilities to participate in the end-of-life decision-making process in the context of dementia.

### 6.3.1 Problematization of trust

Trust is a complex and multidimensional concept, which includes cognitive and affective elements (Lewicki & Bunker, 1996; McAllister, 1995). Rational and instrumental judgements comprise the cognitive dimension of trust: we decide who we trust under what circumstances, based on what we perceive as good reasons (Lewis & Weigert, 1985; Rowe & Calnan, 2006). The cognitive elements of trust are defined by confidence in the competences (social and technical skills and knowledge) of the trustee (Rowe & Calnan, 2006). On the other hand, the affective dimension of trust is based on relationships and bonds between the trustor and the trustee: the belief that the trustee genuinely cares for our welfare (Rempel, Holmes, & Zanna, 1985; Rowe & Calnan, 2006). The affective elements of trust are defined by values such as honesty, confidentiality, caring, and showing respect (Hall et al., 2001; Mechanic & Meyer, 2000). In the medical sector, the vulnerability that is associated with illness makes that the affective component of trust often plays a bigger role than the cognitive elements of trust

(Coulson, 1998; Hall et al., 2001). Due to the complexity of the concept of trust, there is no consensus on what trust means (Carter, 1989; Hall et al., 2001; Johns, 1996).

### 6.3.2 Definitions of trust

The lack of consensus on what trust means makes that various definitions of the concept are used. From literature, it can be noted that there are two types of trust: trust in situations and interpersonal trust. For example, Deutsch (1958) defined trust as a situation in which the expected loss if the trustee abuses the vulnerability of the trustor is greater than the gain if the trustee does not abuse this vulnerability. This definition implies that trust includes taking risks. Later, the definition of trust was adjusted by Zand (1972), and trust was thought to be based on optimistic expectations or confidence about the outcome of an uncertain event in a situation characterized by personal vulnerability, and the lack of personal control over the actions of others. This definition adds the vulnerability of the trustor as well as optimistic expectations about the outcome.

Consequently, the definition of trust was moved towards an interpersonal definition of trust, which is based on a person who is trusting (trustor) and a person who is to be trusted (trustee) (Hosmer, 1995). Lastly, Mayer, Davis, & Schoorman (1995) define trust as “the willingness of a party to be vulnerable to the actions of another party based on the expectation that the other will perform a particular action important to the trustor, irrespective of the ability to monitor or control that other party” (p.712). This definition includes aspects of vulnerability, interpersonal relationship, and the belief that the trustee has the best interests for the trustor.

### 6.3.3 Central elements

As various definitions of trust are used in literature, identifying central elements that are included in most of these definitions can be helpful to better understand the concept of trust. In a literature review about the concept of trust, Hall et al. (2001) investigated various definitions of trust, and state that the majority of trust definitions included in their study emphasize the “optimistic acceptance of a vulnerable situation in which the trustor believes the trustee will care for the trustor’s interests” (pp.615).

In trust-relationships, control over resources or events is transferred from the trustor to the trustee (Rompf, 2014). In the case of the end-of-life in dementia, this concerns control over end-of-life decisions. Because the trustor has something at stake in the trust relationship, he or she becomes vulnerable (Rompf, 2014). In this thesis research, dementia patients have at stake how their end-of-life will proceed. The vulnerability of the trustor increases when there is more

at stake in the interaction (e.g. when dementia becomes more advanced) (Hall et al., 2001; Heimer, 2001). In contrast, when the outcomes of the trust relationship become irrelevant to the trustor, he or she is not vulnerable in the interaction and trust is not necessary (Hall et al., 2001; Mishra, 1996).

Next to patients, family members of patients as well as health care professionals also become vulnerable due to the illness of the patient. A study by Proot et al. (2003) showed that caring for a terminally ill family member caused mental as well as physical burdens, which increased the vulnerability of the family members who acted as caregivers. Furthermore, when having to care for an ill family member, family caregivers were restricted in continuing their own activities, which made them vulnerable for loneliness (Proot et al., 2003). Besides, fear for death of the beloved other and insecurity about the patient's functioning increased the family caregivers' vulnerability, as they felt they had to live day by day (Proot et al., 2003).

In making end-of-life decisions on behalf of the dementia patient, family members and health care professionals become vulnerable when they desire to honour the wishes of the dementia patient (Elliott et al., 2009). Because these wishes may not be known, family members and health care professionals who want to honour the wishes of the dementia patient may feel vulnerable in the trust-relation with the patient (Elliott et al., 2009). Furthermore, family members and health care professionals find it difficult to know when they have the 'right' to make decisions on behalf of the dementia patient (Heinrich et al., 2003). This difficulty is caused by the difference in cognitive status of dementia patients and the unpredictability of the progression of dementia, and may lead to a feeling of vulnerability in the trust relation with the dementia patient (Heinrich et al., 2003). Thus, vulnerability is associated with trust.

Because family members feel directly responsible for decision-making on behalf of their relative with dementia, they may take on the role of decision-maker (Mechanic & Meyer, 2000). As described above, taking on this role exposes them to vulnerabilities. Besides, family members and health care professionals become vulnerable in their trust-relation with the dementia patient as they may feel directly responsible for the patient's dying if they decide to withhold treatment (Bern-Klug, 2006; Sachs et al., 2004; Thuné-Boyle et al., 2010). However, interpersonal as well as situational trust may allow them to accept and cope with these vulnerabilities (Mechanic & Meyer, 2000).

Furthermore, Hall et al. (2001) state that trust is not a behaviour, but an attitude. Having a positive attitude is essential to establishing trust (Mayer et al., 1995; Uslaner, 2002). However, behaviour may indicate the possibility for trust. For example, if a patient wants to follow treatment, this behaviour could indicate that the patient has trust in the physician and the

treatment outcomes. However, the patient may not always have a positive attitude towards the outcome of the treatment. Yet, he or she may still want to follow treatment because his or her illness requires it. Thus, individuals do not necessarily need to have trust in particular outcomes to still act upon them. Merely engaging in trusting behaviour does not automatically create trust (Mayer et al., 1995; Uslaner, 2002).

Besides, trust has an emotional and relational component, which is especially noticeable in medical contexts (Goold, 2002; Hall et al., 2001). Therefore, trust goes beyond expecting good outcomes (e.g. good care), and includes the motivations of the trusted one (Hall et al., 2001). Trust is always directed towards the one that may be trusted (Goold, 2002). It comprises the belief that the trustee has the best interests for the trustor (Becker, 1996; Govier, 1992; Heimer, 2001). Therefore, even an unskilled physician can be trusted if he or she is caring. Furthermore, violation of trust does not merely lead to dissatisfaction because the expected results were not reached, but may create a stronger emotional reaction of indignation (Baier, 1986; Lagenspetz, 1992). Also, interpersonal trust influences how someone perceives the actions of the trustee (Hall et al., 2001). Patients who highly trust their physician are more likely to perceive his or her performance as positive (Caterinicchio, 1979; Mechanic & Schlesinger, 1996; Murray, Holmes, & Griffin, 1996).

Additionally, trust is, as Hall et al. (2001) state, “a forward-looking evaluation of an ongoing relationship” (pp. 617). This way, trust is focussed at the future and the outcome of the interaction cannot be observed in the present (Luhmann, 2018). The trustee’s expected future actions determine whether the trustor will trust the trustee in the present (Rompf, 2014). Therefore, the outcomes of the interaction will be determined later in time (Luhmann, 2018). Besides, current trust can be influenced by past experiences (Goold, 2002). Earlier trust relationships and knowledge can form the expectations of possible future trust relationships (Rompf, 2014).

Furthermore, different types of trust can be distinguished. For example, expectant trust refers to the propensity to trust someone brings to a first meeting (Kramer & Tyler, 1996). This can be influenced by the propensity to trust in general, based on previous trusting experiences (Goold, 2002). In contrast, experiential trust develops based on knowledge of the trustee (Kramer & Tyler, 1996). Besides, identification-based trust is connected to a sense of shared values (Kramer & Tyler, 1996).

Lastly, it is important to mention that the trust that physicians and other nursing home staff has in their patients also plays a role in the trust relation between these actors. Trust by physicians in the abilities of their patients may help patients to become more confident and

competent, which in turn may lead to greater trust in the physician and nursing home staff (Thorne & Robinson, 1988).

## 7. Methodology

This chapter describes the methodology of this thesis research. Firstly, section 7.1 describes qualitative research and why this study uses qualitative methods. Secondly, section 7.2 discusses the paradigm from which this research is executed. Thirdly, the narrative research design is explained in section 7.3. Fourthly, section 7.4 and 7.5 describe the participants of this study and how they are recruited. These sections are followed by section 7.6 on data collection, 7.7 on data analysis and lastly, section 7.8 on the ethical considerations of this thesis research.

### 7.1 Qualitative research

This research is conducted by means of qualitative methods. Qualitative research aims to understand how participants in the study view a particular social situation, event, role, group, or interaction (Creswell, 2003; Denzin & Lincoln, 2011; Maxwell, 2013; Michalos, 2014). The focus lies on the perceptions and experiences of participants, and the way they make sense of their lives (Denzin & Lincoln, 2011; Merriam, 1988; Michalos, 2014). In qualitative research, the researcher tries to reconstruct the participants' realities (Creswell, 2003; Denzin & Lincoln, 2011; Merriam, 1988). As participants may have different views, multiple realities, instead of one, should be understood (Creswell, 2003). Besides, qualitative research is mainly interested in understanding how things occur (Merriam, 1988; Michalos, 2014). Hence, qualitative researchers study social phenomenon in their natural settings (Denzin & Lincoln, 2011; Michalos, 2014). In this study, this constituted the nursing home.

The reason for the use of qualitative methods in this study was the subjective nature of the research questions of this study. Qualitative methods were helpful in exploring the various views participants had on end-of-life and the end-of-life decision-making process in the context of dementia (Denzin & Lincoln, 2011; Michalos, 2014). By using qualitative methods, descriptive data on specific cases rather than generalizations were generated (Creswell, 2003; Merriam, 1988). In this way, rich and detailed data about participant's perspectives was obtained (Denzin & Lincoln, 2011).

## 7.2 Social constructionism

This qualitative, exploratory research was executed from the social constructivist paradigm. This paradigm claims that individuals seek to understand the world in which they live (Burr, 2015; Creswell, 2003; Kukla, 2013). In order to do this, they develop varied and multiple, subjective meanings of their experiences (Burr, 2015; Creswell, 2003; Kukla, 2013). In this research, I aimed to gain insight in the different views participants had on end-of-life and the end-of-life decision-making process in the context of dementia. As these views were subjective, I looked for a broad range of different views rather than narrowing different views into a few categories (Burr, 2015; Creswell, 2003; Kukla, 2013). I stayed as close as possible to the participant's views of the end-of-life decision-making process in the context of dementia (Creswell, 2003). As these views were formed through interaction with others involved in the decision-making process (Burr, 2015; Creswell, 2003; Kukla, 2013), both family members of dementia patients and staff of dementia nursing homes were interviewed. To allow the participants to explain their own views on situations, open and broad interview questions were posed (Creswell, 2003). However, I am aware that the results reflect my interpretation of the answers of the participants (Burr, 2015; Creswell, 2003; Kukla, 2013). Therefore, I acknowledge that my own experiences shape my interpretation of the obtained information.

## 7.3 The narrative research design

This exploratory study utilized a narrative research design. The intent of narrative research is to understand how people create meaning in their lives (Creswell, 2003). In this thesis study, a narrative was defined as: a sequence of events perceived by the speaker as important and that are selected, organized, connected, and evaluated as meaningful for a particular audience (Riessman, 2008). Narratives uncover and reassess memories of past experiences and provide a way to make sense of the past (Denzin & Lincoln, 2011; Riessman, 2008). In this way, narratives have a meaning-making function: storytelling about difficult times brings order to them and encompasses emotions (Riessman, 2008). However, as narratives are constructed in the present, they also bring light to the identity needs and issues of the interviewee at the time of interviewing (DeMichele, 2009). Furthermore, narratives can also encompass ideas about anticipated future experiences (e.g. Wigren, 1994). In narrative research, the investigator focuses on specific actors, in particular social places, at certain social times (Riessman, 2008). In this way, narrative research is a way of conducting case-centred research (Denzin & Lincoln, 2011). The goal of narrative research is to generate a detailed description of past and anticipated future events rather than brief or general answers (Denzin & Lincoln, 2011; Riessman, 2008).

By using a narrative research design in this study, I aimed to understand how family members of nursing home residents with dementia and their caregivers gave meaning to past and future end-of-life decisions. In this way, I investigated the roles of various actors in the end-of-life decision-making process and other influences on this process. Data was collected by means of narrative interviewing. This means that participants were asked to provide stories about their lives related to the end-of-life decision-making process in the context of dementia (Riessman, 2008). The narrator's story was used to guide the interview (Denzin & Lincoln, 2011; Riessman, 2008). This allowed the participants to give answers in ways they found meaningful (Denzin & Lincoln, 2011; Riessman, 2008).

The reason for the use of narrative interviewing for data collection in this study was that, in narrative interviewing, themes emerge because they are important in the end-of-life decision-making process to the interviewee and are not guided by the assumptions of the interviewer (Gilbert, 2002). In this way, the selection of themes and topics, the ordering of the questions, and the wording of the questions did not influence the narrative (Jovchelovitch & Bauer, 2000). This makes that rich and detailed data about participant's views on end-of-life and the end-of-life decision-making process in the context of dementia was collected. Furthermore, narrative interviewing was used to investigate if previous trust experiences influenced the propensity to establish future trust relations.

#### 7.4 Research participants

Family members of Dutch nursing home residents with dementia (N=6) as well as health care professionals who work in the same Dutch nursing home at the dementia department (N=5) were interviewed in this study, because these two groups of people are directly involved in the end-of-life decision-making process. As illustrated in table 1, six women and five men, ranging in age from 27 to 88 years old, took part in the study. In terms of relations with the persons with dementia, one participant was caring for her husband, five participants were looking after their parent(s) and five participants were professional caregivers.

Table 1. Characteristics of the study population

Characteristics	N
<b>Gender</b>	
Women	6
Men	5
<b>Age</b>	
Under 49	2
50-59	6
60-69	2
70 or over	1
<b>Nationality</b>	
Dutch	11
<b>Relation with person with dementia</b>	
Partner	1
Daughter	2
Son	3
Nurse	3
Care coordinator	2
<b>Type of dementia of relative (only for family members*)</b>	
Alzheimer disease	5
Vascular dementia	1

The family members were selected around three dementia patients as central cases. As two patients were from the same family, this study included two families who were given fictional names to guarantee anonymity: the Jansen family and the Visser family. The dementia patients themselves were excluded from this study, as memory and cognitive disorders could have led to difficulties in data collection. For example, as dementia patients suffer from cognitive impairment, they could not have given consent for their participation in this study. Furthermore, poor recruitment could have been a challenge in this research on dementia patients. The Jansen family consisted of five family members, next to the dementia patient (one daughter, three sons and one partner), who were all interviewed and the Visser family consisted of three family members next to the dementia patient (two daughters and one son), of whom one was interviewed. For the Visser family, multiple family members were interviewed, to allow studying the different experiences of and views on the end-of-life decision-making

\* Due to privacy concerns, the interviews with health care professionals were not focussed on specific dementia patients. Therefore, they talked about their experiences with patients with various types of dementia.

process within the same family. For the Jansen family, it was not possible to interview all family members, due to personal matters of the participants.

### 7.5 Sampling

Participants were selected via convenience sampling (participants were coincidentally gathered in one setting or source and assumed to be typical of the population of interest) as well as snowball sampling (an initial contact was asked for referrals to other respondents who may be able to contribute to the research topic) (Bowling & Ebrahim, 2005). In this way, participants who were acquaintances of the researcher were chosen because they had a relative with (advanced) dementia who resided in a Dutch nursing home. Furthermore, initial participants were asked for referrals to other possible participants who had a relative with (advanced) dementia or who worked at a dementia department of a nursing home.

The health care professionals were recruited via one health care professional who worked at the dementia department of a nursing home. She informed three other health care professionals about this research. Furthermore, the health care professional approached one family member of the Jansen family and asked if she wanted to participate in this research. Next, this family member and the health care professionals were contacted by the researcher via face-to-face or telephone contact. The members of the Visser family were recruited via face-to-face contact.

### 7.6 Data collection

Data was collected by means of face-to-face, narrative interviews from November, 2018 through January, 2019. Before the interviews took place, the researcher obtained informed written consent from the participants. The informed consent included information about the study and the goal of the interviews, in order for the participants to make a knowledgeable judgement to participate in the study. It was made clear that taking part in the study was unforced and that the participants could withdraw at any point during the study, independent of the reason. Furthermore, anonymity of participants was ensured. After receiving consent, interviews were scheduled at a location of participant's choice. This enabled participants to feel comfortable, which was important because sensitive topics arose during most of the interviews (Creswell, 2003).

In this study, in-depth, face-to-face, individual interviews were used to obtain narrative data. The interviews were characterized by an interviewer and an interviewee who jointly constructed narrative and meaning (Denzin & Lincoln, 2011; Riessman, 2008). This was done by

collaboratively interpreting past and anticipating future events and experiences. The investigator served as interviewer, as interpretation of the narratives started during the interviews (Riessman, 2008).

Narrative interviewing allowed the interviewees to give answers in ways they found meaningful (Riessman, 2008; Denzin & Lincoln, 2011). Therefore, participants were encouraged to speak in their own words (Riessman, 2008). In the beginning of the interview, participants were asked questions that generated factual and demographical information, to build rapport (Creswell, 2003). Family members were asked to provide stories about their lives related to the decision-making process in the context of their relative's dementia. These stories were specifically focussed on the process of dementia of their relative, whereas the interviews with health care professional were not specifically focussed on one case, but more generally on the course of the decision-making process in nursing homes. Out of privacy concerns, it was not possible to focus the interviews with health care professionals on specific cases. Participants were encouraged to begin at the beginning of the story and follow the process in chronological sequence (Riessman, 2008). Questions that open up topics were asked (e.g. How did you first become aware of the illness of your relative).

The narrator's story was used to guide the interview (Denzin & Lincoln, 2011; Riessman, 2008). However, a limited number of topics or questions that had to be addressed in the interviews was composed before interviewing. These topics included the course of the decision-making process, the roles of family members, nursing home staff and the dementia patient in the decision-making process, trust between these different actors, the last phase of dementia and future choices. I am aware that legal aspects influence the end-of-life decision-making process in the context of dementia, but these aspects are beyond the scope of this research and were therefore not included in the topic list. If a topic of the topic list did not arise in the narrator's story, this topic was brought up by the interviewer. Besides, interviewees could come up with topics during the whole interview. All interviews were recorded and during the interview, the researcher took notes. The duration of the interview sessions was 45-90 minutes.

## 7.7 Data analysis

The recorded interviews were transcribed and prepared for thematic data analysis. This included optically scanning the transcriptions and adding notes from the researcher during the interviews. Also, characteristics of the participants were described, to gain an overview of the study population. In constructing transcripts, I kept in mind that I as a researcher did not merely

present what was said in the interviews, but I was involved in constructing the narratives I analysed (Riessman, 2008).

Next, the transcriptions were read to gain insight in the general ideas of participants, after which the detailed thematic analysis begun. Thematic analysis exclusively focuses on content of the narrative rather than how it is spoken and the local context (Riessman, 2008). The interviews were analyzed one by one, and relevant experiences were organized chronologically (Riessman, 2008). After this was done for all the interviews, underlying assumptions in each of the interviews were identified and coded. Next, these underlying assumptions were compared across different interviews. Eventually, one chronological narrative of all the interviews was composed.

### 7.8 Ethical considerations

In this qualitative research, the relationship between the researcher and the participants may gave rise to various ethical concerns. Anonymity of the participants, confidentiality and informed consent were ensured (Sanjari. Bahramnezhad, Fomani, Shoghi, & Cheraghi, 2014). In order for persons to participate in this research and to talk honestly and openly about their experiences, participants had to trust the researcher on these aspects (Sanjari et al., 2014). Participants were informed about the nature and consequences of their participation in the research, after which they had to voluntarily agree to participate. Furthermore, all personal data was concealed and password protected and personal identifier components in the data were removed to respect the privacy of the participants.

## 8. Results

This chapter presents the results of the conducted interviews. First, section 8.1 presents the results of the interviews with family members of persons with dementia. Next, the results of the interviews with health care professionals are presented in section 8.2.

### 8.1 Interviews with family members

This section presents the results of the interviews with six family members of two different families. The Jansen family consisted of a father and a mother who were both diagnosed with dementia, they have two daughters and one son. One of the daughters of this family was interviewed in this study. The Visser family consisted of a father with dementia, a mother, three sons and one daughter. All children and their mother were interviewed in this study. This

section first describes the moments of main decision-making that were highlighted by family members in the interviews in chronological order for both families. Next, the trust-relationships in these families that influenced the decision-making process are examined.

#### 8.1.1 Main decisions

The interviewed family members mentioned several main decisions they had to make on behalf of their father, mother or husband. The first decision that both families had to make concerned home care. When an urologist discovered intertrigo in Mrs. Jansen, it turned out that she could not take care of herself anymore. This discovery was very confronting for her interviewed daughter. Before, the daughter already found out that her mother could not cook properly and safely for herself and her husband anymore and that her parents sometimes switched their medicine intake, which made them both feel sick.

*They were taking each other's medicine. And then I visited them, and they were both feeling sick. [...] And in the case of my mother that was very worrying, because she had to take blood thinners which have to be taken at a certain time and especially in the right amount. (daughter-1)*

Because Mr. Jansen was, due to old age, unable to take over the care for himself and his wife, home care was arranged. This decision was made by the two daughters and was discussed with Mrs. Jansen. Despite their mother's disapproval, the two daughters of the Jansen family decided to arrange home care, because they knew that once their mother was used to it, she would like it and even enjoy the company.

*We made every decision in conversation with her. But actually, she did not want any change at all. [...] But we also knew that once it was arranged, she would like it. (daughter-1)*

However, Mrs. Jansen showed some resistance towards the assistance with showering and she repeatedly told her daughters that she found it terrible.

*She did not like that at all. She found it terrible that someone came to shower her. [...] She became very rebellious. (daughter-1)*

During the time that Mr. and Mrs. Jansen lived at home, the interviewed daughter experienced some struggles between her and her sister. She thought this was due to the stress and burden they both experienced when caring for their parents. However, they trusted each other during the whole process of their parents' deterioration.

*It is very difficult to align among children if something like that happens with your parents, because the care is so intense. Several times a day, and you also have to work and care for your own family. I think it happens very often that someone feels like she does more than the other one. (daughter-1)*

The son of the Jansen family was not involved in the decision-making for his parents during the whole process, because he did not want this.

*We also have a brother, but he stands a bit further away from her. Actually, he is not involved in the whole trajectory. [...] Everyone has to decide that for themselves. (daughter-1)*

Likewise, the Visser family also chose to arrange home care at a certain point in time. However, this was needed to a lesser extent than for Mr. and Mrs. Jansen, because the wife of Mr. Visser who suffered from dementia was mostly still able to care for her husband. Nevertheless, home care was needed because Mrs. Visser was physically unable to carry out some personal care tasks for her husband. The decision to arrange home care was made collectively by Mrs. Visser and her children. Despite his non-involvement in the decision-making, Mr. Visser did not show resistance towards this decision.

Three years after the dementia diagnosis, Mr. Visser suffered from heart problems. At one point, the decision whether or not to provide him with a pacemaker had to be made. Mrs. Visser and three out of four of their children decided that Mr. Visser would receive a pacemaker, because they believed that he could still enjoy a few years of his life. All interviewed Visser family members shared this opinion. One son of the Visser family did not participate in this decision-making. He believed that the reason for his non-participation in this decision was that he was at work. However, two family members also mentioned that they have less trust in his capability for decision-making. At the point of decision-making, all interviewed Visser family members were very happy that Mr. Visser's life could be prolonged by the pacemaker. However, in present, most of his family members doubt if this was the right decision, as they narrated:

*We were very happy that his life was prolonged by the pacemaker. But now we often say: we should not have provided him with the pacemaker. But that was very difficult. (daughter-2)*

*Then we decided, okay, we will do it. But now, every time the thought arises of what would have happened if we decided not to do it. When would his heart have stopped then? He has to die some way. (son-1)*

A few years later, both interviewed families decided to admit their mother and fathers to a day care facility. In the Jansen family, multiple accidents led to this decision. Due to these accidents, the daughters found out that both of their parents had dementia, as one interviewed daughter described:

*One time, the whole apartment was flooded because my father forgot to close the tap. A tremendous speed water came out of it and they did not know how to stop it. [...] Then, it turned out that they both had dementia. (daughter-1)*

The diagnosis of their father shocked them, because they thought he was deteriorating due to old age. Next to these accidents, Mrs. Jansen was having more memory problems and both Mr. and Mrs. Jansen started wandering around on the streets. Besides, the daughters found that their parents were very inactive. The decision to admit both Mr. and Mrs. Jansen to a day care facility was made by the two daughters of the Jansen family, after it was discussed with their parents. Both Mr. and Mrs. Jansen showed much resistance towards this decision.

*They did not want to go. They showed very much resistance. [...] [She said:] I am not ready for that and so on. (daughter-1)*

Despite this parental disapproval, the daughters decided to go through with their decision, because they knew that when their parents would be at the day care facility, they would enjoy it. Indeed, it turned out that Mr. and Mrs. Jansen enjoyed the company of the people at the day care facility, and they, especially Mrs. Jansen, became very attached to the volunteers of the day care facility.

*Put my mother in a group and she laughs and she participates. So, they actually really liked it there. [...] There were very nice people, volunteers, who they really became attached to. (daughter-1)*

In contrast, in the other interviewed family, Mr. Visser was not included in the decision-making process concerning the admission to a day care facility, because his family members believed he was not aware of his sickness and they found that he always gave questionable answers. Therefore, they perceived him as not being capable of participating in the decision-making process and they did not trust his decision-making competences anymore. Besides, they knew he did not really want to go to a day care facility, as they narrate:

*[My husband] himself did not decide about that, because then it would not be necessary. He did not really want to go. [...] He wanted to be home. Always around me. (partner)  
He was not able to decide for himself. [...] He did not take initiative himself. He never had that, that he took initiative to do something. (son-1)*

For these reasons, the decision to admit Mr. Visser to a day care facility was made by Mrs. Visser and the children, whereby the children encouraged their mother to make the final decision. All interviewed Visser family members shared the same opinion concerning admission to a day care facility.

Eventually, Mr. Visser did sign a form for requesting admission to a day care facility. Yet, it was not known whether he was fully aware of what this form was about. When choosing a particular facility, his known preferences were taken into account. The main reason for the Visser family members to admit Mr. Visser to a day care facility was that they believed this would provide Mrs. Visser with more freedom and lower the tension that she experienced, as she narrated:

*I felt tied to a rope, because he was following me the whole day. [...] I could walk around in the neighbourhood with him, but once we walked the other way around the same block, he sometimes did not know where he was anymore. (partner)*

Besides, the choice to admit Mr. Visser to a day care facility was believed to be beneficial for himself, as his memory could be trained there, and he would be among other dementia patients. However, Mr. Visser showed resistance towards going to the day care facility.

*So, then he went to the day care facility, with very much resistance. That was a problem, every day. [...] That were the most confronting things, that he got really angry in the mornings. (son-1)*

This was confronting for both Mrs. Visser and some of the children of the Visser family and caused feelings of guilt, failure and disempowerment, especially for Mrs. Visser. This all led to a higher burden for Mrs. Visser as well as the children, as they supported their mother.

*In the beginning, [my mother] found it very hard, because she felt like she was putting him away. She felt like she had failed because she could not endure it anymore. (daughter-2)*

*At one point, the burden was so high that I could not handle it properly, while I wanted to myself. So, I did not want to let him go, because I felt very guilty. [...] While actually, I cannot do anything about it. That is difficult. (partner)*

Nevertheless, Mrs. Visser and the children of the Visser family were happy with the decision to admit Mr. Visser to a day care facility, as it was a first step in letting him go. Besides, they believed that he liked the day care facility when he was there.

A few months after the admission to the day care facility, the daughters of the Jansen family applied a request for admission to a nursing home for both of their parents. The reason for this request was that their parents could not take care of themselves at home, which put an enormous burden on the daughters. The interviewed daughter felt disempowered, because she felt like she could not help her parents in another way.

*In the meanwhile, we realized that it could not go any further like this at home, it just could not. [...] Once I entered the room and my mother was standing there without any pants on. She had peed in her pants [...] and father did not know how to take care of her anymore. (daughter-1)*

In the decision-making concerning admission to a nursing home, Mr. and Mrs. Jansen did not participate. However, their known wishes were included in the choice for a particular nursing home. Also, the daughters found it very important that both of their parents could move together to the same nursing home. They preferred a room for couples, but those did not exist in that time. Because they thought it would take a while to find two rooms in the same nursing home, they applied the request early in time. However, within a few months, the interviewed daughter was called that two rooms next to each other were available in the nursing home of their first choice. At this moment, she felt overwhelmed. She and her sister had to choose between taking the rooms, while they thought their parents were not ready for a nursing home yet, or not taking the rooms, and accepting the risk that they could be separated in another nursing home. Within a day, the two sisters decided to accept the rooms.

*You know you have the choice to either choose this, because it overwhelmed us and it went very fast, you either choose this now or you end up separating them. And within a day we decided, well then we have to choose this. (daughter-1)*

The interviewed daughter of the Jansen family found it difficult to make this decision because friends and family of her mother did not see how much the dementia had progressed, as her mother could hide it very well. Furthermore, she found it terrible to have to decide for someone else and especially to tell her parents what she and her sister had decided for them, as she narrates:

*I will never forget that I went to pick up my parents and we told them our decision. [...] The moment you have to tell someone that they cannot live at their home anymore and they have to go to a nursing home. [...] That was the most intense moment of all. [...] That is horrible, to have to decide for someone else. (daughter-1)*

The reason why she found this conversation difficult was because she understood that her parents would not understand their decision, because they were not aware of their sickness. Since she found this conversation very difficult, she received support from a dementia specialist. She liked this support, because she was emotional during the conversation.

*That is the thing with dementia, they do not see it themselves. They thought what are you talking about? That decision is very difficult, really very difficult. And I have always been very happy with the support I received. (daughter-1)*

Rationally, the interviewed daughter of the Jansen family knew that she would be released from a big burden by deciding to admit her parents to a nursing home. However, she found it very difficult to move her parents to the nursing home and see them sitting in their rooms. In the beginning, her parents were waiting every day for the day that they could leave the nursing home. They realized they could not leave the ward, and did not like this, which was very difficult for the interviewed daughter to deal with.

*The first weeks that they lived there were very intense, because they did not want it. [They said:] we go home, we will not stay here. [...] That is difficult because you put, I mean, I can totally imagine that myself. (daughter-1)*

Because Mr. and Mrs. Jansen's dementia was not advanced yet, they got permission from the physician of the nursing home to leave the ward for two hours per day to visit the restaurant. All Jansen family members were very happy with this decision and the interviewed daughter stated that her parents really enjoyed this. However, over the years the dementia progressed, and Mr. Jansen had to sit in a wheelchair. This made Mr. and Mrs. Jansen unable to leave the ward. After some time, they started to visit the shared living room and talked with their co-residents. Especially Mrs. Jansen enjoyed this and seemed happy in the nursing home. In contrast, Mr. Jansen was grumpy and unhappy.

*My father was always a bit more depressed than my mother. My father was never happy there, no. And my mother, you can put her in a group, and she laughs about everything. (daughter-1)*

When Mr. Jansen was diagnosed with pneumonia, he indicated that he did not want to live anymore. Eventually, he passed away. The death of her husband had a huge impact on Mrs. Jansen, because she missed him very much. Because of this, Mrs. Jansen did not feel like doing anything anymore. However, due to the dementia, a few years later she forgot that her husband had passed away and she again enjoyed the company of her co-residents and the activities that

were organized. At the time of the interviews she felt very attached to them and to the nursing home staff.

For the Visser family, the increasing burden on Mrs. Visser and the children about five years after admission to the day care facility was an important reason to admit Mr. Visser to a nursing home. He began to show physical problems, such as incontinence, next to the memory problems. One child mentioned that the day care facility could not handle his physical problems. Besides, he walked away from home, which led to restlessness in Mrs. Visser.

*He became incontinent at night and grandmother had to get up and clean the toilet and [her husband], and got extra laundry. That was the ultimate problem that made that we admitted him to a nursing home. [...] We [the children] heard everything from [our mother] and therefore we also felt, and still feel, a bit of that guilt. (daughter-2)*

When the Visser children thought it was time to admit their father to a nursing home, Mrs. Visser first denied the problems of her husband and the burden she carried. However, the children, who shared the same opinion, encouraged their mother to make the final decision, by pointing out how necessary it was for her to let him go.

*And even when she was called that [her husband] could go to the nursing home, she started to say: yes, but it is not that bad yet. Still denying it. And then we pushed through. (daughter-2)*

Eventually Mrs. Visser decided to admit her husband to a nursing home and her children supported her during and after the decision-making. Feelings that played a role in this decision were disempowerment and fear for resistance of Mr. Visser.

*It could not go any further like this. It just could not. At a certain moment I had to, I was forced to do this. [...] It was just, there was no other option. (partner)*

*Of course, it was stressful to see if he would have any resistance to the admission to the nursing home. He often had those angry moods in the home situation. So, we expected those again with the admission. (son-2)*

The role of Mr. Visser in the decision-making regarding admission to a nursing home was minimal. Once a dementia specialist from the nursing home asked him for his opinion about nursing home admission. From this conversation could be concluded that he was not aware of his illness, and therefore did not want to go to a nursing home at that time.

*When he went to the nursing home, there was a woman who came to talk to him and she completely explained to him: suppose you cannot live at home anymore, then you have to go to a nursing home. What do you think about that? And then grandfather said: if it is necessary, then it has to happen. But it is far from necessary now. (daughter-2)*

Other than this, Mr. Visser's wishes were unknown and therefore the choice for a particular nursing home was based on the wishes of Mrs. Visser and practical concerns (e.g. close to wife's home). When her husband was admitted to the nursing home, Mrs. Visser felt guilty for not being able to care for her husband at home. This was related to her dissatisfaction with the care that was delivered in the nursing home.

*Sometimes he is in his room and I get the idea that the nurses do not know he is there. But he cannot get out of his chair without help. The alarm does not always go off, that is also always difficult. Then I have to complain about that of course. [...] And that will stay this way. (partner)*

In contrast, the children of the Visser family believed that their father is well taken care of. Partly due to her dissatisfaction with the nursing home care, Mrs. Visser doubted whether she had made the right decision and felt obligated to visit her husband as much as possible. She also found it difficult to cope with the illness of her husband and did not comprehend how her husband could have changed this much. However, she recognized and appreciated that she has more peace and freedom since her husband lives in the nursing home, as she narrated:

*You start doubting because you feel guilty. [...] And then you think: did I do this the right way? [...] While actually I have received more peace in the house. Less nerves. That resulted from him living there. [...] Now I have more freedom. Although I still have to go to the [nursing home]. (partner)*

All interviewed members of the Visser family found the admission of Mr. Visser to the nursing home confronting and they stated that, at this point in time, they became more aware of the disease progression. The resistance of Mr. Visser that all interviewed family members had feared during admission to the nursing home was minimal. Some children felt relieved that their father was admitted, and they all had the feeling that their father likes being with his co-residents and feels important in the group of co-residents.

*We drove to the [nursing home] and walked in there and when we stood in the elevator and pushed the button, yes, then there fell a weight off my mind. Then you think: well, okay, we made it. (son-2)*

*It is confronting having to leave someone there like that. Because if you look at it, you think: what do these people have here? Yes, they are amused sometimes, but 90 percent of the time they just sit there. (son-1)*

Looking back on this decision, all children of the Visser family believed that they had made the right decision. One child mentioned that he believes that it may have been better to admit his father at an earlier point in the progression of his dementia, because then his mother would have been less burdened, as he narrated:

*When he went to the [nursing home], I realised that this was not too early at all. The limit was already reached. Maybe he even should have been admitted earlier. (son-1)*

A few months later, when the fathers and mother of the interviewed families were admitted to the nursing home, the families had an intake conversation with the physician and the care coordinator of the nursing home. It was at this point in time that both families were asked whether or not they wanted to sign a non-resuscitation statement for their father and/or mother. When making this decision, the Visser family members asked Mr. Visser what he wanted, but he doubted and could not make a choice. Therefore, his family members encouraged him to sign an indication for non-resuscitation, which he did.

The two daughters of the Jansen family also signed an indication for non-resuscitation for the parents. In this family, Mr. and Mrs. Jansen were not included in the decision-making concerning resuscitation. The daughters of the Jansen family decided to sign this indication, because they both accepted that it would be okay if their parents would pass away due to a heart attack. However, the interviewed daughter did not find it easy to make this decision on behalf of her parents, as she narrated:

*We decided for both of them that they would not be resuscitated and be kept alive no matter what. [...] You do not want to do that to them anymore, but that is not easy to decide. I mean, it still are [your parents] and it is someone else you decide for. (daughter-1)*

As the dementia progressed, Mrs. Jansen started to forget how to walk. Because she did not lift up her feet enough, she had a high risk of falling. Therefore, the interviewed daughter thought that her mother would soon get a wheelchair. However, at that moment, getting a wheelchair was not possible, because this would restrict Mrs. Jansen's freedom\* and that is not allowed. Recently, in a multidisciplinary consultation, the daughters had to decide if they wanted to hospitalize their mother if she would fall and break a hip. At first, the interviewed daughter thought she would definitely choose hospitalization.

*If they would have asked me this in an earlier stage, I would have said no, come on, she will definitively be operated and she would have made it then. [...] So, it depends on which stage she is in. (daughter-1)*

However, she was not aware of the consequences of an operation for her mother. In a conversation with the care coordinator and physician, she and her sister received the news that her mother would not be able to revalidate after the operation, which excluded this option. The other option was to not operate her mother's hip, which would make her bedridden, and eventually she would die because of extreme pain. This news had a huge impact on the interviewed daughter, as she did not realize the consequences of her mother's condition.

*So, you really die when you break a hip if you are in that phase of dementia. We did not realize that at all, and it had a huge impact, when [the care coordinator] told us that. (daughter-1)*

During the multidisciplinary consultation, the daughters were advised to sign a declaration of consent that their mother would not be operated if she fell and broke a hip, which they did, because they felt like there was no other option. Besides, it was not known how Mrs. Jansen would have wanted to live her last days. She sometimes said that she did not want to live in a nursing home, but this was not seen as a serious statement by the interviewed daughter.

*My mother did say sometimes: you do not have to put me in this nursing home. But everyone says that sometimes. [...] But who wants that? (daughter-1)*

Despite the lack of knowledge on their mother's wishes, the daughters of the Visser family never discussed future end-of-life decisions they may had to make on behalf of their mother. A reason for this could be that they most often shared the same opinion after their

\* Mrs. Jansen was still able to walk and was used to standing up from a chair when she wanted to go somewhere else. Because of this, Mrs. Jansen would not stay in a wheelchair. Instead, she would stand up from the wheelchair when she wanted to go somewhere else. In order to make sure Mrs. Jansen would not get up from her wheelchair, and therefore would not fall, she would have to be tied down to the wheelchair, which would restrict her freedom to move.

parents were admitted to the nursing home, as the interviewed daughter stated. Furthermore, the interviewed daughter of the Jansen family did not think that knowing her mother's wishes would have made the decision-making process easier, because she thought that she knew what her mother would have wanted. Also, she thought that end-of-life decisions would still be very difficult to make. The interviewed daughter believed that complications that could come with the dementia of her mother should be cured, as long as this is possible. However, if her mother would choose that she did not want to live anymore, she would accept this and choose a more palliative and symptomatic approach. For example, if her mother would stop eating and drinking, she would not choose to start tube feeding.

*At a certain time, my father stopped eating and drinking. Then we said, if he does not want to eat and drink, then it is done. We will not push him. [...] If that would happen with my mother, that would be the point for me to say, it is done. (daughter-1)*

When Mr. Visser was living in the nursing home for about one month, it was thought that he had a tumour in his belly. At this point, the physician of the nursing home asked Mrs. Visser and the children if they wanted to have the tumour examined in the hospital. He also explained the possible negative consequences of a hospital admission for their father. At this point, Mrs. Visser and the children, who shared the same opinion, decided for Mr. Visser that he would not be admitted to the hospital, because they did not see any added value of a hospital admission. They believed Mr. Visser already did not have a good quality of life anymore.

*The physician thought it was a tumour, and he asked: what is your choice? And then we said that we did not want to transfer him to a hospital for examination, because what will that add? He already does not have a good quality of life anymore. (daughter-2)*

However, the Visser family members used different definitions of quality of life of Mr. Visser. Most family members linked quality of life to interaction between Mr. Visser and his known ones. They believed that Mr. Visser would have a poor quality of life when he did not recognize his family members and when they were not able to have contact with him anymore. Another element that most family members found central to Mr. Visser's quality of life was his emotional status. They believed that he would have a poor quality of life when he became grumpy, angry, frustrated, or sad, and when he could not enjoy things anymore. The last element related to Mr. Visser's quality of life mentioned by some of his family members was his physical deterioration. When he would become bedridden and experience a lot of pain, some family members believed that Mr. Visser would have a poor quality of life. Despite these elements, Mrs. Visser mentioned that she could not decide for her husband when he would have

a poor quality of life, because she believed that he experiences everything differently and his quality of life could not be interpreted by other people.

Afterwards, it turned out that the swelling in Mr. Visser's belly was not caused by a tumour. Therefore, his family members' decision concerning hospitalization had no serious consequences. About one year later, the Visser family members collaboratively decided to give Mr. Visser a flu shot. Reasons for this decision were that he still knew family members and therefore you could still have contact with him. Also, he still seemed to enjoy things. Family members believed that for these reasons, he had a good quality of life.

A few weeks later, Mr. Visser got incipient pneumonia and it was decided to provide him with antibiotics. This decision was made by Mrs. Visser and three out of four of the children. The reason for the non-participation of one of the children in this decision was the physical distance between him and the other children and their mother. However, the son who did not participate in the decision-making supported the decision that was made, although he was doubting for how long they should keep following a curative approach versus a palliative or symptomatic approach. The reason for his doubt stemmed from stories of other people who started to make decisions towards a more symptomatic approach, as he narrated:

*I was talking with a colleague of mine about his father in law who died of pneumonia. His family decided at one point to stop antibiotics, because they experienced people with pneumonia who were cured but who deteriorated very fast after that. [...] Apparently there are people who say, if he gets this complication, we do not want to cure it anymore. (son-1)*

It was not known how Mr. Visser would have wanted to live his last days. Despite of this, the Visser family members never discussed future end-of-life decisions they may had to make on behalf of their father or husband. A reason for this could be that all interviewed family members did not think that Mr. Visser was in the last phase of his life yet, because they believed that he could still enjoy certain things, such as music and he rarely was grumpy, mad, or sad.

*[He is] not in that stage yet. I could not choose for that myself now. I would not want it. Because he is not grumpy, almost never mad, he still enjoys some moments. (daughter-2)*

However, most family members acknowledged that Mr. Visser was not far away from the last phase of his life. They recognized that they would have to make a decision to end his life in the future, but they did not know how this would go or when this would be. Also, the

decision to end the life of Mr. Visser was perceived to be more complicated, as Mr. Visser had a pacemaker which excluded the risk of Mr. Visser dying from a heart attack.

*What is the stage, when do you interrupt? That is really euthanasia, what you will do then. When do you choose to do that? (daughter-2)*

*Yes, that moment will come. When he will have very much pain or something like that. But he has the pacemaker now, so his heart will keep working. I do not know how that will go. (son-3)*

The Visser family members had different opinions about future decisions concerning the life of their father or husband. One son felt that they should keep following a curative approach as long as they could have contact with their father, while another son felt that contact was already not possible anymore.

*As long as he knows his family, I think you can still have contact with him. I think that will be a reason to give him for example a flu shot. (son-2)*

*He can still talk, but really having a conversation is not possible anymore. (son-1)*

Furthermore, the same son thought that when there was no use for their father to keeping him alive anymore, they should switch to a more palliative and symptomatic approach, while the other son thought their father was beyond the point where he still had something to live for. He stated that his father lived on the border of a dignified life, due to his incontinence and the physical complains that limited his mobility.

*When he would become bedridden and he does not recognize anyone anymore, that may be the point that you start to think: what does he have left now? Then it will be of no use for him to keep him alive. (son-2)*

*Actually, that point has already been passed. What does he have left there? He only revives if he hears some music or something like that. [...] So, he really reached the border of a dignified life. And the incontinence, that is really awful. (son-1)*

Dignity seemed to be a core concept for most interviewed members of the Visser family in deciding when the last phase of life begins. Also, the quality of life of Mr. Visser emerged as central to decision-making. Furthermore, the daughter of the Visser family acknowledged that she found herself a bit selfish for wanting to keep her father with her as long as possible. All interviewed members of the Visser family found it difficult to define end-of-life in their father or husband. Most of them believed this was due to the incapability of Mr. Visser to indicate what he wanted and whether he still enjoyed living. Also, the children of the Visser

family doubted about what their mother wanted and felt disempowered to make a decision to end the life of their father.

*We never discussed how this process will end, when it will end, what limits people have, what would our father would think of this and how far would he want to go, what would he not have wanted to happen. [...] But now I also think, what will my mother think of this. What is her limit. [...] But you have nothing to say about it. You can think, well he reached the last phase of his life but then still his life will just go on. (son-1)*

*How do I have to decide about that. In his world he might be happy. Who am I to say that he has nothing left. That is only based on what we see. (partner)*

#### 8.1.2 Interpersonal trust in the decision-making process

Both interviewed families faced multiple decisions during the course of the dementia of their relatives. All interviewed members of Visser family emphasized the collective nature of the decision-making process. They all believed that the decisions concerning Mr. Visser's life should be made together with Mrs. Visser and the children. This underscores the extent to which family members trusted each other concerning the decisions that had to be made. They all emphasized that they believed that every family member wants to make the best choice for Mr. and Mrs. Visser. The trust of the Visser's family members in Mr. Visser's capacity to participate in end-of-life decision-making was minimal. The low level of trust in Mr. Visser was due to the dementia diagnosis, as before, most family members trusted him. Furthermore, all Visser family members trusted the health care professionals of the nursing home in the decision-making process. Besides, from the narratives of the Visser family members, it seemed that Mr. Visser trusted his wife to make decisions on his behalf.

According to the interviewed daughter of the Jansen family, the trust-relationship between her and her sister was very good. She felt like they made decisions together, based on what they thought was best for their parents. The non-involvement of Mr. Jansen early in the decision-making process may indicate that his daughters did not trust his capability to make decisions for himself or his wife. Also, it seems like the Jansen daughters did not trust their mother's capability to make decisions, as they ignored her opinion and felt like they knew better what was best for her.

Besides, the interviewed daughter of the Jansen family did not have a good trust relationship with all of the nursing home staff. She explains that this is due to the high staff turnover:

*In the beginning, they had a very loyal and regular employees who also had a good relationship with my parents. And I believe now there are two of them left with whom they have a very solid connection. [...] In terms of trust I think that is very important. (daughter-1)*

## 8.2 Interviews with health care professionals

This section presents the results of the interviews with five health care professionals, of whom three nurses and two care coordinators. First, the decision-making process and information provision in the nursing home is described. Next, this section explains the different end-of-life definitions of the interviewed health care professionals, followed by the perceived role of health care professionals in decision-making process. Last, the trust-relationship between health care professionals and family members of dementia patients is assessed.

### 8.2.1 Moments of decision-making and information exchange

Following the interviews with health care professionals, an admission of a new dementia patient to the nursing home proceeds as follows. Most patients are admitted to the nursing home when it is no longer justified to let them live at home, because they are considered a threat to themselves or their environment. At the time of nursing home admission, patients vary greatly in the stage of dementia they are in. Most of them only need guidance in daily activities. When a new dementia patient is admitted to the nursing home, the care coordinator of the nursing home visits the patient in his or her home situation in order to understand the lifestyle and habits of the patient. Next, an intake conversation with the patient, the family members of the patient, the care coordinator of the nursing home, and the physician or nursing specialist of the nursing home takes place. In this intake conversation, a care plan is created based on the home-visit, and a life story and medical information about the patient provided by family members.

*They look at what the patient needs. What is his or her day structure? Does he go to a day care facility and how many times? Does he take certain medication? This is all taken into account. (nurse-2)*

When creating the care plan, it is strived for a continuation of the daily schedule of the patient in the home situation, in the nursing home, as this creates a feeling of safety in patients. All decisions concerning daily activities are taken with dementia patients as long as they are competent and in consultation with the first contact person of the patient. However, one

interviewed nurse thought that, at the time of admission, most patients are already not competent anymore to make their own decisions, as this particular nurse narrated:

*Patients come to live here, at a closed ward, due to an indication. And at that moment, you see that people are not able to make their own decisions. Because as long as they can, they do not need to live at a closed ward. (nurse-3)*

When dementia patients are considered incompetent to make decisions, it is especially important that family members know the wishes of their relative with dementia. Two interviewed health care professionals stated that some patients made clear how they wanted to live the end of their lives. However, all health care professionals acknowledged that most patients did not express their end-of-life wishes.

The interviewed health care professionals underlined that the only decision that patients who are in a late phase of dementia can still make to end their lives is to stop eating and drinking, as they are considered incompetent to make other decisions to end their lives (e.g. euthanasia). Three interviewed health care professionals stated that most deaths in dementia patients that they experienced were due to a choice by the patients themselves to stop eating and drinking. They believed that health care professionals and family members have to respect this choice of the patient.

*Persons with dementia who do not know much anymore can indicate one last thing: that they no longer want to eat and drink. And whether that is a conscious or an unconscious choice, we have to respect that. (care coordinator-2)*

Six weeks after the intake conversation, the care coordinator, family members, physician and (when competent) patient have another conversation to check if the patient's daily routine matches the care plan. Also, in these six weeks, family members, together with the patient when he or she is competent, are asked about future decisions regarding care for the patient. This includes the decision whether or not to resuscitate the patient if he or she has a cardiac arrest.

After the six-week-conversation, each half year, the care coordinator, physician and sometimes psychologist of the nursing home discuss the health status of dementia patients with their family members in a multidisciplinary conversation (MDC). The care coordinators stated that patients are often not involved in MDC's, as their partners and children often know what their relative with dementia would have wanted. MDC's focus on the family's experiences within the nursing home. Furthermore, these conversations serve to discuss possible future decisions that have to be made due to medical problems in the dementia patient. Preparatory to

an MDC, a couple of screening profiles are filled in by nurses (e.g. for the risk of falling, decubitus, and nutrition). When these screening profiles show increased risks in certain areas, these risks are discussed with family members of the dementia patient in the upcoming MDC. Family members are asked questions regarding their awareness of the consequences of these risks (e.g. Imagine your relative would break a hip, do you want to admit him or her to a hospital for treatment or not?). Next, the physician and the care coordinator discuss options for care in the case of accidents related to these risks with family members of patients. Based on the perceived added value of the different options, family members and the physician together make future decisions.

*Decisions are made in consultation with family members. It is not like we determine how it goes. It happens in consultation, in which the family as representative of the patient is important. (nurse-1)*

According to the two interviewed care coordinators, family members often have a difficult time when making future decisions. They believed this is due to emotion and reason coming into conflict with each other.

*Those are difficult moments for family members. [...] Emotion and reason come into conflict with each other. Of course, we all understand that given the age and condition, an intervention is not justified. But on the other hand, it is your father or mother you decide for. (care coordinator-1)*

Furthermore, they explained that family members find it difficult to make decisions on behalf of someone else, especially when the wishes of their relative with dementia are unknown.

*Many residents with dementia are cared for via legal representation. So, you have to decide for someone else. Therefore, you have to think about what your mother or father would have wanted. Well that is very difficult, if this is not discussed in advance. (care coordinator-1)*

Nevertheless, future decisions need to be discussed with family members because the nursing home staff needs to know how to act when medical problems occur. However, when previously discussed medical problems occur, the first contact person of the patient is asked again for the family's decision, as they may have changed their decision since the last MDC.

*Family members always have the opportunity to change their decisions. Even if it was 100% certain that the patient would go to a hospital. [...] This decision differs due to the circumstances, and is discussed again and again. (nurse-2)*

When a patient suffers from acute medical problems and a decision has to be made which cannot wait to be discussed during an MDC, the first contact person of the patient has to be informed and asked for an opinion before measures will be taken by the physician of the nursing home. Even if the decision is already discussed in an MDC, the first contact person of the patient is asked if the family wants to go through with the previous made decision or not. Normally, the first contact person discusses the decision that has to be made with other family members, after which he or she communicates their decision to the physician. One interviewed nurse pointed out that she finds it difficult that she cannot share medical information with all family members of the patients, as this all has to go via the first contact person.

*We are only allowed to provide the first contact person with information. So, when the second contact person asks something, we cannot tell anything. That is difficult sometimes, because it still is family, and of course, they are worried and want to be involved. (nurse-2)*

If the physician believes that the family's decision is not justified, he or she can overrule the family's decision. Thus, decisions related to patient's treatment are then taken by the physician of the nursing home in collaboration with the first contact person of the patient. One interviewed nurse underlined that a decision towards palliative or symptomatic care that is made on behalf of the patient will not be fulfilled when the patient does not act in line with this decision. For example, when a dementia patient stops eating, family members may decide to accept this and follow a palliative care approach (e.g. no tube feeding). However, if the patient starts eating again, family members and health care professionals re-evaluate their decision and stop the continuation of the palliative care approach. Thus, the patient is offered food again.

Throughout the year, the first contact person of the patient has the right to look into the electronic clients file (ECF), which displays information concerning the care and well-being of the patient. It provides family members of the patient with easier access to information about their relative, on which they can base the decisions they make on behalf of their relative. One nurse believed that the ECF makes it easier for family members to make decisions because they have more insight in the life of their relative with dementia. The ECF is not meant for only displaying the deterioration of patient, but also for reporting positive moments (e.g. patient enjoyed a singing activity). However, she and another nurse acknowledged that this also sets requirements for reporting in the ECF and that the positive moments are not always reported due to time constraints.

*Of course, we try to rapport everything. But honestly, that is not always possible. [...] We have to take care of 23 patients with 4 nurses. Especially if everyone needs to be cared for at the same time, you sometimes forget some things. (nurse-2)*

Another nurse stated that nurses have to be careful with the information they share, because it can be shocking for family members with little knowledge on the progression of dementia. For this reason, the particular nurse acknowledges that sometimes not everything is reported.

### 8.2.2 Definition of end-of-life

As the end-of-life wishes of most dementia patients are not known by family members, the care coordinators in this study explained that family members make decisions based on what they think their relative with dementia would have wanted. The two interviewed care coordinators underlined that they find it important that people are encouraged to think about their wishes if they would suffer from dementia in the future. However, they found it difficult to find a good moment for this, as they believed it can be confronting to think about future end-of-life decisions.

At one point, family members may decide to follow a palliative or symptomatic approach in contrast to a curative approach. The timing of this switch to a palliative or symptomatic approach differs per family, and depends on the definition of end-of-life in dementia patients that decision-makers use. Because the progression of dementia differs per patient, there is not one definition of end-of-life in dementia patients. The care coordinators and one nurse stated that the decision to switch towards a palliative or symptomatic approach often results from an acute medical problem in the patient. The interviewed care coordinators as well as most nurses stated that families often want to cure medical problems as long as this is not burdensome for the patient. However, when dementia becomes more advanced, curing medical problems becomes more burdensome for the patient or even impossible. Thus, a palliative approach may seem a good alternative. Besides, according to the nurses, family members often choose a palliative approach when the patient shows much resistance towards being cared for.

According to most interviewed health professionals, the family's decision whether or not to switch towards a palliative or symptomatic approach depends on the phase of dementia of their relative. The more advanced the dementia is, the more families choose to follow a palliative or symptomatic approach. Furthermore, the interviewed nurses indicated that, when choosing between a curative and palliative approach, family members focus on making life as

pleasant as possible for their relative. Based on their evaluation of the quality of life of their relative with dementia, they decide whether or not to switch towards a palliative or symptomatic approach. Thus, the perceived quality of life of a dementia patient is central to end-of-life decision-making by family members.

The two interviewed care coordinators explained that they believe that a dementia patient has a low quality of life when living becomes suffering. They indicated that this can be seen in their faces, as they begin to frown.

*You can see that their facial expressions change. They used to smile sometimes, but in the end of their lives, they are completely in their own world and withdraw themselves from the outside world. They start to frown. This indicates that they are suffering. (care coordinator-2)*

They described a dementia patient who is in the last phase of his or her life as living in his or her own world, and experiencing discomfort, restlessness and/or pain. According to them, a clear indicator for the last phase of the life of a dementia patient is that he or she stops eating and drinking.

The interviewed nurses believed that in the last phase of dementia, patients become bedridden and lay in the foetal position. Often these patients cannot express themselves anymore and are, if not already before, fully dependent on family members to make decisions on their behalf. However, not all dementia patients reach this phase, because they are more susceptible to other diseases due to the dementia. They may die before they reach this phase, due to pneumonia, pain complaints or refusal of food and drinks, as the nurses narrated.

All interviewed nurses defined the end-of-life in dementia patients differently. One interviewed nurse defined end-of-life in a dementia patient as the last two weeks of his or her life. It is at this point in time that she would follow a symptomatic approach, which includes a focus on comfort and pain relief. However, she acknowledges that it is difficult to estimate when these last two weeks begin. She would advise the physician to discuss the switch to a palliative or symptomatic approach with family members when a curative treatment would have adverse effects for a patient or when a patient would become bedridden. In contrast, another nurse stated that she believes that the end-of-life in a dementia patient represents the last three months of his or her life. It is at this point in time that she would advise to follow a symptomatic approach.

*Someone is considered terminal if he or she is expected to die within three months. [...] This happens if someone is very lean and refuses medication, food and drinks. [...] At this point, medication and eating and drinking is stopped, and we focus on comfort and good care. (nurse-2)*

Another interviewed nurse believed that end-of-life in dementia patients already begins when they are admitted to the nursing home. However, the particular nurse would advise the physician to discuss the switch to a palliative or symptomatic approach with family members when a patient does not have enough energy anymore, for example when a patient stops eating and drinking and does not get up from his or her chair or bed anymore. Furthermore, the nurse would start thinking about a palliative approach when patients show very much resistance towards care.

*If someone panics during care moments. At one point it is not acceptable for patient to be cared for anymore. When it becomes a battle to care for someone, then you say, this is the end. (nurse-3)*

### 8.2.3 Perceived role of health care professionals in decision-making process

The interviewed nurses perceived it as their role in the end-of-life decision-making process to report on the patient's health and well-being and support family members of the patients. In order to do this adequately, they believed that they have to be recognizable for the patients, as this will create feelings of trust and safety. Also, the interviewed nurses felt that they have to work together with families of their patients, as they both have information that is needed to provide the best possible care for patients.

Also, the nurses underlined that family members and nurses have to enter the process of dementia progression together so they can support each other in the decision-making. Another interviewed nurse also acknowledged the support she can give to and receive from family members in the process of deterioration of patients. All interviewed nurses pointed out that they can imagine the difficulty of making decisions on behalf of a relative with dementia.

*How families make those decisions, I think that must be terrible to do. (nurse-3)*

*I believe the decision to stop curative treatments is very difficult to make for family members. (nurse-2)*

Despite the empathy the nurses have towards family members, two nurses stated that they think they will find it difficult to accept a family's decision towards a symptomatic approach, as they also have a relationship with patients. One of them explained that she can

understand why family members make such decisions, but believes she will find it difficult to support them in their decision.

*I have never experienced this, but I believe I will find it very difficult to say: I support your decision. I understand the decision of course. But it will still be difficult. (nurse-2)*

Furthermore, another nurse explained that he sometimes encountered a dilemma when he did not agree with the decision of family members:

*For example, we as nurses want to follow the diet prescribed by a dietitian. The family sometimes says: we do not want to take the joy he has in eating away from him. Then you face a dilemma. Will you try to convince the family members, or do you say: if you want this, then that is fine. (nurse-3)*

Besides, the two interviewed care coordinators also acknowledged that health care professionals do not always have the same opinion as family members about what is best for the patient. Most of the time, they respect the family's opinion and put aside their own opinions and feelings. However, if the physician thinks that the family's opinion is not justified, he or she can overrule the family's opinion. Furthermore, the care coordinators pointed out that they sometimes have difficulty setting aside their own norms and values in order to make life as pleasant as possible for the patient.

*Our norms and values can be very different from those of a client. The client comes first, so we often have to omit our own norms and values so that the client feels comfortable. (care coordinator-2)*

#### 8.2.4 Trust in the decision-making process

According to the interviewed care coordinators, trust between health care professionals and family members is the starting point of the decision-making process on behalf of a dementia patient. They believed that a trust-relationship between health care professionals and family members occurs automatically, because together they try to find an optimum for care and wellbeing of the patient. Furthermore, they try to build trust between themselves and family members of nursing home residents by having regular contact with family members. However, they acknowledged that the willingness to trust has to come from both parties and that developing a good trust-relationship takes time.

*[Trust] is the starting point with the family, but it has to come from two sides. Trust is not always present. It takes time to develop trust, you have to build it. (care coordinator-1)*

In order to develop a good trust-relationship, one care coordinator believed that family members have to get the feeling that their relative with dementia is in good hands. Both care coordinators believed that telling family members that you have experience with end-of-life care increases the trust family members have in them. Besides, one care coordinator explained that he tries to achieve a feeling of trust by being open and showing empathy towards family members. Furthermore, every patient has a buddy, who serves as the first point of contact for this patient and his or her family members. This way, a nurse narrated, every family has a confidential adviser whom families can contact, which increases the trust-relationship between families and nurses.

One care coordinator explained that a good trust-relationship between health care professionals and family members is important when preparing family members for the end-of-life of their relative with dementia. This particular care coordinator believed that when a good trust-relationship between these parties is present, family members will believe health care professionals when they tell them that the last phase of the life of their relative with dementia begins.

*If you have a good trust-relationship and you see that patients stop eating, you can already prepare family members very carefully for future end-of-life decisions they have to make, such as whether or not to hospitalize the patient for tube feeding. (care coordinator-2)*

Furthermore, in a good trust-relationship, health care professionals believe they can provide support to family members when making difficult end-of-life decisions. Besides, they believe it can be reassuring for family members to hear that health care professionals would have made the same decisions. Thus, according to the interviewed care coordinators, a good trust-relationship between health care professionals and family members is crucial when making end-of-life decisions on behalf of a dementia patient.

## 9. Discussion

This chapter interprets and describes the significance of the findings of this study in light of previous studies about end-of-life decision-making in the context of dementia. Following the structure of the theoretical framework, it explains new understandings and insights about end-of-life decision-making in the context of nursing home residents with dementia. Furthermore, this chapter critically examines strengths and limitations of this study and provides

recommendations for further research on end-of-life decision-making concerning dementia patients.

### 9.1 The decision-making process in dementia

In line with a study by Hill et al. (2017), this study shows that most family members liked to be involved in decision-making concerning a relative with dementia. Furthermore, the results of this study confirm that the most appropriate approach to end-of-life decision-making differs per dementia patient and per family member (Hill et al., 2017).

In general, the participants of my study acted in accordance with the three components of the decision-making process in dementia mapped by Wolfs et al. (2012). When identifying individual needs (first component), family members encountered two dilemma's at different moments of decision-making. Reason and emotion came into conflict with each other in both these dilemmas. The first dilemma concerned the decision whether or not to admit the person with dementia to a nursing home. When making this decision, family members knew that they would feel relieved after admission. However, they found it difficult to leave their relatives with dementia in the nursing home while they were not aware of their sickness. For example, the daughter of Mr. and Mrs. Jansen knew that her parents would not understand her decision to admit them to a nursing home, as they were not aware of their illness and therefore did not want to go to a closed ward. This dilemma relates to anxiety for feelings of guilt and failure, as observed by Küpper & Hughes (2011). These feelings were especially present in the Visser family. For example, when her husband was admitted to the nursing home, Mrs. Visser felt guilty for not being able to care for her husband at home. She doubted whether she had made the right decision.

The second dilemma that family members encountered concerned the decision whether or not to switch from a curative approach to a palliative or symptomatic approach. When making this decision, family members felt like they had to choose between their own wishes (keep their parents with them as long as possible) and the best option for their parents (protect them from a more advanced stage of dementia). When faced with this dilemma, some family members in this study mixed up the interests of the patient with their own interests, as was also observed in a study by Hirschman et al. (2005). The presence of an advance directive may have prevented this (Van Soest-Poortvliet et al., 2013). However, the persons with dementia who were central to this study did not have an advance directive. A possible reason for this may be that end-of-life care, as well as dementia, remain taboo subjects in the oldest generation of our

society. Furthermore, family members did not know the end-of-life wishes of their relatives with dementia, because these were never discussed. A reason for this was that family members in my study did not believe that knowing the wishes of their relative with dementia would have made decision-making easier, because they believed that making an end-of-life decision on behalf of someone else will always be difficult.

In order to make a good decision, family members indicated that they found it helpful to be informed about the disease trajectory of the person with dementia (second component of the decision-making process by Wolfs et al. (2012)). Family members explored possible care options for their relative with dementia in multidisciplinary conversations with a care coordinator and a physician of the nursing home. As was observed in a study by Hendriks et al. (2014), physicians are central to facilitating discussions on end-of-life care. However, my study also shows the importance of the role of the care coordinator in creating a trust-relationship with family members. Due to this trust-relationship, family members were better able to understand how dementia could affect their relative's overall health. In line with the second component of the decision-making process mapped by Wolfs et al. (2012), health care professionals of the nursing home provided family members with advice. For example, care coordinators told family members what option they would choose when the decisions would concern a relative of their own. This most often happened when the care coordinators favoured a decisions towards a palliative or symptomatic approach. All family members in this study appreciated the guidance of health care professionals during decision-making, as they experienced that it was okay to make an end-of-life decision towards a palliative or symptomatic approach.

In accordance with the decision-making process mapped by Wolfs et al. (2012), the interviewed family members made final decisions in consultation with health care professionals of the nursing home (the physician and the care coordinator) and (when possible) the person with dementia (third component). This shared decision-making mostly took place during multidisciplinary conversations twice per year. In line with thee decision-making mapped by Wolfs et al. (2012), denial of the seriousness of the dementia by family members was a hampering factor for final decision-making. For example, because Mrs. Visser first denied the problems of her husband and the burden she carried, the moment of requesting admission to a nursing home for Mr. Visser was postponed. Another hampering factor to final decision-making in the interviewed families were the above described contradicting needs of family members and their relatives with dementia. For example, before Mr. Visser was admitted to a nursing

home, decisions influencing his life were mainly made to disburden his relatives, and especially Mrs. Visser. After admission to a nursing home, decisions were increasingly made based on what was thought to be the best for Mr. Visser himself. Furthermore, anticipatory guilt hampered the decision-making, as Mrs. Visser already felt guilty for thinking about admitting her husband to a nursing home, which is why she did not seriously consider this option at first.

This study shows that, in contrast to the decision-making process mapped by Wolfs et al. (2012), family members often switch between emotion and reason when making final decisions on behalf of the person with dementia. The interviewed family members in this study indicated that, when making end-of-life decisions, they did not want to let their relative with dementia go (emotional decision). In this way, this study parallels the results of earlier studies, which found that families may feel directly responsible for the patient's dying if they decide to withhold treatment (Bern-Klug, 2006; Sachs et al., 2004; Thuné-Boyle et al., 2010). However, despite these emotional feelings, family members in my study felt like they sometimes had no other choice, as continuing a curative approach would be too burdensome for either family members or the person with dementia (rational decision). As a result, rational decisions were sometimes made based on what was perceived to be the best decision for family members as well as the person with dementia. The continuous switching between emotion and reasons complicated end-of-life decision-making on behalf of a relative with dementia.

Furthermore, this study shows that earlier experiences influence current and future decision-making. For example, because Mr. Visser showed much resistance towards his admission to a day care facility, his family members were scared that he would also show resistance towards his admission to a nursing home. However, this study also shows that these expectations might be wrong, as it turned out that Mr. Visser did not show much resistance towards his admission to a nursing home.

## 9.2 Participation in decision-making

As persons with advanced dementia often lack decisional capacity (Rabins et al., 2011), they can become unable to make decisions about their own end-of-life treatment (Carpenter & Flinders, 2004). Research by Smebye et al. (2012) showed that the involvement of persons with dementia in end-of-life decision-making varies considerably per patient. This was also the case for the three relatives with dementia who were central to my study. The most important characteristic that led to this difference in involvement was personality of the patient. Two of the three dementia patients who were central to this study were not involved in decision making

because their partner had always made decisions for them and they were perceived by family members to be more docile and doubtful than the other dementia patient.

Furthermore, the patient's involvement in decision-making varied with the progression of dementia. Most patients were less involved in decision-making when their dementia became more advanced. This was related to their decrease in competence to make decisions, which supports research by Smebye et al. (2012). Also, family members had less trust in the capabilities for decision-making of some patients, which led to less involvement in decision-making of these patients. This can indicate that trust in persons with dementia plays an important role in their involvement in end-of-life decision-making. Another influence on the participation of dementia patients in decision-making was the availability of choices. For example, when the daughters of the Jansen family had to decide what would happen when their mother would break her hip, they felt like they had no other choice than accepting that Mrs. Jansen would not be hospitalized. As they felt like there were no other options, it seemed irrelevant to the interviewed daughter to include her mother in this decision-making.

According to Thompson's taxonomy for participating in decision-making, a patient's demand for involvement in decision-making lowers when the need for health care becomes more serious (Thompson, 2007). As dementia is a progressive disease, the seriousness of the care that is needed increases over time. This can explain the variation in the extent to which persons with dementia in this study participated in the decision-making over time. For example, Mr. Jansen was not involved in decision-making from the beginning of the dementia trajectory. The reason for his non-involvement was not clear, but it seemed that Mrs. Jansen had always made decisions on his behalf, which made his involvement not common. Besides, his daughters did not trust his capability for decision-making due to his old age. However, when Mr. Jansen ended up in a wheelchair and was diagnosed with pneumonia, he indicated that he did not want to prolong his life anymore. This was taken into account in the decision whether or not to cure his pneumonia. However, it remains questionable if this should be considered as direct decision-making.

In contrast to Mr. Jansen, Mrs. Jansen was involved in decision-making in the beginning of the dementia trajectory by multiple dialogues between her and her daughters in which they exchanged information. However, her opinions were not considered for decision-making by her daughters, because her daughters considered her incompetent to make good decisions for herself and her husband (information-giving). This supports research by Smebye et al. (2012), which showed that dementia patients were not given the opportunity to participate when they

were not perceived to be capable of being involved in decision-making. When Mrs. Jansen's dementia became more advanced and she was admitted to the nursing home, she was not involved in decision-making anymore. The reason the interviewed daughter of the Jansen family gave for her mother's lack of involvement in decision-making was the lack of available options to choose from. She believed that the health care professionals provided her and her sister with only one possible care option. Because the other options they could choose were perceived to be too burdensome for Mrs. Jansen, she immediately excluded these options from the available choices. Therefore, it seemed to the interviewed daughter that there was only one choice to make, and therefore it seemed irrelevant to her to ask her mother's opinion on this decision.

When Mr. Visser was diagnosed with dementia, he was involved in decision-making by means of a few dialogues in which information was exchanged between him and his family members. However, his opinions were not considered for decision-making, as his family members considered him incompetent to make good decisions. When his dementia became more advanced, he was not involved in decision-making anymore. Due to his reduced mental capacity, his family members and the health care professionals of the nursing home did not provide him with the opportunity to participate. Therefore, he was not invited to the multidisciplinary conversations in which end-of-life decisions were discussed. The difference in involvement in decision-making between Mr. Jansen, Mrs. Jansen, and Mr. Visser can be explained by contrasting personalities of these persons. Family members perceived Mr. Jansen and Mr. Visser to be more docile and doubtful than Mrs. Jansen. For example, before he was diagnosed with dementia, Mr. Visser already did not participate when decisions had to be made. He had always accepted the decisions that his wife made for him. Also, family members had less trust in the capabilities for decision-making of their fathers. This can indicate that trust in the capabilities for decision-making of persons with dementia plays an important role in the involvement in end-of-life decision-making in the context of dementia.

### 9.3 Trust

In this study, trust was considered important by all participants. In line with earlier research, trust included cognitive and affective elements (Lewicki & Bunker, 1996; McAllister, 1995). All study participants defined trust mostly in terms of affective elements. Especially the trust-relationships between family members and family members and patients were based on bonds and values such as caring. In contrast, the trust-relationships with health care professionals were to some extent based on cognitive elements, as family members had confidence in the caring

and supporting competences of the nursing home staff. However, affective elements of trust also played a role in the trust-relationships with health care professionals, as family members had better trust-relationships with certain health care professionals who were considered to be honest and caring.

### 9.3.1 Interpersonal trust

All family members indicated not to have trust in the decision-making competences of the persons with dementia, which may have been the reason why their involvement in end-of-life decision-making was minimal (Smebye et al., 2012). Furthermore, family members' trust in the decision-making competences of the person with dementia decreased with the dementia becoming more advanced. The other way around, the dementia patients showed less resistance towards end-of-life decisions that were made when their dementia became more advanced, which may indicate that their trust in family members increased (Chrisp et al., 2012; Chrisp et al., 2013; Livingston et al., 2010; Wolfs et al., 2012). However, there may also have been other reasons for the decrease in resistance of the patients, such as the natural course of dementia. Furthermore, health care professionals of the nursing home most of the time did not include dementia patients in the multidisciplinary conversations about future end-of-life decisions. The reason for their non-involvement was the lack of trust that health care professionals had in the competences of dementia patients to make decisions about their own end-of-life.

In contrast, it seems that the dementia patients central to my study trusted the health care professionals of the nursing home, as they did not show much resistance towards them. In contrast, all dementia patients showed resistance towards family members, which may indicate that they did not trust them to make decisions on their behalf. Again, there may also have been other reasons for the level of resistance of the patients, such as whether family members and health care professionals are seen as decision-makers by the patient. Furthermore, as the dementia patients themselves were not interviewed in this study, their trust-relationships with health care professionals of the nursing home and family members could not be assessed.

The nursing home has specially trained staff who initiated end-of-life discussions with confidence in their own abilities. All nursing home staff had a clear role in the decision-making process, and they all were aware of their own role and the roles of their colleagues. The care coordinators who were interviewed in my study considered trust between family members and health care professionals to be the starting point of the decision-making process. Because they put a lot of effort in the creation of trust, they felt that they had good trust-relationships with family members of dementia patients. However, they acknowledged that family members also

have put effort in creating a good trust-relationship. There also seemed to be a basic level of trust present between health care professionals and family members of dementia patients based on their mutual goal to provide optimal care to dementia patients.

The members of the Visser family had a good trust-relationship with all health care professionals of the nursing home where Mr. Visser resided. Therefore, shared decision-making with health care professionals and the members of the Visser family took place. Contrastingly, the daughter of the Jansen family did not have a good trust-relationship with all nursing home staff. Due to the high staff turnover, she did not feel like she could establish a good relationship with all nursing home staff, which she found frustrating. However, she does have a good trust-relationship with the current care coordinator of the nursing home, as they have regular contact. This supports the statement by an interviewed care coordinator that developing a good trust-relationship takes time. As the care coordinator is most involved in the decision-making of all nursing home staff, shared decision-making between him and the members of the Jansen family took place.

The interviewed nurses sometimes encountered a dilemma when they did not agree with the decisions that family members made on behalf of dementia patients. When this happened, nurses explained that they found it difficult to support family members in their decision. This may indicate that the interviewed nurses did not trust the decision-making competences of all family members. However, another reason may be that nurses have a different view on the definition of end-of-life in dementia patients. Because of this different view, they may believe that a particular dementia patient is in his or her last phase of life, while family members do not think their relative with dementia is in this phase yet. Therefore, nurses may believe that complications in this particular dementia patient should not be cured anymore, while family members still want to follow a curative approach.

All family members trusted their own reasoning abilities. However, all family members experienced difficulty with trusting their own abilities to honour the patient's wishes, as these were unknown in all cases. This caused feelings of doubt in family members. Furthermore, most family members did not think that knowing the patient's wishes would have made end-of-life decision-making on their behalf easier, as they indicated that making decisions on behalf of someone else will always be difficult. Despite that some family members thought they knew what their relative with dementia would have wanted, they found it difficult to act according to these wishes. For example, the daughter of Mrs. Jansen believed that her mother did not want to go to a nursing home when she was diagnosed with dementia. Despite of this, she still decided

to admit her mother to a nursing home, as she thought that this was the best decision. Furthermore, most family members trusted other family members to make decisions based on what they thought was best for their relative with dementia, which led to little conflict during decision-making. The other way around, the fact that family members did not have conflict may have created trust between family members. In this way, earlier experiences within a family could play a role in current and future decision-making. However, when asked about future end-of-life decisions, family members had different opinions concerning when to start a palliative or symptomatic approach. A reason for this can be that they had different interpretations of how advanced the dementia of their relative was. For example, one son of Mr. Visser felt that they should keep following a curative approach as long as they could have contact with their father, while another son felt that contact was already not possible anymore.

### 9.3.2 Trust in situations

Next to interpersonal trust, situational trust also influenced the end-of-life decision-making process. The interviewed daughter of the Jansen family showed considerable trust in the situation when both her parents were diagnosed with dementia. In this situation, both her parents were vulnerable because they were not able to participate in decision-making concerning their own lives due to their dementia. Their vulnerability increased when their dementia became more advanced (Hall et al., 2001; Heimer, 2001). Furthermore, the two daughters of the Jansen family were vulnerable because they had to make end-of-life decisions on behalf of their parents, in which they wanted to honour the (unknown) wishes of their parents (Elliott et al., 2009). Despite of this vulnerability, the interviewed daughter of the Jansen family had confidence in the outcome of the decisions she made with her sister for her parents. Because both her parents were diagnosed with dementia, the two daughters of the Jansen family together made end-of-life decisions on behalf of their parents. As they were with only two decision-makers, and they trusted each other, they supported each other after decision-making that they had made the right decisions. Besides, the interviewed daughter of the Jansen family believed that, when making a decision, she and her sister did not have more than one option to choose from. In this way, she did not feel like she actively made decisions on her parents' behalf, and therefore did not feel responsible for merely 'accepting' the only possible option.

Furthermore, when comparing the decision-making process of the Jansen family with the Visser family, it seems that the Visser family had lower trust in the situation when Mr. Visser was diagnosed with dementia. Also, the results of this study show that the Visser family members experienced more doubt and guilt before, during and after decision-making than the

Jansen family. These feelings were mostly present in the partner of Mr. Visser, as she was closer to her husband with dementia. She talked to her children about these feelings, which may have caused that all family members' trust in the situation decreased. As both parents of the Jansen family were diagnosed with dementia at the same time, there was no partner of the dementia patient without dementia present in this family. Therefore, feelings of doubt and guilt might have been less present in this family. However, this is only one possible explanation for the lower situational trust of the Visser family compared to the Jansen family, based on the results of this study. Other influences, such as personality and family history, could have also played a role in the difference in situational trust of the two families.

#### 9.4 The definition of end-of-life

In line with literature, this study found that family members and health care professionals of persons with dementia had difficulty with defining end-of-life in dementia patients. Participants of this study indicated that this difficulty resulted from the unpredictable prognosis of dementia, as well as from the inability of the person with dementia to communicate whether he or she had a good quality of life.

The end-of-life definitions that family members of persons with dementia used were similar to the indicators of stage 7 of the Global Deterioration Scale (Reisberg et al., 1982). Family members based their assessment of whether their relative with dementia was in the end of his or her life on two core concepts: quality of life and dignity. These two concepts are also central to the definition of end-of-life care of this thesis. When evaluating the quality of life of dementia patients, family members focussed mainly on physical and psychosocial problems. In contrast the dementia patient's problems of spiritual nature were not considered when assessing a dementia patient's quality of life.

Firstly, family members believed that persons with dementia did not have a good quality of life when they did not recognize family members anymore and were not able to have contact with other people, because of limited communication skills. This element is similar to the first two elements of the Global Deterioration Scale; 'inability to recognize familiar faces' and 'verbal abilities limited to less than five words'. Secondly, family members used the physical status of their relative with dementia as an indicator for quality of life. When their relative would become bedridden, they would say he or she had a low quality of life. This element is similar to the last two elements of the Global Deterioration Scale; 'total functional dependence' and 'inability to walk'. Lastly, family members believed that persons with dementia did not

have a dignified life anymore when they would become incontinent and were physically limited. These elements also are included in stage 7 of the Global Deterioration Scale.

Next to these elements, family members pointed out another element they believed to be important in defining the end-of-life in persons with dementia, namely their emotional status. Family members found it important to know whether their relative with dementia still has moments of enjoyment, experiences pain or is often grumpy, mad, or sad in order to determine when the end-of-life of their relative begins. With this finding, this study expands on existing work. Literature on estimating the last phase of life in dementia patients acknowledges that non-specific symptoms are better predictors of death within six months in dementia patients than specific cognitive symptoms of dementia (Rabins et al., 2011). However, this literature focussed mainly on bowel incontinence and physical deterioration as main non-specific symptoms (e.g. Rabins et al., 2011; Reisberg et al., 1982). My study shows that family members use the emotional status of their relative with dementia to determine his or her end-of-life phase, and therefore to decide whether he or she is considered suitable for palliative care. In this way, the emotional status of a dementia patient may influence the end-of-life decision-making process.

The nurses interviewed in this study defined end-of-life in dementia patients in terms of non-specific prognostic indicators, such as malnutrition and physical deterioration. According to literature, this is an adequate way of identifying the end-of-life phase in dementia patients (Rabins et al., 2011, Sachs et al., 2004). Furthermore, nurses tried to express the last phase of dementia in terms of time until death. However, all nurses used a different timeframe. Therefore, his study supports earlier work on this topic by showing that the last phase of life in dementia patients cannot be expressed in time (Elliott & Nicholson, 2017).

The interviewed care coordinators stated that the last phase of life in dementia patients often begins due to acute medical problems, which supports literature (Harris, 2007). Like the interviewed nurses, they defined the end-of-life in dementia patients in terms of non-specific prognostic indicators, such as malnutrition. However, according to the care coordinators, the main indicator for the beginning of the end-of-life phase in dementia patients is suffering. They state that when a dementia patient turns into his or her own world and becomes isolated from the world around him or her, the patient entered the last phase of life. This phase, the care coordinators explained, is characterized by discomfort, restlessness, and pain in the dementia patient. This finding matches the definition of family members which includes the emotional status of the dementia patient, and underlines the importance of the influence of this non-specific symptom in defining end-of-life in dementia patients. Therefore, this finding adds to

existing work of estimating end-of-life in dementia patients. Furthermore, the care coordinators' definition of end-of-life included the element 'restlessness', which may point towards problems of spiritual nature that lower the quality of life, following the definition that is used in this thesis.

When comparing the end-of-life definitions of family members and health care professionals, it can be seen that health care professionals focus only on non-specific prognostic indicators of the end-of-life, such as malnutrition and bowel incontinence, instead of on specific cognitive symptoms. As health care professionals are often around dementia patients who are in the last phase of their lives, it is assumed that they have good knowledge on symptoms of advanced dementia. In contrast, family members focus on both non-specific prognostic indicators and specific cognitive symptoms of dementia, such as the inability to recognize familiar faces and limited verbal abilities. This may indicate that family members are merely informed about the specific cognitive symptoms of dementia, and have a lack of knowledge on what the last phase of life of a dementia patient looks like.

Furthermore, the different end-of-life definitions in dementia patients may cause conflict between family members and health care professionals. As they use different definitions of end-of-life in dementia, they may have different opinions about when a dementia patient is considered suitable for palliative care. This can cause conflict between family members and health care professionals. Furthermore, the interviewed nurses used different timeframes for determining end-of-life in dementia patients. This may also cause conflict between different health care professionals on when a palliative approach should begin.

Besides, the dementia patient can also (un)consciously decide when he or she considers him- or herself to be in the end of his or her life. For example, a decision towards palliative or symptomatic care that is made on behalf of the patient will not be fulfilled when the patient does not act in line with this decision (e.g. starts eating again).

Both family members and health care professionals used subjective indicators for determining end-of-life in dementia patients, such as dignity, pain, and discomfort. Although most of the participants mentioned these indicators, they may interpret these differently. As advanced dementia patients are often not capable of indicating how they feel, family members and health care professionals have to make an estimation of how a dementia patient scores on these indicators. This estimation can deviate from the actual feelings of the dementia patient. Therefore, it is important to execute further research on estimating subjective prognostic indicators in dementia patients.

### 9.5 Strengths and limitations

This study examined end-of-life decision-making in two families of Dutch nursing home residents with dementia. Due to this specific group of participants, the findings of this study may not be fully applicable to other populations. Though, this was not the goal of this exploratory study. The goal of this study was to explore influences on the end-of-life decision-making process in the context of Dutch nursing home residents with dementia. This goal was achieved as this study shows various views family members and nursing home staff had on end-of-life and the end-of-life decision-making process in the context of dementia.

Furthermore, this study included a small number of participants, which lowered the generalizability of the results and therefore is a limitation to my study. However, by using qualitative methods, the few participants who were interviewed in this study provided in-depth information about the whole decision-making process in the context of Dutch nursing home residents with dementia. The qualitative methods of this study were helpful in exploring the various views participants had on end-of-life and the end-of-life decision-making process in the context of dementia (Denzin & Lincoln, 2011; Michalos, 2014). By using qualitative methods, descriptive data on specific cases rather than generalizations were generated (Creswell, 2003; Merriam, 1988). In this way, rich and detailed data about participant's perspectives was obtained, which strengthened this study.

Additionally, family members were included in this study at different times in the progression of their relative's dementia, which can raise certain issues. For instance, family members who were interviewed following the death of a relative may have recalled experiences in a different manner from family members who were interviewed prior to the experience of the death of a relative. The last group of family members seemed to highlight the emotional nature of decisions at the end of their relative's life to a bigger degree. In spite of this limitation, including family members who were at different times in the progression of their relative's dementia made it possible to gather more complete information about the whole decision-making process in the context of Dutch nursing home residents with dementia.

Furthermore, due to privacy concerns, the interviews with health care professionals could not be focussed on specific patient cases. For this reason, the perception of health care professionals on the decision-making process of the two central families of this study could not be assessed. However, the interviews with health care professionals did provide valuable data on the general decision-making process concerning Dutch nursing home residents with dementia.

A strength of this research is that within one family, multiple family members were interviewed to allow studying the different experiences of and views on the same end-of-life decision-making process within the same family. This showed that different persons experienced the same process in a different way. These results show that end-of-life decision-making processes cannot be quantified, which underlines the complexity of such processes.

By the use of narrative interviewing in this study, a detailed description of past and anticipated future events rather than brief or general answers was generated (Denzin & Lincoln, 2011; Riessman, 2008). The narrative research design helped to understand how family members of nursing home residents with dementia and their caregivers gave meaning to past and future end-of-life decisions. In this way, the roles of various actors in the end-of-life decision-making process and other influences on this process could be investigated. Also, narrative interviewing allowed the participants to give answers in ways they found meaningful (Denzin & Lincoln, 2011; Riessman, 2008). This made that rich and detailed data about participant's views on end-of-life and the end-of-life decision-making process in the context of dementia was collected.

### 9.6 Recommendations

This study shows that decisions are personal, change over time and are influenced by several factors. As a consequence, the most appropriate approach to end-of-life decision-making differs per dementia patient and per family member. For this reason, no recommendations for decision-making practice concerning dementia patients are provided in this thesis report. However, recommendations for future research are explained below.

This study shows the experiences with end-of-life decision-making of a limited number of families with a relative with dementia and health care professionals who work in a nursing home at dementia departments. As end-of-life decision-making is a personal process, more information from family members and health care professionals is needed to provide greater in-depth details of experiences with end-of-life decision-making on behalf of a relative with dementia. In order to obtain this information, future studies in the context of end-of-life care for persons with dementia should further investigate experiences of family decision-makers and nursing home staff concerning the end-of-life decision-making process on behalf of dementia patients.

These studies should focus on whether knowing the end-of-life wishes of dementia patients facilitates end-of-life decision-making. Health care professionals in this study argued

that they found it important to discuss end-of-life wishes of dementia patients early in the dementia trajectory when they are still competent. In contrast, family members in this study underlined that knowing the end-of-life wishes of their relative with dementia would not make decision-making easier. However, they indicated that not knowing the end-of-life wishes of their relative with dementia caused doubt. The different opinions about the knowing the end-of-life wishes of dementia patients should be investigated in further research.

Furthermore, future studies on end-of-life decision-making concerning dementia patients should focus on the framing of choices by family members and health care professionals. In this study, one family member indicated that she often believed that she had only one care option to choose from. The other options were not regarded as possible choices by her, as they were perceived to be too burdensome for the dementia patient. Therefore, the family member immediately excluded these options from the available choices. As she believed that there was only one choice to make, she did not feel like she actively made decisions on her parents' behalf, and therefore did not feel responsible for merely 'accepting' the only possible option. This led to less feelings of guilt and more situational trust of this family member. Also, in this study, all participants indicated that at one point, dementia patients were perceived to be incompetent for decision-making. However, when the dementia patients would stop eating and drinking, all participants would recognize this as a decision made by the dementia patients. So, despite of their perceived incompetency for decision-making, dementia patients were perceived to be capable of making this one decision. This shows that the framing of decisions by family members and health care professionals influences the decision-making process, such as the involvement of dementia patients in this process. Questions that arise are for example "Do dementia patients make this decision consciously or unconsciously?" and "If dementia patients are perceived to be incompetent for decision-making in general, why are they perceived to be competent to make this particular decision?". These questions, and decision-making concerning dementia patients more generally, should be investigated in further research on end-of-life decision-making on behalf of dementia patients.

Furthermore, the results of this study show that family members consider quality of life to be central for determining the end-of-life in dementia patients. However, as advanced dementia patients are often not capable of indicating how they feel, other persons have to assess their quality of life, which may lead to inaccurate estimations of quality of life in dementia patients. Therefore, further research should aim to understand how families evaluate the quality of life of their relative with dementia. Furthermore, methods to assist decision-makers in

interpreting a dementia patient's quality of life should be investigated. When investigating these methods, it should be kept in mind that the most appropriate approach to end-of-life decision-making differs per dementia patient and family member.

Another finding of this study is that end-of-life decision-making on behalf of a relative with dementia is associated with feelings of guilt, failure, and disempowerment. Further research should determine interventions aimed at reducing these feelings of guilt, failure, and disempowerment in family decision-makers. When determining these interventions, the variation in views on end-of-life in dementia patients should be kept in mind.

## 10. Conclusions

This chapter provides answers to the research questions of this study. Next, it provides a critical reflection on the meaning of the results of this study.

### 10.1 Answers to the research questions

#### *1. How do family members and health care professionals define end-of-life in dementia patients?*

This study shows that family members and health care professionals of Dutch nursing home residents with dementia found it difficult to define end-of-life in dementia patients. Participants of this study indicated that this difficulty resulted from the unpredictable prognosis of dementia, as well as from the inability of the persons with dementia to communicate whether they had a good quality of life. As a result of this difficulty, participants used different definitions of end-of-life in dementia patients.

Family members found quality of life and dignity of their relative with dementia central to determining whether he or she was in the end of his or her life. Next to several specific and non-specific prognostic indicators of dementia, family members pointed out that they believed that the emotional status of dementia patients was an important indicator for their end-of-life phase. In contrast to family members, health care professionals focussed only on non-specific prognostic indicators, such as malnutrition and bowel incontinence. Furthermore, nurses tried to express the last phase of dementia in terms of time until death. However, all nurses used a different timeframe.

Alike the family members, the interviewed care coordinators of this study emphasized suffering of the dementia patient as the main indicator for the end-of-life phase in dementia patients. Furthermore, both family members and health care professionals used subjective

indicators for determining end-of-life in dementia patients, such as dignity, pain, and discomfort. Although most of the participants mentioned these indicators, they may interpret these differently.

2. *Which roles do family members of the dementia patient, health care professionals and the dementia patient have regarding the end-of-life decision-making process?*

### Family members

An important finding of this study is that the most appropriate approach to end-of-life decision-making differs per dementia patient and per family member. Family members in this study perceived it as their role is to make decisions on behalf of their relative with dementia when he or she is thought to be not (fully) capable of making these decisions him- or herself. In order to make good decisions, family members indicated that they found it helpful to be informed about the disease trajectory of the person with dementia. According to the interviewed care coordinators of the nursing home, family members had to understand how dementia could affect their relative's life in order to make good decisions.

This study shows that the decision-making process is associated with emotions such as guilt, doubt, failure, grief, disempowerment and fear for resistance experienced by family members of the person with dementia. Besides, when making end-of-life decisions on behalf of their relatives with dementia, family members continuously switched between reason and emotion. This further complicated the decision-making as family members saw advantages and disadvantages for each care option, making them feel like there was not one 'good' decision to make. Furthermore, they had difficulty with making decisions on behalf of someone else. Despite of these difficulties, most family members in this study wanted to be involved in decision-making on behalf of a relative with dementia because they perceived it as their roles to make end-of-life decisions on behalf of their parents and husband when they were not capable of deciding themselves.

When dementia patients live at home, it is perceived to be the role of their family members to arrange for professional help when needed. Later, when a dementia patient is admitted to the nursing home, family members have to provide the life story of and medical information about their relative with dementia, in order to continue the lifestyle of the patient in the home situation as much as possible. After this, family members have to appoint one person who becomes the first contact person of the nursing home. From this point, health care professionals of the nursing home inform this person when changes occur in the health or

wellbeing of the dementia patient. It is the role of the first contact person to regularly look into the electronic clients file, which shows information about the dementia patient. Normally, the first contact person informs the other family members about the health and wellbeing state of their relative with dementia. When decisions have to be made, family members discuss the possible options with the care coordinator and physician of the nursing home, after which the first contact person communicates the final decision to the physician. The first contact person of the patient has to be informed and asked for a decision before measures can be taken by the physician of the nursing home.

### Health care professionals

The nursing home central to this study has specially trained staff who initiated end-of-life discussions with confidence in their own abilities. All nursing home staff had a clear role in the decision-making process, and they all were aware of their own role and the roles of their colleagues.

Physicians were central to facilitating discussions on end-of-life care, as they provided family members with information about possible care options for their relative with dementia. With the help of this information, family members made the final decisions. However, if the physician believed that the family's decision was not justified, he or she could overrule the family's decision. Thus, decisions related to patient's treatment were then taken by the physician of the nursing home in collaboration with the first contact person of the dementia patient.

Next to the physician, the importance of the role of the care coordinator in the decision-making process concerning dementia patients is highlighted in my study. When dementia patients are admitted to the nursing home, the care coordinator of the nursing home visits the dementia patients in their home situation in order to understand their lifestyle and habits. Besides, the care coordinator conducts the intake conversation with the patient, the family members of the patient, and the physician or nursing specialist of the nursing home. During this intake conversation, family members provide the care coordinator with a life story and medical information about the patient. Based on this information and the home-visit, the care coordinator creates a care plan for the dementia patient. Twice per year the care coordinator and the physician have multidisciplinary conversations with family members of the nursing home residents with dementia. In these conversations the care coordinator discusses with family members the increased risks for the dementia patient and options for care in case accidents

happen related to these risks for the patient. For each care option, the care coordinator, physician and family members discuss the perceived added value for the dementia patient. This way, family members are better able to understand how dementia can affect their relative's overall health. All family members in this study appreciated the guidance of health care professionals during decision-making.

Besides guiding family members of dementia patients in the decision-making process, the care coordinator also has a role in establishing trust-relationships with family members. According to the interviewed care coordinators, trust between health care professionals and family members is the starting point of the decision-making process on behalf of a dementia patient. They believed that a good trust-relationship between health care professionals and family members is important when preparing family members for the end-of-life of their relative with dementia. Furthermore, they believed that in a good trust-relationship, health care professionals can provide support to family members when making difficult end-of-life decisions. The interviewed care coordinators try to build trust between themselves and family members of nursing home residents by having regular contact with family members.

The nurses of the nursing home perceived it as their role in the end-of-life decision-making process to report on the dementia patient's health and well-being and support family members of the patients. In the electronic clients file they display the deterioration of the dementia patients as well as their moments of enjoyment. In order to do this adequately, they believed that they have to be recognizable for the patients, as this will create feelings of trust and safety. Also, the interviewed nurses felt that they have to work together with families of their patients, as they have to exchange information about the patients to provide the best possible care for patients. When providing information about the dementia patient to the first contact person of the family, nurses believed that it is their role to be careful, as it can be shocking for family members with little knowledge on the progression of dementia. Furthermore, they provide the care coordinator, physician and family members with information about the patient. Preparatory to a multidisciplinary conversation, nurses fill in a couple of screening profiles (e.g. for the risk of falling, decubitus, and nutrition). Thus, the role of nurses in the decision-making process is mainly to report on the patient's health and wellbeing to health care professionals and the first contact person of the family.

## Dementia patient

As dementia patients themselves were not interviewed in this study, no conclusions can be drawn on how they perceive their own role in the decision-making process. However, this study obtained information about the perception of the dementia patient's role in decision-making by family members and health care professionals.

In this study, the involvement of persons with dementia in end-of-life decision-making varied considerably per patient. Two dementia patients were involved in decision-making by family members to a certain extent, as they were asked for their opinions on several decisions. However, their opinions were not taken into account by family members when making final decisions, as family members felt they knew better what was the best decision to make. As the dementia patients who were central to this study did not have the opportunity to participate in decision-making, their role in the decision-making process was minimal. Family members as well as health care professionals believed that the only decision that dementia patients can make at the end of their lives is to stop eating and drinking. Besides, a decision towards palliative or symptomatic care that is made on behalf of the patient will not be fulfilled when the patient does not act in line with this decision. Health care professionals believed that they had to respect these decisions of dementia patients.

The most important characteristics that led to the difference in involvement of the dementia patients central to this study were the personalities of the patient. Dementia patients who were perceived to be more docile and doubtful by family members were less involved in decision-making. Furthermore, the patient's involvement in decision-making varied with the progression of dementia. Most patients were less involved in decision-making when their dementia became more advanced. This was related to their decrease in competence to make decisions as perceived by family members and health care professionals. Also, family members had less trust in the capabilities for decision-making of some patients, which led to less involvement in decision-making of these patients. One dementia patient in this study was for example perceived to be doubtful and gave questionable answers, which lowered family members' trust in his decision-making competences. Another influence on the participation of patients in decision-making was the availability of choices. If family members perceived that there was only one choice to make, the dementia patient's opinion was perceived to be irrelevant to decision-making.

- a. *To what extent are previously expressed wishes by a now permanently incapacitated person overridden by family members and health care professionals and to what extent do they think this is acceptable?*

According to two health care professionals, most dementia patients do not express wishes for their end-of-life. Also, none of the dementia patients included in this study had an advance directive in which their wishes for end-of-life were clear. Furthermore, none of the dementia patients central to this study had conversations with family members about end-of-life wishes. Therefore, the wishes of the dementia patients central to this study were mostly unknown. A reason for this could be that end-of-life care, as well as dementia, remain taboo subjects in the oldest generation of our society. Another reason could be that family members in my study did not believe that knowing the wishes of their relative with dementia would have made decision-making easier, because they believed that making an end-of-life decision on behalf of someone else will always be difficult. It is not clear to what extent health care professionals in this study thought that overriding previously expressed wishes by dementia patients is acceptable.

One dementia patient in this study once told family members that he did not want to live anymore when he would have advanced dementia. Yet, family members did not act in line with this expressed wish, as they could not let him go. Furthermore, another dementia patient once said that she did not want to live in a nursing home. However, this statement was not taken seriously by her family members. Thus, despite that some family members thought they knew what their relative with dementia would have wanted, they found it difficult to act according to these wishes. A reason for this could be that family members made more emotional decisions based on what they wanted themselves (e.g. keep relative with them as long as possible), instead of more rational decisions based on what was best for their relative with dementia (e.g. follow a palliative approach). In this way, the family members' wishes for the end-of-life of their relative with dementia countered the wishes of their relative with dementia.

3. *Which other influences play a role in the end-of-life decision-making process?*

This study identified several influences that play a role in the end-of-life decision-making process that were not discussed when answering the other research questions. Firstly, this study shows that trust plays an important role in the end-of-life decision-making process. This concerns trust between and within all persons who may play a role in the decision-making process (dementia patient, family members, and health care professionals). Family members and health care professionals in this study did not trust the decision-making competences of the

dementia patients. Therefore, they were not given the opportunity to participate in the decision-making process. On the other hand, family members and most health care professionals did have a good trust-relationship, which made that shared decision-making took place. Furthermore, health care professionals could support family members during the decision-making process. Besides, the interviewed families trusted all family members who participated in the decision-making process, which led to mutual support, shared decision-making and shared responsibility for decision-making within families.

Secondly, the presence of a partner of the person with dementia who can participate in decision-making might make that the decision-making process is accompanied with more feelings of guilt, failure, and disempowerment. Furthermore, the family in which the partner did not suffer from dementia considered the partner as the final decision-maker, which may have lowered disagreement between family members during decision-making.

Thirdly, the awareness of the illness by the dementia patient plays a role in the decision-making process. The dementia patients central to this study were not aware of their illness. For this reason, family members found the decision-making on behalf of their relative with dementia difficult, because the persons with dementia did not understand the decisions family members made on their behalf.

Fourthly, whether family members accepted the illness of their relative with dementia influenced the decision-making process. In my study, family members who had difficulty with accepting the illness of their relative, by for example denying the seriousness of the dementia, delayed end-of-life decisions and wanted to follow a curative approach for a longer time than family members who accepted the illness of their relative.

Fifthly, the personality of decision-makers also influenced the decision-making process. Family members continuously switched between reason and emotion. Family members with a more emotional personality found it more difficult to let their relative with dementia go and chose to follow a curative approach for a longer time than family members with a more rationale personality. Despite of the personalities, the dilemma between reason and emotions was present in every interviewed family member.

Lastly, earlier experiences influenced current and future decision-making. For example, earlier experiences within a family could affect current trust-relationships between family members. Furthermore, experiences of family members and health care professionals with end-of-life decision-making influenced current and future decision-making.

#### *4. How is dealt with disagreement and doubt when making end-of-life decisions?*

The interviewed family members experienced doubt when faced with decisions that had large consequences. One of these decisions was whether or not to admit the person with dementia to a nursing home. When making this decision, family members knew that they would feel relieved after admission. However, they found it difficult to leave their relatives with dementia in the nursing home. This dilemma relates to anticipatory grief and anxiety for feelings of guilt and failure. Another important decision which was associated with doubt was the decision whether or not to switch from a curative approach to a palliative or symptomatic approach. When making both of these decisions, family members continuously switched between reason and emotion, which further complicated the decision-making process. Furthermore, because the end-of-life wishes of the dementia patients central to this study were unknown, family members doubted whether they made decisions according to the patient's wishes.

Although the different family members experienced doubt regarding end-of-life decisions for their relatives, the two interviewed families did not encounter disagreement between the various family members. However, the care coordinators indicated that big families often struggle with different opinions within one family. The family members included in this study trusted each other to make decisions based on what they thought was best for their relative with dementia. This may have been the reason for little conflict between the different family members. Besides, the presence of the partner of the relative with dementia as final decision-maker in one interviewed family may have lowered disagreement. However, when asked about future end-of-life decisions, family members had different opinions concerning when to start a palliative or symptomatic approach.

Next to disagreement within families, nurses sometimes did not agree with the decisions of family members. When this happened, they explained that they found it difficult to support family members in their decision. Furthermore, the different definitions of end-of-life in dementia patients may cause conflict between family members and health care professionals. As they use different definitions of end-of-life in dementia, they may have different opinions about when a dementia patient is considered suitable for palliative care. Besides, the interviewed nurses used different timeframes for determining end-of-life in dementia patients. This may also cause conflict between different health care professionals on when a palliative approach should begin. However, in my study, family members and health care professionals did not experience disagreement about decision-making due to the different definitions of end-of-life in dementia patients they adopted.

## 10.2 Critical reflection on results

This study provides insight in the complexity of the end-of-life decision-making process concerning persons with dementia. It presents the difficulties and emotions that are associated with making end-of-life decisions on behalf of someone else. Furthermore, this study shows how the variation in and unpredictability of the dementia patient's cognitive status complicates the decision-making process. Thus, an important finding of this study is that the most appropriate approach to end-of-life decision-making differs per dementia patient and per family member. For this reason, the end-of-life decision-making process concerning dementia patients cannot be standardised. This study shows that there is not one simple answer to questions that concern end-of-life decision-making on behalf of dementia patients, as complex processes such as end-of-life decision-making concerning dementia patients cannot be quantified.

Various developments in society and health care, such as new medical possibilities and the increasing life expectancy, led to research focussed on further improving end-of-life decision-making. New interventions such as 'advance care planning' seem a simple solution to the problems related to end-of-life decision-making for dementia patients, as it aims to better attune care to the wishes of dementia patients by early communication about future decisions. However, it is not clear what 'early' means in the context of dementia and how to know if patients are ready for such conversations. Furthermore, interventions such as advance care planning often oversimplify the decision-making process as decisions are personal, change over time and are influenced by several factors. Besides, understanding the different perspectives of patients, family members, and health care professionals on end-of-life (decision-making) is complex.

However, this applies to end-of-life decision-making in general and is not specifically the case for decision-making on behalf of dementia patients. All decisions are personal, may change over time, and may have many different influences. Furthermore, in all medical decision-making processes, it is important to understand the perspectives of the patients, family members of the patients, and health care professionals on end-of-life (decision-making). Eventually, every person, with or without dementia, will be confronted with end-of-life decision-making. I believe that for some people it might be helpful to think about their wishes for the last phase of their lives. Expressing end-of-life wishes might reassure some people. However, I think this does not apply to everyone, as thinking about your future may also be associated with for example anticipated feelings of fear. Also, in the oldest generation of society, end-of-life care, as well as dementia, possibly remain taboo subjects and it is not usual practice to talk about these topics. Furthermore, decisions might change over time, due to

changing circumstances. Therefore, I believe that every person should have the opportunity to decide for him- er herself whether he or she finds it meaningful to think about end-of-life wishes and communicate these to health care professionals and/or family members.

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