Interacting perspectives on 'quality of life' in decision-making about 'ageing in place'

Master Thesis

Name:	Wieke Ligtenberg
Student number:	4077857
Supervisor:	Dr. M.J.M. Hoogenboom
Second reader:	Dr. M. Ball

Master Social Policy and Social Interventions
Social and Behavioural Sciences
Utrecht University

Wordcount: 10.999
Utrecht; July 26, 2018

Voorwoord

Een voorwoord leek me in eerste instantie een beetje overdreven, maar inmiddels ben ik er wel achter; afstuderen is niet niks. Ik ben heel blij en dankbaar voor alle dingen die ik in het afgelopen half jaar heb mogen leren. Ik bedank in het bijzonder de drie families die hun persoonlijke verhalen met mij wilden delen. Dit half jaar was extra leerzaam vanwege mijn stage en de kritische begeleiding bij mijn scriptie. Ik bedankt ook mijn lieve familie en vrienden die ondersteunden waar ze konden. Ayeh, Ingrid, Marcel, Michelle, Steven, Aviva, Tineke, Wouter, Anne, Mark, Danielle, Rianne en Iris - Bedankt!

Abstract

This research investigated how perspectives on quality of life interacted in the decision-making process about ageing in place. Using the *Quality of Life Profile* of Raphael, Waalen and Karabanow (2001) the differences between the perspectives of elderly, their family members and professionals were investigated. The decision-making process was studied in three family cases using semi-structured with a total of 3 elderly women, 14 children and in-laws and 5 professionals. The results showed that there are differences in which domains of quality of life played an important role in the process according to the groups, and there were differences in how the groups valued the aspects within a certain domain. The different perspectives interacted in an ongoing decision-making process of initiating events, struggling with the decision and small decisions, eventually leading to the decision to move. Although, this study was only based on three families and the retrospective design may have caused some bias, this study shed light on a pressing issue in elderly care nowadays. The findings from this investigation can be used to identify potential interventions that can facilitate the decision-making process, by helping families to focus on discussing their preferences about care and ageing in an early stage in the process.

1. Introduction

The Dutch society is rapidly ageing. In 2040 the total amount of elderly above 80 will be 2 million, of which 750 thousand will be living alone (Van Campen & Den Draak, 2011). The increasing ageing population poses new questions to elderly care practices. One of the policy reactions to the ageing population is focussing on 'ageing in place'. This entails that elderly remain living in the community, with some level of independence, rather than in residential care (Wiles, Leibing, Guberman, Reeve & Allen, 2012). Since caring for frail elderly is becoming more and more a practice of caring in networks of different types of caregivers, decisions about ageing in place are influenced by complex person-environment interactions and involve different participants, such as family members and professionals (Van de Ven et al., 2017).

Simultaneously, the health care in general, is changing from focussing on the quality of care to focussing on 'quality of life'. This means that more attention is given to the experiences and personal preferences of people (Dröes & Gerritsen, 2018). Research into the meaning of quality of life to elderly, their family members and professionals has shown that differences occur between their perspectives on quality of life (Berglund & Ericsson, 2003; Richard, Laforest, Dufresne & Sapinski, 2005; Robichaud, Durand, Bedard & Ouellet, 2006). These differences will influence the decision-making process concerning care trajectories and place of residence of elderly. Hence, the question is: How do perspectives on quality of life interact in specific decision-making processes about ageing in place?

The present study aims to address this question. In the theoretical framework the different domains that constitute quality of life and the perspectives of elderly, family members and professionals on the quality of life of elderly will be discussed. After theoretically describing the interaction of perspectives in decision-making processes in health care in general, and specifically in deciding about ageing in place, the methodology of this study is described. The results of qualitative interviews in three family cases are described after which the research question is answered, and the results are discussed in a broader context of research and practice.

2. Theoretical exploration

2.1 Quality of life

Quality of life (QoL) is a multi-level, dynamic and integrated concept, which has made it difficult to come up with concrete and overarching theories. This present study uses a conceptualization of QoL based on the *Quality of Life Profile* of Raphael, Waalen and Karabanow (2001), because it involves a broad range of dimensions of human life. QoL is described using three life domains; 'being', 'belonging' and 'becoming', with each three subdomains, which will be discussed in the next part.

2. 1.1 Being

The domain of 'being', is about 'who one is'. It involves three subdomains; physical, psychological and spiritual being. The first, *physical being*, is about indicators such as health, physical status, mobility and (dis)comfort, nutrition, energy and sleeping (Kane, 2001; Raphael et al. 2001). The second subdomain is called *psychological being*. This domain contains concepts like psychological outlook, cognitive competence, emotions and feelings of happiness and enjoyment (Bowling et al., 2003; Grewal et al., 2006)). The third subdomain *spiritual being*, deals with religious and personal beliefs (Kane, 2001). As humans are meaning-seeking beings, this domain is about the personal convictions of what gives a sense of purpose or meaning in life and hope for the future (Sarvimäki & Stenbock-Hult, 2000).

2.1.2 Belonging

The second domain is called 'belonging', which is about 'the fit' to the physical, social and community environment. The first subdomain, *physical belonging*, can be determined through indicators such as the connection to one's home, workplace or school and neighbourhood (Raphael et al., 2001). A safe environment, a sense of security, privacy, and satisfaction with financial status and possessions are all part of this subdomain (Schalock et al., 2005; Felce & Perry, 1995; Kane, 2001; Dröes et al., 2006).

'Belonging' is also about social capital, measured by indicators like social networks and social relations, such as connections to intimate others, friends, family and caregivers. These connections influence someone's QoL because they are important for acceptance, support and feelings of belonging (Schalock et al., 2005; Dröes et al., 2006). On the other hand, bereavement, the loss of family members and friends, and loneliness or reduced social contacts negatively influence the QoL (Farquhar, 1995).

The third subdomain, *community belonging*, can be determined through indicators such as access to resources of social welfare and local facilities and social activities (Bowling et.al., 2003). Social inclusion, through receiving social support services and participating in educational and recreational programs, but also more general human and legal rights, such as respect, dignity and equality, are important aspects of this subdomain (Schalock et al., 2005; Raphael et al., 2001).

2.1.3 Becoming

The third domain in the conceptualisation of QoL, 'becoming', is about activities of daily life one engages in to achieve goals, hopes and aspirations (Raphael et al., 2001). The first subdomain is *practical becoming*, which is about the importance of fulfilling social roles. This is done through having a job, volunteering, doing household chores or through helping and encouraging others (Xavier, Ferraz, Marc, Escosteguy, & Moriguchi, 2003). The second subdomain involves *leisure* activities. This is about hobbies and activities such as reading, listening to music and enjoying nature (Raphael et al., 2001).

The final subdomain of QoL is *growth*, the maintenance or improvement of knowledge and skills (Raphael et al., 2001). This subdomain is about personal development through for example education and trying new things, and self-realization, by achieving goals and personal values (Schalock et al., 2005) and determinants such as autonomy, personal control and self-regulation (Felce & Perry, 1995).

2.1.4 Conclusion on conceptualisation of quality of life

Quality of life is a very broad concept that is constituted across different domains of life. It has to do with characteristics and values of the individual (*being*), social and material context variables (*belonging*) and the activities of daily life through which one achieves goals (*becoming*). Each individual values the importance of the domains differently, these perceptions are also coloured by own experiences and preferences resulting in different perspectives on QoL. The next part will discuss the perceptions of QoL of elderly, their family members and professionals.

2.2 Perspectives on quality of life

Differences between perspectives of QoL occur due to general differences in opinion, but also through different expectations leading to biases in perception and the impact of personal involvement in the situation. The level of agreement differs significantly dependent on the domain of QoL under discussion. In general, the more concrete and visible the domain, the more accurate and the higher the concordance between the different perspectives (Rand & Caiels, 2015). In the next part perspectives on QoL of elderly and their caregivers will be discussed.

2.2.1 Quality of life of elderly

In self-reports of elderly, aspects of *physical being* (health) and *social belonging* (relationships, social attachment and support, loneliness, loss) are often mentioned as being the most important in constituting their QoL (Bowling et al., 2003; Bowling & Gabriel, 2007; Xavier et al., 2003).

When it comes to *psychological being*, elderly's personalities and psychological characteristics are important. For example, positive psychological outlook is said to increase one's QoL because it leads to mental harmony and feelings of life satisfaction, which in turn are coping strategies to deal with the challenges of old age (Bowling & Gabriel, 2007). *Spiritual being* of elderly is concerned with the use of spirituality to cope with questions about the meaning in life, illness and death (Molzahn, 2007).

When it comes to *physical belonging*, especially with older people, 'attachment to place' describes how independent living gives purpose to life because staying at home

provides a sense of autonomy and independence (Stones & Gullifer, 2016). When it comes to *community belonging*, participating in the community enables elderly to retain social roles and remain attached to the community, after retiring from their paid job (Xavier et al., 2003).

In the domain of *practical becoming*, elderly often report they need to engage in meaningful activities and feel like their life has a purpose (Grewal et al., 2006; Sarvimäki & Stenbock-Hult, 2000). *Leisure* activities, the second subdomain of 'becoming', entails indicators such as listening to music and enjoying nature, and hobbies such as knitting and gardening, which are often mentioned by elderly as contributing to their QoL (Dröes et al., 2006). Within the subdomain of *growth*, (retaining) independence is the most mentioned factor contributing to QoL as reported by elderly (Bowling & Gabriel, 2007). Both primary control, directly influencing the environment and making own decisions, and secondary control, which is associated with cognitive acceptance of physical limitations, are important for elderly (Stones & Gullifer, 2016).

2.2.3 Family members perspectives

The perspectives of family members on the QoL of elderly are influenced by their relationship to older person, for example by the degree of intimacy, proximity and quality of communication (Rand & Caiels, 2015). Research into differences between elderly residents and their family members in the context of residential care, shows how the importance of specific aspects can differ within a certain domain. For example, when it comes to *social belonging*, elderly and family members agreed on the importance of loving care. But where the elderly stressed the importance of sharing good times, taking care of others and maintaining respectful relationships, the family members focussed primarily on the presence of cognitively intact fellow residents. In the domain of *physical belonging*, elderly mentioned the need of having access to adaptive ADL facilities, whereas family members were more concerned with a clean and friendly environment. When it came to *leisure* activities, family members focussed on having access to welcoming activities and spirituality services and opportunities to volunteer, while elderly reported on the need of experiencing the outdoor life. Aspects in the domain of *growth* were only mentioned by the elderly; the importance of preserving a sense of control and having occasions of self-actualization (Robichaud et al., 2006). This shows how perspectives on QoL can differ between and within the different domains.

2.2.4. Professionals' perspectives

Differences between professional's and patients' views of QoL stem from differences between reference systems. Care providers often perceive the QoL of care consumers in narrower terms than the care consumers themselves. Professionals focus on subdomains of *social belonging* (affect, social network, attachment, sufficient care), *physical being* (general health) and *physical belonging* (security, privacy) and focus less on *growth* (self-determination, freedom), *spiritual being* and the financial situation of the patient (Berglund & Ericsson, 2003; Richard et al., 2005; Dröes et al., 2006; Gerritsen et al., 2007). More agreement on QoL measurement is received when a professional has more biographical knowledge about the patient (Gräske, Fischer, Kuhlmey & Wolf-Ostermann, 2012).

2.2.5 Conclusions on perspectives of quality of life

From the previous descriptions it can be concluded that differences between perspectives on QoL occur due to differences in opinion, perception of the situation and the type of relationship. These perspectives are likely to play a part in decision-making in elderly care. This will be discussed in the next part.

2.3 Interacting perspectives when discussing ageing in place

One of the current developments in elderly care is the focus on 'ageing in place', which means that the elderly remain living in the community. At a certain point a decision needs to be made about whether staying at home is still possible. As people age and frailty increases, quality of life becomes an important outcome measure. Caregivers want to improve the QoL of elderly, because of the limited time they have left to spend together (Sandberg, Lundh & Nolan, 2002). Sometimes QoL is the factor influencing the transition to a nursing home, when families conclude that QoL is no longer guaranteed at home. The consequences of the decision to move or to stay also affect the QoL of a person (Koplow et al., 2015).

During shared decision-making (SDM) elderly, professionals and family members share their knowledge and preferences about care to come to the best solution together. The focus in the decision-making processes is on the patients' choices and needs of care and how it affects their QoL (Michael, O'Callaghan, Baird, Hiscock & Clayton, 2014). SDM is becoming increasingly important in outpatient elderly care, because different types of professionals and informal care providers are involved in caring for community dwelling elderly (Van de Ven et al., 2017). This, altogether, makes decision-making processes about ageing in place and eventually moving to residential care a suitable context for studying the different perspectives on QoL of elderly and how they interact in decision-making.

2.3.1 Phases and factors in decision-making

Choosing for residential care is a major life decision for both elderly and their family members. Research into the decision-making process has shown that different stages are part of an ongoing care-giving journey that continues with caregivers ever adjusting to new challenges and demands (Koplow et al., 2015). These different phases can be distinguished in four phases. It starts with events initiating the decision, such as the deterioration of the older person's or the caregiver's physical or psychological condition, conflicting obligations of the family members or pressure from professionals who deem the situation to be too heavy for either older person or family caregiver. Then comes the struggle with the decision, this phase is concerned with gathering information about the options and negotiating with family members. The third phase, making the decision, can be done through different mechanisms. Sometimes family members allow the elder to decide, in other situations they make the decision or push the elderly person to make a decision. This phase might lead to a (partially) consensual decision or to a reluctant decision, depending on the consensus that has been reached between the different participants in the process. The final phase is about making the move, adjusting to it and evaluating the decision (Sandberg et al., 2002; Chang & Schneider, 2010; Ducharme, Couture, & Lamontagne, 2012; Butcher, Holkup, Park & Maas, 2001). A review of the literature shows that nursing home placement has been studied extensively, but the period of ageing in place that precedes it has been researched less.

Research into the housing decisions of older adults has shown the diversity of factors that influence these decisions (Roy, Dubé, Després, Freitas, & Légaré, 2018). These factors can be divided into six dimensions, which reflect some differences and similarities with the QoL domains. The factors with the greatest effect are associated with the domains of *physical being* (changing behaviors and health events), *physical belonging* (comfort, potential adaptability, safety concerns, familiarity and housing market), *social belonging* (proximity of family, social activities and relations in the neighborhood) and *practical becoming* (maintenance, domestic activities and trigger events). Factors with a lesser effect where preferences, stress and aspirations (*psychological being* and *growth*) (Merritt, 2011). The phases in the decision-making process might be relevant to the topics that are discussed among the different participants in the care network and the aspects of QoL that are at stake. There is little research on this topic.

2.3.2 Roles and experiences

When family members make medical decisions with their older parent, they also consider their own situations in terms of values, health and financial status (Chang & Schneider, 2010). They rely on their own beliefs and preferences and life experiences with the patient. Besides, factors like caregiver hierarchy, family decision-making style and cultural factors influence the decision-making interactions (Michael et al., 2014). Although research suggests that family members mostly try to tone down their personal standpoints Söderberg, Ståhl & Emilsson, 2012, less is known about how their personal perspectives on QoL influence the process still.

The role of professionals in nursing home placement decision-making has been researched, suggesting that general practitioners are ideally suited to engage in conversations with older persons and their families about care in the final phase of life (Ott, 2017). This is because they know the patient for years and can visit the patient regularly at home. Besides general practitioners, geriatricians, social workers, home care assessors, and (district) nurses can be involved in discussions about ageing in place. Professionals often need to navigate family caregivers through the health care system and take care of family dynamics (Couture, Ducharme & Lamontagne, 2012). They do this by firstly seeing the need, and then initiating and sustaining discussions and in the end legitimating the decision about placement (Sandberg, Nolan & Lundh, 2002).

2.3.3 Conclusion about decision-making conversations

In conclusion, decisions about ageing in place are influenced by complex person-environment interactions. Research into the phases of the decision-making process and factors influencing the move to residential care shows a diversity of antecedents and possible trajectories of elderly persons and their families before they finally decide for residential care. Less is known about the specific content of what is discussed during the phases of the decision-making process and how it is influenced by the perspectives on QoL of the different participants. This has not yet been extensively studied before, and since decision-making about ageing in place or entering residential care is taking place more often due to an ageing population more research on this topic is needed.

2.4 Research question

Research on decision-making about the placing of elderly persons into residential care has mostly been focused on the different phases of the decision-making process and the experiences and roles of participants in the process. Less research has been done on how aspects of quality of life influence what is (not) discussed in conversations between the different participants. This study aims to get a more in-depth understanding of how the different perspectives on quality of life of elderly come together and interact when it comes to decision-making about ageing in place. The following research question is proposed:

> *What are the differences between the perspectives of elderly persons themselves, their family members and professional caregivers on their quality of life in discussions about ageing in place? And how do these perspectives interact and influence the final decision of moving to a nursing home?*

Sub-questions:

- What are important aspects of quality of life according to elderly persons themselves?
- What are important aspects of the elderly person's quality of life from the perspective of family members?
- What are important aspects of the elderly person's quality of life from the perspective of professional caregivers?
- How do these perspectives interact in decision-making about ageing in place?

3. Research method

3.1. Research design

The proposed research question was answered using qualitative research methods, which fit best with the explorative nature of the research. The multilayered concept of quality of life, the diversity and vulnerability of respondent groups and the limited amount of family cases can be researched using semi-structured interviews with elderly, family members and professionals involved. It is a retrospective study, asking the participants to reflect on the process of decision-making and the aspects of QoL that where discussed. With the use of multi-perspective qualitative interviews complementary and contradictory perspectives could be explored.

3.2. Selection criteria

The participating families were selected by means of purposeful sampling, to select information-rich cases. The families of elderly persons who have recently (max. 3 years ago) moved to residential care, need to be comparable on most of the following characteristics.

The elderly person needed to be at least 75 years old, because this age cohort entails the so-called fourth age, which is characterized by increased needs and vulnerabilities (Baltes & Smith, 2003). To make sure the families were comparable, the older person needed to be a woman, since gender has shown to influence the care-giving practices in families (Grigoryeva, 2017). Women are reported to have more chronic conditions than men, tend to have stronger ties with their children and are said to have higher expectations about the care they want to receive (Grigoryeva, 2017).

Furthermore, as many family members as possible, needed to be included to get a complete picture of the decision-making process. Spouses and grandchildren were preferably not included to make sure the differences in care relationships are limited to the parent-child dyad. Due to the gendered division of care, the composition of the families needed to be mostly similar. This division varies by the gender of the caregiver, but also by the gender of the siblings that share the care-giving. Research suggest that daughters are the one's taking the care responsibilities, resulting in brothers doing less care-giving tasks (Grigoryeva, 2017).

The third criterion was that at least two professionals were willing to participate. Besides the general practitioner, a (district) nurse, case manager and/or social worker could be included.

Participants were recruited using several strategies. Mostly through personal contacts and by posting on social media platforms, e.g. Facebook and LinkedIn. The people that were contacted first, should not only decide about their own participation but also whether their clients, family members or professional colleagues could be contacted and asked to participate too. After I had identified all potential participants in a family case, I emailed or called them to see whether they were willing to participate. In the email, information about the aim and practical aspects of the research and the informed consent form was provided. At the start of the interview this informed consent form was discussed another time, to make sure all potential questions were answered.

3.3. Participants

In the end three families were selected which fitted with almost all inclusion criteria, except for the comparable family composition. A total amount of 22 interviews were held between May 23 and June 22, 2018. The sample consisted of 3 older women with the mean age of 82, 9 children (4 daughters and 5 sons), 5 in-laws (2 males 3 females), and 5 professionals; two general practitioners, a domestic help, a district nurse and a social worker. The interview times ranged from 15 to 85 minutes. Approximately 40 minutes with the elderly women and the professionals and approximately 55 minutes with the children and in-laws. In two cases the children were interviewed with their partner. In the other cases the children and in-laws were interviewed separately. With two of the elderly, their granddaughter was present during the interview for them to feel comfortable. Most interviews took place at the homes or workplace of the participant.

3.4. Interviews and analysis

A topic list based on the literature review was used during the interviews (appendix 2). The topic list was tested during one pilot interview with an elderly person and afterwards fine-tuned also considering feedback from supervisors and peers. The interviews were recorded and transcribed verbatim. Afterwards they were analysed using qualitative analysis software program NVivo 11.4. The codes from the topic list were used initially and some emerging codes can be found in the code tree (appendix 3).

4. Results

4.1 Description of participants

*The **Davis** family is a close family including three daughters and a son. Mother and the three daughters live in the same village, the son lives a 1.5-hour drive away. Six years ago, their father died after a long period of care due to dementia. Home care workers have stayed on to help Mrs. Davis with putting on the support stockings. Over time, the intensity of home care increased. Although the home care workers indicated that certain things did not go well anymore, ageing in place remained the goal for mother and her children. Ultimately, a heavy fall and additional confusions prompted the children to provide 24-hour care in-house, after which their mother was temporarily admitted to a nursing home in the village. During the period of temporary shelter, the diagnosis was made that it would be irresponsible for Mrs. Davis to go back home.*

*During the decision-making process the **Bennet** family consisted out of father, mother and three sons. Although Mrs. Bennet had some serious infirmities, she wanted to continue ageing in place. The youngest son and his wife are the main family caregivers which provided all their parent's needs, to fulfill their wish to stay at home for as long as possible. In addition to the daughters-in-law that helped cleaning and cooking, Mr. and Mrs. Bennet received domestic help and assistance with showering from professionals. They stayed home until Mrs. Bennet was hospitalized by a fall. During her period in the hospital, her demented husband was unable to stay at home alone and needed to go to an emergency shelter. After recovery Mr. and Mrs. Bennet ended up in the same nursing home despite a difference in indication. After they moved to the nursing home in December 2017, Mr. Bennet died in one month.*

*Mrs. **Williams** lived together with her husband for 58 years in a large house on the country side. A few years ago, her husband died of cancer. Mrs. Williams' daughter lives nearby, and she and her husband are the main family caregivers. Mrs. Williams' son lives at more than an hour drive. The general practitioner, a good friend of the family, supported the Williams in their wish not to live in with their daughter and provided more care for them to be able to stay at their own home. When Mrs. Williams' health declined, and her immobility increased, she got professional help with showering. Eventually, the daughter and the general practitioner observed depressive symptoms. After this, the general practitioner and a social worker tried to get Mrs. Williams into a nursing home. After being placed on a waiting list Mrs. Williams unexpectedly received a room.*

The participants of each family case are also listed in appendix 1.

4.2 Perspectives on quality of life

In the first part of this chapter the perspectives of the elderly, family members and the professionals are discussed. Of each respondent group, the subdomains of being, belonging and becoming were investigated. In the second part will be described how the perspectives of the elderly persons, family members and professionals come together when they had to make joint decisions about ageing in place or moving to a nursing home.

4.2.1 Elderly: growing dependencies and attachment to place

The elderly especially mentioned chronic diseases, cystitis and new knees and hips as a reason for declining mobility and increasing need for help, which they received from children and professionals. Ultimately, a fall or cystitis plus additional confusion was a reason for (temporary) admission to rehabilitation or a nursing home. *Attachment to place* is important to the elderly, as Mrs. Williams describes it:

> *I do not want to leave. I have lived here for almost fifty-nine years, with my husband. The children were born here, and we were there since we got married. It still has a certain place in your life. That you have to renounce that, that is not easy*.

Besides, the elderly described social contact with professionals as an enrichment of their social life, even though they first had to get used to physical care by strangers. The elderly looked forward to the (grand)children coming and visiting every week. The temporary absence of children or other visitors provided them with insight into their deteriorating situation.

The elderly participants reported that their main motivation for choices regarding care and living was that they were unable to complete simple tasks, such as cooking or showering independently. They were aware that there is a limit to the help they can receive. Mrs. Bennet: "The children live nearby, but yes, you can hardly have them come every night to cook food." Accepting help and letting go of independence, were important concepts for the elderly participants in the decision-making process. Mrs. Davis reflects: ‘Yes, I've cried… thinking you have to let someone else take care of you’.

According to the elderly, mainly changes in their health (*physical being*), the fact that they need more and more help with daily activities (*practical becoming*), attachment to place (*physical belonging*) and the fact that they want to keep their independence (*growth*) are important aspects when it comes to deciding on ageing in place or moving to a nursing home. These results were in line with other literature, with regards to the aspects that are found to be important to the QoL of elderly (Bowling et al., 2003, Bowling & Gabriel, 2007, Xavier et al., 2003; Stones & Gullifer, 2016).

4.2.2 Family perspectives on quality of life; Children and in-laws

Like the elderly participants, the children refer to developments in physical health as a reason for expanding care and considering moving. The son of the Williams family explains:

> *At a certain point, they both had been in the hospital for a while and then it was on the agenda to move. When they were recovered, it all went fine again and then it was suddenly gone off the agenda again.*

In contrast to the elderly, children state the psychological condition and cognitive decline of their mother as a reason to start thinking about moving. When it came to social contacts, children mentioned the importance of other members of the local community, in addition to contact with close relatives. They indicated that their mother's connection with the village community and her peers enabled her to age in place for a longer time. The fact that their mother has no a partner anymore, is was mentioned by the children to increase the demand for care, since there is no one in the house who can look after her.

Slight alterations to the house, made it possible for elderly to stay at home for a longer period, but the children didn't pay explicit attention to their mother's attachment to the house. The son of the Williams family appoints it: 'Apart from the fact that it was perhaps a wonderful place for them, it was all too big, it took too much maintenance and it was simply impossible to stay there any longer'. Strikingly, children described how during the past years the house became dirty and how dangerous situations arose with cooking, showering and rollators, whilst the elderly did not talk about it.

Like the elderly, the children state that their parents needed help with daily tasks such as preparing meals, showering and cleaning. Children mention seeing their moms deteriorate, through changes in the practice of hobbies and daily activities. Over time, children take over many, mainly practical tasks. The limit is reached when the type of care changes. When it comes to physical care, professional help is requested. Children consider it important that their parents decide for themselves, eventually also about moving. Their moms should be able do the things they can do themselves, for as long as possible. The son of Williams family describes it: 'Of course my mother is still clear-headed. I'm not going to impose things. She can decide for herself.'

In conclusion, the children and in-laws talked mostly about the importance of social contacts and the help their mother (in law) needs with everyday things (aspects of *social belonging* and *practical becoming*) as important elements in the decision-making process about ageing in place or moving to a nursing home.

4.2.3 Professionals: focus on well-being

As expected, the professionals talked a lot about aspects of physical well-being; difficulties with walking, more falling and no longer being able to stand up, an increased chance of breaking legs or hips, pain and poor sleep. All these conditions, and mental conditions such as depressive complaints prompted more care or looking for opportunities to move.

Professionals spoke about aspects of the physical environment in all three cases; but mostly because these were circumstances professionals had to deal with when providing care. They are not mentioned as reasons for moving, because according to professionals, a familiar

living environment is important for elderly: 'You should not move old trees'. When it came to social belonging, the loss of a partner was mentioned several times and professionals also emphasized the importance of informal resources to increase the possibilities of ageing in place. Professionals come into the picture when elderly and children can no longer keep up with the increasing care. Professionals mention that they try to support where they can, but that is also limited. The district nurse of the Davis family:

> *We come, and we leave again. For example, with breakfast, you are there for half an hour. With showering you have been there for three quarters of an hour. And then there will be more than 23 hours left. That is what we must leave with the family*.

Professionals spoke mainly about aspects of *physical and psychological being* and changes in the physical and mental health of the elderly that lead to the seeking of more care or eventually moving. These results fit with the conclusions of Berglund and Ericsson (2003) that professionals value the domains that they can change with their work as more important than other domains.

4.2.4 Differences between and within quality of life domains

When a balance is drawn up of aspects of QoL that, according to the elderly participants, children and professionals, play a role in the decision-making process about ageing in place and relocating, it appears that there are indeed differences between the groups when it comes to the aspects that are viewed as most important. For the elderly in this study, changes in their health (*physical being*), the help they need with everyday things (*practical becoming*) and the fact that they become more dependent (*growth*) play a role in the decision-making process about ageing in place or moving to a nursing home. Children and in-laws are concerned about their mother (in law) having too many or too few social contacts and the increase of help she needs with daily things (*social belonging* and *practical becoming*). Professionals focussed mainly on aspects of *physical and psychological being* and specifically changes in the physical and mental health of the elderly that lead to the seeking of more care and eventually moving to a nursing home. *Spiritual being* and *leisure* aspects of QoL do not seem to have played a significant role in the decision-making process.

The perspectives of the participants differed most in the subdomains of *social belonging*, *psychological being* and *physical belonging*. Children and in-laws were concerned about the amount and frequency of social contacts of their mother, while the elderly talked about the quality of contact with their children and professionals. The elderly participants did not really discuss things part of *psychological being,* but according to children and professionals aspects of this subdomain are important in the decision-making process. In addition, as far as aspects of *physical belonging*, the house and the belongings are concerned, the elderly participants mainly mention these as aspects that make it difficult for them to move. However, for children and professionals characteristics of the house and the environment mainly formed the reason to continue in the process towards moving.

Concerning the first subquestions, the results showed that there are differences in which domains play an important role in the process according to the groups, and there are differences in how the groups valued the aspects within a certain domain.

4.3 Phases in decision-making

In the literature on the decision-making process (Chang & Schneider, 2010, Ducharme et al., 2012, Butcher et al., 2001 and Sandberg et al., 2002), the following phases are distinguished: *initiating events, struggling with the decision, making the decision and making the move.* However, the process is not as linear as the theory suggests. From conversations with the three families in this study it seems to be a circular process of *initiating events* and *struggling with the decision* taking years, before a decision is made which eventually leads to the move to a nursing home. The son of the Williams family describes this process, which is also graphically shown in figure 1:

> *There are just some things that happened that scare you and get you thinking. Then you say yes, we must go through this. A fall is also a good wake up call for everyone. And then everyone goes his own way, and nothing happens. It hangs in your mind, but it does not have the urgency...*

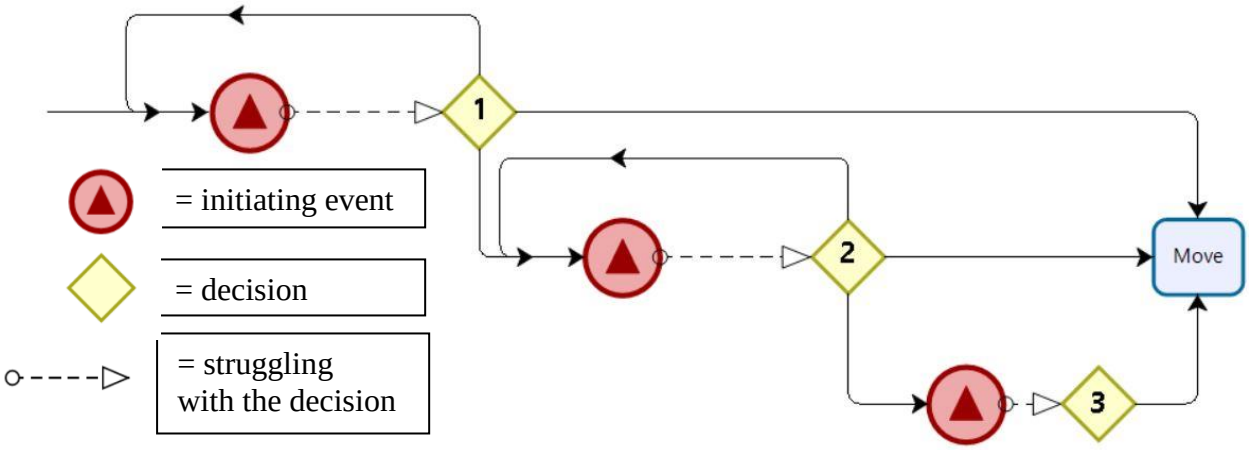

Figure 1: The decision-making process in alternating phases.

4.3.1 Initiating events: deteriorating health and increasing dependence

As initiating events, two things are mainly mentioned by all respondent groups. First, the fact that the elderly person needs more help with daily things (*practical becoming*) and in addition, a fall or developments in physical and mental health (*physical being and psychological being*) are mentioned as a reason to think about moving or ageing in place, which is consistent with research of Cheek, Ballantyne, Byers, & Quan (2007). The elderly participants themselves mentioned that children often take the initiative and start discussing the option of moving;

> *We live a bit outside the village and I only cycle so ... At some point the children did not feel confident with me cycling alone, since I have Meniere's disease. And then they said, 'we should see that we find something for mom'*. (Mrs Williams)

On the other hand, a few children (especially of the Davis family) blame themselves for not seeing or knowing about the decline of their mother's abilities and that for not thinking about the necessity of moving at an earlier stage:

> *Only now we see that there were also other things that we did not see at that time. You see things, but she could hide it quite well from us, and that was very striking*. (daughter of the Davis family)

In-laws also explicitly mention a disruption of the daily structure of their mother-in-law as a reason to start thinking. For the mother-in-law the absence of the most important family caregiver or a change in the daily structure leads to more insight into their situation, which makes her think about moving. The son-in-law of the Williams family:

> *In spring we have been away for a few weeks, going abroad for holidays. Normally you go and see your mother-in-law on a weekly basis. But then suddenly she discovered she lived very remote. And if you then notice that your family does not come, then you think: well, I'm here…*

Initiating events were mainly related to a severe fall or changes in physical and mental health, the fact that the children can no longer cope with the care responsibilities and the growing insight of the mother that she cannot do certain things independently anymore. Aspects of *physical being*, *psychological being* and *practical becoming*, were reason to start looking for (an expansion of) care or relocation opportunities.

4.3.2 Struggling with the decision: quality of life of parents and children

Following an *initiating event* comes *struggling with the decision*. In the decision-making process there are several occasions when people start thinking about moving. But why do people decide to stay at home in most cases?

This seems to be caused mainly by the elderly persons and their children (in law) not sharing their individual perspectives within the family. In the Bennet and Davis family, there was no extensive discussion about moving, because the children did not think about it (Davis) or because the subject was taboo, not discussable for the parents (Bennet). The situation is described as caregivers who 'fill gaps' and elderly who 'mask' the real situation. By using these terms, the children indicate that they are partly aware of the situation, but do not act because they think it will still work out fine.

> *The gaps that fell were filled by my youngest brother. Was I aware of that? Well, of course I knew that he did a lot for them. But, I did not know how big the holes were; let me put it that way*. (middle son Bennet)

In the meantime, insight into the situation grows with the mothers and the children and in-laws. They become aware of the difference between parents and children when it comes to the ideal situation in terms of living and care. The in-laws and to a lesser extent the children tend to see the benefits of a nursing home (good care, safety, social conditions) earlier, while the elderly prefer to stay in their familiar place (autonomy and attachment to place) at home for as long as possible.

The *struggle with the decision* is about revaluing aspects of QoL. What is more important? The safety and availability of care or the wish of the elderly? The daily routine of the elderly or the carrying capacity of the children? The potential social activities to be undertaken in the care home or the familiarity of being at home? Aspects of attachment to the social and physical environment (*belonging*) and the autonomy of the elderly person and their wish to stay at home (*growth*) are the aspects that make it difficult for elderly, children and professionals to decide to move. Because autonomy and self-determination (*growth*) are important for the elderly, children and professionals often let the elderly person's wish be decisive. To fulfil this wish, sometimes it seems necessary that older people or children hand in certain aspects of QoL (an arrow downwards after a decision moment). A decision is then made, but not the decision to move (the process repeats itself). Either the elderly settle for 'less' or children will do 'more' to keep living at home feasible. It is therefore not just about the QoL of the older person, but also about that of the children. The caring capacity of the family caregivers is central in the decision-making process. A daughter-in-law of the Bennet family indicated how the care tasks expanded:

> *For my brothers-in-law, it became heavier. Because apart from groceries, they started taking on more and more care tasks, because of course they live closer by. So, then we thought, we must go more often. And then it feels more like a duty and I sometimes find that difficult. You do it with all your love, but yes you also have your own work, your own life.*

How often the process is repeated, mainly has to do with the possibilities and role of the children in providing (extra) care and the (unspoken) wish of the elderly to stay at home, which is consistent with findings of other studies (Cheek et al., 2007).

4.3.3 Making the decision: reaching the limit

But at what point in the process do families decide to move? The moment in time at which moving becomes a necessary thing, differs among the children. It seems to be related to how the care-giving situation affects their own QoL and their place in the family 'hierarchy'. The lives of the children play a major role in the type and amount care they can provide for their parent ageing in place and it influences their opinions about staying at home or moving. Children indicated that they set limits for themselves (thinking about their own families and work situation) or that they run up against limits, while they would like to do even more (but it turns out to be impossible to combine with their own responsibilities). Until they reach that point, the children hand in aspects of their QoL (such as time and money).

In addition, when it comes to the family ‘hierarchy’ the results show that often the child with the most care-giving tasks is also involved in most decisions. They receive

(unspoken) mandate from the others to decide about care and moving. Children who are further away from the care situation, in terms of physical and emotional distance, seem to be more inclined to indicate that moving is necessary in an earlier stage in the process. These conclusions are in line with findings of other studies that described how worsening caregiver's health status (*physical being* and *practical becoming*) and disturbed family life were factors initiating the placement decision (Chang & Schneider, 2010; Ducharme et al., 2012). Rand & Caiels (2015) also found that the perspectives of on QoL were influenced by their relationship to the care recipient (e.g. by the degree of intimacy, proximity and quality of communication).

In addition to the children, professional care also has a limit. When professionals can no longer provide the care that the elderly need, moving seems inevitable. The circular process of an alternation between *initiating events* and *struggling with the decision* is broken at a moment. Like the studies of Nolan and Dellasega (2000) and Merritt (2011) this study found that professionals played a significant role in the ultimate placement decision, mostly because they are of importance when it comes to medical interventions. They are mainly concerned with support for daily activities and providing physical care, so only at this stage they get involved in the process.

4.3.4 Making the move: or starting the process all over again?

When a decision to move is made, it is not always possible to move immediately. There are external circumstances such as waiting lists and bureaucratic procedures that make people staying at home longer and having to wait for a place. It may happen that, during this period, that participants change their mind. This is the story of the youngest son of the Bennet family:

> *I started once to apply for an indication and halfway through I was stopped again, because that was wrong. Then I had applied for it, I got a piece of paper but then it still went well at home, you know...*

This then delays the actual move because they take a step back in the process until another reason arises to act.

4.3.5 Interacting perspectives

People's perspectives on QoL constantly interact in the decision-making process about ageing in place. The stories of the Davis, Bennet and Williams families indicate that this process is not as linear and unambiguous as laid out in the literature. *Initiating events* are not just one-off events, but it is about the ongoing process of aging, getting flaws and becoming more and more dependent. Sometimes this process is interrupted by incidents, but often it is also just gradual. But the deterioration gets elderly and children thinking about the possibility of moving. Then follows the *struggle with the decision*. This part of the decision-making process is mainly unspoken. While aspects of QoL are weighed against each other, the understanding of mother and children grows that things must change. The struggle does not directly lead to a final decision about moving. Before the decision to move is taken, many more small decisions have been made, for example, for the seeking of more care, or to settle for a lesser QoL of the mother or of the children. They take a step down (figure 1). Often the decision-making

postponed until another event occurs or the process of deterioration has taken a step further. In the exchange of aspects of QoL, the autonomy and the desire of the elderly person ultimately seem to be central (*growth*). In the first instance, children take this as the decisive factor in the choices they make, namely to provide as much care as possible to fulfil the wish of their parent to stay at home for as long as possible. Ultimately, it is only the aspects of *physical being* and *practical becoming* that remain after the importance of the other aspects (of which the most important the connection with people and environment and independence) has vanished.

5 Discussion

5.1 Conclusion

The aim of this research was to map the differences between the perspectives on quality of life of elderly, their family members and professionals in discussions about ageing in place. The results showed there are differences between the perspectives, there is the elderly persons, mostly mentioned aspects of *physical being*, *practical becoming* and *growth.* Family members mainly mentioned aspects of *social belonging* and *practical becoming* and professionals focussed on aspects of *physical and psychological being.* The results showed that there are differences in which domains play an important role in the process according to the groups, and there are differences in how the groups valued the aspects within a certain domain.

The different perspectives interacted in an ongoing decision-making process of initiating events, struggling with the decision and small decisions, that eventually leads to the decision to move. The families described the decision-making process as involving gradual and sudden changes in the lives of the elderly person and the family caregivers. *Initiating events* such as a gradual deterioration of health status and a decline in the ability to do the daily things (aspects of *being* and *practical becoming*) are a reason to start thinking about moving. The *struggle with the decision* often involves weighing different aspects of QoL. For example, emotions, attachment to place, belonging to the community and the importance of daily activities and social contacts (*belonging*), are weighed off during the struggle with the decision. At some point children and elderly persons trade in some aspects of QoL to make sure autonomy and the wish of the elderly person to stay at home is respected (*growth*). The weighing of aspects of QoL then leads to making a decision, for example for the children to provide the meals instead of the older person cooking itself. These decisions are always aimed at maintaining the QoL of the older person or the children as much as possible, whilst fulfilling the older persons wish: to stay at home. After a sudden event, for example a fall or the temporary absence of a primary caregiver, the 'true state' of the older person comes to light. Finally, when considering whether to move, this is usually indicated by the professional. In terms of physical condition or daily living conditions (of the older person or the children) it is better to receive care in a nursing home.

5.2 Research in broader context

Autonomy and the desire of the elderly person to age in place (*growth*) ultimately seemed to be central in the decision-making process. This has to do with retaining independence and *attachment to place*. A recent systematic review of Roy and colleagues (2018) shows how

almost all aspects of quality of life are involved in the experience and the meaning of home to frail elderly. They describe that the home is as a mirror to the self and a place of personal control (*psychological being*), that it gives people access to human resources and is a place for privacy and refuge (*social belonging*) and how safety, accessibility and personal belongings are of importance (*physical belonging*). The current research confirms and illustrates these findings. However, some dimensions that were described by Roy and colleagues (2018) were not explicitly part of this study. For example, the economic dimensions of ownership, financial investment and savings and inheritance and temporal dimensions of a familiar setting, settlement-identity and memories. These dimensions do not fit directly with one of the domains of QoL in the conceptualization of Raphael and colleagues (2001) and therefore were not part of the current investigation. It is suggested to invest future research to create a quality of life conceptualization specifically focused on aspects that are important when it comes to choosing between staying at home or moving.

The results of this research raise questions about the idea of *shared decision making* when it comes to ageing in place. Many decisions were made unspoken by individuals. Nevertheless, when the topic of moving comes up in a family, children are often the first to bring the theme to the table. Parents then clearly show that they do not want (to think about) it. Their desire to stay at home is decisive for a long time. These findings are consistent with Söderberg et al. (2012) who describe that family members try to balance respect for autonomy and self-determination with their desire for the best possible care and their own personal lives. Then, because the topic is neglected by parents, the subject disappears from the surface until a new situation occurs through which the possibility of moving becomes an urgent topic again. Finally, it is then a professional or an unexpected event that cuts the knot. This then means a breakthrough in the ongoing decision-making process. This is in line with expectations from previous research that indicates that family members seek reassurance in their decision, which is then provided by the professional (Butcher et al., 2001).

Strengths

This investigation has deepened the understanding of the domains of quality of life that are at stake when deciding to place an older person in a nursing home. The conceptualization of QoL based on the *Quality of Life Profile* of Raphael et al. (2001) provides a unique approach to compare the different perspectives and to study the decision-making process. The findings suggest multiple factors impact the decision-making process and provide support for a more nuanced description of this process. Previous research on the decision-making process was mostly conducted with only family caregivers as respondents (Nolan & Dellasega, 2000; Koplow et al., 2015; Chang & Schneider, 2010; Ducharme et al., 2012; Butcher et al., 2001). This research design, which involves case studies of three families, involving both elderly persons and professionals, made research on changing caregiver roles and interacting perspectives possible. This has led to a theory that is more situation specific. It explains the decision-making process from the perspectives of all different participants involved, instead of studying just one side of the story.

5.3 Limitations

This study, however, is not without limits. These mostly have to do with representativeness and the retrospective design of this study.

First, since this exploratory research involved only a limited number of families, it is important to acknowledge the lack of generalizability. The families were not comparable in composition (sons and daughters), the Bennet family did not meet the inclusion criteria (at the time of the decision-making process the partner was still alive), the current sample comprised only elderly women and the participants were not racially or ethnically diverse. However, the findings do indicate some central elements in the decision-making process. These need to be researched more extensively in other (family) contexts, to improve the generalizability of the constructed theory. In future research it is important to also reflect the reality of the nursing home placement of widowed men, ageing couples and families from different ethnic backgrounds, because with these families differences in the division of care are expected.

Secondly, the type of design used (family cases), was not suited to answer the first sub-questions, because the proportions in terms of number of persons per perspective were skewed; only 3 elderly, 5 professionals with very different backgrounds (general practitioners, a domestic help, a district nurse and a social worker) and no fewer than 14 children and in-laws participated. Just studying the differences between these three groups could also be done through survey data, with equal amounts of respondents from the different groups. But, the big advantage of studying the different perspectives in a family context is that you are certain that the respondent groups are all talking about the same events.

Thirdly, the recruiting of the participants was influenced by self-selection. Families that look back positively on the decision-making process, are the ones who are open to participation in the research. Others did not want to participate mainly because of negative personal experiences and the persistent sensitivity of the subject within the family. Besides the fact that the children were the ones that provided contact details of professional to be contacted to participate in the study, may have led to a preponderance of close relationships. This might have led to a distorted picture of the relationship between the professionals and the family members during the decision-making process.

Finally, the retrospective view is a limitation. In the Davis and Bennet family the move was more than half a year ago. That is too long for a retrospective study. Most studies use a limit of 90 days (Cheek et al., 2007). Especially the elderly participants, talked more about the things they were concerned about in the current situation, than the things they focussed on during the decision-making process. A solution would be to implement a longitudinal research design in which de families are interviewed several times whilst ageing in place until they move to the nursing home.

5.4 Implications

This study shed light on a pressing issue in elderly care nowadays. The design used in this explorative study gave us an example of the interactions of perspectives on QoL through the different phases of the decision-making process in three families. There is evidence that there are great variations in the way families make the decision to move. The identification of differences between elderly, family members and professionals in the decision-making process highlights the need for further development of the theory for use in a variety of

populations and settings. This can best be done through longitudinal research involving multiple families and conducting in-depth interviews with all different participants during the decision-making process.

Since the decision-making process regarding nursing home placement is particularly trying for families, the findings from this investigation can be used to identify potential interventions that can facilitate the decision-making process. Professionals and policy makers can help families to focus on discussing their preferences about care and ageing in an early stage in the process. This can increase the sense of control and empowerment and prevent crisis situations, as was also suggested by Ducharme and colleague's (2012). Autonomy can be increased by choosing to move yourself, instead of having to be forced by circumstances. A greater diversity of housing types can help, so that there is a less dichotomous choice between ageing in place or moving to a nursing home. By providing more possibilities for combining care and living the 'definite' choice for moving to a nursing home is not the only consideration, nor a choice one needs to scare away from. This way quality of life of elderly can remain central, also in housing decisions.

References

Baltes, P. B., & Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology*, *49*(2), 123-135.

Berglund, A. L., & Ericsson, K. (2003). Different meanings of quality of life: a comparison between what elderly persons and geriatric staff believe is of importance. *International Journal of Nursing Practice*, *9*(2), 112-119.

Bowling, A., Gabriel, Z., Dykes, J., Dowding, L. M., Evans, O., Fleissig, A., ... & Sutton, S. (2003). Let's ask them: a national survey of definitions of quality of life and its enhancement among people aged 65 and over. *The International Journal of Aging and Human Development*, *56*(4), 269-306.

Bowling, A., & Gabriel, Z. (2007). Lay theories of quality of life in older age. *Ageing & Society*, *27*(6), 827-848.

Butcher, H. K., Holkup, P. A., Park, M., & Maas, M. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Research in Nursing & Health*, *24*(6), 470-480.

Chang, Y. P., & Schneider, J. K. (2010). Decision-Making Process of Nursing Home Placement Among Chinese Family Caregivers. *Perspectives in Psychiatric Care*, *46*(2), 108-118.

Cheek, J., Ballantyne, A., Byers, L., & Quan, J. (2007). From retirement village to residential aged care: what older people and their families say. *Health & social care in the community*, *15*(1), 8-17.

Couture, M., Ducharme, F. & Lamontagne, J. (2012). The role of health care professionals in the decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home Health Care Management & Practice*, 24(6), 283-291.

Dröes, R. M., Boelens-Van Der Knoop, E. C., Bos, J., Meihuizen, L., Ettema, T. P., Gerritsen, D. L., ... & SchöLzel-Dorenbos, C. J. (2006). Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature. *Dementia*, *5*(4), 533-558.

Dröes, R. M., & Gerritsen, D. (2018). Uiteindelijk gaat het om behoud van kwaliteit van leven. In *Meer kwaliteit van leven* (pp. 145-162). Bohn Stafleu van Loghum, Houten.

Ducharme, F., Couture, M., & Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitively impaired elderly relative. *Home health care services quarterly*, *31*(3), 197-218.

Farquhar, M. (1995). Elderly people's definitions of quality of life. *Social science & medicine*, *41*(10), 1439-1446.

Felce, D., & Perry, J. (1995). Quality of life: Its definition and measurement. *Research in developmental disabilities*, *16*(1), 51-74.

Gerritsen, D. L., Ettema, T. P., Boelens, E., Bos, J., Hoogeveen, F., de Lange, J., ... & Dröes, R. M. (2007). Quality of life in dementia: do professional caregivers focus on the significant domains? *American Journal of Alzheimer's Disease & Other Dementias®*, *22*(3), 176-183.

Gräske, J., Fischer, T., Kuhlmey, A., & Wolf-Ostermann, K. (2012). Quality of life in dementia care–differences in quality of life measurements performed by residents with dementia and by nursing staff. *Aging & Mental Health*, *16*(7), 819-827.

Grewal, I., Lewis, J., Flynn, T., Brown, J., Bond, J., & Coast, J. (2006). Developing attributes for a generic quality of life measure for older people: preferences or capabilities?. *Social science & medicine*, *62*(8), 1891-1901.

Grigoryeva, A. (2017). Own gender, sibling's gender, parent's gender: The division of elderly parent care among adult children. *American Sociological Review*, *82*(1), 116-146.

Kane, R. A. (2001). Long-term care and a good quality of life: Bringing them closer together. *The gerontologist*, *41*(3), 293-304.

Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: a case for care networks. *Ageing & Society*, *23*(1), 115-127.

Koplow, S. M., Gallo, A. M., Knafl, K. A., Vincent, C., Paun, O., & Gruss, V. (2015). Family caregivers define and manage the nursing home placement process. *Journal of family nursing*, *21*(3), 469-493.

Merritt, R. P. (2011). *The Decision Making Process of Informal Caregivers of Dementia Family Members Regarding Nursing Home Placement*. Virginia Commonwealth University.

Michael, N., O'Callaghan, C., Baird, A., Hiscock, N., & Clayton, J. (2014). Cancer caregivers advocate a patient-and family-centered approach to advance care planning. *Journal of pain and symptom management*, *47*(6), 1064-1077.

Molzahn, A. E. (2007). Spirituality in later life: Effect on quality of life. *Journal of Gerontological Nursing*, 33(1), 32-39.

Nolan, M., & Dellasega, C. (2000). 'I really feel I've let him down': supporting family carers during long-term care placement for elders. *Journal of Advanced Nursing*, *31*(4), 759-767.

Ott, B. (2017). Advance (d) care planning of regeren is vooruitzien. *Bijblijven*, *33*(4-5), 307-312.

Rand, S., & Caiels, J. (2015). Using proxies to assess quality of life: a review of the issues and challenges. *Canterbury: QORU, University of Kent*.

Raphael, D., Waalen, J., & Karabanow, A. (2001). Factor analytic properties of the quality of life profile: Examination of the nine-subdomain quality of life model. *Psychological reports*, *88*(1), 265-276.

Richard, L., Laforest, S., Dufresne, F., & Sapinski, J. P. (2005). The quality of life of older adults living in an urban environment: Professional and lay perspectives. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, *24*(1), 19-30.

Robichaud, L., Durand, P. J., Bedard, R. & Ouellet, J.P. (2006). Quality of life indicators in long-term care: opinions of elderly residents and their families. *Canadian Journal of Occupational Therapy*, 73, 3, 245–51.

Roy, N., Dubé, R., Després, C., Freitas, A., & Légaré, F. (2018). Choosing between staying at home or moving: A systematic review of factors influencing housing decisions among frail older adults. *PloS one*, *13*(1), e0189266.

Sandberg, J., Lundh, U., & Nolan, M. (2002). Moving into a care home: the role of adult children in the placement process. *International Journal of Nursing Studies*, *39*(3), 353-362.

Sandberg, J., Nolan, M. R., & Lundh, U. (2002). The role of community staff in care home placement in Sweden. *Journal of clinical nursing*, *11*(4), 488-497.

Sarvimäki, A., & Stenbock-Hult, B. (2000). Quality of life in old age described as a sense of well-being, meaning and value. *Journal of advanced nursing*, *32*(4), 1025-1033.

Schalock, R. L., Verdugo, M. A., Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X., & Lachapelle, Y. (2005). Cross-cultural study of quality of life indicators. *American Journal on Mental Retardation*, *110*(4), 298-311.

Söderberg, M., Ståhl, A., & Emilsson, U. M. (2012). Family members' strategies when their elderly relatives consider relocation to a residential home—Adapting, representing and avoiding. *Journal of aging studies*, *26*(4), 495-503.

Stones, D., & Gullifer, J. (2016). 'At home it's just so much easier to be yourself': older adults' perceptions of ageing in place. *Ageing & Society*, *36*(3), 449-481.

Van Campen, C. & Den Draak, M. (2011). Kwetsbaar alleen: de toename van het aantal kwetsbare alleenwonende ouderen tot 2030. Sociaal en Cultureel Planbureau.

Van de Ven, L. G., Smits, C., Elwyn, G., Span, M., Jukema, J., Eefsting, J., & Vernooij-Dassen, M. (2017). Recognizing decision needs: first step for collaborative deliberation in dementia care networks. *Patient education and counseling*, *100*(7), 1329-1337.

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. (2012). The meaning of "aging in place" to older people. *The gerontologist*, *52*(3), 357-366.

Xavier, F. M., Ferraz, M., Marc, N., Escosteguy, N. U., & Moriguchi, E. H. (2003). Elderly people s definition of quality of life. *Revista Brasileira de Psiquiatria*, *25*(1), 31-39.

Appendix

1. Table of respondents

Davis family	**1**	Mrs. Davis
	2	Daughter
	3	Daughter
	4	Son in Law
	5	Daughter
	6	Son (+ Daughter in Law)
	7	District Nurse
Bennet family	**8**	Mrs. Bennet
	9	Son
	10	Daughter in Law
	11	Son
	12	Daughter in Law
	13	Son
	14	(Son +) Daughter in Law
	15	Domestic Help
	16	General Practitioner
Williams family	**17**	Mrs. Williams
	18	Daughter
	19	Son in Law
	20	Son
	21	General Practitioner
	22	Social worker

2. Topic list (family members version)

Introductie onderzoek

- Voorstellen
- Doel van studie
- Opname
- *Informed consent*

Betrokkenen & Verhoudingen *Opstellen genogram en overzicht zorgnetwerk.*

- Hoe lang woont u (uw moeder/patiënt) hier al? Waar woonde u/ze hiervoor?
- Op welke manier bent u betrokken bij de zorg voor uw moeder? Hoe lang bent u al professioneel betrokken bij … ?
    - Wie zijn er allemaal nog meer betrokken bij de zorg/hulp die u krijgt?
    - Wie zijn er belangrijk voor u, die niet direct betrokken zijn bij de zorg die u krijgt.
- Kunt u iets meer vertellen over de onderlinge verhoudingen binnen de familie, de relatie met uw vader/moeder, broers en zussen, en de hulpverleners?
    - Is er de afgelopen jaren sprake geweest van veranderingen in verhoudingen?
        - In hoeverre heeft dit te maken met de zorg die verleent moest worden?
        - In hoeverre heeft dit te maken met de keuzes die er gemaakt moesten worden?
- *Kinderen*: Ook vragen naar afstand/reistijd.
- *Professional*: Wat is precies de diagnose of hulpvraag van .. ? In hoeverre bent u volgens uzelf op de hoogte van biografische gegevens van uw patiënt?

Deel 1: Besluiten over thuis wonen

U bent verhuisd, daarvoor heeft u met hulp thuis gewoond. Graag wil ik het hebben over de beslissingen die u heeft moeten maken en welke dingen daarbij belangrijk waren volgens u. Hierbij wil ik vooral ook kijken naar de verschillen en overeenkomsten van standpunten en visies op de situatie met de anderen die betrokken waren bij de beslissing.

- Aanleiding: Wat was de aanleiding wanneer voor het eerst bleek dat volledig zelfstandig wonen niet meer mogelijk was?
- Veranderingen:
    - Welke keuzes heeft u moeten maken om thuis te kunnen blijven wonen? Wat denkt u nu over die keuzes?
    - Wat wilde u? Wat was er belangrijk volgens u?
    - Wat wilden de anderen? (*hierbij terugvragen naar leden uit zorgnetwerk; familie en professionals*)
- Aanloop beslissing verhuizen
    - Wat heeft er uiteindelijk toe geleid dat er besloten is om te verhuizen?
    - Wat gebeurde er voordat de uiteindelijke beslissing was genomen?
    - Hoe kwamen jullie samen tot een beslissing?
        - Hoe zou u de manier waarop er binnen uw familie keuzes gemaakt worden beschrijven?
        - Wat waren de alternatieven?
- Beslissing/Verhuizen/terugblik op keuzeproces
    - Hoe kijkt u nu, na de verhuizing, terug op het proces daarvoor?

Belangrijke dingen voor mezelf (als onderzoeker) om op te letten:

- *Het moet vooral gaan over de periode, gebeurtenissen en beslissingen tijdens het thuis wonen, voor de verhuizing. Hoe spelen aspecten van kwaliteit van leven hierbij een rol?*
- *Expliciet vragen doorvragen op elk topic (kwaliteit van leven).*
    - *'Waarover waren jullie het eens?', Wie vond wat belangrijk en waarom?*
- *Het moet vooral gaan over de **inhoud** van het gesprek en minder over de personen of het proces. Waarover hadden jullie het? Focus op het topic, daarna de verschillende perspectieven bevragen.*
    - *Wat wilde u? Wat was er belangrijk volgens u?*
    - *Wat wilden de anderen? Wat was er belangrijk volgens hen?*

Deel 2: Aspecten van kwaliteit van leven

Bespreking aspecten die eerder niet (uitgebreid) aan de orde kwamen. Tijdens deel 1 doorvragen op aspecten en daarna afstrepen van onderstaande lijst wat al wel aan de orde is geweest. Vervolgens overgebleven topics uitvragen.

- *Hoe belangrijk is … voor u? 'Wat vindt u belangrijk als het gaat om ..?'*
- *Is … ook aan de orde geweest tijdens het keuzeproces? Heeft … ook een rol gespeeld in afwegingen? 'in hoeverre heeft dit aspect een rol gespeeld in de beslissingen die jullie moesten nemen?'*
- *'Vonden de anderen dat ook belangrijk?' …*

- *Practical becoming:* betekenis voor anderen, bezigheden
- *Leisure:* vrije tijd, hobby's
- *Community belonging:* betrokkenheid bij verenigingen en activiteiten plek in de samenleving, voorzieningen
- *Social belonging:* contact met hulpverleners, belangrijke relaties en contacten, eenzaamheid en verlies
- *Physical being:* gezondheid, voeding, mobiliteit
- *Psychological being:* mentaal welbevinden, geluk, zelfbeeld, toekomstbeeld
- *Spiritual being:* geloof, beleving, hoop voor de toekomst
- *Growth:* acceptatie ouder worden, nieuwe dingen leren, (on)afhankelijkheid
- *Physical belonging:* financiële mogelijkheden, veiligheid, woon/leefomgeving

Afrondende vragen (achtergrondvariabelen) + afsluiting

- Opmerkingen, toevoegingen. Dingen die nog niet besproken zijn.

- Eventueel: leeftijd, etniciteit, gender, burgerlijke staat, baan of taak (in werkende leeftijd)/professionele achtergrond

- Verwerken van interview
- Ontvangen scriptie?

Kernbegrip	**Topics**	**Indicatoren**	**Voorbeeldvragen – gericht op ouderen**	**Bronnen**
Kwaliteit van Leven	*Physical being*	• Gezondheid • Ziekte	Hoe gaat het met uw gezondheid? / Wat is voor u belangrijk om zo veel mogelijk gezond te blijven? In hoeverre hinderen uw beperkingen uw dagelijkse bezigheden?	Meulenkamp et al. (2010) Lakerveld & Lamberti (2014) Kane (2001)
		• Pijn • Comfort • Energie • Slapen	Heeft u wel eens pijn? In hoeverre beïnvloed dit uw dagelijks leven? Hoe is het met uw energie? Slapen..	Kane (2001) Conde-Sala et al. (2009) Raphael et al. (2001)
		• Voeding	Wat is voor u van belang als het om eten en drinken gaat?	Meulenkamp et al. (2010) Conde-Sala et al. (2009) Raphael et al. (2001)
		• Mobiliteit	Wat is voor u belangrijk om ergens naartoe te kunnen gaan? Wat is voor u nodig om te kunnen gaan een staan waar u wilt?	Meulenkamp et al. (2010)
	Psychological being	• Cognitieve mogelijkheden, functioneren	Wat is voor u belangrijk om als het gaat om uw mentaal welbevinden?	Bowling et al. (2003) Grewal et al. (2006) Moons et al. (2006)
		• Emoties • Stress	Ervaart u wel eens stress?	Bowling et al. (2003) Grewal et al. (2006) Moons et al. (2006) Schalock et al. (2005)
		• Geluk • Tevredenheid	Bent u gelukkig? Bent u tevreden met uw leven zoals het nu is?	Bowling et al. (2003) Grewal et al. (2006) Moons et al. (2006)
		• Zelfbeeld • Persoonlijkheid	Hoe zou u uzelf omschrijven? Hoe zien anderen u?	Meulenkamp et al. (2010) Bowling & Gabriel (2007)
		• Toekomstbeeld	Heeft u vertrouwen in de toekomst? Waar heeft dat mee te maken? Wat is voor u in de toekomst van belang? Zijn	Meulenkamp et al. (2010)

			er dingen waar u naar uitkijkt? Als u in de toekomst mogelijk steeds minder voor u zelf kunt zorgen. Wat zou u dan willen?	
	Spiritual being	• Religie • Persoonlijke overtuigingen • Transcendentie	Bent u gelovig? Welk geloof belijdt u? Hoe belangrijk is geloof voor u? In welke mate speelt geloof een rol als u een belangrijke beslissing moet nemen? Vindt u het belangrijk om dit te delen (samen zijn/praten) met anderen of beleeft u dit voor uzelf?	Meulenkamp et al. (2010) Raphael et al. (2001) Lakerveld & Lamberti (2014) Kane (2001)
		• Betekenis van het leven • Hoop voor de toekomst	Heeft u hoop voor de toekomst? Waar uit put u hoop voor de toekomst?	Sarvimaki & Stenbock-Hult (2000) Raphael et al. (2001)
	Physical belonging	• Huis of verblijfplaats • Verbondenheid met plaats • Werk/school • Buurt • Privacy • Bezittingen • Schoon, hygiëne	Wat vind u belangrijk aan uw woonomgeving? Hoe voelt u zich in uw leefomgeving? Kunt u beschrijven hoe u zich verbonden voelt met deze omgeving? In hoeverre zijn uw spullen belangrijk voor u? Hecht u aan een schone omgeving?	Meulenkamp et al. (2010) Raphael et al. (2001) Schalock et al. (2005) Felce & Perry (1995) Kane (2001) Droes et al. (2006)
		• Financiële status, mogelijkheden	Zijn er dingen die u niet kunt of kon betalen, maar die voor u eigenlijk wel nodig zijn (of waren) om een prettig leven te kunnen leiden?	Meulenkamp et al. (2010) Schalock et al. (2005) Felce & Perry (1995) Kane (2001) Droes et al. (2006)
		• Veiligheid	Wat zorgt ervoor dat u zich voldoende veilig voelt in uw woonomgeving?	Meulenkamp et al. (2010) Schalock et al. (2005) Felce & Perry (1995) Kane (2001) Droes et al. (2006)

	Social belonging	• Sociaal netwerk • Relaties • Vrienden • Familie • Huwelijk	Met wie heeft u contact in uw dagelijks leven? Welke contacten zijn het meest belangrijk voor u?	Meulenkamp et al. (2010)
		• Support • Verbondenheid	Wat is voor u belangrijk in het samen kunnen zijn of kunnen ontmoeten van anderen? Als u belangrijke vragen heeft of kwesties wilt bespreken waar je niet zomaar met iedereen over spreekt, met wie kunt u dat dan bespreken? Bent u tevreden over de sociale steun die u ervaart? Hoe belangrijk is dit voor u?	Meulenkamp et al. (2010) Lakerveld & Lamberti (2014) Schalock et al. (2005) Raphael et al. (2001) Droes et al. (2006)
		• Verlies	Hoe lang geleden is uw partner overleden? Heeft u andere dierbaren verloren? Wat betekent dat voor u?	Bowling et al. (2003) Lakerveld & Lamberti (2014) Farquahar (1995)
		• Eenzaamheid	Voelt u zich wel eens eenzaam?	Farquahar (1995)
		• Zorgverleners, ontvangen zorg	Wat vindt u van de hulp die u krijgt? Van wie wilt u graag zorg krijgen? Waarom door deze persoon? Wat maakt het prettig dat deze persoon u verzorgt/zou verzorgen? Vindt u het belangrijk zelf te kunnen bepalen wie de zorg geeft/hoe de zorg gegeven wordt? Hoe ziet de ideale samenwerking eruit tussen uw familie en de verzorging?	Meulenkamp et al. (2010) Boumans & Deeg (2011)
	Community belonging	• Mensen rechten • Respect, waardigheid, gelijkheid		Meulenkamp et al. (2010) Schalock et al. (2005) Raphael et al. (2001)
		• Betrokkenheid bij activiteiten in de buurt of stad	Bent u betrokken bij een club of vereniging? Gaat u wel eens naar activiteiten die in uw stad georganiseerd worden?	Bowling et al. (2003) Schalock (1990)

		• Toegang tot voorzieningen	Hoe ervaart u (de toegang tot) voorzieningen waar u gebruik van maakt/kunt maken?	Schalock (1990) Bowling et al. (2003)
	Practical becoming	• Sociale rollen • Betekenisvolle bijdrage aan/plaats in samenleving • Baan • Vrijwilligerswerk • Huishoudelijke taken • Helpen van anderen • Een doel hebben	Wat voor bezigheden zijn voor u belangrijk om te doen ? Heeft u (vrijwilligers)werk? Heeft u het idee dat u in uw leven nu iets kunt betekenen voor anderen? Hoe belangrijk is dit voor u?	Meulenkamp et al. (2010) Bowling et al. (2003) Moons et al. (2006) Xavier et al. (2003) Raphael et al. (2001)
	Leisure	• Hobby • Dingen voor plezier doen • Genieten • Relaxen • Lezen • Muziek luisteren • De natuur in gaan, buiten zijn • Creatief bezig zijn	Gaat u wel eens naar buiten? Is dit belangrijk voor u? Gaat u wel eens op vakantie of een weekend weg? Of gaat u mee met uitjes? Heeft u hobby's?	Meulenkamp et al. (2010) Bowling et al. (2003) Schalock (1990) Conde-Sala et al. (2009) Raphael et al. (2001)
	Growth	• Persoonlijke waarden • Zelfregulering • Accepteren van toestand	Sommige mensen hebben wel eens moeite met ouder worden, andere mensen hebben dit niet. Hoe is dit voor u? Hoe gaat u om met verandering?	Meulenkamp et al. (2010) Raphael, Waalen, & Karabanow (2001) Felce & Perry (1995)
		• Het behouden en ontwikkelen van vaardigheden en kennis • Nieuwe dingen proberen • Zelfontplooiing • Doelen bereiken • Onderwijs	Zijn er dingen die u leert of (nog) wilt leren? Doet u wel eens nieuwe ervaringen op? Welke doelen of dromen wilt u nog bereiken? Hoe doet u dat?	Meulenkamp et al. (2010) Raphael, Waalen, & Karabanow (2001) Raphael et al. (2001) Schalock et al. (2005)
		• Autonomie	Sommige mensen vinden het heel belangrijk om	Meulenkamp et al. (2010)

		• Onafhankelijkheid	zo min mogelijk afhankelijk van anderen te zijn. Hoe ligt dit voor u? Maakt u graag alleen keuzes of met/door familie/kinderen?	Felce & Perry (1995)
		• Controle hebben	In welke mate heeft u in uw leven zelf kunnen bepalen wat er ging gebeuren?	Lakerveld & Lamberti (2014) Felce & Perry (1995)
Besluit vormings processen	<u>Rollen</u>	Veranderende rollen - Sociaal - Support - Zorg	Wie waren er betrokken bij keuzes die u moest maken over zorg, ondersteuning en verblijfplaats? Hoe beschrijft u uw rol in de keuzes rondom zorg van de afgelopen tijd/jaren? Is die rol in de loop van de tijd veranderd?	Keating, Otfinowski, Wenger, Fast, & Derksen (2003)
	<u>Fasen</u>	1. Aanleiding – gebeurtenis, (conditie van ouderen, conditie van mantelzorger, professional die het aangeeft, andere factoren)	Wat was de aanleiding wanneer voor het eerst bleek dat volledige zelfstandig wonen niet meer mogelijk was?	Chang & Schneider (2010)
		2. Onvermijdelijke beslissingen – wie/wat	Welke keuzes heeft u moeten maken om thuis te kunnen blijven wonen? Wat denkt u nu over die keuzes? Wat wilde u? Wat was er belangrijk volgens u? Wat wilden de anderen? (hierbij terugrvragen naar leden uit zorgnetwerk; familie en professionals) Wat gebeurde er voordat de uiteindelijke beslissing was genomen? Wat heeft er uiteindelijk toe geleid dat er besloten is om te verhuizen?	Chang & Schneider (2010)
		3. De beslissing nemen – wie/wat, op welke manier, consensus	Hoe kwamen jullie samen tot een beslissing? Hoe zou u de manier waarop er binnen uw	Chang & Schneider (2010)

			familie keuzes gemaakt worden beschrijven? Wat waren de alternatieven?	
		4. Verhuizen – aanpassen, evalueren	Hoe kijkt u nu, na de verhuizing, terug op het proces daarvoor?	Chang & Schneider (2010)

References:

Boumans, J., & Deeg, D. J. H. (2011). Veranderingen in de kwaliteit van leven van thuiswonende ouderen: speelt de vorm van zorg een rol?. *Tijdschrift voor gerontologie en geriatrie*, 42(4), 170.

Conde-Sala, J. L., Garre-Olmo, J., Turró-Garriga, O., López-Pousa, S., S., & Vilalta-Franch, J. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. *International journal of geriatric psychiatry*, *24*(6), 585-594.

Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: a case for care networks. *Ageing & Society*, *23*(1), 115-127.

Lamberti, C. A. H., & Lakerveld, S. P. T. (2014). *De dood went, gemis maakt angstig: confrontatie met sterfgevallen en persoonlijke doodattituden van ouderen* (Master's thesis).

Meulenkamp, T. M., van Beek, A. P. A., Gerritsen, D. L., de Graaff, F. M., & Francke, A. L. (2010). Kwaliteit van leven bij migranten in de ouderenzorg: een onderzoek onder Turkse, Marokkaanse, Surinaamse, Antilliaanse/Arubaanse en Chinese ouderen.

Moons, P., Budts, W., & De Geest, S. (2006). Critique on the conceptualization of quality of life: a review and evaluation of different conceptual approaches. *International journal of nursing studies*, *43*(7), 891-901.

Schalock, R. L. (1990). *Quality of life: Perspectives and issues*. American Association on Mental Retardation, 1719 Kalorama Rd., NW, Washington, DC 20009.

3. Code tree

Being
- Physcial being
- Psychological being
- Spiritual being

Belonging
- Physical belonging
- Social belonging
- Spiritual being

Becoming
- Practical becoming
- Leisure
- Growth

Fasen
- **Aanleiding** – initiating events
    - Gezondheidsgebeurtenis, val
    - (meer) hulp nodig bij praktische, dagelijkse dingen
    - Niet gezien-geweten
    - Disruptie van structuur
    - Inzicht moeder – overtuigen oudere
    - Het huis – locatie/mobiliteit
    - Te veel sociaal contact
    - Kinderen nemen initiatief
- **Struggling** - veranderingen
    - Alternatieven
    - Er wordt niet gepraat
    - Familie kan het niet aan – mogelijkheden/rol kinderen - draagkracht
    - Inzicht kinderen, inzicht moeder, verschil ouder – kinderen
    - Het huis
    - Psychologische stap
    - Uitstellen
- **Beslissing** - decision
    - Ambivalentie – ervaring, gevoel, emotie
    - Ineens is er een mogelijkheid – onverwacht – na tijdelijke opname
    - Instemming moeder
    - Procedure
    - Instemming professional, professional spreekt zich uit
    - Noodgedwongen – gedwongen door omstandigheden
    - The place to be
    - Wie maakt de keus? Onderbouwde keus
- **Move** – verhuizen - terugblik

➔ *Dit is niet geanalyseerd omdat het bij nader inzien niet bij de onderzoeksvraag paste.*

Rollen

➔ *Dit is niet geanalyseerd omdat het bij nader inzien niet bij de onderzoeksvraag paste.*