PROEFSCHRIFT

Susan Hupkens

At home with meaning

Older persons' meaning in life, good home nursing and nurse education

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Older persons' meaning in life, good home nursing and nurse education

Betekenisvol Leven in de Buurt
Zingeving door ouderen, goede thuiszorg en educatie van zorgmedewerkers (met Nederlandstalige samenvatting)

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Chapter 1

General introduction

Introduction

I am joining home nurse Amy[1], by bicycle, on her daily round today. It is one of the first cold mornings of this year, the beginning of December. We arrive at the apartment of Mrs. Sadler around 10 AM. Mrs. Sadler opens the door. I guess she is in her 80ies. She is still in her dressing gown, barefoot on the cold floor. Like many patients, she has set up a Christmas tree. However, besides partial functioning lights, it has no decoration. Amy enquires about the lights and provides some suggestions concerning a cheap replacement of them. Amy must do a medicine check with Mrs. Sadler. We sit down at the table and Amy asks about Mrs. Sadler's night-rest: did she sleep well? Mrs. Sadler tells that she hardly slept. 'I have been worrying about my children: why are they not visiting me? Besides, I watched a thriller on TV in the evening.' Amy doesn't say much. She checks the medicines and makes notes in the patient file. They talk about the week to come. Amy tries to activate Mrs. Sadler, but she is raising objections all the time: She won't go to the hairdresser; maybe he is not as competent as the last one. She won't go to the activities in the community building; she may be feeling that she has nothing to talk about with those people. She doesn't know what to do with her 12-year old granddaughter spending a day with her next Saturday… Then Amy asks Mrs. Sadler about a colouring book. The nurses of her team made a St Nicolas present for all their patients and this was Mrs. Sadler's. Mrs. Sadler shows a book with mandalas. Some of the images are partly coloured. She made them in bright colours. Mrs. Sadler's face brightens up as well. Amy compliments her on the choice of the colours. We have been half an hour with Mrs. Sadler. Amy has to move on to her next patient.

1 Names of nurses and patients in this thesis are fictitious.

This fragment sketches a home nurse's[2] visit to an older patient[3] on her daily round. For this research project I had the opportunity to join home nurses on their rounds for participant observations. The situation above is not exceptional: many nurses will recognise a situation like this. Nurses are confronted with older patient's meaning in life (MiL), or the lack thereof, on a daily basis. However, knowledge about these situations, and education regarding this subject, is largely missing until now. Nurses of a homecare provider in Rotterdam (the Netherlands) realised that they felt incompetent in situations where patient's MiL came to the front. They had many questions: What could they say? What could they observe? What could they do? Was it right what they did? And, who could help them? The nurses turned to spiritual counsellors of a nursing home, asking them if they could provide support. This PhD project started in practice, like many projects in applied science, with nurses, spiritual counsellors and researchers who wanted to improve practice. In this project two spiritual counsellors provided education to home nurses, in order to make them more sensitive and competent in attuning care to patient's MiL, which was a novel practice in the Netherlands in 2015. Research was part of the project from the outset. I was the main researcher in a research team and participated in the project group. And so our journey started. The name of my thesis 'At home with meaning', not only refers to MiL of older adults ageing in place[4] but also to the aim of the project: the wish that home nurses should feel more at home, more confident, in providing good care when they find themselves confronted with older patients' MiL.

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2 In this thesis we use 'nurse' for all professionals who provide home nursing for patients at home: registered nurses, nursing assistants, nursing aids. Most times nurses are referred to as 'she' and patients as 'he' for reasons of clarity.

3 In this thesis we use 'older adults', 'aged adults', 'older persons' and 'older people' as synonyms. In relation with nurses they are referred to as 'older patients' or 'aged patients'.

4 Older adults ageing in place are older persons who stay in their private homes in their neighbourhoods in later life (instead of living in an institution). They are also mentioned: community-dwelling older persons.

1 Background

This section, firstly, introduces the concept of meaning in life (MiL), the central subject of this thesis. Subsequently, it focusses on meaning in later life; the societal context of this thesis; home nursing related to older patient's MiL and education. This background not only shows the urgency in practice to improve home care with respect to older persons' MiL but, additionally, multiple gaps in the scholarly literature.

1.1 The concept of meaning in life (MiL)

Did you ever ask yourself:

'What is the meaning of human life on earth?'
'What is my contribution to this world in the end?'
'What made today a good day?'

These are questions that many people ask themselves now and then. Besides you and me, scholars of many disciplines have been asking these questions for a long time. The questions all refer to meaning but convey different, although interrelated concepts. The first question (What is the meaning of human life on earth?) is about the meaning *of* life, cosmic meaning. It is meaning that is attributed outside of ourselves [1], for instance by a god, or the universe, weighing the meaning of our lives in the end. Life may even be pointless. Meaning *of* life depends on one's worldview, for instance a religious or humanistic worldview [2]. Meaning *of* life is not the concept we will scrutinise here. This thesis is about *personal* meaning, meaning *in* life (MiL); the meaning we personally attribute to our lives. The second and the third question at the beginning of this paragraph are about this concept. Many scholars from many different disciplines (e.g. psychology, philosophy, anthropology) have written about MiL. Due to its heterogeneity, literature about MiL is hard to grasp. As a definition for this research we used Brandstätter's broad description of MiL, which was synthesised of 54 previous definitions:

> *'Meaning in life (MiL) is a highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them.*

Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging [...] MiL comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfaction or lack thereof.' [3], p. 1045

MiL is thus a complex, multifaceted construct. However, the different elements of the construct often remain unarticulated in the literature. We discerned several elements of MiL in the literature:

1. The *content* of MiL: What are the components of MiL? Victor Frankl, who is cited in many texts regarding MiL, developed his ideas about the concept of MiL while imprisoned in a concentration camp during World War II. He discovered that having a purpose in life could make the difference between life and death. Frankl explains how every person must find out themselves what life asks of them; MiL is something different and unique for every individual and from moment to moment [4]. Despite the personal and dynamic character of MiL, many scholars, both internationally and in the Netherlands, have provided different theories, frameworks and models with respect to the components of MiL, which are partly overlapping. They sketch elements, needs, areas or dimensions that together form the content of MiL [4-9]. A generally accepted overarching framework is still lacking.
2. The *level* of MiL: global or situational [10]. Global (ultimate or existential) meaning is our perception about the overall MiL in our own lives. The second question at the beginning of this paragraph (What is my contribution to this world in the end?) is a question about existential MiL. Situational meaning in life, or 'daily meaning' refers to the attempt to understand the value and purpose of experiences and encounters on a day-to-day basis. Our last question (What made today a good day?) is about this level.
3. The *process* of finding MiL: How can MiL be attained? Reker and Wong discerned two major ways in which individuals find meaning: by creating and by discovering. To create meaning we do something active, for instance, deciding to start dancing lessons and go there; To discover meaning we reflect on the givens of life, for instance, thinking back on an unexpected encounter[11].
4. The *sources* which provide meaning to people's life: What brings MiL? Empirical studies found many different (frameworks of) sources in different populations, for instance human relationships, activities, personal growth and health [12-15].
5. The *experience* of MiL: How does it feel when you experience MiL? What sensation does it bring? Baumeister explained that although MiL may provide satisfaction or fulfilment, the feeling is temporal, as our lives constantly change [8].
6. The *circumstances* of MiL: What promotes MiL? Literature shows that MiL is influenced by many circumstances, such as health, educational level and social integration [16, 17].

Various of these elements are further explored in this thesis regarding a specific group of older persons (receiving home care). Besides the definition of Brandstätter e.a., we also used Derkx' dimensions as a conceptual background for this thesis (especially in chapter 4). Derkx' dimensions are: Purpose; Moral values and justification; Efficacy; Self-worth; Comprehensibility; Connectedness; and Excitement or wonder [7, 18]. Both the definition of Brandstätter e.a. and Derkx' dimensions offer a broad scope regarding MiL, allowing space for various perspectives. This is important, because, in the empirical work, we wanted to be open for, as many as possible, different voices and insights of our participants. Furthermore, Derkx' dimensions were already successfully used in a professional standard for nurses [19] and proved to be helpful in education in this regard.

Although we adopted a broad perspective on MiL, we also limited the concept, through discerning MiL from happiness. This distinction was made by several authors, mainly in the field of positive psychology. They discern two types of well-being: eudaimonia (MiL or psychological well-being) and hedonism (happiness or subjective well-being) [20-24]. With respect to eudaimonia (MiL) they refer to the Greek philosopher Aristotle. Eudaimonia means living and acting (morally) well, in equilibrium with the soul [25]. Hedonism (happiness) is described by the Greek philosopher Epicurus and more related to individual emotions. Hedonism is the ego-centred desire to avoid pain and seek pleasure [26]. Happiness is more related to taking, while MiL is more related to giving, but the two concepts are highly interconnected. [27, 28].

1.2 Meaning in later life

In this thesis we focus on older persons' MiL. Accumulating research reveals that meaning in later life is associated with many desirable outcomes: healthier lifestyle [17, 29], lower prevalence of age-related diseases [30] such as Alzheimer [31] or stroke [32] and longevity [30, 33, 34]. Moreover, MiL is not only associated with longer life but also with better quality of life [35, 36], which may be equally important in later life. However, beside these positive associations, MiL is not only a means to an end; It is important as such [7]. Literature shows mixed results regarding meaning in later life: Although some research reveals that older persons experience as much, or more, MiL as younger groups [37-39], others report loss of MiL in the later years due to loss of dear ones, loss of valued roles [40], loss of physical capacities, loss of personal growth or loss of purpose [41-43]. Retaining MIL is challenging during later life.Some older persons even experience their life as an unbearable burden and give up on life [44]. Knowledge regarding older persons' MiL is needed for nurses and social workers who want to support their older patients in maintaining MiL. However, although scholars have been writing about older persons' MiL for a while worldwide, a review of the literature was lacking when we started this project.

1.3 Growing societal interest in older persons' MiL

Besides in science, interest in older persons' MiL has been growing in (Dutch) society, over the last years. When we prepared this PhD project, in 2014, MiL was not a trending topic. However, this changed during the project years. Increasing percentages of older persons in populations, both in the Netherlands [45] and worldwide [46], and financial constraints urged policymakers to reconsider care systems. The Dutch government emphasised a civil society (Dutch: participatie-samenleving) and dismantled the welfare state (Dutch: verzorgingsstaat)[5]. This included major healthcare reforms in 2015. On top of this, budget limitations and management problems caused difficulties in many healthcare organisations in the Netherlands. The organisation where we conducted our empirical research was one of those. All these changes reflected in the lives of older persons and in daily home nursing practice.

Neoliberal thinking was dominant in the Netherlands around 2015, like in other Western-European countries [47, 48]. The Dutch government framed health as 'one's own responsibility', care as an 'expensive product', (older) patients as 'clients', and highly focused on 'self-reliance' and 'participation'[6]. However, at the same time, the far-reaching changes and austerity policy in healthcare gave rise to a shift in the public debate. Other voices emerged that asked for a more humane perspective on later life and care (for older people)[7]. A 'Silver Pact' (2017) was established, an initiative of societal and political organisations, emphasising that old people deserve a complete role as dignified, valuable citizens in society, as all human beings[8]; followed by a 'Golden Pact' of humanistic organisations which emphasised autonomy, dignified care and an inclusive society[9]. This shift in the societal debate fostered interest in MiL. Older patients' advocacy organisations claimed that MiL is a pivotal subject in later life. They stressed that more attention was needed to MiL in care for older persons [49-51].

At the local level, in Rotterdam, attention to MiL of older persons, ageing in place, had awakened earlier. A report of the municipality concluded in 2010 that several groups of older persons who lived in the community needed support in maintaining MiL but were difficult to reach [52]. A health centre included spiritual counsellors in

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5 See for instance the King's Speech in 2013: https://www.rijksoverheid.nl/documenten/toespraken/2013/09/17/troonrede-2013

6 Idem 5

7 See for instance the Socrates lecture of Hedy d' Ancona https://files.humanistischverbond.nl/cms/files/Socrateslezing_Hedy_d'_Ancona.pdf and the lecture of Desanne van Brederode: https://www.zorginstituutnederland.nl/publicaties/publicatie/2016/02/22/zorg-is-een-waarde-in-zichzelf-lezing-bij-het-afscheid-van-bert-boer

8 See: www.waardigouderworden.nl

9 See: https://www.humanistischverbond.nl/watwedoen/onze-programmas/met-zorg-omzien-naar-elkaar/het-gouden-pact-voor-de-zorg/

the team[10], and several teams of volunteers and spiritual counsellors (from a religious background) visited older persons at home[11]. This changing societal context regarding MiL offered a dynamic background for our project, the first project about older persons' MiL in homecare, as far as we know.

1.4 Home nursing related to older patient's MiL and education

The healthcare reforms in 2015 rapidly resulted in a large percentage (more than 90%) of older persons ageing in place, instead of in an institution [53]. This is not specific for the Netherlands: Most older people worldwide stay in their private homes in their later years [54]. Many of them receive home nursing: In 2016, 28% of 75-plus and 40 % of 85-plus (Dutch) persons received home nursing [53]. Besides high numbers of older patients, home nurses in the Netherlands were confronted with higher complexity, compared to earlier days, due to limited access to nursing homes. [53, 55]. As the situation of Amy and Mrs. Sadler (at the beginning of this introduction) shows, patient's MiL can be part of this complexity.
In the Dutch nursing core competence profile, MiL issues are mentioned in the core patient problem set, which are the principal problems on which nurses should focus [56]. One of the professional roles of the nurse is health promotion [56]. In order to understand this role, the definition of health in the core competence profile is pivotal. It defines health as 'positive health': 'the ability to adapt and self-manage in the face of social, physical and emotional challenges' [57]. Positive health is considered as the most relevant definition of health in chronic care and older persons' care [58] and is being implemented in many health care settings in the Netherlands and beyond. Positive health consists of six dimensions and MiL is one of them. Therefore, the nursing role of health promotor includes promoting MiL. Positive health focuses on positive outcomes, instead of disease [22, 59, 60]. Although MiL is associated with many positive outcomes (see 1.1.2), and is regarded as highly important, there is a knowledge gap in terms of what good home nursing is in relation to older patients' MiL. The Centre for Existential Questions of Older People (Dutch: Centrum Levensvragen bij Ouderen) registered a standard in 2015: Existential questions of older people [19]. However, this may be only partly applicable in home nursing, because it was mainly based on research in, and targeted at, nursing homes. So still, although the majority of people age in place, in the Netherlands, and worldwide, scholarly literature about MiL of home nursing patients is largely lacking.

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10 See homepage Levinas: https://www.gc-levinas.nl/zorgpaden/geestelijke-zorg
11 For instance: Motto: https://www.samen010.nl/projecten/alle-projecten/motto/ and wijkpastoraat: http://www.stichtingwijkpastoraatrotterdamwest.nl/

As we sketched at the beginning of this introduction, home nurses in practice asked for support. Orientating interviews with home nurses in the homecare organisation of the project [61, unpublished] revealed that they recognised some 'big' existential problems of their patients in practice but were unable to give examples of daily MiL. As the situation of Amy and Mrs. Sadler shows, home nurses do encounter patient's MiL in their daily work, but descriptions of situations like this were lacking in the scholarly literature. Furthermore, nurses in the orientating interviews were unsure whether they responded well to MiL, if they noticed it; Or, neglected what they noticed, because they didn't know how to respond. What is good care with respect to older patient's MiL? If we look at the nursing situation at the beginning of this paragraph: Was Amy's approach the right thing to do? Because MiL is different for every person [4], care should be attuned to the individual patient. An important aspect of good care is responsiveness: the extent to which the care responds to the position of the patient as he expresses it [62]. The patient's perspective is thus pivotal if we want to know more about good care in this respect. What do older home nursing patients expect or value with respect to attunement of home nurses to their MiL? And what is the consequence for them of attuned care in this respect? None of these questions was answered in the scholarly literature, when we started our project.

A last knowledge gap is concerned with education: If we know what good care related to older patient's MiL entails, how can a nurse learn this? Again, scholarly literature was largely absent, especially regarding the field of home nursing.

To summarise: Notwithstanding an articulated urgency in nursing practice, and growing interest in older person's MiL in society, the scholarly literature contains multiple gaps: MiL of older home nursing patients; home nursing with respect to patient's MiL; and education in this regard. Lack of knowledge and competence contributes to nurses' dissatisfaction and may influence patients' health and quality of life.

2 Objectives of the thesis and research questions

The theoretical objectives of this thesis were threefold: to add knowledge about meaning in life of older persons to the existing literature, especially regarding adults who age in place and receive home nursing; to generate knowledge how nurses should attune to patient's MiL; and to generate knowledge how nurses can learn this.

Research questions for this thesis are:

1. How do older persons find MiL, what are their MiL sources and what are circumstances that are associated with older persons' MiL?
2. How do older home nursing patients find meaning in daily life and what are their MiL sources?
3. What are situations in daily home nursing in which MiL of older adults, or the lack thereof, comes to light?
4. What are the experiences of older home nursing patients in relation to nurses' attunement to MiL?
5. What are outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL?
6. What is the underlying learning-teaching process of an educational programme, provided by spiritual counsellors, about attunement of care to aged patients' MiL in home nursing?

This thesis contributes to scientific knowledge. Additionally, as I am a researcher and lecturer in a university of applied science, the practical objective of this work is to contribute to good professional practice and to education with respect to older patients' MiL.

3 Outline and methodological approach

The thesis consists of three parts:

- Part 1: Older persons' MiL
- Part 2: Home nursing with respect to older patients' MiL
- Part 3: Education regarding nurses' attunement to older patients' MiL.

All three parts contain two chapters. Each chapter answers one research question. We used various methods and perspectives, which suited the specific research questions. Chapter 2 is a literature review; the other chapters are empirical work. Multiple, largely qualitative, data collection methods were used: participant observations, interviews, logs of participants, surveys and a focus group. The outline in table 1.1, contains short descriptions of the chapters with respect to study design, main perspective and the used material. More details about the used methodology can be found in the separate chapters. The thesis ends with a general discussion.

Table 1.1: Outline

Chapter	Research question	Research question	Study design	Main perspective	Material (number of participants)
Part 1: Older persons' meaning in life					
2	1	How do older persons find MiL, what are their MiL sources and what circumstances are associated with their MiL?	Integrative review	Researchers	44 heterogeneous scholarly texts
3	2	How do older home nursing patients find meaning in daily life and what are their MiL sources?	Hermeneutic phenomenological approach. Three waves of interviews, using photo elicitation	Older persons	60 interviews (24 patients) 1st part
Part 2: Home nursing with respect to older patients' meaning in life					
4	3	What are situations in daily home nursing in which MiL of older adults, or the lack thereof, comes to light?	(participant) observations	Researchers	197 descriptions of home nursing visits
5	4	What are experiences of older home nursing patients in relation to nurses' attunement to MiL?	Hermeneutic phenomenological approach. Three waves of interviews	Older persons	60 interviews (24 patients) 2nd part
Part 3: Education regarding nurses' attunement to older patients' meaning in life					
6	5	What are outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL?	Evaluation through Perceived Benefit Approach. Mixed methods: interviews (3 waves), two surveys and a focus group, using photo elicitation.	Nurses	- 39 interviews (16 nurses) - 114 responses of nurses to first survey; 65 to second survey - focus group (7 nurses)
7	6	What is the underlying learning-teaching process of an educational programme, provided by spiritual counsellors about attunement of care to aged patients' MiL in home nursing?	Action research. (participant) observations, interviews, surveys, focus group, logs.	Researchers, nurses, spiritual counsellors, patients	- 36 descriptions of observations of group sessions in nursing teams - 39 interviews (16 nurses) - 7 interviews (2 spiritual counsellors) - 114 responses to first survey; 65 to second survey (of nurses) - a focus group (7 nurses) - 84 logs of spiritual counsellors (3 spiritual counsellors)

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Part 1

Older persons' meaning in life

Chapter 2

Meaning in life of older persons

An integrative literature review

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Abstract

Background: Meaning in life of older persons is related to well-being, health, quality of life and 'good life'. However, the topic is scarcely covered in nursing literature.

Objective: The aim of this integrative review for nurses is to synthesize knowledge from scholarly literature to provide insight into how older persons find meaning in life, what are influencing circumstances, and what are their sources of meaning. The review serves as a starting point for including meaning in life of older persons as a major concern for nurses in their role as health promotors.

Method: an integrative review was performed including empirical research literature and texts on theoretical perspectives.

Findings: 44 texts were included in this review. Older persons find meaning through a developmental process, by creating and discovering. Meaning in life is found in connection with self and others. Health, living together, high socio-economic status, social relations, activities, and religion are associated with experiencing meaning in later life. The main source of meaning in life of older persons is human relationships. Other sources of meaning in life vary by age and culture.

Discussion: There are several gaps in knowledge: literature is culturally biased; research on discovery of meaning and daily meaning is limited; research from a nursing perspective is lacking. In practice, nurses have many opportunities to attune to meaning in life of patients.

Conclusion: Older persons find meaning in life through different processes. Meaning in life is associated with the circumstances old persons live in. Human relationship is the major source of meaning. The knowledge from this review is a necessary knowledge base for nurses to include meaning in life of older patients in care Further research is needed.

Keywords: Meaning in life, care of the older person, well-being, nursing, literature review.

1 Introduction

Meaning in life of patients: a major concern for nurses

The recent WHO Report on Aging and Health defines healthy aging as 'the process of developing and maintaining the functional ability that enables well-being'. Functional abilities are the attributes that enable persons to be, and do, what people have reason to value [1], in other words: the abilities that provide well-being and meaning in life. Health, well-being and meaning in life are related concepts [2-6], that differ more or less according to their definitions. Huber et al. [7] defined a conceptual framework for health, consisting of six dimensions:bodily functions, mental functions and perception, daily functioning, quality of life, social and societal participation and the spiritual dimension, including meaning in life. Thus, meaning in life is a contributing component of health or well-being. Yet meaning in life is also regarded as an important topic in ethical debates about what constitutes a good life [8-11]. There are reasons to think that the main difference between well-known conceptualizations of subjective well-being [12] or psychological well-being [13] on the one hand and meaning in life on the other is exactly the moral component in meaning in life[8, 14].

Nurses have a broad view on health, as patients have. Both groups value all of Huber's dimensions of health equally, different from e.g. doctorsand policymakers who generally emphasize bodily and mental functions [7]. Meaning-in-life-problems are considered core problems for nursing care [15], but the subject is mainly covered in psychology, anthropology, theologyand philosophy literature, leaving a gap of knowledge in the scientific nursing literature.Nurses have a major role to play in prevention, in maintaining health and well-being of patients [15, 16]. Therefore meaning in life of older persons is an important concern for nurses with regard to this role [17, 18]. Supporting patients in maintaining, or attaining, meaning in life promotes well-being, health, quality of life and the 'good life' of patients. However, many nurses seem to stick to the physical aspect of care. They lack the attitude, skills and knowledge to provide care related to meaning in life of patients [19-23]. This integrative review provides nurses with a necessary knowledge base of meaning in life of older persons, as a starting point for including this major concern for nurses in their role as health promotors.

1.1 The concept of meaning in life

"What is the meaning of life in general?" "What does my life mean in the end?" "What is meaningful in my life at this moment?" These are three questions every human being may ask now and then during his or her life. All three questions are about meaning, but they are referring to different, although interrelated, concepts. The first question is aboutcosmic meaning, or: meaning of life [24].There are many different views on meaning of life [25],e.g. from a religious, existentialistic or a humanistic point of view.The second and third question at the start of this paragraph are on meaning in life, or personal meaning (in life). This is the concept we focus on in this review.Meaning in life is a comprehensive construct that is conceptualised in several ways. Brandstätter, Baumann, Borasio & Fegg synthesized definitions of meaning in life from more than 50 authors:

> *'Meaning in life is a highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them. Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging. Some authors differentiate between meaning and purpose, the latter being more goal or action-oriented, whereas others use meaning and purpose interchangeably. Meaning in life comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfactionor lack thereof.'*[26]

Meaning in life is thus a multidimensional construct. Derkxdistinguishes seven dimensionsof meaning in life [8, 27]:

- Purpose: What are the goals and aims I strive for?
- Moral values and justification: What are underlying values? When and why do I believe a goal is (morally) worthwhile?
- Efficacy: Do I feel competent? Do I experience that I can influence something, my own life?
- Self-worth: Do I know myself valued for who I am and what I do? Self-worth is also influenced by being held in high esteem by others.
- Comprehensibility: Do I sense coherence in life? Can I understand how events make sense in the larger story of my life?
- Connectedness: Do I feel connected to others? Am I part of something valuable?
- Excitement or wonder: What makes me curious? Do I feel engaged in something or someone?Is something important at stake for me?

As the questions in this paragraph illustrate, meaning in life encompasses a moral judgement, based on (personal and societal) values [8, 10, 28, 29]. In personal meaning we can distinguish two levels: *global* and *situational* meaning [30, 31]: Global, ultimate or existential, meaning involves the 'big questions in life' about the ultimate meaning of one's individual life, like: "Who am I? What should I do (or have I done) with my life to make it worthwhile? Where do I belong ?" [32]Situational meaning in life, meaning of the moment, or daily meaning refers to the attemptto understand the value and purpose of experiences on a day-to-day basis [30, 31]. We'll use the term 'daily meaning'.

Some other constructs are overlapping with meaning in life. *Psychological* well-being as defined by Ryff [6, 13, 33] is partly overlapping with the dimensions of Derkx of meaning in life. But, *subjective* well-being as defined by Diener is more related to satisfaction with life than with meaning in life [12, 34, 35]. The concepts of meaning in life and spirituality are partly overlapping as well.Although meaningin life is important in spirituality, spirituality is also connected to a transcendent experience: 'a higher power', 'the sacred'or 'deepest reality' [4, 36-39], which may not be necessary to experiencemeaning in life.

1.2 Meaning in life of older persons

Meaning in life during the later years is important, as in all stages in life [40]. It is associated with well-being [4, 41-44], quality of life [45, 46] and living in place instead of in institutions [47]. Furthermore, meaning in life, especially the dimension purpose in life, reduces the risk of Alzheimer's disease or mild cognitive impairment in aging persons [48] and even the mortality risk [47, 49-51]. Although later life may come with functional decline and personal losses, some authors argue that in this period people are well capable of preserving meaning in life [52, 53], or that old age is a period of spiritual growth [40, 54, 55] and even transcendence [56].Indeed, some empirical research reveals that older adults still report a good level of meaning in life [57, 58]. However, empirical findings are mixed. Other research indicates a decline in meaning in life in later years, especially in the domainspurpose in life and personal growth [6, 13, 33, 59-62]. In face of end of life older personsmay reflect on existential questions [52]. Older persons can experience the search for meaning in this life stage as a source of distress which limits well-being [41]. In the oldest old (85+) adverse events may lead to a decline in sense of coherence, one of the dimensions of meaning in life [63]. Clearly different angles, and measures, show other perspectives: preserving meaning in life may be challenging in old age.

1.3 Aim of the review and research questions

The aim of this integrative review for nurses is to synthesize knowledge from scholarly literature to provide insight into how older persons find meaning in life, what are influencing circumstances, and what are their sources of meaning. The review serves as a starting point for including meaning in life of older persons as a major concern for nurses in their role as health promotors.

We focus on three questions:

- How do older persons find meaning in life?
- What circumstances are associated with meaning in life in older persons?
- What are sources of meaning in life for older persons?

2 Methods

We performed an integrative review of different types of scholarly literature. An integrative review is the only review method which allows the combination of different methodologies (quantitative, qualitative) and theoretical literature. This method is suitable for complex concepts, theories or healthcare problems [64]. The review consisted of the five stages of Whittemore & Knaft [64]: problem identification, literature search, data evaluation, data analysis, presentation. The problem identification is described in the introduction of this article.

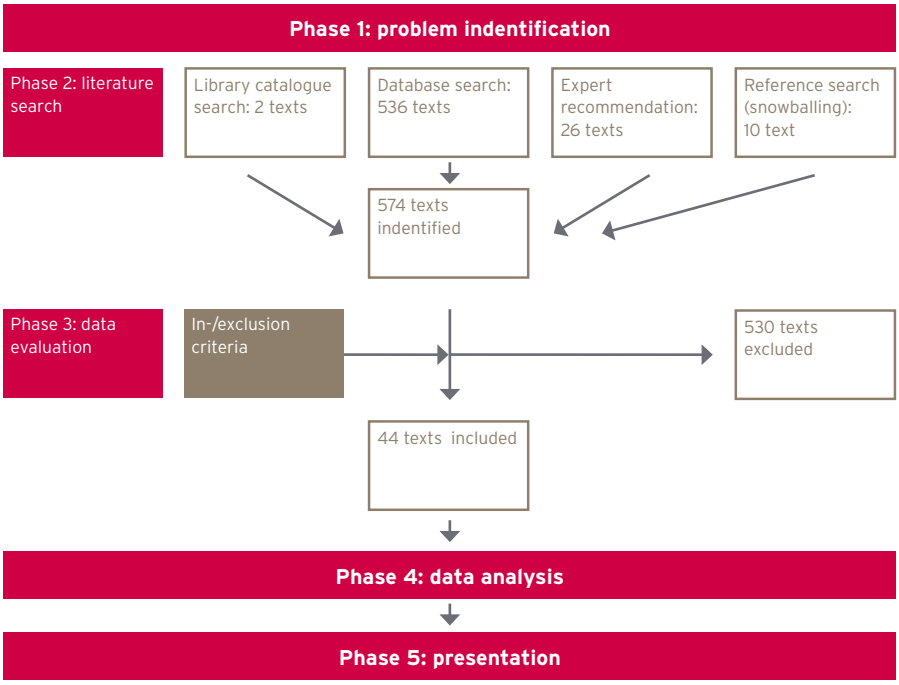

Figure 2.1: flow chart literature search and evaluation

2.1 Literature search and data evaluation

The search and evaluation of literature is summarized in figure 2.1. Databases Scopus, Cinahl Complete, Medline Complete, Nursing Allied Health Collection, Invert and Picarta were searched for relevant articles and book sections.The

following search terms were used: (“meaning in life” OR “meaning of life” OR “searching for meaning”) AND (ag* OR old* OR eld* OR “later life”).The search was limited to English and Dutch literature and to relevant disciplines (psychology, nursing, social science, humanities).There was no time limit applied. Catalogues of two university libraries[12] were searched.Furthermore, we read literature suggested by experts.References of relevant articles and books were scrutinized for more literature (snowballing). The search resulted in 574 texts which were subsequently evaluated. Texts were included if they were about meaning in life of old persons, responding to one of the research questions and were written to academic standards: academic (peer reviewed) articles and book sections from scholarly literature.Exclusion criteria were: articles about a specific medical condition, articles about meaning in life ofyounger persons only, articles that were about other constructs (resilience, spirituality, well-being) without relation to meaning in life in the problem statement or abstract, articles about validation of instruments orabout therapeutic interventions, texts without scientific background.
The included texts were very heterogeneous in type and discipline, varying from qualitative, quantitative research articles to academic textbooks and (philosophical) essays. Because of the heterogeneity of the texts we did not apply an instrument to further assess the quality of the documents besides the in- and exclusion criteria. The aim of this review is not to provide evidence, but to give an overview of the scholarly literature.

2.2 Analysis and synthesis

Eligible articles and book sections were read several times and summarized. Themes in and through the texts were analysed using both the themes that were already in the included texts, and themes that emerged from the data inductively. Subsequently we combined themes to categories.Finally, we synthesized the findings in two figures (2.2 and 2.3) which give a more imaginative overview of the results of this review.

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3 Results

In the review 44 texts were included (table 2.1). Three theoretical articles and 23 research articles were included. The 23 selected research articles incorporated qualitative methods (seven), quantitative methods (thirteen) and mixed methods (three). We also included 18 book(section)s. These offered mainly theoretical perspectives, although most were as well based on empirical research.

Table 2.1

Sources (44)	Author, year, reference number
Book (section) (18)	Baars, 2011 [65] ; Baars & Phillipson, 2014 [66]; Bateson, 2010 [54]; Bohlmeijer 2007 [67]; De Lange, 2008 [68]; Derkx, 20118; Erikson & Erikson 1998 [40]; Greenstein & Holland, 2015 [55]; Tromp [69]; Huizing & Tromp 2015 [70]; Marcoen, 2006 [52]; McAdams, 2012 [71]; Kaufman, 1986 [72]; Reker & Wong 1988 [73]; Reker & Wong 2012 [74]; Tornstam 2005 [56]; Westerhof, 2010 [75]; Westerhof, Dittmann-Kohli & Bode, 2003 [76]
Research article (23)	**Qualitative (7):** Ebersole & De Paola, 1987 [77]; De Paola & Ebersole, 1995 [78]; Thomas, Kraus & Chambers, 1990 [79]; Dwyer, Nordenfelt & Ternestedt, 2008 [18]; Moremen, 2005 [80]; Ditmann-Kohli, 1990 [81]; Moore Metcalf & Schow, 2006 [17] **Quantitative (13):** Alea & Bluck, 2013 [82]; Prager, 1996 [83]; Reker & Woo, 2011 [57]; Fegg, Kramer, Bausewein & Borasio, 2007 [84];Bar-Tur, Savaya & Prager, 2001 [85]; Van Ranst & Marcoen, 1996 [86]; Pinquart, 2002 [59]; Phillips & Ferguson, 2013 [87]; Krause, 2004 [88]; ; Krause & Hayward, 2012 [89]; Braam e.a., 2006 [90]; Clarke, Ryff & Rosenthal, 2000 [60]; Haugan, 2013 [46] **Mixed methods (3):** Takkinen & Ruoppila, 2001 [91]; Westerhof & Dittmann- Kohli, 1997 [92]; Grouden & Jose, 2014 [93]
Theoretical article (3)	Carstensen, 2006 [94]; Randall & Kenyon, 2004 [95]; Scheibe & Carstensen, 2010 [96]

With regard to the first research question 'how do old persons find meaning' we identified the following categories and themes and in the texts:

- Developmental process:continuity, discontinuity, old age as life stage;
- Creation of meaning: understand through reminiscence, engagement, learn through experience, adaptation to negative events (coping styles, coping strategies);
- Discovery of meaning: silence and contemplation;
- Daily meaning;
- Connection: self, others, something greater than oneself, society.

With regard to the second question 'What circumstances are associated with meaning in life in older persons?' we identified one common theme in selected texts: associations with meaning in life.

With regard to the third question 'what are sources of meaning for old persons?' we identified the following categories and themes:

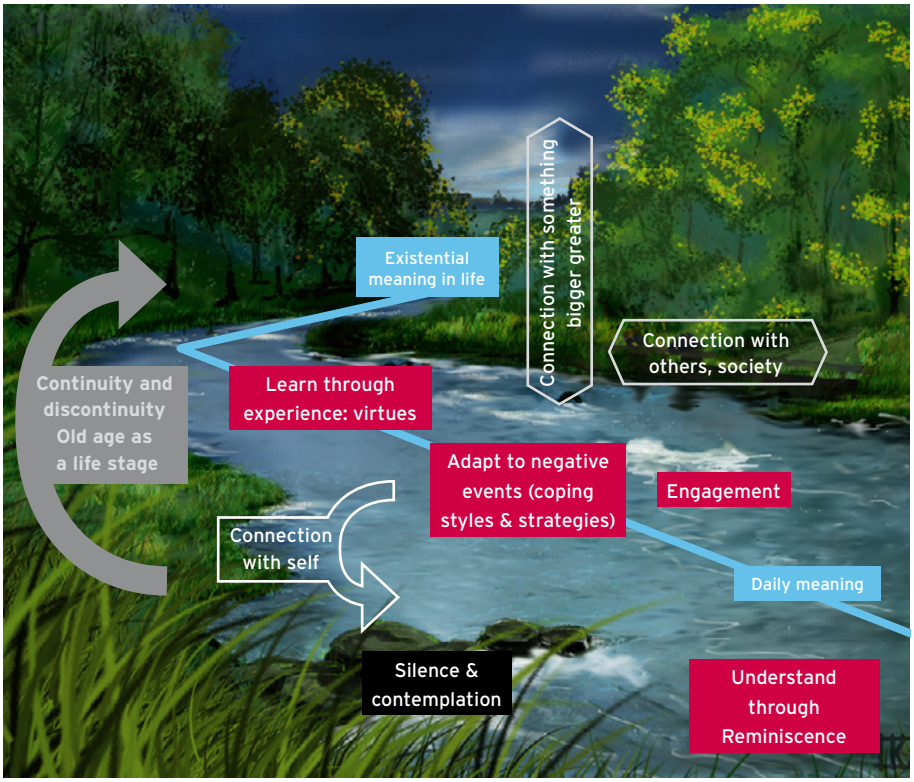
- Most important sources;
- Differences in sources: age differences, cultural differences.

We describe our findings regarding the three research questions in the next three paragraphs with the help of two figures.

3.1 How do older persons find meaning?

Finding meaning in later years is described in different ways. Based on the literature we compare it with a winding river, finding its way through the scenery (figure 2.2): changing and developing during quiet and turbulent times in connection with the environment. Several streams contribute to the flow of the river, as several processes may contribute to finding meaning in life. In this section we elucidate the different processes which we found in the literature review. Many authorsdescribe meaning in life asa developmental process, related to the continuity and discontinuity of life [54, 55, 72, 97,] or related to a specific task which is set for a life stage [40, 56.] Finding meaning in life is by most authors described as an active process of conscious choices: creation of meaning. In the comparison with a river we imagine a flow or stream in the river, or even sometimes whirling water and accelerations. Yet, a river can also be smooth, almost unruffled, with suddenly bubbling something up to the surface.In comparison: finding meaning can as well emerge passively, as a discovery in contemplation [74, 95]. Finding meaning during later years is thus a dynamic process. Meaning-finding comprises two levels: to the ultimate (global, existential) meaning in their whole life, as well a day-to-day level: daily meaning. Connection with self, others, or something greater than oneself and society, is pivotal for finding meaning.

Figure 2.2: The river of finding meaning in later years



3.1.1 Developmental process

Meaning: continuity and discontinuity. Meaning is created both in continuity and discontinuity of life. Older persons generally perceive themselves as the same self as they have always been [72]. During life they relate to initial cultural pathways:societal norms and expectations how a life should be. These cultural pathways provide continuity in life and meaning [72]. However, life is not always a gently flowing river. In every life there are moments in which a person chooses, or is persuaded by circumstances, to continue a chosen path, or change direction: attaining or missing turning points like birth or death, marriage, career.

Bateson [54, 97] articulates these discontinuities as moments in which people 'compose' their life, and meaning. In these discontinuities people create a pattern of multiple activities and experiences, which expresses who they are and what they believe in. According to Bateson and Kaufman meaning creation is a non-linear creative process. Bateson compares this process to a work of art or the preparation of a meal. Greenstein & Holland [55] stress that for leading meaningful lives both continuity and development through crises (discontinuity) are important.

Meaning in old age as a life stage. Many authors describe aging as a specific life stage in which a person can grow to another (higher?) level of functioning. Among them Erik Erikson is the most influential author. He defined eight stages in life, from infancy to old age. In each stage one has to deal with a crisis with a specific theme. If one overcomes this crisis a certain strength can be developed, although the tension will remain. If not, a core-pathology will develop as a result. For old age the theme is: integrity versus despair. By overcoming this crisis, a person will develop wisdom. If one is not able to deal with this crisis disdain will follow [40]. Erikson did not mention how to overcome the crisis in a life stage. Several other authors have based their theories on Erikson's work [54-56]. Tornstam describes a Theory of Gerotranscendence [56]. Through analysing qualitative interviews with Swedish seniors he identified developmental changes in three main dimensions: the cosmic dimension (e.g. connection to earlier generations, life and death,mystery in life), the dimension self (e.g. self-transcendence, body-transcendence, ego-integrity) and the dimension of social and personal relationships (e.g. changed meaning of relationships, modern asceticism, everyday wisdom). Tornstam views gerotranscendence as a possibility: old age can be different from person to person. In empirical research a gerotranscendent meaning pattern was found in 27-32 % of aging populations [57, 86]. In a later edition of Erik Erikson's life stages model Joan Erikson added a ninth stage, a stage leading to gerotranscendence [40]. Bateson describes old age as a life phase of active wisdom, in which individuals have both consciousness of mortality as well as a greater commitment to life [54]. All of the above sketched developmental changes may not be limited to aging.Several authors stress that the changes may as well develop earlier during adulthood [8, 55, 56, 90].

3.1.2 Creation of meaning

Understand through reminiscence. In the process of finding meaning, persons use cognition, motivation and emotion. Especially reminiscence, commitment and optimism are important for meaning creation in a life-time perspective: reminiscence to create meaning from the past, commitment (or engagement) to derive meaning from the present and optimism to have a basis for meaning in the future [73, 74]. Older persons reflect on their life:Through an inner dialogue of thoughts and memories older persons recognize what is really meaningful to

them and may find peace of mind [18]. Older persons can tell others, or write, their life story,but more often short fragments or comments about their life serve as an opportunity for reflection [70]. Reflections on (events in) one's life can provide an explanation for identity and destination in life [67, 69-71]. In the metaphor of the river: by looking back over of the river in the landscape one can understand its course. Older persons can recognize connection between separate events, which can contribute to (re)construction of a coherent life story [69, 70, 95]. In later years reminiscence, evaluation of experiences, seldom leads to new directions for life. The goal rather is integration[73]. One study illustrates this: Younger adults seem more likely to actively redirect their behaviour based on reflections of their past than old adults [82].

Engagement. During old age it is important to stay committed to what one holds dear: going on with living one's life [17, 65]. Older persons can create meaning by engaging in (multiple) activities, which express who they are [54]. De Lange argues that it is important for aging persons to engage in concrete projects and ideals to realize one's potentials, even in difficult circumstances. He considers self-realization as the ultimate goal in post-modern life, also during old age: to strive to become a person as close as possible to one's ambition or dream [68].

Learn through experience: virtues. Greenstein & Holland [55] explain that older persons have experience in creating meaning in good and bad times. As a result, they develop multiple virtues, or character strengths. The authors describe the growth of virtues as an oak, growing thicker and having more branches through years of favourable and unfavourable circumstances, or in our metaphor: many streams that make a strong river. They identified seven virtues of older persons from literature and qualitative research. Wisdom (Erikson, Bateson) and transcendence (Tornstam) are two of these virtues. The other five are: humour, humanity and social justice, courage, temperance and passing to the next generation [55]. Moore, Metcalf & Schow mention other virtues, as a result of living through negative conditions: inner strength, determination, resourcefulness and resilience [17].

Adaptation to negative events. Although many older persons experience meaning in old age, this life period is also characterized by physical and emotional losses and the ending of life, which all may challenge meaning in life [8, 17, 18, 52, 68, 76, 81]. In our image of the river we recognize here the turbulences and waterfalls, sometimes caused by obstructions like stones or radical changes in the landscape. In qualitative research regarding meaning in life older persons speak about their losses, their struggle to overcome fear and depressive feelings and the way they create meaning in adversity [18, 81, 98]. Especially when negative circumstances have impact on a highly valued social role, e.g. mother or friend, it is difficult to find new meaning in life [88].

Older persons adapt to the negative situation based on their coping styles and by using different coping strategies:

- *Coping styles.* The way persons adapt to negative events (coping) is not the same for every person. Marcoen & van Ranst [86] describe three groups of older persons with a different meaning orientation: a self-preoccupied, a self-realization, and a self-transcendent group, deriving meaning from different sources (see also Reker & Woo, 2011, Reker & Wong 2012). The groups differ in coping style as well. The three groups apply all of mentioned (six) coping styles but differ in prevalent style.The self-realization group more often applies an instrumental coping style: they actively try to solve the situation or turn to others for help. The self-transcendent group more often applies a religious or existential coping style: they search support in religious believes, philosophical reflections and search for meaning. The self-occupied group applies all styles less than the other two groups [86].
- *Coping strategies.* Research reveals strategies that older persons apply to cope with negative events:
  - Older persons often turn to the present:They value more highly what is already given and may still be available. They hope for maintaining the positive instead of fearing the negative [17, 81]. According to Carstensen & Scheibe turning to the present is a consequence of limited time perspective of older persons and may as well occur in other circumstances where time is constrained [94, 96].
  - Older persons change their goals in life. Instead of having high expectations of life realization and self-development, they have maintaining goals: they want to preserve who they are and how they live now [81]. Carstensen's Socioemotional Selectivity Theory explains that in conditions when time is constrained the most salient goals will be those that can be realized in the short-term.The author suggests that socio-emotional goals are more likely to be attained in short time than goals related to new experiences and knowledge. As a consequence goals from which persons derive emotional meaning prevail for older persons [94].
  - Older persons shift to a positive self-attribute, often compared to other: 'I look still good for my age'. Older persons are even grateful for lack of disaster compared to others. They become more self-accepting [17, 81].
  - In negative events older persons search for values that provide them with meaning. Marcoen [52] describes three value categories, earlier described byFrankl [28] : Creative values engage persons in activities in work, nature or art;Experiential values inspire a contemplative and receptive approach to what life brings;Attitudinal values foster a more attentive self-transcendent approach to life: if suffering and losses are inevitable the only thing to change is one's attitude to it. People can give meaning to a difficult situation by connecting it to something beyond oneself: mankind,God, the universe [52].

3.1.3 Discovery of meaning

Silence and contemplation. Finding meaning in life is not only about creating and taking action, but also about being open and receptive: through a contemplative attitude towards life, a person may discover what is meaningful in life [52]. Some authors argue that in later years older persons may have a greater need for silence or solitude [56, 95]. It enables a person to be open to what life brings, such as special moments with others, precious memories, nature, a beautiful work of art or music [95]. In the metaphor of the river this may be a quiet spot in the river where suddenly something bubbles up to the unruffled surface.

3.1.4 Daily meaning

Some authors pay attention to daily meaning.Marcoen explains how older persons can express what gives meaning to them in their daily activities, however small. As an example, he describes an old lady who is a good hostess. Even when ill, she can still receive her guests in style [52]. Dittmann- Kohli describes in her research how older persons turn to the present and enjoy the good things and activities that are (still) available for them as gardening, music, thinking of their children, sunshine or learn something new [81]. Moore et al. describe similar findings: Older persons can find meaning in ordinary daily things like dancing or walking [17]. Daily meaning may be connected to another (existential) level. Tornstam provides examples from his research how small commonplace things, such as nature or art, may have a significant meaning: *'I see the trees, buds, and I see how the leaves are coming – I see myself in the leaves'* [56].

3.1.5 Connection

Through the way individuals create or discover meaning they connect with self, others, and with something greater than oneself [17, 52, 98]. Meaning-finding is not an individual matter, it is interacting with society [8, 54, 66, 68, 72, 73, 76, 95]. In our image of the river: the river doesn't exist on its own, but is part of nature, the universe, e.g. connected with clouds, the earth, vegetation and animals.

Self. Dittmann-Kohli [81] and Moore et al. [17] observe a positive self-acceptingattitude towards self in older persons. Tornstam's Gerotranscendence Theory indicates that aging can come with a shift from egoism to altruism (self-transcendence) and coming to wholeness (ego – integrity) [56].

Others. For finding meaning in later life relationships with others,such as family and friends, are important [17]. If relatives have passed away, or contact is difficult, older persons may miss the togetherness with family [18]. Older persons may derive meaning

from social roles performed with others, such as being a good grandparent or being an esteemed volunteer [17, 88].When these roles are highly appreciated by them, stressors in these roles may erode meaning. Support from others can help to restore meaning in life [88]. However, giving help to others, can provide meaning as well [89].

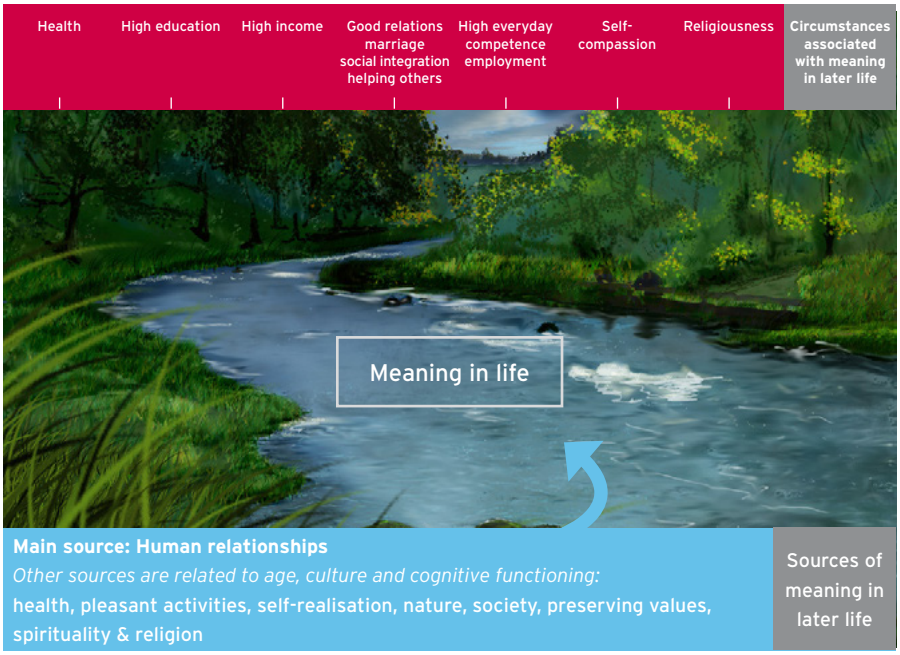
Something greater than oneself. Religion can be very important for older persons. A connection to God can be meaning-giving and help to transcend suffering [17] and self [86]. However, without believing in God, old persons may as well experience being connected to something bigger: cosmic transcendence. According to Tornstam's Gerotranscendence Theory, cosmic transcendence is one of the changes that may come with aging [56]: Through later life older persons may develop a broad view on knowledge and perceive an understanding beyond words. They may reflect on the mystery of life and death and of being part of the universe. Older persons may get another perception of life time, realizing their position in the chain of generations and passing on important values to the future. Braam e.a. demonstrated in empirical research that this cosmic transcendence is more pronounced in non-religious persons, in persons older than 75 years and in persons who were widowed [90].

Society. Values of persons, and as a consequence, their meaning in life,are embedded in the society they live in [8, 54, 66, 68, 72, 73, 76, 95]. There are important differences between, and within, cultures [66]. Older persons may have values that are rooted in a society which doesn't exist anymore and find it difficult to understand actual values [52]. The socio-economic situation in a society has an impact on values as well and, as a consequence, on meaning of life [76, 92].

3.2 Circumstances that are associated with meaning in life of older persons

The results of question 2 and 3 are summarized in figure 2.3. Meaning in life of older persons is related to the circumstances they live in. Pinquart conducted a meta-analysis of 70 studies regarding the correlates of purpose in life with other measures. Purpose in life of older persons is one of the dimensions of meaning in life (see par.1.1). The meta-analysis included more than 23.000 respondents [59]. Health is an important issue: Bad health in older persons is associated with less purpose in life [59, 60], although the decline is not as strong as could be expected consideringthe health conditions [59] Authors suggest that meaning in life may provide a framework for coping with suffering.Later studies find as well higher scores in meaning in life in persons with better physical and emotional functioning [46, 89].. Other factors associated with higher purpose in life scores of older persons are: higher education, higher income [59, 60],good relational quality, social integration, high everyday competence, employment andmarriage [59]. Meaning in life is also positively associated with self-compassion [87], helping others and religiousness [89].

Figure 2.3: relations and sources of meaning in later life



3.3 Sources of meaning in life of older persons

3.3.1 Human relationships are most important source

The main source of meaning in life of older persons is human relationships, especially the relationship with family [77, 78, 84-86, 93, 99]. Older persons who lived in a nursing home considered the relationship with nursing staff a source of meaning as well, although they experienced the communication as limited [18]. Due to different methodology and different populations in the research literature, other common sources were not found, although many sources were mentioned, such as health [77, 78, 84, 93], pleasant activities in work or leisure time [57, 77, 78, 84, 91, 93], self-realization [57, 86], preserving values [86, 99], spirituality and religion [57, 84]. Reker & Wong postulated that persons who have a broad range of values will have a greater variety of sources for meaning. If a sourceof meaning is hindered by physical or other limitations there may be enough sources left then to ensure meaning in life [73].

3.3.2 Differences in sources

Since values of persons in societies develop during the lifespan, sources for meaning evolve as well. Sources of meaning in later life are related to age [75, 84, 85, 92, 93, 99], culture[57, 79, 85, 86, 92, 99], and cognitive functioning [91].

Age differences in sources of meaning in life. Although studies are heterogeneous, we recognize a rough pattern: Older persons derive less meaning from their individual achievements, related to work and other activities than younger adults [75, 84, 92, 99]. Instead, they experience, more meaning from relatedness to others and to something greater than themselves: family, societal issues, traditions, nature, religion and spirituality [75, 84, 85, 92, 93, 99], although they reflect less on self and their relations with others [75, 92].

Cultural differences in sources of meaning in life. Older persons in different cultures derive meaning from different sources because they are embedded in other cultural pathways [72].Some studies illustrate these cultural differences: English and Indian men showed different metaphors related to their meaning in life: English men showed the metaphor of 'a loner' in nature, while the Indian men showed a building metaphor embedded in social structure [79]. Zairean and Dutch older persons differed mainly in two domains of meaning in life: death and dying and health and illness [92]. Between Arabs and Jews were many, but small, differences in meaning in life sources: Arabs derived more meaning from materialistic concerns and communal values, while Jews derived more meaning in life from self-development and leisure [85].Even between Western cultures there may be differences, although few [99]. Furthermore there are groups in society with different meaning orientation(s), among older persons as well, deriving meaning from different sources, e.g. an individualistic, collectivistic or transcendent meaning orientation [57, 86, 100]

4 Discussion

4.1 Discussion of methodology

The method of an integrative review proved appropriate for this subject, because texts on this subject are very heterogenic, ranging from philosophical texts through in-depth qualitative studies to quantitative and mixed methods designs. Strength of this methodology is that it enabled us to identify major themes in the vast amount of literature, find relevant answers to our review questions and synthesize a large number of heterogenic sources into an overarching image. However, the heterogeneity of the texts limits the validity of results as well. We used general search terms to find literature, such as 'meaning in life' and 'age'.Although we reviewed many papers, the search terms may have limited our results. Meaning in life is a comprehensive construct, with many dimensions. A search strategy that included all these dimensions could have provided more information.

4.2 Discussion of results

Meaning in life is, during the lifespan,related to health, well-being and 'the good life' [2-7, 9, 10, 101, 102]. In later life meaning in life is important as well: it is associated with well-being [4, 41-44] and quality of life[45]. However, to find meaning in later life may be challenging.Up till now nursing literature scarcely covered the subject of meaning in life of patients. In our review we identified texts from several disciplines, but only one study had a health care context [18]. Our review provides a broad insight in the way aging persons find meaning in life, which is highly relevant for nurses.

Several authors describe finding meaning in life as part of a developmental process. Meaning can be found by creating and discovering. However, most literature is focussed on creating meaning as an active purposeful process, especially as an adaptation to negative events. Only a few texts described the discovery of meaning through contemplation and silence. This may be a consequence of the origin of the literature, mainly from western countries, resulting in cultural bias. Another gap in literature is daily meaning:finding meaning in daily experiences. This is a relevant subject for nurses who interact with older persons on a daily basis. Meaning in life is connection: with self, others, and with something greater than oneself. However, many studies offer only an individual perspective and lack insight into how meaning is created through relationships. Some authors, and the WHO, criticize society (and science): aging has been problematized as an individual concern, leading to ageism [66, 103]. In today's western society much emphasis is placed on independence of older persons, neglecting the interconnectedness between people duringwhole life [54, 66, 104]. Post-modern societies have omitted to provide older persons with satisfying social roles through which they can find meaning [54, 66, 68]. Persons who are in a bad health condition, live alone, have a low socio-economic status, are socially isolated, have no activities, or non-religious older persons are at risk for loss of meaning in life [59, 89, 105]. Some of these influencing factors may be inevitable with reaching a (high) age: aging comes with health problems and with losses, e.g. of persons who are dear to us. On the other hand the determinants may open up possibilities for improvement: In old age new relations can be found, improvement of health status may be possible, new inspiration can be found, activities from volunteering or helping others may promote meaning and even for socio-economic problems solutions may be possible. The most important source of meaning in life of older persons found in existing research literature is human relationships. Sources of meaning in life of older persons differ according to age and culture and cognitive functioning. The cross-sectional design in many studies concerning age differences in meaning in life is a limitation: the results could as well be due to cohort differences instead of age differences. Longitudinal design is needed to reveal if there is a developmental change through aging. Another issue is related to cultural differences: Westerhof & Dittmann-Kohli argue that cultural differences may not always be the cause of different sources of meaning among different cultures. Socio-economic situation may have a larger impact [92]. As said before, most of the studies in this review were done in western countries, resulting in cultural bias.

Nurses have a major role to play in prevention, in maintaining health and well-being of patients [15, 16]. Meaning in life of older persons is an important concern for nurses with regard to this role [17, 18]: Supporting older patients in maintaining, or attaining, meaning in life should promote well-being, health, quality of life and 'good life' of patients. However, many nurses seem to stick to the physical aspect of care. They lack the attitude, knowledge and skills to provide care related to meaning in life of patients [19-23]. Nurses interact, through their work, on a daily basis with older patients, in everyday life and at special life events. They have the opportunity to build strong connections with them [17]. Especially in homecare, where nurses enter in the private lifeworld of patients, opportunities exist for incorporating meaning in life of patients in care.

From a moral point of view 'good care' encompasses: attentiveness, responsibility, competence and responsiveness [104].First nurses and policymakers in healthcare should acknowledge that meaning in life is an important need for (older) people (attentiveness). We hope this review contributes to this attentiveness. A next step can be that nurses recognize meaning in life in daily practice as well. Secondly nurses have to explore what their responsibility can be. Meaning in life is mentioned in the core competency profile of (Dutch) nurses. However, there is ample professional literature on this subject. To what extent can nurses be responsible for the care related to meaning in life of patients? And what is the role of other professionals like spiritual counsellors? In the Netherlands guidelines were developed for palliative care [106], but this is not the same as care for old persons. Thirdly nurses need the competence to recognize meaning in life of patients in their daily work setting. Nurse-patient interaction is crucial for care that is attuned to meaning in life of patients [107]. To address meaning-in-life-concerns nurses need to develop attitudes and skills like openness, wondering, empathy, presence, communication skills and reflectiveness [16, 20, 22, 23, 107, 108].Responsive care is care that is provided according to the value system of the other[104].Maybe this fourth and last is the most difficult ethic element to achieve. Can nurses perceive the 'otherness' of old persons and provide the care that is 'good' according to the patient, instead of care that meets the own standards. Training of nurses is needed to develop attentiveness, competencies and responsiveness regarding meaning in life of old patients. Spiritual counsellors could have an important role in training and further exploration of the responsibilities of nurses in this regard.

4.3 Implications for practice and research

Insights from this review may be a starting point for nurses to include meaning in life of patients in their work and contribute as so to 'good life' of patients.

Nurses should be aware of, and attentive to patients related to:

- Personal values and meaning orientation;
- Cultural and socio- economic context;
- Personal coping style related to adverse events;
- Virtues, or character strengths, of patients;
- The life story of a patient and how the patient reflects on that;
- Daily meaning in ordinary things;
- Preserving of meaningful activities and roles;
- Preserving health in order to maintain meaningful activities;
- Connectedness to others (family, friends) of older patients, and maybe to something bigger than oneself.

This attentiveness is especially needed for patients who are at risk for decline in meaning: those with a deteriorating health condition, living alone, with a low socio-economic status, social isolation or non-religious persons [59, 61, 89]. Besides attentiveness, nurses should develop competencies to attune to meaning in life of old persons.

A need for more (empirical) research evolves from this literature review. Important questions are: What is meaning in life of older persons who receive healthcare? How do they experience daily meaning in life? Do they find meaning by creation and/or discovery?Other questions explore the role of the nurse: What are situations in daily care in which meaning in life is involved; how can nurses attune to meaning in life of old persons; can training help nurses to develop competencies to address meaning in life of patients?

5 Conclusion

Older persons find meaning in life through different processes. Meaning in life is associated with the circumstances old persons live in. Human relationship is the major source of meaning. The knowledge from this review is a necessary knowledge base for nurses to include meaning in life of older patients in care, in order to further develop the nursing role of health promotor. The results of this review suggest there are many opportunities for nurses to address meaning in life of older patients in their daily work that need to be explored, followed by further research.

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Chapter 3

‘Meaning in life? Make it as bearable, enjoyable and good as possible!’

A qualitative study among community-dwelling aged adults who receive home nursing in the Netherlands

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Abstract

The population of adults ageing in place and using homecare services is growing rapidly worldwide. Meaning in life (MiL) of this group of clients is relevant for healthcare and social workers. MiL is associated with many positive outcomes but can be challenging for aged persons. Objective of this study was to explore MiL in daily life of community-dwelling aged persons who receive homecare. A hermeneutic phenomenological approach was followed. Three waves of semi-structured interviews took place among 24 clients of a homecare organisation in the Netherlands between November 2015 and July 2018. Photo-elicitation was part of the interview procedure. Interpretative Phenomenological Analysis and dialogues enhanced understanding. Findings show that participants derived meaning from self, others, environment and living. The process of retaining MiL involved maintaining, adapting and discovering. We conclude that community-dwelling aged adults can draw MiL from many sources. Retaining MiL is interwoven in everyday life and requires continuous adaptation to ever-changing life conditions during later life. Although relevant general themes were sketched in this paper, the importance of each, and the connections between them, vary and come to light at the individual level. The themes in this paper and the cases in the appendices provide insights that may help professionals recognise MiL in their work. Besides listening to the stories of aged adults person-centred interventions should support aged adult's strategy to retain MiL.

Keywords: Quality of life, aged, independent living, public health, home care services, social work, qualitative research.

What is known about this topic?

- Happiness is about 'feeling good'; MiL is about 'being or doing good'.
- Several circumstances are positively associated with MiL: health, higher SES, cohabiting, good relationships, living independently, social integration, and high everyday competence.
- Loss (of: functions; preferred roles; personal growth; dear ones) compromises MiL in the later years.

What does this paper add?

- Retaining MiL by adapting to conditions requires energy and perseverance of community-dwelling aged persons.
- Reciprocity in relationships fosters MiL of community-dwelling aged persons.
- The home and neighbourhood of community-dwelling aged persons influence MiL.

1 Introduction

Older adults are a group of interest in healthcare and social care. The percentage of aged adults in population is growing worldwide, with a projected increase to 29% in high-income countries by 2030 (WHO, 2015). Most older adults age in place (WHO, 2015). Many of them receive help from family and professionals. In the Netherlands, where this study was conducted, more than 90% of adults older than 75 age in place, with over 40% receiving informal and/or formal care or support (De Klerk, Verbeek-Oudijk, Plaisier, & den Draak, 2019). Therefore, well-being of this group of clients is relevant for healthcare and social workers. Positive psychologists distinguish two philosophical approaches to well-being(Deci & Ryan, 2008; Ryff, 2012): Hedonism, (subjective well-being or happiness) is related to minimising discomfortand maximising pleasure and life satisfaction. Eudaimonia (psychological well-being or meaning in life (MiL)) is related to identifying and fulfilling one's potentials. Although happiness and MiL appear connected in life (Shmotkin & Shrira, 2013), there are considerable conceptual differences: MiL is, more than happiness, related to giving than taking, to expressing the self (Baumeister, Vohs, Aaker, & Garbinsky, 2013; Esfahani Smith, 2017). Happiness is about 'feeling good' while MiL is about 'being or doing good' (Esfahani Smith, 2017). After decades of emphasis on happiness, MiL is gaining attention in contemporary research. Literature reviews (Bellin, 2012; Brandstätter, Baumann, Borasio, & Fegg, 2012) show the complexity of the construct of MiL. A comprehensive description of MiL is:

> *A highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them. Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging [...] MiL comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfaction or lack thereof (Brandstätter et al., 2012).*

Literature about MiL comprises theories and research about four elements of the construct:

1. Content: *What* provides MiL: frameworks of components, needs or sources of MiL (e.g. Baumeister, 1991; Derkx, 2011, 2015; Wong, 1998);
2. Process: *How* MiL can be attained (e.g. Frankl, 1959; Reker & Wong, 2012)
3. The *experience* of MiL: How does it feel, what does it bring? (e.g. Baumeister, 1991; Brandstätter et al., 2012)
4. What *circumstances* promote MiL (e.g. Carstensen, 2006; Pinquart, 2002)

MiL is thus a multifaceted construct. Moreover, the relations between the elements of meaning are extremely complex (Bellin, 2012; Brandstätter et al., 2012).

1.1 Meaning in life of aged persons

Accumulating research shows positive association of MiL with many desired outcomes in older adults: quality of life (Haugan, 2013; Low & Molzahn, 2007), longevity (Boyle, Barnes, Buchman, & Bennett, 2009; Buettner, 2008; Zaslavsky et al., 2014), healthier lifestyle (Steptoe & Fancourt, 2018), use of preventive healthcare services and fewer hospital nights (Kim, Strecher, & Ryff, 2014) and lower prevalence of age-related conditions (Zaslavsky et al., 2014) such as Alzheimer 's disease (Boyle, Buchman, Barnes, & Bennett, 2010) or stroke (Kim, Sun, Park, & Peterson, 2013). However, experiencing MiL seems increasingly challenging through later life. Ageing comes with physical constraints, loss of dear ones and loss of valued roles, which compromise MiL (Krause, 2004). Although many older individuals preserve MiL (Fagerström, 2010; Steger, Oishi, & Kashdan, 2009), others experience loss of meaning due to a decline in personal growth, loss of purpose or declined sense of coherence (e.g. Clarke, Marshall, Ryff, & Rosenthal, 2000; Lövheim, Graneheim, Jonsén, Strandberg, & Lundman, 2013; Ryff, 2014). Several circumstances are positively associated with MiL: health, higher education, higher income, marriage or cohabitation, good relationships, living in the community instead of an institution, social integration and high everyday competence (Hedberg, Gustafson, & C., 2010; Pinquart, 2002; Steptoe & Fancourt, 2018). Literature reveals several processes through which aged persons find MiL: a developmental process, creating, and discovering (Hupkens, Machielse, Goumans, & Derkx, 2018). Human relationships are widely regarded as the most important source of MiL (Hupkens et al., 2018). Although the body of knowledge on MiL is rapidly growing, we discovered two gaps in literature which are relevant for workers in the community: a dearth of studies on *community-dwelling* aged persons who use homecare servicesand on finding meaning in *daily life* (Hupkens et al., 2018). The purpose of this study was therefore to explore meaning in daily life of community-dwelling aged persons who receive home nursing. Research questions were limited to two elements of MiL which are most salient for social and healthcare workers:

1. What sources provide MiL in daily life for community-dwelling aged persons who receive home nursing?
2. How do they find meaning in daily life?

2 Methods

2.1 Design

This study is part of a larger project about MiL of community-dwelling aged persons, and how professionals can attune their care to MiL. We followed a qualitative hermeneutic phenomenological approach in order to understand MiL of community-dwelling aged persons as they perceive it in their lifeworld. In hermeneutic phenomenology researchers explore by opening up, especially to 'otherness', through questioning and dialogue (Dahlberg, Dahlberg, & Nystrom, 2008; Gadamer, 1975, 2004; Malpas, 2018). Aim is to arrive at understanding (*Verstehen*), a 'fusion of horizons', from which both researcher and participants learn (Dahlberg et al., 2008; Gadamer, 1975, 2004; Malpas, 2018).

2.2 Data collection

Respondents were clients from a home nursing provider in Rotterdam, the second Dutch city. Four neighbourhoods were purposefully selected based on different socio-economic status (as this affects MiL, see introduction). We asked community nurses in these neighbourhoods to select 4-8 participants among their older clients that reflected client diversity (age, gender, cultural background, health status). From November 2015 to June 2017 participants were included in the study and between November 2015 and July 2018 respondents were interviewed three times, with 5-7-month intervals, to arrive at a profound understanding about MiL of community-dwelling aged adults. Four persons were unable to participate in a second interview, and four more in a third interview (Appendix 1). Reasons for drop-out were: deteriorating health (3), death (1), moving to a nursing home (2) and 'having nothing more to add' (2). Data saturation was approached during data analysis (appendix 2). However, in hermeneutic phenomenology researchers acknowledge that understanding is always timely and horizons are always moving (Gadamer, 1975).

2.3 Interviews

We developed a list of topics for semi-structured interviews. Interview questions were open-ended and asked about lived experiences and examples, rather than knowledge or opinions (Smith & Eatough, 2016; Thomas & Pollio, 2002). Photos were

used as an elicitation method to facilitate deeper insight. We used a photo set that was specifically developed to discuss psychological well-being (Cuijpers & Vooren, 2015). Photos can be a means towards emotions, thoughts and feelings that are difficult to express in words (Harper, 2002; Hupkens, Nijhuis, & Kuiper, 2011; Steger et al., 2013). After 10 interviews the topic list was evaluated. Minor changes were made in the formulation of questions. Main questions in first and second interviews were: 'Please select a picture that depicts MiL for you at the moment.' and 'Can you mention a recent situation in which you experienced MiL?' We asked follow-up questions to further explore with participants. In the second and third interviews dialogues about the insights of earlier interviews and preliminary interpretations took place to enhance mutual understanding. Much attention was paid to an open, attentive attitude towards respondents. The interviewer followed the flow of the conversation while preserving the orientation on the subject. We also gathered background data to enable transferability: gender, age, marital status, living alone or cohabiting, self-reported health status, religion, and cultural background. Back-ground items were chosen based upon relevance for MiL (see introduction). The main researcher (SH) performed all in-depth interviews with the participants at their homes. Mean duration was 61 minutes (range: 32-112, Appendix 1). Most interviews were conducted with single participants. Two couples, all clients of the homecare organisation, were interviewed together. Three respondents spoke limited Dutch and were assisted by their family during the interview.

2.4 Data analysis

Interpretation in hermeneutic phenomenology is characterised as a dialogue with the texts (Fleming, Gaidys, & Robb, 2003; Gadamer, 1975). We analysed the data in an iterative process at two levels: at the individual level to understand participants in context, resulting in cases which include all interviews of one participant (figure 3.2, appendices 3-8); at a general level, to find overarching themes. Analysis repeatedly moved in and out, from the parts (individuals) to the whole (all respondents) and back again (Dahlberg et al., 2008; Gadamer, 1975). See figure 3.1. The six steps of Interpretative Phenomenological Analysis (IPA) were used as guidance, for their alignment to this approach and the philosophical background (Smith & Eatough, 2016). In this approach themes emerge from the data. Interviews were mostly analysed by the main researcher (SH). In all stages of the analysis further refinement took place in dialogues in two research groups. The first group consisted of nurses, spiritual counsellors, researchers and an aged adult who received home nursing. The second research group consisted of researchers (nurse/health scientist, health scientist, philosopher, philosopher/ social scientist) and was university-based. Researchers were aware of their pre-understanding, which was derived from both professional work (research, literature, nursing) and personal experiences with aged family members. The introduction of this paperand our review article regarding MiL of older persons (Hupkens et al., 2018) sketch our preconceptions.

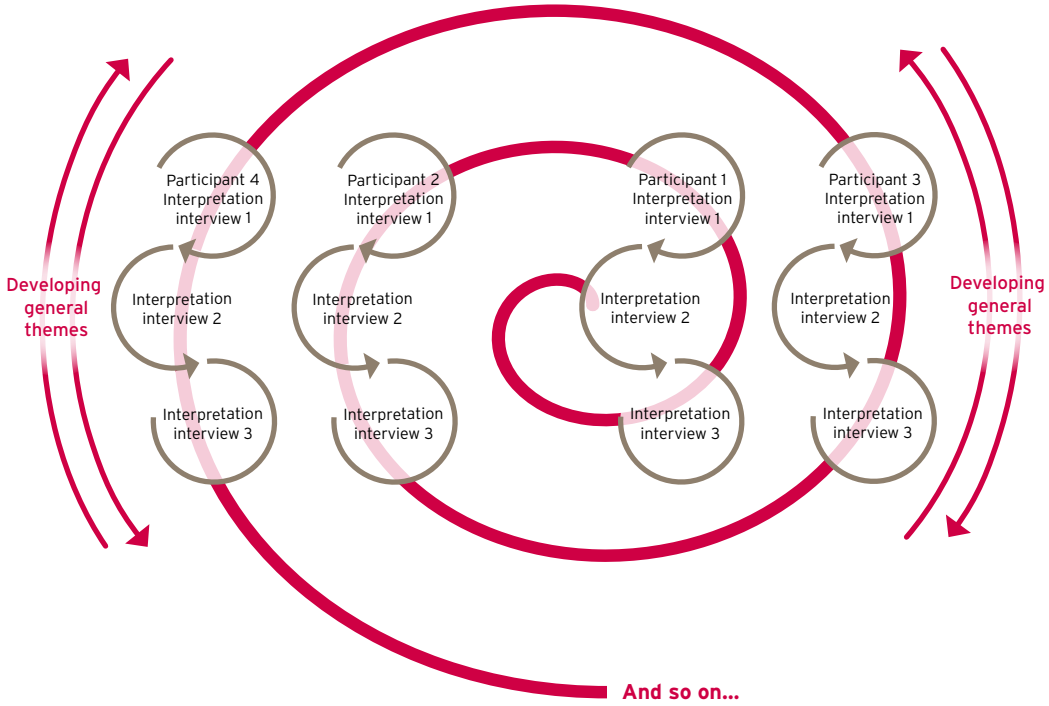

Figure 3.1: Schematic Presentation of analysis at individual and general level

2.5 Rigour

To promote credibility we conducted multiple interviews with most respondents; findings were validated by respondents and through dialogues in research groups (Fleming et al., 2003; Thomas & Pollio, 2002). Dependability and confirmability were fostered through recorded and verbatim typed interviews, analytic steps and analytic software (Atlas-ti 6.2.28)(Creswell, 2013; Smith & Eatough, 2016). We also utilised a diary to reflect on evolving understanding (Dahlberg et al., 2008; Fleming et al., 2003). The COREQ was used for the reporting of this study (Tong, Sainsbury, & Craig, 2007).

2.6 Ethical considerations

An ethical committee assessed the research proposal and found the research not to be subject to the Dutch Medical Research Involving Human Subjects Act (WMO). Respondents received written and oral information about the study on beforehand and signed an informed consent form. For this paper we changed names and minor details to protect anonymity. A data management plan was part of the study design, to meet the European General Data Protection Regulation. The researchers adhere to the national ethical codes for research of Dutch Universities (Andriessen, Onstenk, Delnooz, Smeijsters, & Peij, 2010).

3 Findings

3.1 Participants

The 24 participants originated from four different neighbourhoods in the metropolitan area of Rotterdam. Mean age in the first interview was 82.3 (median 85). Most participants were women (18), lived alone (18) and had a Dutch background (18). Sixteen participants had a religious background, although one-third of them were no longer practising. The majority (18) had a low educational level. Participants rated their health mostly as moderate (Table 3.1), although many of them spontaneously shared impressive lists of adverse health conditions with us during the interviews. In this paper participants can be identified by a code. As an example: A1 is the first participant from neighbourhood A. The second interview with this person is coded: A1.2.

Table 3.1: Background of participants

Age, yrs, 1st interview	
61-65	1
66-70	1
71-75	2
76-80	5
81-85	5
86-90	6
91-95	3
96-100	1
Gender	
Male	6
Female	18
Marital status	
Married/cohabiting	5
Divorced	2
Widowed	15
Single	2
Living arrangement	
Together	6
Alone	18
Cultural background	
Dutch	18
Surinamese	4
Turkish	1
Cape Verdian	1
Religion	
Christian	14
non-practicing	5
Muslim	1
Hindu	1
No religion	8
Highest educational level	
No schooling	3
Primary school	5
Lower vocational	10
Medium vocational	2
Higher	4
Self-rated health, 1st interview	
Excellent	1
Good	8
Moderate	9
Poor	6
Very poor	
Self-rated health, 2nd interview	
Higher score than 1st	8
Same score	9
Lower score	3
Self-rated health, 3rd interview	
Higher score than 2nd	4
Same score	7
Lower score	5

3.2 Results of two levels of analysis

As can be expected from our analysis, our results appear at two levels. We firstly present seven cases (individual level) and end with general findings.

3.3 Jill, Laetitia, Willy, Romeo, Ed, Yamini and Corinne

The cases in figure 3.2 and appendices 3-8 are examples of the results of the analysis at the individual level. The cases represent respondents from different neighbourhoods and backgrounds.The cases provide the reader an in-depth understanding of the meaning and interconnectedness of the general themes for aged individuals in context.

Photo	Jill (B2) age 86
	I visit Jill (86) after her afternoon nap, otherwise it would be too tiresome for her because of her fragile physical condition. She sits in a comfortable chair. Two cupboards with drawersbeside her, everything at hand, without the need to get up or ask her husband. She tells: *'I try to be as self-supporting as I can, I am surrounded with handy stuff. We have a knackfor coming up with something different if we cannot do certain things anymore.' 'Bad prognosis? I am not living with that. I just stumble along.'* She thinks she's still better off than other elderly. (B2.1, B2.2) She pays attention to eating healthy. Jill embroiders mandalas with extremely tiny stitches, and likes to choose unusual colour combinations and compositions. She says it helps her get through the day. It is kind of meditative. *'I never had time to be busy with myself before, to think things over. But now I embroider, I embroider, I embroider.'*(B2.1) Her children, grandchildren and great-grandchildren are very important to her. They visit frequently and she is grateful for their help. *'We have moved a lot during our life. It was alright with me, as long as I had my progeny with me.'* She follows news and politics and worries about the future of her children, grandchildren and great-grandchildren. As long as they're okay (B2.1) Jill chooses a photo of a child jumping into the water. It reminds her of the happy family life they had, of summer holidays. *'After a period of hard work, we could rest there, children playing in the water (dreamy look) ... That's the place where my ashes will be scattered.'* (B2.1) She explains meaning in life is far more difficult than it used to be: *'It depends on the situation you're in. It is not easy to accept help if you used to be the one who was helping. And now I am in a situation where I have to give meaning to life while sitting. And you have to be able to do that! When you are as old as we are, you are standing a bit outside of society. And of course, you try to have a good look at your environment, but that is only a small circle. And that is what you can do: be attentive to your small circle.'* (B2.1, B2.2) She looks at her husband (smiles), *'and we are privileged, because we are together. For if you were alone, you would be scratching the walls, so to speak. But we are together, so we can laugh together, cry together, say things, scold, ... mention it; we are together!'* (B2.1, B2.2) Jill says they regularly go to bed late at night, because they watch operas on television together. *'That is so wonderful! I have always loved music, went to concerts, sang myself. Verdi is awesome. Unbelievable what he made! Amazing. I've said before: If a situation came where I don't know which way to turn, just switch on the television to the opera channel.'* (B2.1, B2.2) *'Meaning in life? We don't talk about it so much. When you are so old you have to accept how you are now and that life provides you with meaning. You live here and now. We live in the here and now, so it is pivotal to make it as bearable, enjoyable and good as possible!'* (B2.2)

Photo: Cuijpers & Vooren, 2015, Vilans
Figure 3.2: Jill

	Source (subthemes)	Process (subthemes)
	Home and neighbourhood	
	Physical and mental abilities	Adapting to conditions
		Being myself
		Taking care of myself
	Activities	Openness and sense of wonder
	Autonomy	
	Life story	Reflecting about life
	Personal relationships	
	Life story	
		Staying connected to MiL sources
	Community and society	
	Life story	Reflecting about life
		Looking ahead
	Values	
		Adapting to conditions
		Reflecting about life
		Being myself
	Personal relationships	Staying connected to MiL sources
	Character strengths	
	Personal relationships	Staying connected to MiL sources
		Reflecting about life
		Openness and sense of wonder
	Art and media	
	Life story	
		Looking ahead
	Values	Openness and sense of wonder
		Adapting to conditions

3.4 General theme

Figure 3.3 is a representation of the general themes of the present study. We earlier represented MiL in the later years as a flowing river: ever-changing by multipleprocesses, sources and circumstances that mingle together (Hupkens et al., 2018). Our actual findings support this metaphor; therefore we modified the image in order to depict the results of the present study.

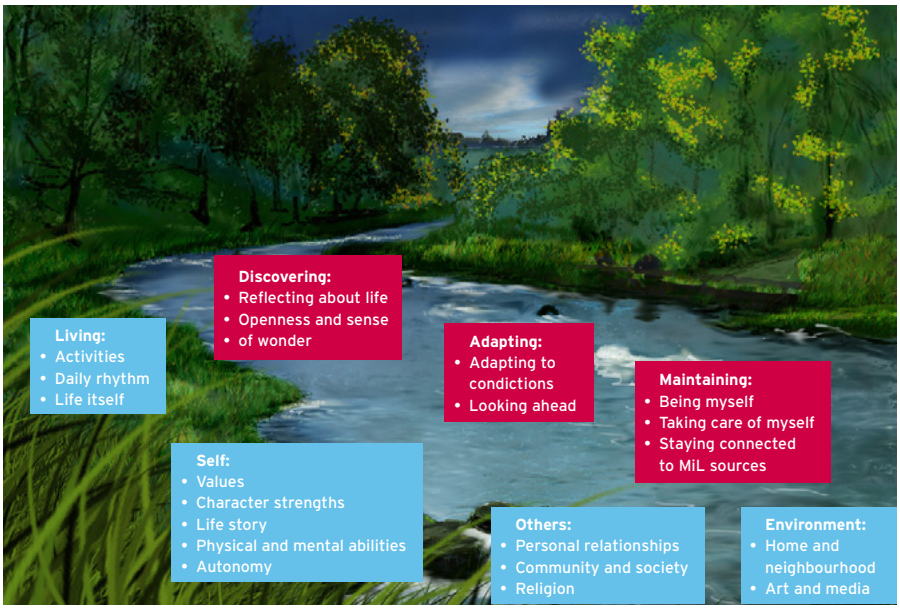

Figure 3.3: The river of meaning in life for community-dwelling aged persons who receive homecare

Process of retaining MiL

Sources of MiL

3.4.1 WHAT: Sources of meaning in life

Most participants mentioned many different sources of MiL (Appendix 2). Main themes were: self, others, environment, living. Subthemes were highly interconnected. Several subthemes could be related to more than one main theme. An example is the subtheme ‘values’, which besides ‘self’ is also connected to ‘others’ and ‘living’. In this section themes are written in bold, subthemes italicised.

Self. Self was an important source of MiL of participants.

Values: All respondents mentioned important values that provided them with MiL, such as respect, friendliness and faith. These values were mostly adopted in their youth, through their upbringing or through a cultural or political background. Values that had guided them throughout life were reflected in respondents' habits.

> *'We are all equal. My father taught me: All groups have good and evil persons.' (C6.2, age 82)*

Character strengths: Many participants drew on their character strengths as a source of MiL, such as optimism, strength, perseverance, creativity and generosity. They told how these strengths had helped them before, in good and bad times. Some participants mentioned that they learned these virtues from beloved relatives who had passed away.

> *'I am a giving person, just like my grandma. I always have something in my handbag to give to others.' (C1.2, age 87)*

Life story: Participants shared their life story with us during the conversations. They explained that beautiful memories of past life contributed to MiL in the present, while unfavourable events had shaped their character strengths and values. Photos and artefacts in the house reminded respondents of precious moments and persons.

> *'The fact that I have been able to be of service to people in my professional life provides me with fulfilment.' (D6.2, age 86)*

Physical and mental abilities: Many participants mentioned their good physical and mental abilities as sources of MiL, particularly as compared to other aged persons. Especially mental abilities were highly valued.

> *'The doctor told me I am not demented. That's the most important thing. I'd rather be dead than demented!' (D1.2, age 86)*

Autonomy: Several participants emphasised that living their life as they wanted it, and making their own choices, contributed to MiL. They enjoyed living (relatively) independent. Some expressed a feeling of freedom, which was especially meaningful after a long period of caring intensively for relatives.

'I don't want someone else to dispose of my life, to decide for me. As long as I can think independently, I stay who I am.' (B6.3, age 73)

Others. Besides self, others appeared to be vital for MiL of our participants.

Personal relationships: For all respondents, other persons contributed to MiL: spouses, brothers and sisters, children/grandchildren, friends. Respondents still cherished relationships with loved ones who passed away. Daily rituals kept them in their lives. Participants who had pets highly appreciated their friendship. Many attached value to being a good mother, a funny grandfather or a good neighbour. They expressed that, for MiL, reciprocity in relationships was important. Despite age, several participants mentioned assisting family or neighbours, although this was becoming progressively strenuous.

'That I can mean something for my wife, that's my fulfilment...MiL is today: that's all there is ... that we can live this life together.'(B1.1, age 90)

'That dog is my everything.' (A3.1, age 78)

Community and society: A community, e.g. of neighbours, provided meaning for some participants. Others felt a bit detached from society because of shrinking social networks or loss of a specific social role, such as being a brilliant professional or the perfect host. Respondents attached importance to staying informed about topical issues in the world through reading, television and radio. Some were concerned about social developments and, specifically, the future of their children and grandchildren. Several supported good causes.

'I hope that all children that have been put on this world by our generation will enjoy prosperity like we did. We have to ensure that. (B5.2, age 73)

Religion: Some participants mentioned religion as a source of MiL. Religion provided them with a community and important values and habits, such as praying and lighting a candle. It connected them to something, or someone, 'higher'.

'For me, it is God in the first place. The narrow road is the good one. I walk this road of God.' (C3.1, age 78)

Environment. Participants not only found meaning in others and self, but also in the environment where they lived.

Home and neighbourhood: Many participants told that their home and close neighbourhood contributed to MiL: their belongings, the convenient location, shops and other facilities. Many mentioned nature as a source of MiL, especially when it could be enjoyed through the window or on a short walk in the neighbourhood.

> *'To live here again (after a hospital stay), in my own house! I love the view, especially the children's playground.' (D2.2, age 95)*

Art and media: Some participants had works of art in their houses, which were valuable for them. Several adults mentioned music, films and media as important sources of MiL.

> *'When it's silent in the house I watch television. And I imagine I'm there with those people … And I love music. It brings life into the house!' (C2.3, age 85)*

Living. Participants expressed that living was a source of MiL.

Activities: Most respondents told us that their activities provided them with MiL in daily life. Moreover, 'doing something' helped them in adverse situations. Participants stressed that both beginning and finishing an activity were important. Meaning-providing activities varied. For several respondents 'just doing something' was not enough to experience MiL: the activity needed to contribute to something they regarded as valuable, like supporting good causes in the community or making something beautiful or useful. Many aged persons mentioned a favourite activity like reading a good book, gardening or doing craftwork. For several, daily chores took more and more time, impeding favourite, MiL-providing activities.

> *'I have so many activities to do; I would like to make three days out of one!' (B3.2, age 84)*

Daily rhythm: Everyday rhythm provided some respondents with MiL. Precious habits like walking the dog or home organisation, filled them with MiL.

> *'Well, most times I even don't have the time to read the paper… I have other things to do. At the moment the washing machine is working as well. And when that is all set, that feel's good. Yes, it provides me with fulfilment' (B7.1, age 88)*

Life itself: Some participants expressed that life itself provided them with MiL – waking up in the morning and being able to live another day. A few respondents experienced nature as a connection to the larger structure of life.

> *'When I wake up I think: seize the day ... I am still there! And that is always very important. And I make a cup of tea and sit here for a while.' (D3.3, age 91)*

3.4.2 HOW: the process of retaining meaning in life

Although most respondents experienced MiL almost daily, many saw it as an increasing challenge because of declining health and loss of many dear ones. Activities became problematic and loss of mobility limited going out and visiting others. Our participants explained that retaining MiL was a continuous process that fluctuated with life conditions. Most of them used several strategies, (Appendix 2).Three main themes evolved in the analysis for this process: maintaining, adapting and discovering MiL (figure 3.3).

Maintaining MiL. Participants explained that they didn't have to create new meaning every day. They rather maintained MiL through different strategies.

Being myself: Most participants emphasised that, to maintain MiL, they just 'stayed who they were and did what they had always done'. When we asked follow-up questions, they explained how they had overcome difficult periods before in their life. Just as in previous situations they used their character strengths and kept up daily rituals and favourite activities, which provided a structure for carrying on and maintaining MiL.

> *'I go on as I always have. Because if you stick to your trouble it will determine you. You have to switch over' (A3.2, age 76)*

Taking care of myself: Respondents told that taking good care of themselves supported MiL. They paid attention to their appearance, maintained a healthy lifestyle (food, exercise), and did their best to make a nice day for themselves.

> *'Some days I go up and down the stairs six times or more, otherwise soon I won't be able to do that anymore.' (A1.1, age 69)*

Staying connected to MiL-sources: Participants actively undertook steps to stay connected to their MiL-sources, for instance by engaging in meaning-providing activities. When receiving guests they did their best to be good company, show

interest in others and enjoy their visits. Some told that they did not ask or expect too much from family carers, in order to keep the relationship healthy.

> *'I always take care of myself to have this sociability of playing cards and so on.' (B8.2, age 85)*

Adapting. When maintaining MiL was impeded by deteriorating conditions, participants used several strategies to retain MiL through adaptation.

Adapting to conditions: Participants revealed that they adapted continuously to deteriorating health conditions. Several told, and showed, how they found creative solutions for lost abilities, for instance phoning relatives instead of visiting them. They accepted help from family, friends and homecare services. Several turned to other sources of meaning. During our dialogues, participants provided insight into the increasing time and energy this process of adaptation costs as decline progressed. A few respondents expressed that adaptation had almost reached a limit, especially when they experienced too much pain or felt exhausted, or when meaning-providing activities or preferred roles where hindered.

> *'When I want to cook chili con carne, I plan it a day ahead. I do the shopping the day before, and start early in the afternoon. I take some bowls and cut peppers and leeks, and then I take a rest, because it costs energy. I take breaks and spare my other hand.' (A2.3, age 64)*

Looking ahead: Participants told that they look ahead. Some feared further decline and took precautions, like ordering a mobility scooter, which secured the ability to 'walk' the dog. Some hoped for the best for the future. For several aged persons, making final arrangements provided them with MiL, as they did not want to bother their family with that.

> *'I want to call the funeral director. It is a very big step for me. You know, then you talk about the end of life … But I definitely want to do it, for my son. It would take away a lot of trouble from him.'(B8.3, age 85)*

Discovering. In dialogues with participants another process of finding meaning came to the surface: discovering.

Reflecting about life: Most respondents looked back on their past life, at times with relatives (or the researcher), often during the night. Participants observed the 'pieces of the puzzle' of their memories and discovered connections and meaning. Some wondered if they did the right thing in specific situations.

'I have led a normal life, I didn't do any evil, I have been an honest person. I have peace of mind.' (C1.2, age 87)

Openness and sense of wonder: Many participants described an attitude of openness and wonder towards life, which enabled them to discover unexpected meaning in their daily life: in the beauty of nature, changes in the city, music, or unexpected encounters with others.

'Meaning in life is seeing something that attracts or touches you. Little ducks in the water. Children on my daily walk.' (D 5.2, age 97)

4 Discussion

In this paper we explored MiL of community-dwelling aged adults who receive home nursing. Through the hermeneutic approach, this research expanded our horizons and those of our study participants: many respondents told us they highly enjoyed the in-depth conversations. Some missed this kind of exchange in their later years. Most of the themes that derived from our analysis support earlier literature, yet findings reveal a few interesting novel aspects. Main contribution of this paper is it's in-depth first-person's insight in MiL in the later years.
Our respondents showed that retaining MiL is interwoven in everyday life.
Although general themes emerged from the analysis, MiL was something different for every individual in their own context, as also stated by Frankl (1959). In the participants' stories, the elements of MiL are highly interconnected in an individual way: an overall structure was not found. However, the findings lent support to our overarching image of a river of meaning in later life (figure 3.3).

4.1 Sources of MiL revisited

Although we expected many sources for MiL, we were impressed by the number of sources our respondents mentioned. As the broad themes show – others, self, environment, living – MiL can be derived from many things.

Meaning from relationships with others was frequently mentioned, both by our respondents and in previous research (e.g. Bar-Tur, Savaya, & Prager, 2001; Duppen, Machielse, Verté, Dury, & De Donder, 2019; Fegg, Kramer, Bausewein, & Borasio, 2007). Our study further contributes to insight into the reciprocal character of relationships, as receiving and giving contributes to MiL. Especially the capacity to fulfil favourite roles (e.g. mother, friend) was very important to our respondents. Loss of favourite roles erodes meaning, as shown in research by Krause (2004). His research provides a hopeful perspective: this loss of meaning can sometimes be restored by emotional support of others. Our findings reveal the importance of relationships with pets: for some aged adults they are a vital source of MiL.

Although we, like others, have highlighted personal relationships as a major source of MiL (Hupkens et al., 2018), we learned that other sources may be equally important. Loss of dear ones is inevitable in later life. Participants showed that, at that point, other sources become crucial. Self (character strengths, values and life story) can be a stable source. Most respondents relied on their selves to retain MiL, which confirms findings of other authors (Dittmann-Kohli, 1990; Greenstein & Hollander, 2015; Nygren et al., 2005).

A new insight from our study is that home and the environment are a source of MiL. With an increasing population of adults ageing in place, this is a salient topic. Our study puts activities of community-dwelling aged persons in the light of MiL. Which activity is meaningful is different for each individual. Independence gave many respondents a sense of autonomy and freedom, contributing to their MiL. On the other hand, daily chores frequently demanded so much time and energy that they inhibited starting other, more meaningful activities. Beginning something is important to feel human (Arendt, 1958), and aged persons are no exception to this. Besides beginning, finishing the activity is crucial. As a respondent mentioned: activities have little meaning when one lacks the energy to finish them.

We expected daily rhythm to be a source of MiL for our respondents, as mentioned by others (Bellin, 2012; Dittmann-Kohli, 1990; Moore, Metcalf, & Schow, 2006). Our findings show that, moreover, life itself can be a source of MiL: waking up in the morning and being able to live another day.

4.2 The process of retaining MiL revisited

Participants showed us that retaining Mil is a continuous process in old age, due to ever-changing life conditions. In our review article we made a distinction, like Reker & Wong (2012), between *creation* and *discovery* of MiL. Through dialogue with participants in this study we learned that 'creating' MiL in old age is not a proper understanding: aged adults do not have to create meaning, they rather

maintain MiL or *adapt* to changing conditions during old age in order to retain MiL. Participants explained that, to maintain MiL, they simply 'are, and do, what they have always done'. This implies active involvement though: participants stay related to their initial value framework, their cultural path, according to Kaufman (1986); they also showed us, like previous authors (Dittmann-Kohli, 1990; Moore et al., 2006), that MiL is retained by good self-care and connecting to one's MiL sources. Yet MiL takes energy and perseverance when aged persons have to adapt to conditions, especially when pain and/or daily tasks make increasing demands from an older individual. The philosopher Gude emphasised, while struggling from terminal cancer, that retaining MiL required daily effort. MiL is sometimes an exhausting struggle, a 'crafting endeavour' (Steenhuis, 2017). Some participants explained that life turns meaningless when this struggle becomes too much. Retaining MiL, as described in our findings section, shows similarity to the Selection Optimisation and Compensation Theory (Baltes & Carstensen, 1996; Freund & Baltes, 1998). The processes of adapting (this study) and compensation (Baltes et al.) are comparable. However, for our participants, selection of goals and optimisation was frequently loss-based: to keep the current level (instead of election-based: deliberately choosing goals in order to attain a higher level).

Another way to find meaning is discovering it. Discovering is finding meaning by coincidence, not intentionally. Our respondents showed us that discovering meaning occurred by looking back, as described earlier (McAdams, 2012; Tromp, 2011), but meaning seemed to evolve foremost from a mindset of wonder (Derkx, 2015; van de Goor, Sools, Westerhof, & Bohlmeijer, 2017). Our participants confirm authors who wrote that openness and receptiveness towards life enables enjoying what crosses your path (Marcoen, 2006; Randall & Kenyon, 2004; Reker & Wong, 2012; Tornstam, 2005). The process of discovering MiL through wonder is seldom studied, but of high interest, as this mindset may remain largely unaffected by many deteriorating circumstances during old age.

4.3 Implication for practice and policy

MiL is associated with many positive outcomes such as health and quality of life. For this reason, MiL of aged persons ought to be on the agenda of professionals and policymakers in social care and healthcare. The themes in this paper and the cases in the appendices provide useful knowledge that may help recognise MiL in practice. Because every individual is different, a valuable next step should be listening to the stories of aged adults and learn from them, as we did. A phenomenological attitude of openness, questioning and attentiveness proved to be a good start for a conversation about MiL. Interventions in the community and in healthcare should not only focus on sources of MiL, but also empower aged adults to retain MiL. The UK programme '5 ways to wellbeing' is influential

internationally and mirrors some of our findings, although it is based on another definition of wellbeing ('mental wellbeing') (Aked & Thompson, 2011; The Government Office of Science, 2008). Furthermore, policymakers should consider the impact their decisions have on MiL of aged adults, especially in relation to environmental and social aspects.

5 Limitations

Our study has limitations. Transferability is limited due to sampling, as well as by attrition, which is common in follow-ups, especially among aged persons. Understanding of participants who dropped-out may be limited. Although the photo-elicitation provided us with many valuable insights, the use of photos was confusing for two persons who had limited cognitive functioning and not feasible for two others who had impaired vision. The presence of family in three interviews with non-Dutch-speaking respondents influenced the conversation – and thus the credibility – of those interviews.

6 Conclusion

Community-dwelling aged persons can derive MiL from many sources. Retaining MiL is interwoven in everyday life and requires continuous adaptation to ever-changing life conditions during later life. Although relevant general themes were sketched in this paper, the importance of each, and the connections between them, vary and come to light at the individual level. Besides listening to the stories of aged adults person-centred interventions should support aged adult's strategy to retain MiL.

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Part 2

Home nursing with respect to older patients' meaning in life

Chapter 4

Meaning in life of older adults in daily care

A qualitative analysis of participant observations of home nursing visits

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Abstract

Aim: To explore situations in daily home nursing regarding meaning in life of older adults.
Design: Qualitative research design.
Methods: 197 participant observations were conducted during home nursing visits between September 2015 and May 2018. Descriptions were thematically analysed. The themes of this analysis were subsequently linked to dimensions of meaning in life. Dialogue in research groups expanded understanding.
Results/Findings: Four main themes were found: being in a private environment; nurse-patient encounter embedded in a relationship; personal care; conversation.
Conclusion: Meaning in life of older adults may come to light in every situation during daily care. Hence there are many opportunities for nurses to attune their work to patients' meaning in life.

Keywords: *home nursing, meaning in life, older adults, quality of life, well-being, care quality, participant observation, nurse-patient relationship, nursing education, spirituality.*

Impact:

- **What problem did the study address?**
  Meaning in life is important for health, well-being, quality of life and what is considered 'a good life'. However, in daily practice, nurses have difficulties to perceive meaning in life.

- **What were the main findings?**
  Older adults' meaning in life may come to light through the nurse-patient relationship and being in a private environment. Personal care and conversation are opportunities for revealing older adults' meaning in life.

- **Where and on whom will the research have an impact?**
  This paper may help nurses in practice to recognise MIL in their daily work; Nurse education should learn nurses howto perceive patients' meaning in life; Healthcare managers and policy makers should consider the influence their decisions have on nurses' ability to perceive meaning in life.

1 Introduction

People generally strive to live meaningful lives. In recent years the concept of meaning in life (MIL) internationally has gained attention in society and in healthcare settings. MIL is considered pivotal for 'a good life' (Collin & King, 2004; Derkx, 2011, 2015; Esfahani Smith, 2017). MIL is important for nurses because of its positive association with health (Huber, van Vliet, Giezenberg, & Knottnerus, 2013; Ryff, 2012; Steger, 2012), well-being (Steger, 2012; Westerhof, Thisen, Dittmann-Kohli, & Stevens, 2006) and quality of life (Haugan, 2013; Pitkala, Laakkonen, Strandberg, & Tilvis, 2004). However, MIL is not only a means to an end, it is important on its own merits (Derkx, 2011; Esfahani Smith, 2017).

1.1 Background

For many people, MIL is not a common subject. It may entail something different for every single person (Frankl, 1959). MIL is a comprehensive dynamic construct, as the description of Brandstätter Baumann, Borasio and Fegg explains:

> *'Meaning in life is a highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them. Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging... Meaning in life comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfaction or lack thereof.' (Brandstätter, Baumann, Borasio, & Fegg, 2012, p 1045).*

However, the broad definition and individual perspective of MIL poses a problem for healthcare practice: How can a professional recognise when MIL is involved? MIL problems are considered as core issues in nursing (Schuurmans, Lambregts, & Grotendorst, 2012) and nurses acknowledge that MIL is important (Huber et al., 2013). The relevance of the topic is stressed by patient advocacy, and healthcare bodies (Van Harten & Van Haastert, 2015; Wijgergang, Ras, & Reijmerink, 2016). In nursing methodology – the nursing process – professionals are encouraged to think critically and explore the situation of a patient in depth and breadth, from a holistic perspective (Herdman & Kamitsuru, 2014; Wilkinson, 2011). One of the most applied classifications for nursing diagnoses, the North American Nursing

Diagnosis Association (NANDA), provides many diagnoses related to MIL, for example in the mental and existential domain (Herdman & Kamitsuru, 2014). However, nursing literature regarding MIL of older adults is largely lacking (Hupkens, Machielse, Goumans, & Derkx, 2018). Several researchers mention that nurses do not recognise MIL of older adults in daily practice (Begemann & Cuijpers, 2015; van der Vaart, Arisse, Weijers, & Elteren, 2015). A first step to recognising is perceiving when MIL is at stake in daily practice. Perceiving is a prerequisite to attentiveness (Klaver & Baart, 2016), which is a first step towards responsive 'good' care (Tronto, 1993). However, it is unclear what nurses could perceive in their daily practice regarding patients' MIL.

Although there are individual differences, we can identify seven dimensions of MIL (Derkx, 2011, 2015):

1. Purpose: What are a person's goals and strivings?
2. Moral values and justification: When and why does someone believe a goal is morally worthwhile, means are acceptable, and what are the underlying values?
3. Efficacy: Does a person feel competent and able to influence something?
4. Self-worth: Does a person feel of worth for who they are and what they do? This may be influenced by being valued by others.
5. Comprehensibility: Do persons' life stories, including small events, make sense to them? Can they perceive coherence?
6. Connectedness: Does a person feel connected to other people, nature, something bigger and valuable?
7. Excitement or wonder: Does a person experience engagement in something worthwhile? Is there wonder and excitement in life?

In this article we elucidate situations in everyday home nursing to diminish the mentioned knowledge gap, and connect them to the theoretical framework of the dimensions of MIL.

2 The study

2.1 Aim

The aim of our study was to explore situations in daily home nursing related to MIL among older adults. The research question was: What are situations in daily home nursing in which MIL of older adults, or the lack thereof, comes to light?

2.2 Design

Qualitative research and, more specifically, observation, is appropriate for exploring behaviour in a natural setting as it takes place (Baarda, de Goede, & Teunissen, 2009; Kumar, 2014), such as daily nursing visits. As a preparation for this study, we interviewed nurses (not included in our sample) about MIL of older patients in their work, in order to explore the subject for a broader study. The interviews showed that nurses recognised the 'big questions' patients were struggling with, but could not mention *daily* situations in which MIL or the lack thereof was involved. Through participant observations of home nursing visits we wanted to elucidate those daily situations. Qualitative observations could provide us with the thick descriptions that were in line with our aim.

2.3 Sample

Home nursing teams in the Netherlands consist of professionals with different educational levels, who cooperate to provide nursing at patients' homes.Teams were purposefully selected for our study. Purposeful selection is common in qualitative research to include participants who can help answering the research question (Baarda et al., 2009; Creswell, 2009). We selected teams in districts with different socioeconomic contexts, because socioeconomic status influences MIL (Pinquart, 2002). After having received information on the project, professionals of the teams were asked for their cooperation. We accompanied registered district nurses, assistant nurses and nursing aides (in this article, all 'nurses') during their daily rounds. The selection of nurses in the teams was a convenience sample. Most rounds were regular nursing rounds that consisted of many visits to patients at home.

2.4 Data collection

The participant observations were conducted between September 2015 and May 2018 by three researchers. Most participant observations were conducted during the day, but we also participated in a few evening rounds. Observations ranged from a few hours to a complete round. To enable an open attitude in the observation, no observation checklist was used (Baarda et al., 2009). Our participation during the observations was limited. For instance, observers joined slightly in conversations to avoid participants and patients feeling uncomfortable, or lent a helping hand turning patients in bed. Short handwritten field notes were made during the rounds and were transcribed to thick descriptions as soon as possible after the observations.

2.5 Ethical considerations

We followed standard procedures for the Netherlands, including the Dutch Code of Conduct for Applied Research for Higher Professional Education (Andriessen, Onstenk, Delnooz, Smeijsters, & Peij, 2010). An ethical committee assessed the research proposal following Dutch guidelines. The research was found not to be subject to the Dutch Medical Research Involving Human Subjects Act. Nurses participated voluntarily. Patients received written information in advance about the project, which emphasised that they could refuse without any consequences. Participants and patients were invited to ask questions. Permission of patients was requested in advance by their nurses and repeated at the start of every home visit. Researchers behaved respectfully towards participants, patients, families and private space. Special attention was paid to anonymity in all notes and observation descriptions. In this article we changed minor personal details and used pseudonyms and codes for the observations.

2.6 Data analysis

The thick descriptions of observations were thematically analysed as described by Clarke and Braun (2015). Codes were initially grounded in the data (inductive coding). An additional, deductive phase was added to link the themes to the dimensions of MIL of Derkx (Table 4.1). Data was primarily analysed by the main researcher (SH). Dialogues took place in two interdisciplinary research groups in all phases of the coding process. Dialogue is regarded as a means to deepen and broaden understanding (Gadamer, 2004; Halling & Leifer, 1991), hence dialogue about preliminary findings guided latter observations and expanded interpretation of the data. This resulted in a cyclical process to understand the research topic.

2.7 Rigour

To establish *credibility,* researchers were engaged in the field for a long time (>2.5 years) (Creswell, 2013). We also observed daily practice in diverse neighbourhoods with a variety of patients and home nurses with different educational levels. Rich descriptions provided details for *transferability* of findings (Creswell, 2009). *Trustworthiness* and *reflexivity* were fostered by several strategies: multiple researchers conducted the observations (Baarda et al., 2009); a reflective journal log (Baarda et al., 2009; Kumar, 2014); dialogue in research groups (Baarda et al., 2009; Creswell, 2013); and the use of analytical software (Atlas-ti 6.2.28).

3 Findings

In this section we describe themes and subthemes (Table 4.1). Detailed examples are used to enable the reader's in-depth understanding. We refer to Derkx' MIL dimensions by numbers in brackets. Findings are based on analysis of 197 nursing visits to patients in eight Rotterdam-area districts. The examples show different neighbourhoods, nurses, patients and observers.
There are many situations in daily home nursing where MIL of patients (or lack thereof) comes to light. This can be summarised in four main themes: being in a private environment; nurse-patient encounter embedded in relationship; personal care and conversation.

Table 4.1: Codes, themes/subthemes and dimensions of patients' meaning in life in daily home nursing

Inductive phase			Deductive phase
Themes	Subthemes	Codes	Dimensions of meaning in life *
1. Being in a private environment	Entering	Entering the house	2, 3, 4, 6
		Family and pets	1, 6
	Signs and symbols	Interior and artefacts	1, 2, 3, 4, 5, 6, 7
		Maintenance and housekeeping	2, 3, 4
2. Nurse-patient encounter embedded in relationship	Greeting	Hello and goodbye	1, 2, 3, 4, 5, 6, 7
	Seeing the patient	Mood, emotions, expression	1, 5, 6, 7
		Physical condition	3
		Self-care	2, 3
		Activities	1, 3, 4, 7
	Focus of attention	Intervention	3
		A whole person in interaction with family/pets and environment	2, 4, 6, 7
	Interaction with nurse	Nearness-distance	2, 5, 6
		Familiarity and trust	2, 4, 5, 6, 7
		Reciprocity	2, 4, 6
		Rituals	2, 6, 7
		Time and pace	1, 3, 4, 6, 7
		Non-verbal communication	4, 6
3. Personal care	Adaptation to patient	Choice and decision	1, 2, 3, 4
	Touch	Quality of touch	4, 6
4. Conversation	Communication skills	Language	3, 4, 6
		Communication ability	3, 4, 5, 6
		Speak, listen, ask, silence	1, 2, 3, 4, 5, 6
	Subjects	Care and health	3, 5
		Life story	2, 5, 6, 7
		Family, friends, neighbours	2, 5, 6, 7
		Actual problem	1, 2, 3, 4, 5, 6,7
		Activities and special events	1, 2, 3, 4, 5, 6, 7
		Plans	1, 2, 3, 4, 5, 6, 7
		Nurse and family	4, 6
		Healthcare organisation	4, 5
		Society, news, politics	1, 2, 3, 4, 5, 6, 7

* 1= purpose, 2= moral values and justification, 3= efficacy, 4= self-worth, 5= comprehensibility, 6= connectedness, 7= excitement

3.1 Being in a private environment

Home nurses enter the houses of patients. We observed that being, and perceiving, in a private space provides insight into MIL of older adults. Subthemes for this theme are: entering, signs & symbols.

Mr Brown and nurse Kate
When we arrive at Mr Brown's house, Kate shows the bag of the care provider through the window. Then Mr Brown (age 86) can be sure she is a trusted person and opens the door. In the living room pictures have lost colour, plants are dehydrated. Newspapers lie on the table in a neat pile, unread. A large calendar-clock stands on a visible place. When we enter, Mr Brown immediately walks to the kitchen, with brisk steps, without greeting us. (B-151209-OZ1-2)

Mrs Livingstone and assistant nurse Zehra
While we are cycling to Mrs Livingstone's, Zehra tells me her patient is very ill and may die soon. She hopes that Mrs Livingstone's daughter, who lives in the same house, will be there, but when she opens the house with a key only a cat comes to greet us. Zehra silently climbs up the stairs. Maybe Mrs Livingstone is still sleeping. The house is untidy. It smells bad. Mrs Livingstone lies in the sleeping room in an adjustable bed. Above the bed hang a crucifix and a beautiful black-and-white picture of Mrs Livingstone when she was young. (C-170209-OZ1-3)

3.1.1 Entering

Like Mr Brown, many patients attached great importance to opening the door themselves (4). When patients were not able themselves, the nurse opened the door (3). Nurses frequently paid attention to the fact that they were entering a private environment by ringing the bell, greeting, or taking off their shoes (2, 4). Sometimes significant others were there (even, in Mrs Livingstone's case, by being absent), sometimes a pet that needed attention. Pets are frequently of great importance, providing purpose in life for patients (1, 6).

3.1.2 Signs and symbols

Entering the house provided opportunities to observe and experience the private environment of patients. Are there photos of precious moments or relatives (5, 6, 7), fresh flowers (4, 6, 7)? Is the apartment well-kept (2, 3, 4)? Are there signs of what the patient was doing before the nurse entered (1, 2, 3, 7)? There may be

spiritual artefacts (2). The house 'tells a story' about the person who lives there (2, 5). All observations can be the subject of a conversation with the patient.

3.2 Nurse-patient encounter embedded in relationship

Relationships in home nursing are usually long-term and close-knit. This fact coloured the daily visits we observed (5, 6). MIL could be perceived in many aspects of the encounter between nurse and patient. Subthemes are: greeting, seeing the patient, focus of attention, interaction with nurse.

Mr Brown and nurse Kate
Mr Brown has been waiting for us. He is wearing his pyjamas inside out, two different socks, his hair is dishevelled and he has a distressed look. Mr Brown tells, annoyed, that someone keeps hiding his teabags. Yesterday he found some under his pillow. Kate asks him if he wants to search together. When Mr Brown finds a teabag, Kate makes a cup of tea for him. She quietly mentions what she is doing: 'I am making a cup of tea with the teabag you just gave me'. (B-151209-OZ1-2)

Mr and Mrs Graham and nurse Gregory
When we enter, a lot of family members appear to be around. Gregory takes off his shoes. Although Mr Graham is terminally ill and Mrs Graham wants to avoid unnecessary turmoil, she insists on drinking a cup of tea. Gregory quietly sits with Mrs Graham and listens to her story. She tells: 'He has been sleeping only for a few hours, but that's not enough. It is so terrible when you wake up at night and call out, but nobody responds. I know that from my own experience.' Gregory: 'Yes, of course he needs rest. I can see you are doing things perfectly.' He seems familiar with her. (E-151008-GV1-5)

3.2.1 Greeting

When nurse and patient meet they usually greet each other. The greeting sets the tone for the visit. In our observations greetings were cordial, sometimes with a kiss when there was a warm relationship, sometimes more formal (2, 4, 6, 7). Just like saying hello, saying goodbye was another important moment in the encounter. Appointments were made for the next visit or the nurse referred to an activity, e.g.: *'have a nice visit with your granddaughter!'* (1, 3, 5, 7).

3.2.2 Seeing the patient

The nurse sees the patient and vice versa. From the case of Mr Brown and Kate we can learn that the appearance of the patient revealed information about him (1, 3, 5, 7). He was waiting for help (1, 3) but did not trust anyone (2, 6). From Kate's reaction we can understand that she perceived his confusion and attuned to his interpretation of the situation (5, 6).

3.2.3 Focus of attention

We observed that the nurse's focus of attention differed. In some encounters the nurse was concentrated merely on the intervention that had to be performed, such as wound care or an injection (3). In other situations, the attention was focused on the whole person, family and environment (4, 6), like in the situation of Mrs and Mr Graham (1, 3, 6, 7). Attention to the patient as a whole human being may contribute to the experience of being a valuable person (4, 6).

3.2.4 Interaction with nurse

As the subthemes reveal (Table 4.1), we distinguished several characteristics. Some patients, like Mr Brown, were unsure as to whether they could trust personnel in their private space, sometimes due to cognitive decline. In this situation the contact was distant, promoting self-respect and comprehensibility for Mr Brown (2, 5, 6). Other situations (see example~~s~~) reflected nearness, familiarity and appreciation (2, 4, 6, 7). We frequently noticed reciprocity in the encounter (6). Despite their own sorrow, Mr Graham's family insisted on drinking a cup of tea, which reflected their value of hospitality (2). We observed nurses and patients who were accustomed to an appreciated ritual, like a specific greeting or a joke (2, 6, 7). Non-verbal communication, such as a glance or a hug, was important. It expressed connectedness probably more than conversation (4, 6). Interaction was further characterised by time and pace. Mostly the care had to be done in time, either because time is always constrained in home nursing or because the patient had an activity, for instance a visit to a doctor (1, 3, 6, 7). However, several nurses, as shown in the examples provided, chose to take their time and adapted to the pace of the patient (3, 4, 6).

3.3 Personal care

Most times personal care was the central element in nurses' visits to patients. Subthemes for this theme are: adaptation to patient, touch.

Mrs Livingstone and assistant nurse Zehra
When we approach her bed, Mrs Livingstone opens her eyes. She is over 90 years old. She looks fragile. Zehra says she has known Mrs Livingstone for a very long time already. 'Mrs Livingstone worked very hard all her life.' Mrs Livingstone smiles. She tells Zehra she has a new grandson and she has seen him already: 'He is so little!' and her eyes radiate. Mrs. Livingstone says she would like to get out of bed for a little while. Zehra doubts: she doesn't know when Mrs Livingstone's daughter will return. It might take too long for Mrs Livingstone to stay up. Then Zehra asks her which clothes she wants to wear. Zehra shows her items that are comfortable both when seated and while lying in bed. Zehra helps Mrs Livingstone with a bed bath, getting dressed, combing her hair. She is very gentle with her. They don't speak much. Mrs Livingstone has many contractures. Zehra carefully turns Mrs Livingstone and helps her find a comfortable position in bed. All of Zehra's gestures express respect and tenderness. During our visit Zehra's son calls her: he is home again. Zehra tells that it is important for her to know that he is all right. Mrs Livingstone smiles and says: 'That's how mothers are. I know that!' (C-170209-OZ1-3)

3.3.1 Adaptation to patient

Many nurses, like Zehra, adapted the care according to the wishes and possibilities of the patient, while taking consequences into account (1, 2, 3). Nurses paid attention to the dignity and self-worth of patients by letting them decide, for instance, about clothing and the way to perform the care (4).

3.3.2 Touch

As Zehra showed us, touch is not solely instrumental. It is also an opportunity to express connection with the other as a valuable human being (4, 6).

3.4 Conversation

Conversation usually started when the nurse entered the house: 'Hello! How are you today?' 'Did you sleep well tonight?' Sometimes it was the patient who started the conversation. Some patients talked from the moment we came in until we left (1, 6, 7), others preferred to share as little as possible (2). Subthemes for this theme are: communication skills, subjects.

Mr Roberts and nurse Beth

On our way to Mr Roberts Beth tells me that nurses assist him since he fell some time ago. Mr Roberts is an 83-year-old man diagnosed with cognitive disorder and depression. When we enter the house, Mr Roberts is already dressed. Beth motivates him to shave too. In the bathroom a conversation starts. Mr Roberts tells Beth he does not feel well, there is no pleasure in life anymore. He says he wants euthanasia. Beth takes the time to listen. She asks him what is troubling his mind. Mr Roberts tells her he had to give up his driver's licence. That robbed him of the freedom to go wherever he wanted. Since his wife died long ago, he managed to be independent. 'To lose my freedom is the most terrible thing.' Beth listens and confirms that it is hard to accept. Then he tells about the burglary in his house recently… A neighbour chased them out. Mr Roberts continues talking, now about his granddaughter: she is going to be a mother. It will be his first great-grandchild! He says he is very excited about it. I can see his face brighten up. (D-170801-GV3-1)

3.4.1 Communication skills

Although most patients we visited were able to speak, we also met patients who had difficulties expressing themselves. In multicultural districts nurses visited older patients who did not speak Dutch (3). Nurses had different cultural backgrounds and sometimes spoke with patients in their mother tongue (4, 6). Other patients had physical conditions that impeded speech (3). In all these situations non-verbal communication of nurses was crucial to show connection and respect (4, 6). Communication skills of nurses and patients play an important role. The nurses in our examples were skilled in listening, asking and using silence. This expresses not only respect (4) and connectedness (6) but can be related to other MIL dimensions as well.

3.4.2 Subjects

Conversation often started with common subjects like the weather or daily activities (1, 7). Many times, the actual health status and care provided were subject of discussion (3, 5). As in other aspects of the interaction, the focus of the communication differed: sometimes it was directed at a technical intervention, sometimes at the patient (or his family), but more often it was reciprocal (5, 6, 7). We observed that in the casualness of personal care, small talk easily developed into a conversation about existential issues of the patient. The example of Mr Roberts illustrates this. Nurses and patients discussed many things, and sometimes several in one visit, such as their activities for that day, plans for the weekend,

their life story, children and grandchildren (1, 2, 3, 4, 5, 6, 7). Sometimes patients reflected with nurses on their past: Why did it happen that way? Did I do the right thing (2, 5, 6, 7)? Older patients were concerned or wondered about the future: What will be in it for me or for my grandchildren (2, 5, 6, 7)? Many patients spontaneously shared their concerns, e.g. about changes in the healthcare organisation, politics, society, the position of older people, safety in the world and the daily news (1, 2, 3, 4, 5, 6, 7). Nurses shared their worries about recently deteriorated working conditions (6). Frequently a nurse brought in a topic from the outside world that might interest a patient. Many times, patients also asked nurses about their life, family and work (4, 6, 7).

4 Discussion

Our findings have implications for knowledge, practice, education and public debate.

This paper provides professionals with *knowledge* of situations in daily home nursing related to older adults' MIL. As far as we know, this is the first empirical article about this subject. This paper adds a practical view to the current, mainly theoretical, literature about MIL. Our results show that patients' MIL is highly perceivable in daily home nursing: in the private environment; in the nurse-patient encounter embedded in a relationship; in personal care; and in conversation. To summarise, MIL may come to light in every situation in (home) nursing.
Our paper may help nurses *in practice* to recognise MIL in their work. However, understanding MIL goes beyond knowledge of themes or dimensions. Our exemplars show that MIL is embedded in nurse-patient relationship and the context of the situation. Nurses also need to learn *how* to perceive MIL. This implies opening-up for what can be perceived. Martinsen (2006) explains how nurses can 'see with the heart's eye', which combines two ways of seeing: the first is *perceiving* the other and feeling touched personally ('the other is a person like me'), the second is reflective and *understanding* ('the other is not me, I might be of help'). 'The heart's eye' lies in the interaction, and the space, between perceiving and understanding.

As we can learn from Zehra and the other nurses in our study, 'seeing with the heart's eye' is the start of responsive 'good' nursing (Tronto, 1993). Therefore,

nursing *education* should not only provide knowledge about MIL, but moreover, challenge students to 'see with the heart's eye'.

Finally, our findings show that organisational and societal circumstances influence nurses to perceive MIL during their visits. Several authors mentioned previously that nurses are unable to perceive what is really important for the patient as a person, because institutions and politics put pressure on nurses to narrowly focus on aspects that can be registered, like symptoms, minutes, observation scales and interventions. This leads to alienation from the perspective of patients (Baart, 2011; Ranheim & Dahlberg, 2012). Martinsen (2006) describes this as 'the recording eye'. We therefore hope that this article will contribute to the *public debate about healthcare*. If MIL is important, healthcare managers and politicians should, besides nurses, be aware of the influence their decisions have on nurses' ability to perceive meaning in life.

4.1 Limitations

Our study has limitations. Firstly, we observed single visits to patients, which are actually part of a longer nurse-patient relationship. This may have limited our understanding. Secondly, the nurses and patients may have behaved differently than usual during our observations (Hawthorne effect). However, observations did last several hours. We noticed that initially nurses were 'trying to do their best' but behaved more 'naturally' after a short time. Another limitation of the method (observations) is that findings do not explicitly reveal the voices of the observed persons. An avenue for future research may include the use of qualitative interviews, to elicit their perspective.

5 Conclusion

The aim of this study was to explore situations in daily home nursing related to MIL of older adults at home. All of Derkx's MIL dimensions were recognisable in our observations. Using these dimensions allowed us to analyse situations in detail and, by doing so, bridge conceptual thinking about MIL to nursing practice. We

conclude that MIL of older adults may come to light in every situation of daily home nursing. This implies that there are many opportunities for nurses to attune their work to patients' MIL. Empirical research is needed to further explore the nursing role regarding this subject. Nurses should be enabled at the educational, institutional and political level to develop perception and understanding – to have a 'heart's eye'.

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Chapter 5

Nurse's attunement to patient's meaning in life

A qualitative study of experiences of Dutch adults ageing in place

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Abstract

Background: Meaning in life (MiL) is considered to be an important part of health and is associated with many positive outcomes in older adults, such as quality of life and longevity. As health promotors, nurses may take patients' MiL into account in the care process. There is a knowledge gap in terms of what constitutes good care in relation to older patients' MiL, and what the benefits may be for patients when nursing is attuned to this aspect. The purpose of this study was to explore the experiences of home nursing older adults in relation to nurses' attunement to MiL.

Methods: Gadamerian hermeneutic phenomenological design with semi-structured interviews. Participants were 24 aged home nursing patients. A framework of care ethical evaluation was used in the analysis. Multiple dialogues enhanced understanding.

Results: Patients did not expect nurses' regard for their MiL. They rather expected 'normal contact' and adequate physical care. Nurses showed that they were open to patients' MiL by being interested in the patient as a person and by being attentive to specific and hidden needs. Participants explained that the nurse's behaviour upon arrival set the tone: they knew immediately if there was room for MiL or not. All participants had positive and negative experiences with nurses' behaviour in relation to MiL. Valued nursing care included maintaining a long, kind and reciprocal relationship; doing what was needed; and skilled personalised care. Participants mentioned 'special ones': nurses who attuned to them in a special way and did more than expected. Benefits of care that was attuned to patients' MiL were: experiencing a cheerful moment, feeling secure, feeling like a valuable person and having a good day. Older adults also stressed that consideration for MiL helps identify what is important in healthcare.

Conclusion: Aged homecare patients value nurses' attunement to their MiL positively. Although patients regard MiL mostly as their own quest, nurses play a modest yet important role. Managers and educators should support nurses' investment in reciprocal nurse-patient relationships.

Keywords: *Meaning in life, older adults, patient's perspective, nurse-patient relationship, home nursing, quality of care, well-being, healthy ageing, positive health, ageing in place.*

1 Background

Because of ageing populations worldwide (1), nurses' patients increasingly consist of aged persons. Healthy ageing is considered to be an important objective for both nurses and patients (2). What 'health' means depends on one's definition (3, 4). 'Positive health' is regarded as most relevant in the care for chronically ill (older) patients due to its holistic and subjectivist character (3). Positive health is described as an individual multidimensional process that focusses on positive outcomes in order to enable adaptation to life's challenges (5-8). Huber included six dimensions of positive health in her model: bodily functions, mental functions & perceptions, quality of life, social & societal participation, daily functioning, and MiL & spirituality (5). She regarded MiL as the most important dimension (9). As suggested by adherents of positive health, research confirms that high levels of MiL in aged adults are associated with a higher quality of life (10), a healthier lifestyle (11), longevity (12-14) and a lower prevalence of age-related conditions (13, 15, 16). In this article we focus exclusively on MiL. Human beings desire to live meaningful lives (17-19). MiL is a personal perception or understanding about one's life and activities and the value ascribed to them (20). MiL encompasses both the 'big questions in life' (existential meaning) and the meaning of experiences on a daily basis (daily meaning) (21, 22). Nurses have a fundamental responsibility to promote and restore health (23). Since MiL is an important part of health, nurses may take patients' MiL into account in the care process. Patients regard MiL as important and believe that health professionals, including nurses, can play a role (24). What this role should be and what the patient's benefits are, is scarcely discussed in empirical literature. Research in nursing homes shows that nurses play a role in patients' MiL by taking care of their physical and mental well-being, by promoting cherished activities (25), and by a confirming and kind relationship that includes careful listening and respect for the patient as a person (26).

A limitation of the few available studies is that they all have been conducted in nursing homes, whereas nowadays most people age in place (2), steadily using more home nursing services (27). In the Netherlands, where this study was conducted, 94% of persons over 65 age in place (28). People ageing in their own homes could provide a different perspective on care in relation to MiL than those living in nursing homes, as living at home is an important source of MiL among older adults (29, 30). There is a knowledge gap on the subject of home nurses' recognising and responding to older patients' MiL. Furthermore, the possible benefits of this care for patients are unclear.

Because MiL is different for every individual(19, 29) and older adults have different strategies to retain MiL (29, 31, 32), good care with respect to MiL requires individual attunement. We chose Tronto's four elements of good care as a theoretical lens, as they clearly include this individual attunement.

The elements are (33):

- *Attentiveness:* Recognising the needs of the other. Attentiveness requires suspending one's opinion or goals; it is concerned with the perspective of the other.
- *Responsibility:* Includes responsibility of many persons in society and is rooted in one's cultural role: What can we do for the other from our position?
- *Competence:* This is related to practical caregiving. If care is not provided adequately and tailored to the individual, it can never be good.
- *Responsiveness:* Engagement with the position of the other (the patient) as he or she expresses it. In other words, does the care feel good from the patient's standpoint (34)?

To understand what good care is in relation to a patient's MiL, we clearly need insight into the patient's perspective. Hence the aim of this study was to explore the experiences of older adults who receive home nursing, in terms of nurses' attunement to patients' MiL.

Research questions were:

- What do older adults who receive home nursing expect and value from nurses regarding attunement of care to their MiL?
- What is the consequence of this care for the older adults?

2 Methods

2.1 Setting

Setting for the study was a large care provider in the metropolitan area of Rotterdam, a large multicultural city in the Netherlands. Home nursing in the Netherlands is provided by neighbourhood-based teams consisting of one or two registered nurses and 10-18 nursing assistants of various educational levels (in this paper all referred to as 'nurses' and 'she'). They work in shifts. Nurses of the care provider noticed that a growing number of home nursing patients confronted them with their MiL issues, which nurses found difficult to respond to. During the research period nursing teams followed a training and coaching programme on MiL. At the start of the programme patients from four teams were asked to participate in this study in order to explore their experiences with nurses' attunement to patients' MiL. In the research period the care provider went through several organisational transitions, which resulted in numerous changes in nursing personnel and modifications of many procedures.

2.2 Design

We chose a Gadamerian hermeneutic phenomenological approach for this study. This includes exploring the lifeworld of the participants through opening up, questioning and dialogue in order to arrive at a shared understanding, a 'fusion of horizons' (35-38).

2.3 Participants

We asked nurses of three home nursing teams to find 4-8 patients who reflected the diversity in their neighbourhoods in terms of age, gender, cultural background, socio-economic status and health. When data saturation was approached, we selected a last fourth team to include patients, resulting in 24 participants. Mean age of participants was 82.3 (median 85). Most of them rated their health as moderate and lived alone (n=18), were women (n=18) and had a Dutch cultural background (n=18). Sixteen participants had a religion, but five of them were no longer practising (Table 5.1).

Table 5.1: Background of participants

Age, yrs, 1st interview	
61-65	1
66-70	1
71-75	2
76-80	5
81-85	5
86-90	6
91-95	3
96-100	1
Gender	
Male	6
Female	18
Marital status	
Married/cohabiting	5
Divorced	2
Widowed	15
Single	2
Living arrangement	
Together	6
Alone	18
Cultural background	
Dutch	18
Surinamese	4
Turkish	1
Cape Verdian	1
Religion	
Christian	14
non-practicing	5
Muslim	1
Hindu	1
No religion	8
Highest educational level	
No schooling	3
Primary school	5
Lower vocational	10
Medium vocational	2
Higher	4
Self-rated health, 1st interview	
Excellent	1
Good	8
Moderate	9
Poor	6
Very poor	
Self-rated health, 2nd interview	
Higher score than 1st	8
Same score	9
Lower score	3
Self-rated health, 3rd interview	
Higher score than 2nd	4
Same score	7
Lower score	5

2.4 Interviews

The main researcher (SH) interviewed participants three times, with 5-7-month intervals, between November 2015 and July 2018 in their homes. The aim of repeating interviews was mainly to arrive at a deeper understanding about our research topic. An interview guide was developed specifically for this research project (see Appendix 1). The semi-structured interviews consisted mainly of open questions, focussing on participants' experiences (39, 40). After ten interviews we evaluated the interview questions and made minor changes in formulation.In the interviews we firstly invited the aged person to share experiences on their MiL. These findings are reported in a separate article (29). We subsequently asked the respondents about experiences with nurses' attunement to MiL. Main questions were: Can you tell me something about your relationship with nurses? Do you think/ notice that nurses are aware of your MiL? Can you tell me what you expect/value in this respect? Can you tell a recent example in which the nurse was attuned to your MiL? What was the consequence for you? We followed the flow of conversation and asked follow-up questions to explore the experience in more depth. Additional background information of participants was gathered (Table 5.1). For reasons of transferability, we gathered relevant background information of participants in the first interview. We chose items that, according to large-scale research, are associated with MiL (41-43). Self-rated health was repeated in the successive interviews because this fluctuates in later life. Mean duration of interviews was 61 minutes (range: 32-112). In most interviews interviewer and participant were the only ones in attendance. Two couples, both partners clients of the homecare organisation, were interviewed together. Three participants were assisted by (translating) family members during the interviews because their Dutch language proficiency was limited. Most participants were interviewed three times (n=16), four twice, and four once. Reasons for drop-out were deteriorating health (n=3), death (n=1), moving to a nursing home (n=2) and 'having nothing more to add' (n=2).

2.5 Data analysis

Interviews were transcribed verbatim. In the analysing process we followed the steps of interpretative phenomenological analysis (40). Data were analysed at two levels: firstly at an individual level and subsequently at an overarching level. At the individual level all interviews of each participant were analysed to arrive at a broad and deep understanding of the participant's unique experiences in context. Next, overarching themes were interpreted for all data. This movement from the parts (individual) to the whole and vice versa (36-38) was repeated several times.

In Gadamerian hermeneutic phenomenology interpretation of data is characterised as a dialogue with the texts (36, 37, 44). To analyse the content of

our data we used a modified framework of care ethical evaluation of Kuis & Goossensen (34), which served as a 'dialogue guide' in this process and as such helped us to arrive at a shared understanding, a 'fusion of horizons'. Both our study and care ethical evaluation intend to explore care from the perspective of patients and are inspired by Tronto's four moral dimensions of care (34).

The (modified) framework consists of four main aspects:

1. What is at stake for the aged person?
    a. What are MiL sources for the aged person?
    b. How does the person retain MiL?
    c. What does he/she expect from the nurse?
2. Does the nurse recognise the person's MiL (and the way he/she deals with it)?
3. How does the nurse respond to the patient (attunement to MiL)?
    a. to the struggle, concern, vulnerability, need or pain of the aged person?
    b. to the strength and resilience of the aged person?
4. Does the care well to the patient?
    a. What is the consequence of that?

In accordance with our research questions this article focusses on aspects 1c-4a. Findings of aspects 1a and 1b are reported in a separate article (29), but are included in the analysis of the interviews at the individual level (see Appendices 2-7). Initial analysis was done by the main researcher (SH). To further develop understanding as a 'fusion of horizons', dialogue was part of all phases of data analysis. In a dialogue, through open questioning and answering, an understanding emerges which transcends the subjective opinions of the participants (36, 37). Firstly, dialogues about interpretations were part of the successive interviews with older adults. Secondly, dialogues took place in two research groups: the first one was based within the homecare organisation and consisted of patients, nurses, spiritual counsellors and researchers (MG and SH), the second research group was university-based and consisted of a nurse/health scientist (SH), a health scientist (MG), a philosopher (PD) and a philosopher/social scientist (AM).
Pre-understanding of researchers derived from professional work in nursing, philosophy, research, reading, and personal experiences with ageing dear ones.

2.6 Rigour

Multiple interviews per participant and continuing dialogue promoted credibility of this study (39, 44). Dependability and confirmability were established by recorded and verbatim-transcribed data; analytical software (Atlas-ti 6.2.28); and analytical steps and an analytical framework (40, 45). Reflexivity was fostered through a research diary and dialogues (38, 44). In reporting this article we follow the COREQ (46).

3 Results

3.1 Good care in relation to MiL at two levels

Findings have meaning first of all at the individual level in their own context. We therefore provide six examples as results of the individual analysis, structured by modified framework of care ethical evaluation (Appendices 2-7). To enable the reader to understand the findings in context, the examples include all aspects of this framework. The examples are chosen from the four neighbourhoods (A-D) and display the diverse backgrounds of our participants (see table 5.1).

Next, we present our findings at the overarching level structured by analytical aspects and themes (see Table 2: Themes). The background of participants is summarised in Table 1.

Table 2: Themes

Analytical questions	Themes
Expectations What does the person expect from the nurse?	**'Simply normal contact',** don't expect consideration for MiL from nurses
	Adequate physical care, no MiL support
Recognising MiL Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Setting the tone
	Showing interest in the person
	Being attentive to specific and hidden needs of patients
Response How does the nurse respond to the patient (attunement to MiL)?	Maintaining a long, kind and reciprocal relationship
	Doing what is needed
	Skilled personalised care
	The special ones
Consequence Does the care offered do well to the patient?What is the consequence of that?	A cheerful moment that lifts me up or a superficial encounter
	Feeling secure or insecure
	Feeling like a valuable equal person, a dependent patient, or the nurse's coach
	Having a good day thanks to good humane care, or suffering due to bad care
	Emphasising what is important in healthcare

3.2 Expectations of older persons

Participants shared their expectations with us regarding their contact with nurses and the provided care in relation to their MiL.

3.2.1 'Simply normal contact', don't expect consideration for MiL from nurses

Participants expressed that they mainly expect 'normal contact'. When we asked what 'normal contact' was for them, they mentioned many expectations about nurses' attitudes. They expected nurses to be friendly and polite. Several participants reported experiences of nurses being impolite or rude. They wanted to be treated like a competent grown-up and not as a 'demented granny'. Participants expected nurses to be discreet and not impertinent, for instance by not looking in cupboards unasked. Participants expected nurses to meet their duty to arrive on time and provide care as agreed.

I expect simply normal contact, just being kind to each other. (C1.1, age 86-90)

Many participants told us that the contact with nurses is superficial. They said they don't expect nurses to have regard for Mil and seldom share MiL issues with them. They preferred to share this with near ones or keep these issues to themselves, for they experience MiL as something they must achieve by themselves. They do not want to bother others with it.

I don't think they [nurses] know what is important to me. We talk about normal superficial subjects like children, holidays. Things about meaning in life are mine. If I shared them with anyone, it would be with my son or other family members and not with the nurses. They go from one patient to the other and in the end, I am not more than a number to them. (D2.2, age 96-100)

I told them about the loss of my last friends ... eh ... and they sympathised with me, but you know, they have their own family. So, I keep it as much as possible to myself. You know, you shouldn't bother others with your grief and worries. You just shouldn't. (A3.3, age 76-80)

3.2.2 Adequate physical care, no MiL support

Many participants believed that nursing is limited to physical care. First of all, they expected nurses to provide this care adequately and with technical proficiency.

They are there for their work. They help me with taking a shower; they dry and rub me with body lotion. They even dry the shower stall. (A3.2, age 76-80)

Some participants expressed that they don't believe nurses are competent to provide support in MiL, but most of all they experienced that nurses lack the time, knowledge or attitude.

I am expecting practical things from them, like fastening a button. To ask: 'Can I mean something for you?'... They can mainly do something for me. 'To mean something' is deeper. Then you must sit down, stay seated and listen. (D5.3, age 96-100)

3.3 Recognising what is at stake

Although most participants did not expect nurses to take MiL into consideration in their care, they nonetheless shared several examples with us showing that nurses were open to patients' MiL. Participants also provided examples where nurses neglected MiL.

3.2.1 Setting the tone

In our dialogues the older adults explained that nurses already set the tone for the encounter when entering the patient's house. Participants said they immediately notice whether the nurse is in a good or a bad mood, when there is something bothering her, if she is in a hurry. They explained that they adapt to this condition of the nurse. For some participants the encounter had a large impact on their day, for others this was less important.

They are like the weather: When they are in a bad mood, they are unable to enter joyfully. And I won't react too much. But if they enter with good cheer, it gives me a boost like: Cheer-up! Let's go for it! (D4.1, age 76-80)

The nurse's behaviour upon arriving also sets the tone for space for MiL. Many participants did not experience this space with nurses because of their time slots and their task-oriented behaviour.

Sometimes the nurse enters and from the hall she yells: 'How are you?' And I am here. Then she throws down her coat and focusses on the book (patient file). I don't know what to answer then. 'How are you' is a big question. But if it is asked in such a way, I cannot respond. Yes, if you sit down and ask me while you sit close to me.... (B1.1, age 86-90)

3.2.2 Showing interest in the person

Participants appreciated that most nurses show interest in them as a person. Nurses asked, for instance, if they slept well or about the plans for the day. Participants told that nurses sometimes have time for a short talk or a cup of coffee, although this had become rare after organisational changes by the home care provider. Although they considered most talks to be superficial, without touching upon their MiL, they explained that it was nevertheless important for them that nurses be interested in them as whole persons.

> *There are nurses who come back to a conversation we had three weeks ago! Then I conclude: they listened to me with attention, they took the effort to remember it and continue the conversation. And then I feel very happy.*
> *(D4.2, age 76-80)*

And yet, participants also gave examples of nurses who seemed there only to carry out their technical tasks. They experienced this as denigrating.

> *When I feel that they solely come to pour that drop into my eye and put on those elastic stockings, only for the bare fact of doing this, it feels denigrating to me. I would like them to approach me with a basic interest in me. (D4.3, age 76-80)*

3.2.3 Being attentive to specific and hidden needs of patients

Participants related experiences with nurses who noticed specific needs. Sometimes the older adults tried to hide their pain or sadness, but nurses who knew them for a long time immediately recognised the signs. Others told about situations they could not oversee, when a nurse understood perfectly what they needed.

> *Only those from the regular group, the ones I know already for a very long time, they immediately see if something is wrong … they see it in the person. I cannot hide it from them. Especially [name] and [name] … [name] asked: what is wrong? And I said: nothing. And we sat chatting for a little while and, eh … she just knew anyway! (A2.2, age 61-65)*

By contrast, some participants mentioned situations when nurses were inattentive, sometimes failing to properly assess the needs of the patient or omitting to ask follow-up questions to learn more about their situation.

They could keep their eyes and ears more open to the people in the neighbourhood. I think people show more than they notice. If you are telling something, they come up with a story that is ten times worse. And then I won't tell it anymore ... They could ask a bit deeper: what is it that isn't going well? It is this attentiveness that I'm missing. (A1.1, age 76-80)

According to some participants, the organisation asks too much attention, which blurs the focus of nurses' real work: the patient.

The nurses are being jerked around. Those changes in the organisation are an excuse for other procedures here. And [name nurse] has to explain all that to us, in her free time. But that has nothing to do with us. That's not our business. We listen to them, but it distracts from what they come for. But most of all, it limits the pleasure they have in their work. And that is important to us too. (B5.2, age 71-75)

3.4 Nurse's response

Although most participants mentioned that they don't expect nurses to have consideration for their MiL, they nevertheless reported many experiences of care which they considered to be attuned to it. They also shared examples of non-attuned care.

3.4.1 Maintaining a long, kind and reciprocal relationship

Participants expressed special affection towards nurses or permanent staff who had cared for them for a long time. They explained that knowing the nurses was important to them. Then both patient and nurse share other things, like experiences with dear ones, hobbies, etc. Participants enjoyed this immensely. In our dialogues with participants the reciprocal character of the nurse-patient relationship emerged as pivotal theme. Participants appreciated nurses sharing their own lives with them. Many participants were already aware of the reciprocal character of the relationship, others realised it during our dialogues. Participants told that, just as nurses do with them, they do their best to be friendly and interested in the nurse as a person. Instead of only receiving, participants took pleasure in giving nurses something in return. Some offered fruit or drinks, others gave little presents.

Well, they see all those materials on my table, and they ask about it and say: 'you have been making such nice things!' And I give them away to them. [name] had had a grandson and I have a little basket with baby socks which I made. And I asked her to choose one for her grandson. And then later on she gave me a picture of the child with the socks. And that is so nice! (B3.1, age 81-85)

Sometimes when they have a free hour they come to my home. I tell them: come to me. I'll make you tea, coffee, whatever you want. And then they eat their lunch sandwich here and I really enjoy that. Then you have different conversations. More about what's on their mind. And they say to me: You are just like a mom to us. And then we're joking around. (A3.3, age 76-80)

Participants also told us that they functioned as a 'sounding board' for the nurses. They listened carefully to their worries and gave them advice.

This morning [name] was here and she told me about the problems she had with her children. And I was able to give her some advice. She also tells her own stories and that's fine with me. We have a good relationship and that is part of it. (A2.2, age 61-65)

Participants felt sorry for the nurses' poor working conditions. They tried to help them by doing as much as possible by themselves. They also refrained from asking for more time or attention. Many participants complained about the large number of temporary workers. They feel less at ease with them.

3.4.2 Doing what is needed

Participants especially valued nurses' decisiveness. They told us about incidents when they genuinely were in trouble, due to extreme pain, sickness, exhaustion or an unforeseen situation. The nurse who visited them immediately understood the position of the patient (attentiveness) and acted adequately, for instance by calling the family doctor, arranging devices, providing the right physical care, or by sitting next to the patient and listening.

There are a few women [nurses], especially [name], who I really trust. I know her from the very first day and she would take care of anything I needed, without me even telling or asking her. She just did it. She arranged the dial-a-bus, a shower chair, everything. (D1.1, age 86-90)

3.4.3 Skilled personalised care

Although self-rated health of participants hardly changed in the three interviews (table 1), many stories of participants revealed how their condition deteriorated. They explained that skilled personalised care is very important to them. They have their own habits and wishes, fitting with their values. Besides, adequate care means less pain and fatigue.

> *They do their work well: fast and well … When they dress my wound, they are very careful not to hurt me. That's humane. And they bind my slippers onto my feet, so bacteria don't get into my wound, because I cannot see it. They are caring.' (C6.2, age 81-85)*

Participants shared that they preferred to be cared for by nurses they already knew for a long time: those nurses knew exactly what to do and how to do it properly. Additionally, those nurses do not take over activities that participants can still do themselves, or exactly the opposite: nurses do take over extra activities on a bad day. Participants complained about the frequent interim personnel. Some of the temporary workers showed limited technical skills. Every detail had to be explained to them, exhausting patients and causing them distress.

> *Those few nurses do the care well. My leg is extremely painful. If you touch it like that, it hurts already. And one of those temporary nurses, she didn't know how to bandage, although I told her how. And yes, after a little while the bandages fell off. And the consequence was that my legs became thicker and even more painful during that day. (A2.3, age 61-65)*

Many participants complained about the fact that home nurses were rarely on time. Others expressed their appreciation for nurses who were on time, so they could for instance go to church, which was important for them.

3.4.4 'The special ones'

Almost every participant mentioned a favourite nurse, 'a special one'. These were nurses with whom a special connection was felt; they were attuned in a special way to the personality and needs of the patient. Many of these nurses showed all the positive themes mentioned in sections 3.3 and 3.4, and more. According to our participants, these 'special ones' did something extra for patients, something that was not prescribed in the nursing plan, even against the rules of the organisation, but which was highly appreciated. We heard many stories of 'special ones'. For

instance, a favourite nurse took letters to the mailbox for a patient with limited mobility; came by in her private time to show her new-born baby; walked the dog for a sick patient; enjoyed and danced to music together.

> *[name] is my darling. When she visits me and my son's music plays, she stands here dancing and I say: Hey, there is Tina Turner again! And she jokes about my untidy hair. We make fun of each other. And I say to the Lord: You give me exactly the girl I need! (C3.2, age 76-80)*

3.5 Consequences for the older person

Our participants explained how the care, which they considered to be attuned to their MiL, or the lack thereof, impacted their life. Participants also mentioned a consequence for healthcare service.

3.5.1 A cheerful moment that lifts me up or a superficial encounter

For most participants the visits of the home nurse were gleeful moments during the day, especially if the nurse was one of their favourites. They told that a pleasant visit of a nurse helps start the day joyfully, it breaks the day and as a consequence they feel uplifted.

> *Sometimes I am alone all day and they come twice a day. Most times they are busy, but sometimes I offer them a cup of coffee and we have a little talk. It gives a pleasant atmosphere and provides me with a cosy feeling. (D5.3, age 96-100)*

> *I feel happy when the nurse enters my home, even if she can only stay for five minutes. It is attention and I always say: for human beings attention is more important than food. And when they pass my window they always wave, and in fact that is already contact. Marvellous. (D3.3, age 91-95)*

As explained before by participants, temporary staff, or a negative tone when the nurse arrives, resulted in encounters that remained superficial.

3.5.2 Feeling secure or insecure

The friendly, reciprocal contact with nurses provided participants with a sense of security: a known, trusted person was watching over them.

> *They come to look after me because I am very old and have nobody. They check on me. That feels safe. They sit here for a little while and they always say: it is so cosy with you. They can rest here for a little while. I can relate to them, start a light conversation with them, because I worked with people all my life. (B4.3, age 96-100)*

A few participants told about nurses who did not respect their privacy or even displayed intimidating behaviour, which resulted in feelings of stress and unsafety.

> *The big man [male nurse] was standing in front of me and said: you can hire me privately and I will be on time. You can pay me directly. And I thought: If I don't promise to hire him, he'll hit me … That's unseemly behaviour. I have been of service to others my entire life in my job. I think things are moving the wrong way with healthcare. (D6.2, age 86-90)*

3.5.3 Feeling like a valuable equal person, a dependent patient, or the nurse's coach

Participants shared with us that the long reciprocal relationship with permanent staff nurses, particularly the special ones, provided them with a feeling of trust and equality. They explained that it is important for them to be regarded as equal human beings instead of dependent patients. Participants felt valued when nurses thanked them for listening.

> *Yes, they are open to me, so nice. They don't sit here like a nurse but more like a good acquaintance. That's what I like so much … As a patient you can be pitiable and as a human being you just feel normal. That's it: I don't feel like a patient. I don't want to. I just want to be human among other humans … There is one nurse who calls me her friend. That's so nice. (D1.3, age 86-90)*

> *I appreciate the trust she has in me. Because when she is asking me, she knows I have an honest opinion… however, most times I am just listening to them. (A1.3, age 76-80)*

Although participants appreciated a reciprocal relationship with familiar nurses, for some of them the balance between giving and receiving was off: the attention they paid to nurses' worries overshadowed their own problems**.**

When they run into difficulties in their work, they come to me. [Tells an example of another patient.] And then they turn to me for advice. Honestly, that puts a burden on me, because I keep thinking about it … There is hardly any focus on me. Well, on the other hand, I don't take the opportunity to tell about myself … (A1.3, age 76-80)

3.5.4 Having a good day thanks to good humane care, or suffering due to bad care

Participants explained how skilled care has a large impact on their life. If physical care is done correctly it limits pain, suffering and exhaustion, leaving room for them to do what is important to them, like gardening or visiting family. The provided care is a prerequisite for having a good day, living their life as they want to.

They [permanent staff] are good women. They know everything, I don't have to explain, and they do their work very well and then it is not painful. I am not stressed anymore. I can sleep again and eat again. (C5.1, age 66-70)

Waiting for the nurse for no reason feels pointless for participants and limits the activities of that day.

We still have an active life. I do as much as I can by myself. I had to be in the hospital on time. The taxi will not wait. It intrudes in my life when they are too late. I was there sitting and waiting, and they even didn't call to say they were late … I was used to care independently for myself and my partner all my life. And when they don't come on time, I lose part of my life. We don't blame those nurses we know. It's taken away by the policy of an organisation. It makes me feel curtailed. (B5.2, age 70-75)

3.5.5 Emphasising what is important in healthcare

Many participants considered healthcare services to be deteriorating. Participants stressed that nurses' concern for patients' MiL was not only important for them as individuals, but also for healthcare in general. They explained that the focus on patients' MiL also restored attention to what's really important in healthcare.

Well, I think that the higher you come in the organisation, the less focus there is on this aspect [MiL] and on emotions. And that is important for the people who give those trainings: that these very tiny spiritual notes are most important in the big picture.' (D4.3, age 76-80)

4 Discussion

The aim of this study was to explore the experiences of older adults who receive home nursing in terms of nurses' attunement to patients' MiL. To our knowledge, it is the first study on this subject from the perspective of adults ageing in place, which is the majority of ageing people (2, 28). MiL is an important part of health (5) and is vital for healthy ageing (13-16). The results of this study provide a valuable insight into good (and bad) nursing care in relation to patients' MiL. In this section we discuss our results in the context of other, rather scant scholarly literature. Our findings reveal that older adults receiving home nursing did not expect nurses to pay specific attention to MiL. At the same time, all our participants shared with us good and bad experiences of care that they considered as attuned to their MiL (or not) and which impacted their life. Our reflections on the findings are structured by Tronto's four dimensions of good care. We end with some remarks about the nurse-patient relationship in homecare, as our results clearly show that good care attuned to patients' MiL is embedded in this relationship.

4.1 Good care in relation to patients' MiL

As our results reveal, both at the individual level (Appendices 2-7) and the overarching level (Themes), good care in relation to MiL covers all four moral dimensions of Tronto: attentiveness, competence, responsibility and responsiveness.

Attentivenes. On the one hand our participants related positive experiences with nurses who were interested in them as a person, took the time and were attentive to their – sometimes unuttered – needs. On the other hand, participants complained about nurses who disregarded basic polite behaviour, didn't have time

for them, and paid attention exclusively to technical interventions. Because our study is concerned with the *patient's* perspective, we are unable to reveal what happened inside the *nurses'* minds and hearts – as one of our participants said, '*I cannot know what they perceive.*' Klaver & Baart unruffled elements of attentiveness (in oncology nursing): attentiveness is not only perceiving something but also realising what one perceives (interpretation). Attentiveness is enhanced if nurses have space and time to pay attention (47), which they mostly lack according to our participants. This study adds that a longstanding relationship enhances attentiveness, since observations can be interpreted in the context of the patient's life. Healthcare managers should therefore guarantee adequate space and time to enable nurses to invest in longstanding relationships. To our participants, attentiveness to MiL is not only important in the nurse-patient relationship but also at an institutional level, as awareness of MiL emphasises what is important in healthcare.

Competence. Participants were unanimous about the importance of skilled personalised care for their MiL because it limits pain, exhaustion and stress, which they regard as negative conditions for MiL. This was also described for nursing home patients (25). Some respondents doubted whether nurses were competent to provide support with MiL.

Responsibility. This dimension of good care emerged at three levels in our results. Firstly, participants considered nurses to be responsible for providing technically skilled care, keeping their commitments, arriving on time, doing what was needed, and adjusting the care to the specific needs and wishes of the patient. Secondly, participants were very clear that nurses' (poor) working conditions were the responsibility of the management of the healthcare organisation. They blamed management for the nurses' lack of time and the discontinuity in personnel, which negatively influenced their life. Thirdly, participants stressed that they regarded MiL as their own responsibility. This seems to contradict studies in nursing homes and in the general population, where authors conclude that nurses have an important supportive role in patients' MiL (24-26). Our results seem to deviate from these conclusions (for home nursing). Our participants emphasised that finding MiL is predominantly their own quest, although they sometimes shared MiL issues with family or friends. At first glance they expected 'normal' contact and adequate physical care from the nurses but no specific MiL support. Nonetheless, participants showed in their examples that through a kind equal and reciprocal nurse-patient relationship and skilled personalised care, nurses do support them: they enhance (or deteriorate) the conditions under which patients themselves maintain or find MiL. In other words, by attuning to patients' MiL in their 'normal' daily behaviour nurses can support them in maintaining their MiL. We should not overestimate this role of the nurse though: the examples in the appendices of this article and earlier literature (42, 48-50) show that other circumstances play an

important role regarding MiL in old age, such as deteriorating health, loss of dear ones, and other (negative or positive) life events. Compared to those conditions, nurses' role may be modest yet remains important. The role of nurses is especially promising because home nurses have many opportunities during daily care to attune to patients' MiL (51). We therefore confirm that nurses have an important supportive role, as described in other papers (24-26), but our study adds that this role should be considered in the context of many other influencing circumstances. What's more, recent healthcare interest in patients' MiL should not lead to taking over patients' responsibility through a formal approach – a 'registering eye', as Martinson described it (52). Rather, professionals should adopt a modest caring role. By creating openness and space, allowing both personal closeness and professional (more distant) understanding, nurses can be present in the patient's world yet without possessing it (52).

Responsiveness. Although participants did not expect nurses to attune care to their MiL, they were all able to provide positive examples of this behaviour. Care that was attuned to patients' MiL felt good and participants benefitted from it: they were lifted up by a cheerful moment, they felt secure and valuable as persons instead of as patients, and had a good day thanks to good humane care.

4.2 Reciprocal nurse-patient relationship in homecare as a vehicle for good care

As our results show, participants highly valued long, kind and reciprocal relationships with nurses. Attunement to patients' MiL was embedded in this nurse-patient relationship. Literature supports centrality of the nurse-patient relationship in homecare, as our study did. With familiar and trusted nurses patients feel at ease, accepted and connected; those nurses provide physical care that is adjusted to the person; patients feel known as equal, valued individuals and are encouraged and motivated (53, 54). Our participants emphasised that especially feeling as an equal person, instead of a patient, was important to them. The nurse-patient relationship provided them with the opportunity to enact favourite (social) roles and use their character strengths, which are pivotal for MiL (29, 55). In a reciprocal relationship both partners give and receive. Although patients experienced benefits from giving something in return to nurses, this gradually became a burden for a few of our participants when their support of nurses' problems started to overshadow their own. In reciprocal relationships, balancing giving and receiving is a continuous endeavour that affects both partners – in this case patients and nurses.

4.3 Methodological considerations

The Gadamerian hermeneutical phenomenological approach enabled us to arrive at a mutual understanding of this subject, together with the participants. Multiple interviews with participants deepened understanding. Diverse backgrounds (of participants and researchers) and in-depth dialogues contributed to new insights, a 'fusion of horizons', for both researchers and participants (36). Many participants greatly enjoyed our conversations, as they seldom had the opportunity to discuss topics beyond a superficial level. The theory of Tronto and the questions of care ethical evaluation proved to be a helpful framework to analyse nursing in relation to MiL.

Our study has limitations. Firstly, sampling and attrition limit the transferability of this research. Secondly, the credibility of three interviews was compromised by the presence and translation of family members of non-Dutch-speaking participants, even as this enabled us to include participants of more cultural backgrounds. Thirdly, considerable organisational transitions during the research period definitely impacted the results of this study. But healthcare is always changing anyway. The organisational turmoil revealed the important role that management plays in safeguarding conditions that promote – or inhibit – good care in relation to patients' MiL. A last remark can be made regarding self-rated health: this measure failed to reflect the deteriorating physical condition of most of our participants, although their stories showed so. Others concluded before that older people tend to be over-optimistic in this measure (56, 57).

5 Conclusion

In this study we explored what older adults who receive home nursing expect and value from nurses in terms of attunement of care to their MiL. We also investigated the benefits of this behaviour. We conclude that aged homecare patients value nurses' attunement to their MiL positively. Although patients regard MiL mostly as their own quest, nurses play a modest yet important role. Benefits of this care for patients are experiencing a happy moment, feeling like a valuable person and having a good day. Besides, participants regard consideration for MiL as conducive to emphasising what is important in healthcare.

This article provides nurses with valuable knowledge and examples that may help them attune care to aged patients' MiL. Nurses should have the opportunity to invest in reciprocal relationships with patients, which facilitates possibilities for MiL. Tronto's four moral dimensions of good care could be a valuable framework for nurses to discuss good care in relation to patients' MiL, as it was for our research. This paper may lead to healthcare management's awareness of how staff discontinuity and lack of time negatively affects MiL of aged patients. Management should invest in an organisational culture that supports nurse-patient relationships. This paper (and the appendices) can serve as inspiration for nursing education. We hope it motivates nurse educators, both in schools and in practice, to facilitate reflective sessions on patients' MiL and the role of the nurse.

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Part 3

Education regarding nurses' attunement to older patients' meaning in life

Chapter 6

Evaluation of an educational programme for home nurses, provided by spiritual counsellors, aimed at attunement to older patients' meaning in life

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Under review

Abstract

Meaning in life (MiL) is part of health and important for living a good life. MiL can be a challenge during old age. Nurses have a supporting role in this respect but feel incompetent. Objective of this study was to evaluate outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL. Data was collected through interviews, surveys and a focus group. Findings are discussed in relation to Tronto's four elements of good care. We conclude that spiritual counsellors can play an important role in education about attunement of care to aged patients' MiL. Nurses benefit both professionally and personally from this education. Nurses' enhanced attitude and competences contribute to what nurses and patients regard as good care. Integration of MiL in nursing should be embedded in the policy and organisation of homecare providers.

Keywords: *meaning in life; education; spiritual counsellor; older persons; home nursing*

1 Introduction

This article evaluates an educational programme aimed at improving sensitivity and competence of home nurses in attuning their care to patients' meaning in life. The programme was provided by spiritual counsellors. Spiritual counsellors are professionals that are specialists in supporting spirituality and MiL of individuals (and groups). In the Netherlands, where this project was conducted, they sometimes operate out of a specific religion or worldview, like chaplains, but they can also be broadly orientated, as our spiritual counsellors were. As in most European countries, spiritual counsellors work in the Netherlands mainly in institutions. Working in the community is a relatively new field of practice. Besides the provision of individual care, education of healthcare professionals is an important task for them (Visser et al., 2020). We'll first introduce the concepts and context of this study.

1.1 Meaning in life

Meaning in life (MiL) is important for living a good life (e.g. Derkx, 2011; Esfahani Smith, 2017; Wolf, 2010). Interest in this concept is growing last decades in many disciplines, resulting in a variety of definitions. Brandstätter, Baumann, Borasio, & Fegg provided a comprehensive description of the concept in their literature review regarding this concept (2012): 'Meaning in life (MiL) is a highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them. Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging [...] MiL comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfaction or lack thereof'. Park & Folkman (1997) made a distinction in two, interconnected, levels of Mil: existential (or: global) meaning anddaily (or: situational) meaning. Existential MiL encompasses the fundamental 'big questions' in life, while daily MiL involves finding meaning in daily experiences. The concept of MiL largely overlaps with 'spirituality', but MiL is less focused on a higher power or a transcendent experience (Steger, 2012), which makes MiL more suitable for secularising societies, like in Western Europe (Sahgal et al., 2018), including the Netherlands (Schmeets, 2018), where this study was conducted. In our project we focussed on MiL of older persons.

1.2 Older patients' meaning in life

The growing interest in MiL in healthcare is related to the increasing influence of the concept positive health. Positive health is described as: an individual multidimensional process that focusses on positive outcomes in order to enable adaptation to life's challenges (Huber et al., 2013; Ryff, 2012; Ryff & Singer, 1998; Seligman, 2008). Positive health is a 'broad' concept of health. Huber et al. (2013) mentioned six dimensions of positive health. MiL is regarded as the most important dimension (Huber, 2019). Scholars frequently use a 'narrower' concept of health, which doesn't include MiL. Those studies nevertheless show the interconnection between MiL and (this narrower concept of) health in the later years: MiL is associated with lower prevalence of age-related diseases (Boyle et al., 2010; Kim et al., 2013; Zaslavsky et al., 2014) and longevity (Boyle et al., 2009; Buettner, 2008; Zaslavsky et al., 2014) in the later years. However, maintaining Mil can be a struggle in the later years, related to loss of (physical and mental) capacities, dear ones and social roles (Hedberg et al., 2010; Hupkens et al., 2020b; Krause, 2004; Read et al., 2005; Steger et al., 2009).

Although older patients regard MiL mainly as their own quest (Hupkens et al., 2020c), nurses have a modest, yet important, role in supporting older patients in this respect. (Drageset et al., 2017; Haugan, 2013; Hupkens et al., 2020c; Van Harten & Van Haastert, 2015). This is especially relevant for home nursing, because the majority of aged population ages in place (De Klerk et al., 2019; WHO, 2015). In spite of recognition of this relevance, nurses in practice feel incompetent in situations where patient's MiL is involved (Adriaansen, 2014).

1.3 Education regarding MiL

Education is an important strategy to improve competences of nurses. Three studies evaluated education regarding patient's MiL, but they were targeted ata different field of nursing: palliative/oncology care and mostly hospital-based (Fillion et al., 2009; Henoch et al., 2013; Morita et al., 2009).Yet, we did not find any published research addressing the evaluation of education on this subject in homecare related to the highly relevant group of older patients.
Therefore, the objective of the present study was:

> to evaluate outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL.

We evaluated the outcomes from the perspective of the nurses, because their self-reported incompetence was the start of our project. Besides for nurses, the outcomes are relevant for spiritual counsellors in their role as educators. Findings may, furthermore, be interesting for healthcare managers.

1.4 The project: Education by spiritual counsellors

Our project started with home nurses who asked help from spiritual counsellors. They told them that they frequently found themselves confronted with patient's MiL problems in their work but felt incompetent in this regard, which left them with dissatisfaction. Orientating interviews (Hupkens, 2015, unpublished) revealed that nurses did recognise existential MiL issues of patients but were unaware of daily meaning. Furthermore, nurses said that they often neglected patients' existential meaning problems out of uncertainty how to address them; or only briefly discussed them based on nurse's own values. In our project 'At home with meaning' we aimed to improve the sensitivity and competence of home nurses in order to attune care to patient's MiL. Two spiritual counsellors played an important role as educator for home nurses. They developed an educational programme, guided by a project group (of nurses, spiritual counsellors and researchers). During our project our spiritual counsellors provided the educational programme to sixteen nursing teams (249 nurses) of a large homecare organisation. Nursing teams usually consisted of 10-20 nursing aids, nursing assistants and one or two registered nurses (all referred to as 'nurses') and exhibited considerable heterogeneity (see table 6.1). Therefore, the programme had to be flexible and adjustable to specific needs. Our educational programme consisted of five modalities (figure 6.1): team sessions, coaching on the job, individual consultation, presence in teams, short messages. During the project the homecare organisation went through a turbulent period due to organisational problems and financial constraints.

Modality	Short explanation
Team sessions	Interactive sessions in the nursing office with spiritual counsellors, generally focused around a theme, e.g. daily meaning, existential questions, ageing well, loneliness, cultural identity, dementia and meaning in life. Themes were adjusted to the team's needs. Handouts with theory and inspiration were provided. Initially 4-6 monthly sessions were held with the participating teams. Many teams had a follow-up session 6 months after the initial sessions.
Coaching on the job	Spiritual counsellors accompanied nurses during their rounds. They observed and/or participated in nurse-patient contacts and provided support and feedback. Nurses were encouraged to invite spiritual counsellors to join them when they experienced meaning-in-life-related difficulties with a patient. Coaching on the job was voluntary. Clients received (written and oral) information on beforehand and were asked for permission.
Individual consultation	Nurses could call the spiritual counsellor for support and advice, e.g. when their own meaning in life was at stake in a care situation.
Presence in teams	Spiritual counsellors were empathically present during lunch breaks or before/after meetings and were open for questions dialogue or reflection.
Short messages	Spiritual counsellors regularly sent short messages (by e-mail) to all home nursing teams, usually a poem or maxim, at the start of Ramadan, International Nurses Day or other occasions related to meaning in life.

Figure 6.1: Educational programme

2 Methods

2.1 Design

We adopted a Perceived Benefit Approach to evaluate the outcomes of the educational programme for nurses. This approach is appropriate for evaluation of interventions (like a training programme) in complex situations (such as homecare for aging patients with MiL problems) where universal procedures are lacking. In a Perceived Benefit Approach, the subjective perspective of the target group (home nurses) is pivotal. It enables a broad and deep interpretation 'from within' the perspective of the target group as they perceive their reality. Therefore, outcomes are not predefined by the researchers (Goossensen, 2014; Machielse, 2015)2015. In this approach we used a prospective longitudinal mixed methods design (Plano-Clark et al., 2014).

2.2 Data collection

Data were collected (by SH) from the nurses that received education from the two spiritual counsellors. Figure 6.2 presents an example of the research planning per team.

	Months	1	2	3	4	5	6	7	8	9	10	11	12
Educational programme	Group sessions	I Initial sessions	II	III	IV	V						Follow-up	
Educational programme	Other modalities	Continuous											
Research planning		T1					T2						T3
	Interviews nurses	1					2						3
	Survey						S1						S2

Figure 6.2: Research planning per team

2.2.1 Interviews with nurses

Four home care teams were purposefully selected (Guest et al., 2013) reflecting different neighbourhoods within the city. After data-analysis of three teams, little new information emerged regarding our research objective (data saturation) (Guest et al., 2013). Therefore, the fourth team was decided to be the last one. From these four teams, sixteen nurses were purposefully selected based on diversity in educational level, age and cultural background. These sixteen respondents were invited personally or by e-mail. They were interviewed three times: at the start of the education (=T1), after the last (initial) group session (=T2), and 4-6 months after T2 (=T3). Most respondents (nine) were interviewed in all three waves. Due to sick leave or new jobs two respondents dropped out after T1, five after T2. Respondents were encouraged to tell lived experiences in order to get insight into their first-person perspective (Thomas & Pollio, 2002). In the first semi-structured interview they were invited to tell examples from practice in which they noticed patient's MiL. Then they were asked to tell about a situation in which they attuned to patient's MiL. In the second and third (semi-structured) interviews respondents were asked to tell about changes they noticed related to the education. They were asked again to tell recent examples of practice where they noticed patient's MiL and reflect on their own attunement to this. In all interviews follow-up questions were asked to explore further and deeper.

2.2.2 Survey

All the nurses (N=249) of the sixteen participating teams were invited to fill out a web-based survey (Survey Monkey) after the initial group sessions (T2). The survey contained twenty statements/questions, mostly scored on a 3 or 5-point Likert scale. Examples are: 'I notice MiL of patients in my daily work'; 'I can respond appropriately to MiL issues of patients'; 'I know how to refer to other disciplines related to patient's MiL'; 'I can ask support in dealing with patient's MiL' 'Due to the education I can better….' Open fields enabled the respondent to add comments. To examine the sustainability of potential changes, all nurses were requested to respond to a second (similar) questionnaire 4-6 months after the initial sessions (T3). Team members received two reminders. For the second survey a small incentive (€ 20) was offered to teams who reached a high response rate. Besides, nurses could register the time spent on the survey (or interviews) as working hours. The response rate for the first survey was 46% (N=114) and 32% (N=63) for the second.

2.2.3 Focus group

At the end of the project, after analysing all interviews and surveys, a focus group was organised to validate the findings (Creswell, 2013). All members of participating teams were invited to participate in this session. Respondents in the focus group (n=7) originated from five of the sixteen teams. Photo-elicitation was used to enhance deeper understanding (Harper, 2002; Hupkens et al., 2011).

2.3 Participants

Majority of respondents was aged 40-plus (54% S1) and female (Table 6.1). Respondents showed diversity in educational level (Table6.1). and cultural background.With respect to cultural background (open question, 58% response rate S1), they mentioned both countries (e.g. Netherlands, Suriname, Cape Verde) and religions (e.g. Christianity, Islam).

Table 1: Background of respondents

	Survey 1 (N=114)	Interviews (N=16)	Focus group (N=7)	Participating teams (N=249)
Education				
Registered nurses (higher vocational training)	13 (11%)	3 (19%)	1	20 (8%)
Registered nurses (intermediate vocational training)	14 (12%)	3 (19%)	-	33 (13%)
Nurse assistant (intermediate vocational training)	44 (39%)	10 (62%)	4	137 (55%)
Nursing aid (basic vocational training)	13 (11%)	-	2	44 (18%)
Not answered	30 (26%)	-	-	-

	Survey 1 (N=114)	Interviews (N=16)	Focus group (N=7)	Participating teams (N=249)
Age				
20-29	7 (6%)	1 (6%)		
30-39	15 (13%)	3 (19%)		
40-49	18 (16%)	2 (12%)		
50-59	34 (30%)	9 (57%)		
60+	9 (8%)	1 (6%)		
Not answered	31 (27%)	-		
Gender				
Female	80 (70%)	15 (94%)		
Male	4 (4%)	1 (6%)		
Not answered	30 (26%)	-		

2.4 Data analysis

Quantitative data (surveys) were analysed with the web-based program Survey Monkey (frequencies and percentages). Qualitative data (open questions of surveys and interviews) were thematically analysed (Clarke & Braun, 2015) using software (Atlas-ti 6.2.28) to organise data and findings. Qualitative coding was inductive, allowing new insights to emerge. Special attention was paid to comparison of examples in all the interviews of each individual participant, because those might reveal the changes in their performance in practice. Interpretations were validated in second and third interviews with the respondents. Two research groups participated in interpretation of data; one group was project-based and consisted of spiritual counsellors, nurses, patients and researchers (SH and MG); the other was university based (all authors). The research groups discussed and connected qualitative and quantitative data in order to arrive at an in-depth understanding (Creswell, 2009; Plano-Clark et al., 2014). In our discussion we relate our findings to Tronto's elements of good care (1993), because the respondents experienced 'good care' as main benefit of the education.

2.5 Ethical considerations

Respondents received oral and written information, were encouraged to ask questions about the study, and took part voluntarily. All interviewees signed an informed consent form. An ethical committee assessed the research protocol and found the study not to not to be subject to the Dutch Medical Research Involving Human Subjects Act. The authors adhere to the national ethical codes for research in Dutch universities (Andriessen et al., 2010).

2.6 Study quality

Several approaches were applied to establish the quality of the study, e.g. long engagement in the research field, tape recorded and verbatim typed interviews, use of a reflective journal, use of analytic software, triangulation of data collection methods and researchers, dialogue about results, and validation of findings by the respondents (Creswell, 2009; Lincoln & Guba, 1985).

3 Results

In this section findings are presented in themes (figure 6.3). In the text we merged qualitative and quantitative findings, as we did in our analysis. The results comprise three main themes: perceived benefits, limited benefits and sustainability of benefits.

3.1 Perceived benefits

Interviews and surveys show that nurses benefitted from the education in various ways: It enabled them to deliver good care for patients, which provided them with a sense of fulfilment; it promoted pleasure in their work; it contributed to their personal growth.

	Themes	Subthemes
Perceived benefits	Good care for patients provides a sense of fulfilment	Attentiveness
		Empathy
		Attunement
		Teamwork
		Refer to others
		Do what is important for patients
	Pleasure in work	Correspondence with vision
		Surprise and challenge
		Togetherness with colleagues
	Personal growth	Awareness of own meaning in life
		Do what is important for me
Limited benefits	'Did it already'	
	Insufficient implementation in care process	
	Organisational pressure	
Sustainability of benefits	Further development of competences	
	Attention for MiL and knowledge evaporate	

Figure 6.3: Themes and subthemes

3.1.1 Good care for patient provides a sense of fulfilment

Main benefit, as described by the respondents, was that the educational programme enabled them to deliver good care which provided them with a sense of fulfilment and appreciation of patients.

'I 'm collecting more of those quality moments with the people. That's important for both: I think it's very important for patients, as they're getting the care they deserve. Furthermore, it also gives me more fulfilment in my work when I'm able to add meaning to it.' (FGR6[13])

13 The letters and numbers refer to data source, team, wave and respondent:IA2R1 is the second interview with respondent 1 from team A; FGR6 is respondent 6 in the focusgroup; S1 is survey 1

'You get something in return from the people: a smile, a pat on the back, a cup of coffee together… or simply, saying "hey, how nice of you". Just that.' (ID3R1)

Respondents explained why they provide better care, due to the education. They perceived that they had developed in (subthemes): attentiveness; empathy; attunement; teamwork; refer to others; do what is important for patients. *Attentiveness.* In the survey, nurses stated that their ability to recognise MiL aspects of their patients in daily practice had improved (68% S1, 70% S2). Respondents said they were more aware of the signs and signals of MiL in the patient's house. Many said that they had become better listeners and observers. This is also reflected in examples which the respondents provided in the second and third interviews. Registered nurses mentioned that their intake has always been based on a holistic approach, but they became more aware of that.

'I 'm more conscientiously searching to make care more personal - more than just those stockings or medication control. That you ask whether something has happened today, or you ask something about a photograph - simply all kinds of things.' (FGR6)

Empathy. Many respondents said and explained, through examples in second and third interviews, that they are more empathic with their patients. They explained that they opened-up to patients, became less judgemental, and feel more equal to patients as a human being. Respondents stated that they pay more attention to *the person* instead of the patient (51% S1, 70% S2).

'I take some steps back, think about it, not only listen, not only speak, have more empathy, go in the flow of the patient and – maybe - we can find a solution together. Then I really listen, you know. Because she's a human being who wants to be heard … and feel that I really mean it… And that gives a good feeling - because I cared for the patient in a good way' (IA2R1).

Attunement. Respondents stated that they react more appropriately on patient's Mil aspects than before the education (62% S1, 71% S2). Many said that they better attune their care to what is important to the patients, than before (44% S1, 57% S2) and more frequently stimulate the patient to give time and attention to what is meaningful to them (50% S1, 70% S2). Respondents explained, and showed in examples, what they developed during the education to attune care better to patient's Mil:

- Attitude: taking time and space for the patient, leaving choices to patients, accepting personal limits of patients, adapting practical care to wishes of patients, being authentic as a person.
- Communication skills: listening, observing, asking follow-up and open-ended questions, non-verbal communication, deliberating with the patient and family about preferences.
- Organisational skills: taking/organising time for patients, ensuring continuity of staff, consulting colleagues, inserting MiL in the care plan.

Respondents told numerous stories which illustrate how they grew in attunement to patient's MiL. They considered this as good care. Here's just one of many:

> *'I am aware of the relations of patients. When I have a little time, I prefer to stay with people that are a bit lonely. In my evening shift I spent some time with a man who lost his wife recently and who doesn't have children. That evening I was in time at his house - I had to rub his legs and it's a moment of checking up as well. I had brought some cake and gave it to him for his teatime and he asked me to accept a cup of tea - he said he enjoyed this greatly but admitted that he missed his wife terribly. Then I asked: "How do you get through the days?" He said: "I'm at home whole days..." I took the time and he told me about the old days and his wife - and then the tears came. I thought "It's better to express it, it's alright." And today someone from the support care team is coming - I arranged that. The weather is nice, so I hope they'll go out for a walk, play a game, drink something together, do some shopping, and prepare the evening meal together.' (IB3R5)*

Teamwork. After the education 38% of respondents (S1) reported better cooperation with their colleagues. They asked (52% S1, 64% S2) and provided (58% S1, 68% S2), support to colleagues related to MiL issues of patients. According to them, this improved cooperation, resulting in better care for their patients.

> *'Through careful listening and asking we've grown closer to each other - with the result that we've found good solutions, also for the patients.' (FGR3)*

Refer to others. Many respondents (60% S1, 70% S2) expressed that they sometimes refer patients to (diverse) professionals from other disciplines or volunteers when MiL issues of patients are at stake. The spiritual counsellors were sometimes consulted (7 times S1, 4 times S2). Although registered nurses maintain large networks in their neighbourhoods and other team-members regard them as the 'experts' when referring is needed, many of them expressed that they feel uncertain who to refer to in case of MiL problems.

Do what is important for patients. Respondents explained that, as a result of the education, they prioritise better:They do what is most important for patients. Some told they had become less dependent on the rules of the organisation.

> *'She's alone and has lost so many people in a short period ... and besides that, she was ill, had a cold - but it was that loss too - and that dog is everything to her. I took the dog out. I did it on my own accord - we don't have to, but we all did it - only five minutes. I asked: "Shall I take him out?" She was so happy, so grateful... Can't I do what I want to do for her in that half hour? I think: what's important? What's imperative? There are so many things that are not allowed.' (IA3R4)*

3.1.2 Pleasure in work

For 34% (S1) of respondents pleasure in work had improved due to the education. Respondents explained in the interviews why (subthemes figure 6.3): correspondence with vision; surprise and challenge; togetherness with colleagues. *Correspondence with vision.* Especially the registered nurses stated that the education aligned with their (holistic) vision and with contemporary ideas about nursing and health. They regarded attentiveness and attunement to patients as the core element of nursing and felt supported by the spiritual counsellor in their efforts to deliver good care. The education enriched them in this respect.

> *'You have to pay attention to the positive of a person: What is important for them in life? Nursing is about the whole person, not only the physical... And about the environment. That has been part of my professional development for a long period. It is in the nursing magazines at the moment. Actually, We can free-ride on societal developments.' (IC3R1)*

Surprise and challenge. Some respondents mentioned that they were surprised about what they encountered once they asked more MiL-related questions to patients and listened more closely to responses. They remembered specific formulations of questions of the spiritual counsellors and applied these in practice. Some nurses explained that they felt challenged to find solutions for constraints. The education triggered the nurses' playfulness and creativity.

> *'I frequently visit a woman, and, in my eyes, she is sitting at home all day, watching television, reading a paper, nothing more. At a certain moment I just asked her "What is a meaningful day for you?" and she started telling about gardening and how satisfied she was with it. I wonder if she does it, but it is fun: having a surprising conversation with a person with dementia.' (IB2R2)*

'I stayed working on it because those answers were so surprising. Not only that woman, but many other patients, especially when you think that you have known them for so many years. Actually, it turned my world upside-down!' (IB3R2)

Togetherness with colleagues. Respondents said that they benefitted from the openness and exchange of ideas and experiences in the team sessions. Their appreciation and respect for their colleagues increased. More than previously, the nurses enjoyed working together and sustained each other.

'Most sessions were interesting, but in that one everyone contributed: thinking, talking... And through this experience we feel more concerned with each other; there is a sense of togetherness, there is more openness to ask and provide help.' (ID2R3)

3.1.3 Personal growth

Some respondents expressed that they benefitted from the fact that the spiritual counsellor took the time to listen to them as a valuable person. The education had a positive influence on their private life.
Awareness of own MiL. Some respondents became aware (again) about meaning (or the lack thereof) in their own life. In the education they reflected on their experiences, motivation, feelings and life events. For several this was confrontational because they were looking back on lost ideals, dear ones, and places. Some found new orientation about what was important in their life now.

'I'm returning to the Sophie (fictitious name) of the old days. I used to be a bit philosophic and at a certain point in life that tends to decrease ... and I noticed that this Sophie is returning a little bit. I had arrived at a point in life that all those things seemed to be hidden in a drawer and the drawer has been pulled open again - because the project was there.' (IA2R2)

Do what is important for me. As a consequence of a (new or renewed) orientation on their own MiL, some respondents said that they felt stronger to make their own explicit choices in their personal life. One nurse decided to go on holiday after many years of staying at home. Another took the step to discuss with her family her wishes about end of life. Some respondents mentioned that they now 'stand up' if they do not agree with their working conditions.

'I took another trail - if I don't like something, I just say it. I'm more aware: in my work, for my colleagues - how things go. I disagreed with the team procedures and I simply went to my manager and told her the truth. I wouldn't have done that before, but now I do. I'm standing firm and if I don't agree - I stand up to her and just tell her.' (FGR5)

3.2 Limited benefits

Although respondents expressed that they benefitted from the education, there were, at the same time, critical voices. Respondents explained they had not benefitted from the education as they possibly could have, due to several reasons (subthemes figure 6.3).

3.2.1 'Did it already'

Most respondents (56% S1) stated that they already attuned care to what is important for patients before the education of the spiritual counsellors. In the interviews, some respondents explained that the education emphasised what they already did for their patients from their own motivation. In de comparison of examples in all interviews of individual respondents this is recognisable for some of them, while others show that they did take a step forward in their development (as described above in 'good care'). A similar development is shown in the benefits 'pleasure in work' and 'personal growth'. Many respondents doubted if their development was a consequence of the education; They believed this was also related to their personality and to private circumstances such as disease, divorce, and the loss of dear ones.

'To be honest, I think I did all those things already. I was already aware of providing not only task-oriented care... What is at stake for the patient? What is important?'(ID2R1)

'I think it is a combination: The project made me more aware. And on top of that, I recently lived through a quite intense period in private life, and there was this situation with this patient who was my age, I guess that influenced me even more.' (IA2R2)

3.2.2 Insufficient implementation in care process

Respondents mentioned that they had little expertise and experience to include MiL of patients in the care plan. Although some of them had found solutions, many mentioned that they needed support to more effectively integrate MiL in the formal nursing process in order to expand the focus on patient's MiL.

3.2.3 Organisational pressure

Some respondents reported that they were unable to experience any benefits from the education due to continuous pressure from the organisation to focus on production and efficiency; This limited their time and attention for patients. They explained that personal mental space is a prerequisite for empathy with patients, which was minimised because organisational issues demanded all space. Many respondents stressed that education in MiL only makes sense if the organisation supports them with proper conditions.

> *'We have to work very task-oriented: I come for giving that pill, I give it and report it. That's important of course, but... I don't report regarding the surgery of the patient's daughter, while... that's what really counts for her, isn't it? And that's exactly the problem: we must spend as few minutes as possible, so anything extra you do costs time, costs money. We are not allowed to do that, and, for me, that's extremely frustrating.' (ID2R2)*

3.3 Sustainability of benefits

Respondents were ambiguous about the sustainability of the education: Although most experienced that they further developed in what they had learned, they stressed that attention and knowledge evaporate overtime.

3.3.1 Further development of competences

The results show that many respondents still benefitted from the education, 4-6 months after the initial sessions. Majority of respondents in the second survey (79% S2) stated that they were still engaged with the education content. They even regarded themselves more competent compared to just after the education (77% S2) and mentioned that they had further developed in: listening, taking time and space, thinking actively about MiL, asking better questions, empathy, and monitoring own limits.

3.3.2 Attention for MiL and knowledge evaporate

However, at the same time, nurses stressed in the interviews that attention to MiL, and especially knowledge, fades away over time. The same applied to the team process: due to the stress of everyday routines, the improved team spirit 'evaporated'. Furthermore, respondents were aware that communication skills need continuous brushing-up. Majority of respondents claimed that they needed follow-ups at regular intervals to keep MiL on the agenda.

'Other things ask our attention, which causes MiL to disappear. If the spiritual counsellor is revisiting us, we take time to reflect: What's at stake in our team? What can we mean to each other? And what can we mean to our patients? Because that's in line with each other.' (IC3R3)

4 Discussion

Retaining MiL is a challenge during old age (Hedberg et al., 2010; Hupkens et al., 2020b; Krause, 2004; Read et al., 2005; Steger et al., 2009). Nurses can support older patients to maintain MiL (Drageset et al., 2017; Haugan, 2013; Hupkens et al., 2020c) but feel incompetent in this regard in practice. In our project nurses received education from spiritual counsellors to improve sensitivity and competency in this regard. This paper evaluated the outcomes of this educational programme and is, as far as we know, the first paper in this regard in the highly relevant field of homecare for older patients. Previous papers, in other fields of healthcare, evaluated restricted predefined outcomes (Fillion et al., 2009; Henoch et al., 2013; Morita et al., 2009). We added a more comprehensive insight into the benefits of this education through a Perceived Benefit Approach. Although many nurses claimed that they did attune care already to patient's MiL, others mentioned impressive benefits from the education. These benefits included both the professional and personal domain, which is a compelling outcome of an educational programme, not only for nurses, but also for spiritual counsellors (educators), homecare managers and patients. Main benefit of education is that it facilitated nurses, from their viewpoint, to provide good care for patients. An important question is whether the changes they mentioned do in fact contribute to good care. To discuss our results in the light of good care, we turn to Tronto(1993). Good care encompasses four elements: *attentiveness, responsibility, competence and responsiveness*.

- With regard to *attentiveness*, nurses expressed that their attentiveness regarding patients' MiL had been enhanced, as had their empathy with patients. They opened-up, felt equal as human beings and paid more attention to the person instead of the patient; They learned to see 'with the heart's eye' (Martinsen, 2006). Although many nurses stated that they already had this attentiveness, any improvement in this regard is valuable, because empathy of nurses tends to diminish over time in practice, when nurses are confronted with difficult situations (ten Hoeve, 2018; Ward et al., 2012). Some nurses claimed that their attentiveness was hindered by organisational focus on productivity and lack of time.Martinsen (2006) called this focus a 'registering eye'. As she explains, it leaves no space and time to see a significant other and reduces the patient to an object.
- Nurses explained that they felt more *responsible* to do what is good for the wellbeing of the patients (and for themselves). The education empowered them to stand-up for what they regarded as important, even if this challenged the rules of the organisation. Their newly developed 'heart's eye' clashed with the 'registering eye' of the organisation. Respondents emphasised that good care is not only a responsibility of nurses: Healthcare organisations have a responsibility to facilitate nurses in providing good care. Dialogue is needed in healthcare (society and politics) to arrive at a shared understanding what good care comprises. Contemporary definitions of health and wellbeing should be included in this discourse and consequences translated in policy and practice. Spiritual counsellors are, more than any other professions in healthcare, trained to facilitate this moral dialogue and should play a paramount role in this respect.
- The aim of our project was reached: Nurses expressed that they benefitted from the education by enhanced attitude and *competences* with respect to attunement to patients' MiL. This aligns with the studies of Henoch (Henoch et al., 2013) and Morita (Morita et al., 2009), although heterogeneity of studies inhibits detailed comparison, Similar to the present study, the studies re-measured after 4-6 months and found that many outcomes were sustainable.
- Whether improved attitude and competences of the home nurses were indeed promoting good care can only be judged by patients (*responsiveness*). An earlier article described patients' experiences regarding nurses' attunement to their MiL although the article did not evaluate changes overtime (Hupkens et al., 2020c). Patients' experiences largely reflect the perspective of the nurses in this study. Patients do agree with nurses that interest in them as persons (not only as patients), and (longstanding) nurse-patient relationships are crucial for good care. Patients value nurses' attitude of doing what is needed. Both patients and nurses agree that healthcare organisations must take up their responsibility and ensure proper working conditions for nurses which enable nurses to have

space and time for the patient as a person. However, there are also some interesting differences. Patients emphasise the reciprocal nature of this relationship as vital for MIL, which is less reflected in the nurses' stories. Nurses do acknowledge patients as equal human beings, but they do not mention the relationship as one of mutual giving and receiving, as patients do. With respect to competences, patients value communication skills and organisational skills, as nurses, but they also emphasise that care-technical skills are vital, because these limit pain and suffering and enable them to maintain MiL.

Other benefits of the education were related to nurses' pleasure in work and personal growth. Nurses benefitted from the education because it complied with their vision and values. The spiritual counsellors were interested in the nurses as valuable persons. They listened to them during a difficult episode in their work and accompanied them in their search to provide good care This approach, which characterises spiritual counsellors, has definitely influenced the positive outcomes of the education (Hupkens et al., 2020a). Pleasure and meaning in work are relevant for any employee. Conflicts between personal and organisational values erode professional's meaning in work (Graeber, 2018; Steenhuis, 2017). Other research (Fillion et al., 2009; Morita et al., 2009) reported increased job satisfaction after education regarding MiL. These benefits of education are not only relevant for nurses, but also for healthcare managers, who are confronted with actual and future shortages of staff.

Our findings must be considered with some limitations: Firstly, the data originated from a single organisation (which went through a turbulent period) and is restricted to a specific educational programme. Contextual findings are usual in qualitative research and limit transferability. We hope our description of the context is useful for readers in this regard. Secondly, credibility is restricted by attrition, which is common in longitudinal research (Plano-Clark et al., 2014). The small number of participants in the focus group also affects credibility, even though multiple teams were represented.Finally, as the nurses explained, the benefits were probably not exclusively due to the education provided by the spiritual counsellors, but also to experiences in the nurses' personal life.

5 Conclusion

We conclude that spiritual counsellors can play an important role in education about attunement of care to aged patients' MiL. Nurses benefit both professionally and personally from this education.Nurses' enhanced attitude and competences contribute to what nurses and patients regard as good care. Integration of MiL in nursing should be embedded in the policy and organisation of homecare providers.

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Chapter 7

Learning to attune care to aged patients' meaning in life

Action research to understand the underlying educational process

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Under review

Abstract

Background: Meaning in life (MiL) is an important part of health and therefore relevant for nurses. During old age, maintaining MiL can be challenging, related to loss of (physical and mental) capacities and dear ones. Home nurses can support their ageing patients in this respect but due to a gap in the educational literature, it is unclear how nurses actually can learn this and how behaviour of educators promotes such learning.

Aim: To understand the underlying learning-teaching process of an educational programme, provided by spiritual counsellors, about attunement of care to aged patients' MiL in home nursing.

Methods: Action research. Multiple data were collected through interviews, participant observations, surveys, logs. Understanding of data was developed together with stakeholders.

Findings: A supportive relationship with the spiritual counsellor served as a basis for nurses' learning. The learning-teaching process further consisted of eight learning phases which were promoted by specific behaviour of the spiritual counsellor. The eight phases were: Being touched; Opening-up; Awareness of own meaning; Broadening and deepening understanding; Turning point - awareness of the patient as other; Exploring and reflecting; Working, practising and reflecting; Taking responsibility.

Conclusions: Learning to attune to patient's MiL evolves through a learning-teaching process of eight phases, which starts with 'Being touched'. 'Awareness of the other' is the pivotal phase. The relationship with the educator, reflection and experiential learning are crucial in this process. The described model may serve as a basis for future education on this subject.

Keywords: *education; learning; teaching; meaning in life; home nurses; aging patients; action research.*

Highlights

- The relationship with the educator fosters learning about meaning in life;
- Learning to attune to patient's meaning in life starts with 'being touched';
- The pivotal phase is: turning from one's own meaning to that of the other;
- Spiritual counsellors can provide a valuable contribution to nurse education.

1 Introduction

'I see that my patients are confronted with grief and loss. Some experience no meaning in life anymore. I feel powerless. What can I do?' Our project, entitled 'At home with meaning', started with questions like these from home nurses. They felt incompetent regarding the meaning in life issues of their ageing patients. Meaning in life (MiL) is: 'a highly individual perception, understanding or belief about one's own life and activities and the value and importance ascribed to them. Meaning and purpose are related to terms like order, fairness, coherence, values, faith and belonging [...] MiL comprises the engagement in or commitment to goals or a life framework and the subsequent sense of fulfilment and satisfaction or lack thereof' (Brandstätter, Baumann, Borasio, & Fegg, 2012,p.1045). MiL is considered as an important part of health (Huber, van Vliet, Giezenberg, & Knottnerus, 2013; Ryff, 2012) and, therefore, relevant for nurses as health promotors.

1.1 Meaning in life of aged persons and education of nurses

Research reveals that MiL is associated with many desired outcomes in later life: longevity (Boyle, Barnes, Buchman, & Bennett, 2009; Buettner, 2008; Zaslavsky et al., 2014), healthier lifestyle (Steptoe & Fancourt, 2018) and lower prevalence of several age-related diseases (Boyle, Buchman, Barnes, & Bennett, 2010; Kim, Sun, Park, & Peterson, 2013; Zaslavsky et al., 2014). However, old age comes with loss of (physical and mental) capacities and dear ones, which challenges MiL (Hedberg, Gustafson, & C., 2010; Hupkens, Goumans, Derkx, & Machielse, 2020a; Steger, Oishi, & Kashdan, 2009). The growing interest in MiL of aged patients, both in society and research, is especially relevant in home care, since, internationally, most older people age in place (in their own home), instead of in an institution (De Klerk, Verbeek-Oudijk, Plaisier, & den Draak, 2019; WHO, 2015).Nurses have a modest, yet important, role to play in supporting aged patients' MiL (Drageset, Haugan, & Rranvåg, 2017; Haugan, 2013; Hupkens, Goumans, Derkx, & Machielse, 2020b). Patients benefit from, for MiL, attuned care; it contributes, among others, to feeling a valuable, equal human being and to having a good day (Hupkens et al., 2020b)However, it remains unclear *how* nurses should actually learn to attune their care to patients' MiL. There is little empirical educational literature on this subject: We found only three article (Fillion et al., 2009; Henoch, Danielson, Strang, Browall, & Melin-Johansson, 2013; Morita et al., 2009) which describe a training

intervention in this regard and evaluate the outcomes; yet they do not explain the learning-teaching *process*: *how* participants *learn* about MiL of patients and which *behaviour* of educators *promotes* learning. Reflection on this learning-teaching process is highly important because it enables optimisation of actual education and provides foundation for future programmes (Horsfall, Cleary, & Hunt, 2012). Therefore, the aim of this paper was: To understand the underlying learning-teaching process of an educational programme, provided by spiritual counsellors, about attunement of care to aged patients' MiL in home nursing.

1.2 Spiritual counsellors as educators in homecare

The questions, about nurses' lacking competence, that started our project, were addressed at spiritual counsellors working in a nearby nursing home. A spiritual counsellor is a professional who is a specialist in supporting individuals and groups in MiL questions. In the Netherlands, spiritual counsellors are sometimes connected to a specific religion or worldview but can also be broadly orientated. With increasing secularisation (Sahgal et al., 2018; Schmeets & van Mensvoort, 2015) these general spiritual counsellors are specifically relevant. Nevertheless, they should also disclose their background). In most European countries, spiritual counsellors usually work in institutions such as nursing homes and hospitals and not in homecare. Only recently, since 2018, the Dutch government supports spiritual counselling in homecare, including education of personnel. Our educational project (starting 2015) was one of the first developments in this regard.

2 Methods

2.1 Design

During the 3-year project, a flexible educational programme was developed, evaluated and improved, guided by our growing understanding of the underlying learning-teaching process. An action research methodology was applied. Action research is a pragmatic collaborative process of stakeholders, engaging in research and action, which leads to understanding and resolving a problem they encounter in practice. Action research is characterised by a recurring cycle of observation

(data collection), reflection (analysis) and action (Stringer, 2014; van der Zouwen, 2018). Three groups facilitated the action research process:

- A project group, consisting of spiritual counsellors, nurses and researchers (SH and MG), coordinated the project and undertook actions to (further) develop the programme;
- An organisation-based research group, consisting of stakeholders in the project (nurses, patients, spiritual counsellors) and researchers (SH and MG) provided direct feedback in the project, based on preliminary understanding of data;
- The second, university-based, research group (all authors) operated on a more conceptual level and supervised the research quality.

Recurrent action research cycles during the 3-year project gradually improved the educational programme and, simultaneously, deepened and broadened understanding of the underlying learning-teaching process. This paper focusses on the latter.

2.2 Setting

The project setting was a large homecare provider in the Netherlands. Prior to the development of the educational programme we conducted orientating interviews with nurses (unpublished) to enquire their learning preferences. They revealed that they needed background information, and easy to follow suggestions from someone close to practice, favourably on the work spot. Furthermore, nurses asked attention for their own vulnerability in MiL issues. They needed someone who could be there for them.

Two general spiritual counsellors were selected to design and provide education to the home nurses.Sixteen home nursing teams were added to the project in phases. Adding teams at different moments during the three project years enabled multiple action research cycles. Home nursing teams of this homecare organisation usually consisted of 10-20 nursing assistants, nursing aids, and one or two registered nurses (all referred to as 'nurses').

The programme, which was developed in the three year project through recurring action research cycles, finally consisted of five different modalities which together form the programme (figure 7.1): team sessions, coaching on the job, individual consultation, presence in teams, short messages. In this paper we focus on this underlying learning-teaching process of this (total) programme.

Modality	Short explanation
Team sessions	Interactive sessions in the nursing office with spiritual counsellors, generally focused around a theme, e.g. daily meaning, existential questions, ageing well, loneliness, cultural identity, dementia and meaning in life. Themes were adjustable to the team's needs. Handouts with theory and inspiration were provided. Initially 4-6 monthly sessions were held with the participating teams and many teams had a follow-up session 6 months after the initial sessions.
Coaching on the job	Spiritual counsellors accompanied nurses during their rounds. They observed and/or participated in nurse-patient contacts, and provided support and feedback. Nurses were encouraged to invite spiritual counsellors to join them when they experienced meaning-in-life-related difficulties with a patient. Coaching on the job was voluntary. Clients received (written and oral) information on beforehand and were asked for permission.
Individual consultation	Nurses could call the spiritual counsellor for support and advice, e.g. when their own meaning in life was at stake in a care situation.
Presence in teams	Spiritual counsellors were empathically present during lunch breaks or before/after meetings and were open for questions dialogue or reflection.
Short messages	Spiritual counsellors regularly sent short messages (by e-mail) to all home nursing teams, usually a poem or maxim, e.g. at the start of Ramadan, or on International Nurses Day.

Figure 7.1: Educational programme

2.3 Data collection

In action research, mixed data collection methods and sources are used to understand the problem from diverse perspectives (Stringer, 2014; van der Zouwen, 2018). From September 2015 until October 2018, multiple data were collected from and with the principal stakeholders: nurses and spiritual counsellors (figure 7.2).

Data collection method	Respondents	Teams	Amount	Duration per session (minutes)
Survey 1 nurses	114	16	114	12 (mean)
Survey 2 nurses	65	15	65	16 (mean)
Interviews nurses	16	4	38	33-62
Focus group	7	5	1	108
Participant observations group sessions	2	-	7	50-123
Logs of spiritual counsellors	2	-	84	-

Figure 7.2: overview of data

2.3.1 Interviews with nurses

Interviews in action research provide understanding in stakeholders' own terms (Stringer, 2014). Four teams, with a different starting date in the project and from diverse neighbourhoods, were investigated more closely than the other twelve (figure 7.3). In these teams, sixteen nurses were purposefully selected based on diversity in educational level, age and cultural background, reflecting the diversity in home nursing teams. Semi-structured interviews took place in three waves: at the beginning of the education (T1), after the initial team sessions (T2) and 4-6 months after the initial sessions (T3). Nurses were asked to explain *how* they had learned and invited to come up with detailed examples to provide more insight. Due to sick leave or change of jobs, seven of the interviewed nurses were unable to participate in follow-ups.

	T1	T2	T3	
All teams		Survey	Survey	Focus group
4 selected teams	Interviews	Interviews	Interviews	
	Observation team sessions			

Figure 7.3: Data collection in home nursing teams

2.3.2 Survey

Surveys in action research are used to extend insights of qualitative findings to the entire population (Stringer, 2014). All teams participated in two surveys. In the sixteen participating teams, all nurses (n=249) were invited to fill out a web-based survey (Survey Monkey) at T2, including six questions about the learning-teaching process (mostly 3 or 5-point Likert scale). Open fields enabled the respondents to add comments. To assess the sustainability of the learning, all nurses were requested to respond to a second (similar) questionnaire at T3. The response rate for the first survey was 46% and for the second 32%.

2.3.3 Participant observations

Observations allow data collection about behaviour and help develop understanding in lived experiences of participants (Stringer, 2014). We (openly) observed 36 group sessions in six teams, mostly in the four teams described in 'interviews with nurses'. Participation of researcher was modest, for instance: lending a hand to the spiritual counsellor or sharing an experience when asked. By this 'light participative' approach, and by attending many sessions in the same teams, the nurses were accustomed to the researcher and experienced the

observations as unintrusive. Other meetings organised by the spiritual counsellors were also observed, e.g. a meeting about MiL for professionals in the community. During the observations brief notes were made, which were transcribed to rich field notes.

2.3.4 Logs of spiritual counsellors

To gain more insight, the two spiritual counsellors were asked to keep a log of their experiences and reflections during the project. They shared a variety of (anonymised) documents (n=84), e.g. notes of sessions and encounters, correspondence, and short reflections.

2.3.5 Interviews: spiritual counsellors

Semi-structured interviews were performed with each spiritual counsellor (three with one, four with the other) to further explore their reflections concerning the education. Topics for the interviews were based on insights that emerged from preliminary analysis of the data.

2.3.6 Focus group

After preliminary analysis of existing data, a focus group was organised to validate the findings. Nurses from all participating teams were invited to join. Respondents in this focus group (n=7) originated from five of the sixteen teams. In this focus group, a preliminary version of the learning-teaching process model was discussed.

2.4 Data analysis

The mixed-methods design resulted in rich data. Quantitative data (surveys) were analysed for descriptive statistics using the web-based program Survey Monkey (quantity, percentages). Qualitative data were thematically analysed (Clarke & Braun, 2015) using software (Atlas-ti 6.2.28). Coding was inductive, no theoretical framework was used during this phase. Dialogues in the two research groups, and the project group, about preliminary findings further developed the themes and merged findings of diverse data sources to broadened and deepened mutual understanding of the learning-teaching process. The themes were finally visualised in a model and validated in the focus group with nurses and in the project group.

2.5 Ethical considerations

Participants received written and oral information about the study on beforehand, were encouraged to ask questions, and took part voluntarily. All interviewees signed an informed consent form. The researcher asked permission to take (anonymised) observation notes at the beginning of each team session and participants were invited to refuse this if this felt uncomfortable for them (which would mean their contributions would be left out of the observation notes), but this never happened. Patients received written information about the project, including the possibility that a spiritual counsellor could join their nurse. Patients were invited to ask questions to the nurse, the spiritual counsellor or the researcher, and were reassured that refusal had no consequences for them. Before, and at the beginning of each nursing visit patient's permission was requested. An ethical committee assessed the research protocol and found the study not to be subject to the Dutch Medical Research Involving Human Subjects Act.

2.6 Study quality

Van der Zouwen (2018) mentioned quality criteria for action research based on three pillars of practice-oriented research: practicability (relevance, usefulness, transferability), trustworthiness (credibility, dependability, confirmability), ethicality (adequate, attainable, ensuring wellbeing of participants). To meet these criteria, we took several steps: inclusion of stakeholders in the project; long engagement in the research field; triangulation (methods and researcher); recorded and verbatim typed interviews; dialogue concerning the findings; thick descriptions; use of a reflective journal; use of analytic software; validation of interpretation with participants.

3 Findings

Figure 7.4 shows the model of the learning-teaching process. It shows the learning phases of nurses (forming the circle) and the behaviour of educators (red arrows) which promotes this learning process. The text is structured by the learning process of the nurses. We provide excerpts from the various data sources[14] as examples.

3.1. Experiencing a supportive relationship with the spiritual counsellor

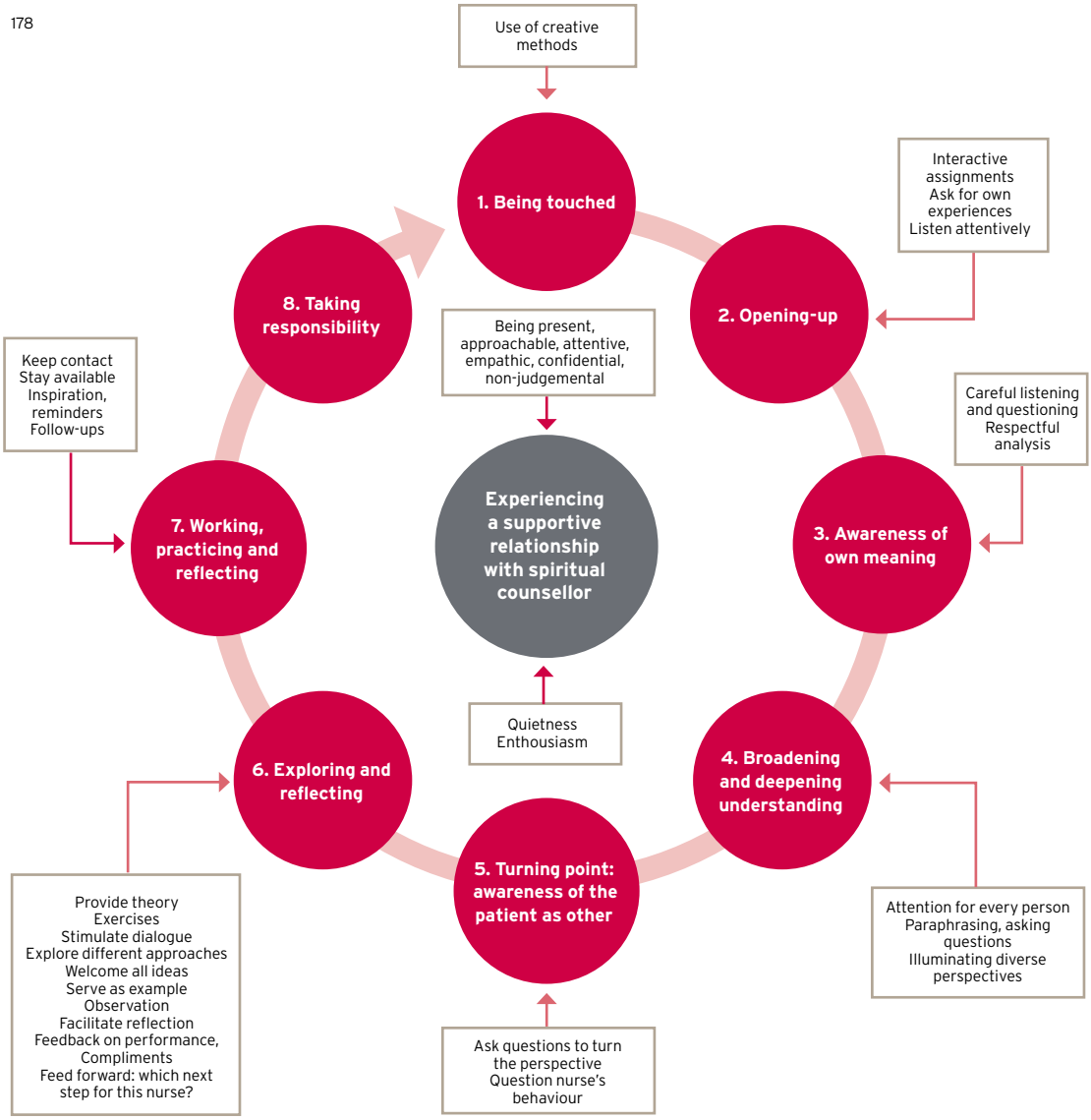
A supportive relationship with the spiritual counsellor functioned as a basis for the learning process. Respondents in the survey and interviews characterised the spiritual counsellors as: 'attentive, quiet, non-judgmental, empathic, confidential, authentic, enthusiastic'. Nurses had the feeling that the spiritual counsellors were there for them and felt free to share what was on their minds. Team sessions took place in a comfortable, quiet and confidential atmosphere.

'She/he [the spiritual counsellor] made it very clear that we could feel safe with her, that there had to be trust and confidentiality, otherwise you cannot be open for this. And I really appreciated that.' (F.E.1)

3.2 Phases of the learning-teaching process

The eight phases of the learning process (Figure 7.4) are interrelated and apply to the educational programme (figure 7.1) as a whole. The sequence of phases was frequently recognised in the data.

14 Between brackets we refer to the origin. For instance: In.B.3.2 is interview 2 with nurse 3 from team B; Is.2.1 is interview 1 with spiritual counsellor 2; F.A.1 is participant 1 from team A in the focus group; O.D.4 is observation 4 in team D;Ls.1.12 is log 12 from spiritual counsellor 1.



Legend figure 7.4

Learning process of nurses

Promoting behaviour of educator

Figure 7.4: Learning-teaching proces

3.2.1 Being touched

Spiritual counsellors made a habit of using creative methods (poems, songs, photographs), which touched nurses and set the tone for learning. Several nurses explained that these creative methods touched them and that this was relevant to them, because they 'work with their heart'.

> *The spiritual counsellor takes things out of a bag and hands them to the team members: a little figure of a farmer, a medallion with an angel, and many more. She/he explains why some of the things mean so much to her/him: association with dear ones, identity, memories. The nurses react enthusiastically; they recognise this immediately and start taking things out from their own bags, speaking at the same time. (O.C.5)*

Personal experiences of the nurses could also be a (touching) entry for education. Nurses spontaneously came up with compelling cases, both in the group sessions and in individual contacts with spiritual counsellors.

3.2.2 Opening-up

Creative methods and personal stories of experiences with patients stimulated nurses to 'open up'. Group sessions generally included short interactive assignments (e.g. a set of questions) to explore for themselves. The spiritual counsellors asked for the nurses' own experiences, listened attentively to every single person. Several nurses expressed that this triggered them: not only to tell but, moreover, to listen.

> *'At a certain moment she/he [spiritual counsellor] showed us a picture of an older person and she/he asked: how do you think about yourself in 30-40 years? What will life be like? That was a very special moment for me. It guided my thought: you can look differently, think differently...' (In.C.1.2)*

3.2.3 Awareness of own meaning

Triggered by the creative methods, assignments, or the attitude of the spiritual counsellors, the nurses became aware of their own MiL and discussed this with each other. Often this was many times an emotional and intimate sharing with their colleagues. The logs of the spiritual counsellors revealed that, in many individual sessions of employees, a personal moral dilemma lay at the bottom of

the problem. Through careful listening, questioning and respectful analysis of the spiritual counsellor, nurses realised what was at stake for them.

> *'Looking back, I had to admit that I felt sad... and disappointed. For my colleagues had not joined me. And she/he [spiritual counsellor] noticed that. Sometimes someone else has to push you in order to see it in yourself.' (In.A.2.3)*

3.2.4 Broadening and deepening understanding

Spiritual counsellors urged team members to listen to each other. Listening to stories of others awakened nurses' understanding that people differ in issues related to MiL. The spiritual counsellors had attention for every person, paraphrased, illuminated less heard perspectives, and asked questions to arrive at a deeper level.

> *The spiritual counsellor asks to share what the nurses noted on their paper. She/he pays attention to every individual member and paraphrases themes as 'connectedness'. Many nurses tell about their children and grandchildren. The spiritual counsellor pays extra attention to a nurse who is married to a person of the same gender. The nurse explains that, for her/him, friends are more important than family. (O.B.2)*

3.2.5 Turning point: awareness of the patient as other

In the learning process there was generally a turning point: 'If MiL is important and we differ in this respect, then what will it be like for our patients?' Sometimes the nurses made this turning point themselves; sometimes the spiritual counsellors initiated it by asking questions. Whereas in the beginning of the process the focus was on the perspective of the nurse, it now turned to the patient's. At this point, the nurses often started sharing their experiences with patients, sometimes heart-breaking stories. This was another phase when many nurses were touched and expressed their motivation to care for their patients. In this phase the dialogue moved to nurses' behaviour towards patients: 'How can I attune to MiL of this person? What does this entail for my behaviour as a nurse?'

Then the spiritual counsellor asks: "How would this be for your patients? What would their dreams have been? Were they married or widowed? Which choices have been made? What do you know about that? And if connectedness is important, what would be your role as a nurse?" One of the nurses starts telling about a patient who is lonely but is always very cheerful when the nurse visits her/him. The team members discuss what they know about her/him and how they can attune to her/his situation. (O.B.2)

3.2.6 Exploring and reflecting

In this phase, the nurses and spiritual counsellors explored ways of supporting MiL of patients. In the team meetings, the spiritual counsellors provided elementary theory and suggestions, accompanied by handouts. Most nurses (87%, first survey) valued the spiritual counsellors as experts in their field. Sometimes there was a small exercise, e.g. asking questions to arrive at an existential level. In dialogue, different approaches could be explored, and any creative idea of team members was welcomed. Spiritual counsellors also explained that they wanted their behaviour towards the nurses to serve as an example for a meaningful nurse-patient relationship (role-modelling).

In the 'coaching on the job' the nurse and spiritual counsellor visited the patient together in every day's complexity. Several nurses said they preferred 'learning by doing'. The spiritual counsellor observed the nurse's interaction with the patient while, in turn, the nurse observed the spiritual counsellor. The nurses experienced this 'eye of another professional' as highly effective: spiritual counsellors perceive practice differently than a colleague nurse. On their way back (while bicycling) they reflected upon their approach. The spiritual counsellors provided feedback on performance; they frequently complimented the nurses about positive behaviour; they also facilitated them to look forward (feed forward) on what might be a next step for this specific nurse.

'I stand next to the nurse [in the coaching on the job] and listen. We listen and look together, from that viewpoint. And I listen to the patient... The nurse afterwards said: "the way that you listen to patients and ask questions..." And that is interesting: to link that to their own behaviour. (Is.2.3)

3.2.7 Working, practising and reflecting

The learning process continued after the team sessions. Spiritual counsellors kept contact and stressed they stayed available for nurses. The short, emailed, messages served as inspiration and reminders for the nurses. In the interviews, some nurses said they remained aware of MiL, whereas others mentioned that it faded away. The second survey revealed that learning continues in practice for the majority after the team sessions: 77% expressed that they had been improving competences after the initial sessions and coaching on the job, nurses 'took it with them in their work': They were aware of MiL, observed, tried, and dared, to practice new approaches, reflected and built up experience. Meanwhile, they learned through feedback of patients, which fostered their self-trust.

'We had this information during the team sessions, and we discussed how you can tackle it, then you take it with you anyhow... And then you recognise it, ... Yes, I dare to undertake those conversations, I'm not saying it's the best way, but it's a step in the right direction for me and I get compliments in return... And that does well. It's not that you know a lot, but still it's something to go on with, get more experience. Simply, I have it inside of me, not in my head, but in what I'm doing and not doing.' (InD.3.3)

3.2.8 Taking responsibility

The awareness that MiL is important, and the experience that they were able to play a role, awakened nurses' empowerment to take the lead in their work: they stood up for what they regarded as meaningful for patients.

'Whatever I do, I stand up for the patient... I am more aware of that. And that gets the action going.' (F.A.2)

4 Discussion

4.1 Discussion of results

This paper describes the underlying learning-teaching process of an educational programme, about attunement of care to aged patients' MiL, which was developed, evaluated and improved during a 3-year project. The programme was, and still is, provided by spiritual counsellors. To our knowledge, this is the first study on this specific topic, the process how nurses learn, and spiritual counsellors teach in interaction. The present study provides insight into this process, the 'black box' of education, through a model, which comprises eight phases. Understanding of this model provides a valuable basis, not only for the continuation and expanding of this specific programme, but also for the development of other and future educational programmes on this subject, which is important in the light of contemporary definitions of health and, even more important, for the wellbeing of patients.

Although our model was synthesised from (inductive) analysis of the data, we see similarities with other practice-oriented educational theories and models.

- Our learning-teaching circle clearly shows a similarity to Kolb's Experiential Learning Theory (ELT). In ELT, learning is a process where knowledge is created by persons in interaction with the environment, through phases of experiencing, reflecting, thinking and acting (Kolb & Kolb, 2009). ELT is widely accepted as a valuable framework for learning processes, which supports the trustworthiness of our findings.
- Reflection plays an important role in our model, reminding us of the 'reflective practitioner' of Schön: reflection while doing creates possibilities for the learner to reshape the situation (Schön, 1987). Therefore 'coaching on the job' appeared to be especially powerful for learning. The coaching role of the spiritual counsellor, exploring together, is also supported by Schön (1987), who emphasised that the coach needs to be capable in dialogue and explore together with the learner.
- The supportive relationship of the spiritual counsellor is close to Titchen's 'critical companion' (Titchen, 2003). A supportive relationship, characterised by interest in the nurse, confirmation, dialogue and role-modelling, is regarded as a prerequisite for learning in practice (Hilli & Sandvik, 2020; Noddings, 2013; Titchen, 2003).

An interesting question for further research is whether the required teaching behaviour is specific for spiritual counsellors and how educators can learn this. The phases of our model reflect what education for nurses should be. Nursing education should bring together head, heart, body and spirit, by integrating motivation, values, emotions, different types of knowledge (rational, experiential and intuitive) and doing (Kolb & Kolb, 2009; Martinsen, 2006; Noddings, 2013; Titchen, 2003) and by providing space for inspiration, wondering, exploration and creativity. Therefore, the first phase of the process, i.e. 'being touched', serves as a trigger for learning. The phase 'awareness of the patient/other' was the most important phase and served as turning point. According to Biesta (2017) education is nowadays too ego-centred, concentrating mainly on the desires of the students; he emphasises that the world needs another approach: a directedness towards the needs of the other in order "*to awake the desire to live in the world in a grown-up way*". Biesta mentions three educational interventions that may contribute to this 'desire': interruption, suspension and sustenance. Our model of the learning-teaching process includes all three: *Interruption* of own perspective is induced in the turning point phase: 'awareness of the patient as other'; the spiritual counsellors challenge the nurses to *suspend* their opinion and actions, mainly in the phases 'broadening and deepening' and the phases where 'reflection' play a key role. *Sustenance* is the basis of the process, in a supportive relationship with the spiritual counsellor. This learning-teaching process involves nurses' awareness of patients' perspectives and improvement of competences, and finally leads to responsibility and empowerment to do what is needed for the patient. These are all qualities which are highly valued by older patients (Hupkens et al., 2020b).

4.2 Study limitations

This study has limitations. Firstly, all data originated from a single organisation (even though sixteen teams were involved); this limits transferability to other contexts. Secondly, although we were frequently present in the teams and nurses were familiar with us, the presence of the researcher (in the team sessions), or the spiritual counsellor (coaching on the job), may have influenced the behaviour of participants during observations.Finally, observations and interviews were performed by only one researcher; however, triangulation and dialogue in research/project groups provided a deeper/ broader understanding of the findings.

5 Conclusions

The main conclusions emerging from this study is that learning to attune to patient's MiL, evolves through a learning-teaching process of eight phases, which starts with 'Being touched'. 'Awareness of the other' is the pivotal phase. The relationship with the educator, reflection and experiential learning are crucial in this process.

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Chapter 8

General discussion

In recent years, older persons' meaning in life (MiL) has become a major topic in the debate about good, dignified or healthy ageing (see par.1.1.3). However, our research started not in public debate, but in practice; with home nurses who turned to spiritual counsellors because they felt incompetent to respond well in situations where older patient's MiL was at stake. Retaining MIL is challenging during later life.Although some studies reveal that older persons experience as much, or more, MiL as younger groups [1-3], others report loss of MiL in the later years due to loss of dear ones, loss of valued roles [4], loss of physical capacities, loss of personal growth or loss of purpose [5-7]. Some older persons even experience their life as an unbearable burden and give up on life [8]. Since most older persons in the Netherlands age in place (in their private homes), home nurses frequently encounter older patients with MiL issues.In the Dutch nurse competence profile, MiL issues are mentioned in the core patient problem set, which are the principal problems on which nurses should focus [9]. Notwithstanding an articulated urgency in nursing practice, and growing interest in older person's MiL in society, the scholarly literature contains multiple gaps: MiL of older home nursing patients; home nursing with respect to older patient's MiL; and education in this regard. The objective of this thesis is to generate knowledge concerning these subjects. Additionally, this work contributes to professional practice and to education with respect to older patients' MiL.

8.1 Main findings, integration and reflection

In this section we answer the research questions, integrate findings with other literature and reflect on the findings. Table 8.1 provides an overview of the main findings regarding the research questions. This section is structured as follows: Older persons' MiL; Home nursing with respect to older patients' MiL; Education regarding attunement to older patients' MiL.

Table 8.1: Overview of main findings

Chapter	Research question	Research question	Findings
Part 1: Older persons' meaning in life			
2	1	How do older persons find MiL, what are their MiL sources and what circumstances are associated with their MiL?	Texts were heterogeneous in type and discipline. The synthesis of findings resulted in the image of MiL as a river, springing from several sources, finding its way in the environment and adapting to changing circumstances. -Old persons find meaning through several processes: a developmental process; meaning creation; discovery of meaning; daily meaning; and in connection (with others, self, something greater). - Health, living together, high socio-economic status, social relations, activities and religion are associated with experiencing meaning in later life. - The main source of meaning in life is human relationships Other sources of meaning vary by age and culture. Gaps were found in the literature with respect to discovery of MiL and daily meaning. Cultural diversity was lacking. Studies from a healthcare perspective were limited.
3	2	How do older home nursing patients find meaning in daily life and what are their MiL sources?	Interviews were analysed at the individual and at a general level. Cases of individual analysis (appendices) provide an in-depth understanding of the meaning of themes and the interconnectedness of them. The general analysis supports the image of MiL as a river. - Most participants mentioned many sources of MiL. Overarching themes were self, others, environment and living. - Retaining MiL is interwoven in everyday life. Respondents experienced it as a challenging process which costs energy and perseverance. Three processes of retaining MiL were identified: maintaining, adapting and discovering.

Chapter	Research question	Research question	Findings
Part 2: Home nursing with respect to older patients' meaning in life			
4	3	What are situations in daily home nursing in which MiIL of older adults, or the lack thereof, comes to light?	There are many situations in daily home nursing where MiL of older patients (or the lack thereof) comes to light: - Being and perceiving in the private environment of patients provides insight into patient's MiL; - The encounter between nurse and patient, embedded in relationship, may relate to MiL; - In nurse-patient communication MiL can be at stake. - In personal care to patients, nurses can attune to patients MiL; All Derkx's dimensions of MiL were recognizable in the descriptions of home nursing visits.
5	4	What are the experiences of older home nursing patients in relation to nurses' attunement to MiL?	Interviews were analysed at the individual and at a general level. Examples of individual analysis (appendices) provide in-depth insight into the attunement of nurses to patient's MiL and the consequences this has for a patient.General themes show: - Patients did not expect attention, nor attunement, to their MiL from nurses. - At the same time, all participants told examples of care which was attuned to their MiL and which they appreciated highly. Patients also shared examples of bad care which was not attuned to MiL. - Relating to MiL, patients value attention of nurses for them as a person, longstanding, kind and reciprocal relationships with nurses, decisiveness and skilful care. - Care which is provided in such a way contributes to a cheerful moment, a good day and feeling valued as an equal person. Older adults also stressed that focus on MiL restores attention to what is important in healthcare.

Chapter	Research question	Research question	Findings
Part 3: Education regarding nurses' attunement to older patients' meaning in life			
6	5	What are outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL?	Nurses benefited in three ways from the educational programme: - It enabled them to provide good care which provided them with a sense of fulfilment. Nurses mention many competences which they (further) developed during the education. - It contributed to pleasure in their work both with patients and in the team - They experienced personal growth due to (new) awareness of own MiL and doing what is important. Many nurses reported limited benefits. They state that they already attuned care to patient's MiL before the training, they experience insufficient implementation in the care process; or explained that organisational pressure on productivity limits benefits. Nurses are ambiguous with respect to sustainability of benefits of the education.
7	6	What is the underlying learning-teaching process of an educational programme, provided by spiritual counsellors about attunement of care to aged patients' MiL in home nursing?	A model of the underlying learning-teaching process of the educational programme was developed. The model consists of eight interrelated phases, which are embedded in a supportive relationship with the spiritual counsellor. The learning phases are: being touched; opening-up; awareness of own meaning; broadening and deepening understanding; turning-point - awareness of the patient as other; exploring and reflecting; working, practising and reflecting; taking responsibility. The relationship with the educator, reflection and experiential learning are crucial in this process.

8.1.1 Older persons' MiL

Main findings regarding research question 1: How do older persons find MiL, and what are circumstances that are associated with older persons' MiL?

Through an integrative literature review (chapter 2) we found answers in heterogeneous scholarly texts about this research question. This review focused on (non-specified) older persons. We identified five themes in the existing literature about the process of finding meaning (How?): developmental process; creation of meaning; discovery of meaning; daily meaning; and connection. Developmental processes are part of people's life stages. Older persons find meaning in a *developmental process*, both in continuity and discontinuity of life

and in relation to their cultural values [10-13]. Several authors view old age as a (possible) stage of wisdom and a greater commitment to life [14, 15]. MiL can be, actively, *created* in the later years through reminiscence, commitment and motivation, e.g. in composing one's life story or in activities [16-25]. Older persons have experience in life, which has provided them with virtues (character strengths), such as humour, humanity and temperance, that help them to find MiL [11, 25]. They adapt to negative events by various (coping) strategies, such as preserving who they are and valuing what is given [16, 21, 25-28]. People differ in these strategies. Besides creation, MiL can also be found through *discovery:* through silence and contemplation, instead of acting. An attitude of openness and receptiveness may bring MiL, for instance in an unexpected moment with others, or in the beauty of nature [15, 20, 29]. Only a few authors described *daily meaning:* finding meaning in daily activities, ordinary things, such as music or walking. [15, 25, 27, 29]. Tornstam mentioned that the meaning of these daily activities may be connected to an existential level [15]. Finding meaning is not only an individual process. It is a process of *connection* and interaction, with self, others, society or something greater than oneself, e.g. God or the universe [10, 20, 22, 24-26, 29-34].

Literature revealed many circumstances in life that are positively associated with MiL: health [6, 35, 36], higher education, higher income, good relational quality, social integration, high everyday competence, employment, marriage [35], self-compassion [37], helping others and religiousness [38].

Authors mentioned multiple sources of MiL (What?) in different populations. One source was prevalent: human relationships, especially the relationship with family [39-45]. MiL sources were different among age-groups [41, 42, 46, 47] or cultural groups [10, 42, 43].

Analysis and synthesis of themes in the literature resulted in our representation of a 'River of meaning in later life'. Finding MiL is a process which is like a river, winding its way through later life in quiet and turbulent circumstances. Several streams contribute to a river, just as several processes and sources contribute to MiL in connection with the environment. Several gaps in the scholarly literature were found: texts with respect to the discovery of MiL and daily meaning were scarce. Study samples reflected little cultural diversity. Furthermore, studies from a healthcare perspective were largely missing.

Main findings regarding research question 2: How do older home nursing patients find meaning in daily life and what are their MiL sources?

In our empirical work, we focused on the field of homecare and the specific group of older persons ageing in place and receiving home nursing (chapter 3). This group is particularly relevant, because 90% of Dutch older persons (75+) age in place and many of them are receiving home nursing [48]. Through three waves of

semi-structured interviews (the first part of the 60 interviews) with 24 older home nursing patients we explored their MiL sources (What?) and the way by which they found meaning in their daily life (How?). Most respondents had many sources of MiL (*What*). Analysis at the individual level (all interviews of one person) resulted in cases which reveal the meaning and interconnectedness of (sub)themes, which are different for every person (see the appendices of chapter 3). In the analysis at the general level we identified four overarching themes: Self, others, environment, living. With respect to s*elf:* To live according to one's values was a major source of MiL for all respondents. Using one's character strengths provided them with MiL, for instance, being optimistic, creative or generous. The respondents told about their life and how beautiful memories stayed a source of MiL in their present life. They regarded their physical and mental abilities as a source of MiL. Furthermore, autonomy, 'living my life as I want to', was mentioned as an important source of MiL. *Others* was an overarching theme as a source of MiL*:* Personal relationships were mentioned by all respondents: Spouses, brothers and sisters, children, grandchildren, friends, neighbours, but also pets, contributed to respondents' MiL. Even dear ones who passed away could still be an important source of MiL. Role fulfilment was important for respondents, e.g. being a good mother or neighbour. Reciprocity in relationships was pivotal for them: they not only want to receive; they give and help as well. Besides individual personal relationships, communities were a source of MiL, such as a group of friends or a parish. Half of the respondents mentioned religion as a source of MIL. The third overarching theme was the *environment*: home and one's belongings, the view, convenient shops in the neighbourhood, art, music and media, such as the TV. The last overarching theme was *Living:* For many respondents, their activities were a source of MiL. Both beginning and finishing the activity was regarded as important for MiL and the activity had to contribute to something valuable. Some respondents experienced daily rhythm or life itself as a source of MiL: waking up in the morning and being able to live another day.

In this chapter (chapter 3) we also analysed *how* older persons find meaning in daily life. Three processes of retaining MiL were identified: maintaining, adapting and discovering. Many respondents experienced retaining MiL as an increasing challenge due to declining health and loss of dear ones. They *maintained* their MiL through being themselves, going on as they were used to, by taking good care of themselves, and by staying connected to their MiL sources, such as relations, activities and music. Respondents *adapted* continuously to the changing conditions: They accepted help or found creative solutions for themselves. They also adapted on beforehand to the future, by looking ahead and taking precautions, for instance making final arrangements. Respondents experienced retaining MiL as a continuous process, which costs energy and perseverance. Some explained that this had a limit, when pain or exhaustion became too much or when preferred social roles were hindered. The last process which was identified in the

interviews was *Discovering*. Respondents reflected about life, 'observed the puzzle' and found connections and meanings they had not seen before. Many of them described a sense of wonder and openness towards life, which enabled them to discover unexpected meaning in their daily life; while looking out of the window, listening to music, or in unexpected encounters. The analysis of interviews of respondents at the general level supported the image of meaning in later life as a flowing river, (the representation from the literature review, chapter 2), ever-changing by multiple processes, sources and circumstances.

Integration and reflection regarding older persons' MiL (who receive home nursing)

Our empirical work provides insight into MiL of a highly relevant group that was hardly studied until now in this respect. The literature review (chapter 2) and the empirical study (chapter 3) show mostly similarities. Yet, the empirical work adds some interesting differences and nuances to the literature. Our empirical findings show the daily character of MiL. The aged adults in our research did not recognise the, frequently used, difference between existential and daily MiL (see introduction). They explained that for them daily and existential MiL were the same, completely connected. This could be a consequence of their limited timespan [49], or probably the difference is superfluous. Furthermore, the respondents in the empirical study experienced retaining MiL as a continuous process; Ageing comes with many losses over time, such as loss of dear ones and gradual physical and mental decline, which results in a continuous process of retaining MiL, rather than occurring at intervals.

Respondents retained MiL in various ways during later life; they did a lot to experience MiL. The first two processes which we analysed from the interviews (maintaining and adapting) show similarity to the Selection, Optimisation and Compensation Theory. Baltes et al. [50, 51] view ageing as a process wherein persons make choices which goals and competences they wish to keep at a current level or develop more. According to them, choices can be elective – from a pool of possible choices, or loss-based – in response to a decline. The mostly very old respondents in our empirical study showed only the last one: based on decline. Many showed perseverance and creativity in their daily adaptation to these deteriorating conditions in order to retain MiL, although for some this developed into a severe and painful daily struggle. If we consider health as 'the ability to adapt to the challenges of life' [52], most of the respondents in our empirical research may be regarded as healthy in this respect. Both our empirical study and the literature differentiate between an active and a contemplative process of finding meaning. Reker & Wong named this creating (choosing, acting, relating to others) and discovering (reflecting) [21]. This division can also be recognised in our empirical

study: The processes of maintaining and adaptation, which emerged in the empirical study, are active processes (creation). For some respondents this was even hard work, as Gude mentioned at the end of his life [53]. Many respondents also showed discovering: They explained how they discovered MiI in what came their way, by being reflective. Our research shows, in addition to Reker & Wong, that older persons discover MiL by being open and wondering. This was also mentioned by others [15, 20, 29].

Although MiL may be a struggle in later life, all respondents in the empirical study revealed sources of meaning in their daily life. Apart from one, all told that they experienced MiL. Most of them even mentioned an abundance of sources. We arrived at four overarching categories of sources: Self, others, environment and living. Our categories are broader than the more detailed categories of other authors [42, 54, 55]. Our broad categories of MIL sources show that MiL can be derived from many things and the appendices (of chapter 3 and 5) show that it is personal what is meaningful for every single person, as Frankl wrote [56]. Human relationships (family, friends) are frequently mentioned as the most important source of meaning in later life [42, 45, 57]. Our empirical research confirms this and adds pets as vital others. In relationships, reciprocity is important for older persons; not only receiving but also giving. Particularly maintaining roles which are highly valued by oneself (e.g. mother, neighbour) was considered important by respondents, as Krause has already mentioned [4]. Unfortunately, loss of dear ones is inevitable in later life. Respondents in our empirical study showed that, when this happens, other sources are crucial. Self can be a stable source [11, 27, 58], including character strengths [11] and values [10]. Although home and the neighbourhood are generally considered as important for community-dwelling older persons [59-61], our study adds that these are also important as sources of older persons' MiL. This is a noteworthy insight, since more older people age in place, nowadays and in the future.

8.1.2 Home nursing with respect to older patients' MiL

Main findings regarding research question 3: What are situations in daily home nursing in which MiL of older adults, or the lack thereof, comes to light?

Through participant observations (chapter 4) we discovered that MiL comes to light in daily home nursing in several ways. We found four main themes: being in a private environment; nurse-patient encounter embedded in relationship; personal care; conversation. When home nurses enter the *private environment*, they perceive signs and symbols which reveal patient's MiL, for instance a photo of a beloved person. They meet important others of the patient, family and pets. *Encounters* in home nursing are frequently embedded in *long-term relationships*.

In nurse-patient interaction can be nearness or distance, trust, appreciation. A reciprocal relationship may contribute to MiL. When a nurse sees a patient it can provide her with information about a patient's MiL: is he feeling well, engaged in an activity? The nurse-patient encounter reveals the direction of nurse's attention: Although some nurses were merely focused on a technical task, such as an injection, many others paid attention to the whole person, including MiL. Besides verbal communication, non-verbal communication revealed the direction of this attention. Some nurses integrated MiL in *personal care* by touching with respect and adaptation of care to the values of patients. During the nursing visits *conversation* contained many MiL issues: for instance: plans for the day, worries about the future, loneliness and grief. In some visits this had a reciprocal character. All Derkx' seven MiL dimensions were recognisable in daily home nursing, indicating that MiL is highly perceivable in home nursing practice.

Main findings regarding research question 4: What are the experiences of older home nursing patients in relation to nurses' attunement to MiL?

Because MiL is different for every person, good care should be responsive: respond to the position of the patient as he expresses it [62], attuned to person's MiL. The second part of the interviews with 24 older home nursing patients revealed their experiences with, to their MiL, attuned care (chapter 5). Respondents explained that they didn't expect attention nor attunement of nurses to their MiL. They preferred to keep MiL to themselves, regarding MiL as their own quest. From nurses they expected *'simply normal contact'* and *adequate physical care*. Some respondents didn't believe that nurses are competent for conversations regarding MiL, and moreover, they experienced that nurses even lack the time for a normal chat. Nonetheless, respondents shared examples of situations where nurses showed to be open for patient's MiL. The *tone* for MiL was already set when the nurse was entering the patient's house. Respondents immediately felt if there was space for MiL or not and they adapted their behaviour to this space. Respondents appreciated it if nurses showed *interest in them as a person*, even if they experienced the contact as superficial. However, they also told about situations where the nurse was only interested in a technical task. They experienced this lack of interest in them as denigrating. Respondents told about nurses who *recognised hidden needs* or suffering, for instance pain or sadness. However, they expressed that the attention of nurses was blurred by organisational issues. Respondents moreover shared experiences of attuned care for MiL. They told about the *long, kind, and especially reciprocal, relationship* with some nurses. They valued nurses who *do what is needed* and provide *skilled personalised care*, because this limits suffering and discomfort. In contrast, they complained about nurses who were never in time or delivered inadequate technical care.

The respondents explained what the consequences are of care that is attuned to their MiL: they enjoyed the nursing visits as a *cheerful moment*, *felt secure* and *treated as a valuable, equal person*. They had a *good day due to good care*. Some respondents added that attention to MiL restored *attention to what is important in healthcare*. Again, the individual analysis of interviews provided cases that enabled in-depth insight into unique nurse-patient interaction in their own contexts and the consequence that this behaviour had for the individual patient (see the appendices chapter 5).

Integration and reflection regarding home nursing with respect to older patients' MiL

Our observations of home nursing visits revealed that home nursing is saturated with situations where patient's MiL comes to light, and thus includes many opportunities for nurses to attune to patient's MiL. Dutch - patient and older peoples' - advocacy organisations conclude, based on surveys among their members, that more attention should be given to patients' MiL in healthcare [63] and that care professionals can contribute to patients' MiL [64]. Our research shows that attunement to older patients' MiL contributes to a cheerful moment, a good day, feeling secure and valued as an equal person.Attunement to MiL in home nursing involves, among others, interest in the patients as a person, skilled, personalised physical care, and long, kind, reciprocal relationships. Reciprocality is considered to be important for nurse-patient relationships in home nursing[65, 66]. It entails, for both parties, giving and receiving and balancing both.

The respondents in our empirical study considered MiL mostly as their own quest and their responsibility. They didn't expect support from home nurses in this respect, but, at the same time, highly valued care which they regarded as attuned to their MiL. Studies in nursing homes concluded that nurses have an important role in supporting older patient's MiL [67, 68]. However, patients who still live in their private homes are more independent than those who live in nursing homes, also with respect to MiL. Therefore, in home nursing, nurses' supportive role with respect to MiL should be subtle and modest: it requires sensitivity to the space that the patient allows to the nurse and flexibility to attune to the specific situation, as the cases in the appendices show. It requires 'seeing with the heart's eye', as formulated by Martinsen [69]:Seeing with the heart's eye implies opening up for what can be seen through two ways of seeing. The first one is feeling touched personally by the patient in his situation ('the other is a person like me'); the second is reflective and understanding ('the other is not me; I might be of help')'. The heart's eye lies in the space and interaction between both ways of seeing, between nearness and distance.Nurses who focus on production and procedures foster a 'registering eye' [69], which alienates nurses from the perspective of the patient, and can even harm the patient [70, 71]. As patients in our research explained: it distracts from what is important in healthcare.

8.1.3 Education regarding nurses' attunement to older patients' MiL

In our project spiritual counsellors provided an educational programme to home nurses in order to improve their sensitivity and competence in attuning care to older patients' MiL. The programme consisted of five interrelated modalities: team sessions; coaching on the job; individual consultation; presence in teams; short messages.

Main findings regarding research question 5: What are outcomes of an educational programme, provided by spiritual counsellors, aimed at improvement of home nurses' sensitivity and competence in attuning care to older patients' MiL?

We evaluated the benefits of the educational programme from the perspective of the nurses (chapter 6). Firstly, nurses experienced that the education enabled them to give *good care to patients and this provided nurses with a sense of fulfilment*. Nurses explained that they had developed in attentiveness, empathy, and attunement to patient's MiL through the educational programme. They emphasised that, as a result of the education, they, first of all, do what is important for patients (instead of for the organisation). They prioritise better and have become less dependent on the rules of the organisation. Furthermore, they refer more adequately to others, if needed, and they cooperate better in their teams. Additionally, many nurses experienced *more pleasure in their work,* due to the education, because the coaching enabled them to work more in line with their own vision of what good care consists of. Some nurses mentioned that, since the education, they enjoy the surprise and challenge of the interaction with patients more. During the education, they also benefitted from the togetherness with colleagues. Finally, some nurses reported *personal growth*; they became more aware of their own MiL, which gave them the strength to do what was important for themselves, like booking a holiday to a special destination.

Although nurses expressed that they benefitted from the education, there were at the same time, critical voices: Most nurses (56%) stated that they *already did* what the education aimed to learn them: attune care to what is important for patients. Comparison of examples in the interviews of nurses provide mixed results about this. Some nurses told that what they learnt could *not be sufficiently integrated in the care process*. Some nurses reported that they were unable to experience any benefits of the training due to the continuous *pressure of the organisation* on production and efficiency. Nurses were ambiguous regarding the sustainability of the education. Although the majority stated that they had *further developed* in what they learned, even after the education, they stressed, at the same time, that *attention to MiL evaporated over time*. Although the outcomes of education were

mixed, many nurses developed sensitivity and competences in attuning care to patients' MiL, in accordance with the aims of the project.

Main findings regarding research question 6: What is the underlying learning-teaching process of an educational programme, provided by spiritual counsellors, about attunement of care to aged patients' MiL in home nursing?

The underlying learning-teaching process of the education was analysed and synthesised through multiple data collection methods, perspectives and dialogues (chapter 7). It resulted in a model of eight interrelated learning phases, which are embedded in a *supportive relationship* with the spiritual counsellor. The learning phases are: being touched; opening-up; awareness of own meaning; broadening and deepening understanding; turning-point - awareness of the patient as other; exploring and reflecting; working, practising and reflecting; taking responsibility. The behaviour of the spiritual counsellor facilitated these phases. The first phase, 'being touched', serves as a trigger for learning. The phase 'awareness of the patient as other' is the pivotal phase, because it turns the direction of attention from the nurse to attentiveness for, and understanding of, the patient and opens possibility for transforming behaviour of the nurse into attuned care. The relationship with the educator, reflection and experiential learning are crucial in the learning-teaching process.

Integration and reflection regarding education with respect to older patients' MiL

Our findings support previous work [72-74] which all conclude that nurses' competences (regarding support of patient's MiL) improve after education, and are sustainable for 4-6 months. In addition to other work, our research shows additionally that nurses also benefit from education regarding MiL in their personal growth. From the perspective of the nurses, the main benefit was that the education enabled them to give good care to patients and this provided them with a sense of fulfilment. This is congruent with other studies that showed that education related to patient's MiL contributes to work satisfaction [72, 73].

If we compare chapter 5 (patients' perspective) and 6 (nurses' perspective), we see that nurses indeed learned many things which patients mentioned as good care (which is attuned to their MiL): they developed an attentive attitude (e.g. taking the time), learned to be more empathic, paid more attention to the person instead of the technical task, learned better communication skills (e.g. listening, asking open questions), attuned their care to what is important to patients (e.g. in physical care) and prioritised better. Our evaluation shows that nurses do, more than before the education, what matters for patients, instead of what is important for the organisation. They dare to stand up and take responsibility: they act in a 'grown-up way' [75]. Biesta states that education generally is too ego-centred nowadays and

should focus more on needs of the other instead of self. The education of nurses by spiritual counsellors improved both: awareness of own MiL and the directedness to the other (patient). On top of that, it strengthened the desire to act. Our research provides insight into the 'black box', the learning-teaching process, of the educational programme, while other studies on this subject focused solely on outcomes[72-74].

Experiential learning was important in the learning-teaching process. Although all learning modalities were experiential, coaching on the job during nursing rounds (Dutch: 'meefietsen') challenged the nurses most to change behaviour, through acting, experiencing and reflecting, which is in line with Experiential Learning Theory of Kolb [76]. Especially 'reflecting in action' is powerful, because it shapes possibilities for change [77]. The supportive relationship with the educator (spiritual counsellor) was a prerequisite for learning in this respect, as others mentioned before [78, 79].

8.2 Methodological reflections

In this thesis we used various methods to answer the research questions. All methods are discussed in detail in the separate chapters. A few overarching strengths and limitations of the work in this thesis can be mentioned. A major strength of this thesis is that it contributes to all dimensions of practice-oriented research: Science; professional practice; and education. In practice-oriented research three pillars support the quality of research: practicability (relevance, usefulness, transferability), trustworthiness (credibility, dependability, confirmability), ethicality (adequate, attainable, ensuring well-being of participants)[80].

- Our work for this thesis is *practical*: it is relevant for older persons, nurses, educators/spiritual counsellors, managers and policymakers. It contributed to useful and sustainable development of practice, both in nursing and in education.
- The work is *trustworthy:* Interviews were audiotaped and verbally transcribed; we made thick descriptions of observations; I used a diary to reflect on the research; Software was used in the analysis; dialogue improved the data-analysis [81, 82], For chapter 6 and 7 we also used triangulation of data collection methods [81]. As main researcher I was engaged for more than three years in the field of enquiry, in order to enlarge understanding [83]. We based our research on broad theoretical concepts of MiL (Brandstätter e.a. and Derkx), which allowed space for new insights from different perspectives of participants in the empirical studies. The thesis connects, and reflects on, theories from different disciplines, e.g. psychology, gerontology, nursing and pedagogy.

- This thesis is also *ethical:* As our results show, we used suitable methodology to answer our research questions. In the data analysis stakeholders from practice were involved, including patients, which enabled meaningful interpretation from their perspectives; ethical procedures were followed with respect to informed consent; the researchers adhere to the ethical code of conduct [84]. This included an overall attitude of openness and respect towards participants.

A main limitation of this thesis could be the transferability of findings. The empirical data were restricted to one home nursing organisation in the Netherlands and a limited number of respondents and participants. However, transferability was enhanced by purposeful selection of participants from diverse backgrounds and by rich descriptions of the context, both in the chapters and in the appendices [83, 85]. A strength and limitation of this thesis is the largely qualitative design: on one hand this enabled in-depth 'first-person's' understanding, which is highly relevant for nurses [86]. On the other hand, it limits comparison to other studies with other (quantitative) methodology.

8.3 Directions for further research

This thesis adds knowledge to the existing literature. However, with new findings, other questions arise. Many avenues for research are viable and interesting to go. A few suggestions are provided in this section.

8.3.1 MiL of older persons

This thesis builds on existing literature in the area of MiL of older persons (chapter 2) and adds knowledge regarding a specific group: older persons ageing in place and receiving home nursing (chapter 3). Although we offered a contribution, research with respect to this specific, highly relevant, group is still in its infancy and needs further work. Among many subjects, I only highlight three:

- *Wonder as a way to discover MiL in later life*. This is a promising subject, because wonder may stay unaffected by physical decline in the later years. Recent work explains how specific meaningful moments contribute to MiL (of younger adults) [87]. Further research could focus on the question how wonder in daily life of older persons contributes to MiL, and whether wonder can be fostered.
- *Home and the environment as MiL sources of older persons ageing in place*. With a growing population ageing in place this is a highly relevant topic. What are features of an environment that contributes to older persons' MiL?

- *Desired support regarding MiL*. Older persons' MiL is currently a 'hot topic' in healthcare. The Dutch minister of health launched a program of support, provided by spiritual counsellors, for older persons ageing in place (and palliative patients)[15]. Older persons in our research didn't expect support of their MiL of professionals. Yet, they highly valued care by nurses which was attuned to MiL. This ambiguous finding raises a question: What do older persons actually need, wish or value, regarding support in this respect and from whom?

8.3.2 Nursing

Although valuable findings were shared in this thesis, knowledge about MiL and nursing in the field of home nursing is still extremely limited. Larger studies with varied populations of community-dwelling older persons and home nurses could build on our work regarding this subject. Suggestions for further research are:

- *Reciprocity in the nurse-patient relationship.* As our research shows, this is an important subject, not only for the well-being of patients, but also for nurses. Further studies could explore how reciprocal nurse-patient relationships grow, what characterises this reciprocity, and how nurses (and patients) can balance it in a proper way.
- Another direction for research is the *image of nursing* in society. MiL is mentioned in the core competence profile; Nurses in practice and nursing/caring theories claim to have a holistic view on people since long, which includes MiL of patients (for example nursing theories of Martinsen [69], Swanson [88], Parse[89], Grypdonck [90] and McCormack & McCance [91] are interesting with respect to MiL); MiL is an important dimension of the popular concept of (positive) health which is a foundation of the Dutch nursing profile. Yet, many people, also patients and some nurses in our research, still consider nursing as a profession that is mainly focused on physical health. Research could focus on the way this image is conveyed and, if desired, what nurses can do to change it.

8.3.3 Nursing education

Our findings have implications for the knowledge base of nursing education (pedagogy) with respect to attunement to patient's MiL. Our research is the first regarding this subject in the field of home nursing. Therefore, more research in

15 See: https://www.zorgvoorbeter.nl/nieuws/factsheet-subsidieregeling-geestelijke-verzorging-thuis

this specific field is needed. To improve comparability of studies, researchers could use identical instruments. Our educational programme was developed for home nurses in practice. Further research could enquire the applicability of the process (of 8 phases) in initial vocational nursing education and in education of other professionals regarding patients' MiL. Another topic of interest is which qualifications are needed for educators/spiritual counsellors to be able to provide the programme.

8.4 Implications for practice and further development

Findings of our research have many implications for practice: for older persons, home nurses, educators and spiritual counsellors, management of healthcare organisations and policy.

8.4.1 Older persons

Retaining MiL can be a challenge in later life, due to many losses during this life stage. Our research shows that older persons (who receive home nursing) do a lot every day to maintain MiL. They should not only be considered as a vulnerable, or frail, group in this respect, but also as experts in adapting to their deteriorating conditions. Most of them manage to retain MiL and have many MiL sources. Further development of support regarding MiL should facilitate empowerment of ageing persons to maintain MiL during old age. If we consider MiL as part of health, why don't we provide health promotion in this regard as we do for other dimensions of health? Knowledge from research in this regard should firstly be at the disposal of ageing persons themselves. The Dutch advisory board for older persons (Dutch: Raad voor de Ouderen) recently advised[16] the government with respect to older persons' MiL and they added an appeal to ageing persons themselves to prepare for the later years, including resources for MiL. In the UK, and several other countries worldwide, programmes[17] have been developed in this regard, which could be an inspiration for the Netherlands.

16 https://www.beteroud.nl/beteroud/media/documents/Advies-RvO-Zingeving-november-2019-(003).pdf

17 See for example: https://www.mentalhealth.org.nz/assets/Five-Ways-downloads/mhf-5-ways-a3-vert-bubble-poster.pdf andhttps://neweconomics.org/2008/10/five-ways-to-wellbeing

8.4.2 Home nurses

The impact on nursing practice of this thesis started in 2015, developed with the project, and continues until now, because the educational programme is still applied. Some participating nurses enthusiastically supported 'BLIB' (Dutch name of the project: Betekenisvol Leven in de Buurt). The educational programme, and the publications connected with this thesis, may keep inspiring nurses in practice, and contribute to good, to MiL attuned, care for older patients ageing in place. This includes, among others: being in time, providing skilled personal physical care, and paying attention to the whole person (instead of a technical task). Three suggestions for further development are highlighted.

- *Person-centredness*. Individual analysis of interviews showed that MiL of older persons is specific in every single situation. An important implication for practice is that, more than anything, attentiveness, an attitude of openness and directedness to the unique other, is needed. Responsive person-centred nursing interventions should focus on (re)connecting patients with their MiL sources and supporting them in their strategies to retain MiL. This approach is in line with the conviction of older patients that MiL is their quest.
- Another important suggestion for practice is *implementation in the (formal) nursing process*. Although MiL can be recognised and registered in many nursing diagnoses [92], bureaucratic procedures regarding MiL should be limited. At the same time, some registration is needed to enable nurses to spend time in this regard. Nurses in practice need more training and experience how to do this in such a manner that they ensure time and space for attunement to MiL, without losing themselves in procedures.
- Finally, but most important, professionals should *invest in, long, kind and well-balanced reciprocal relationships,* because this enables both, the older person and the nurse, to feel a valuable person, who gives and receives.

8.4.3 Educators and spiritual counsellors

The successful educational programme, which was developed in our project, can be downloaded for free[18] and used by other educators (spiritual counsellors). The programme exists of five interrelated modalities (see chapter 6 and 7). All five modalities together contribute to the benefits described in this thesis; therefore, they should favourably not be used separately. The underlying learning-teaching process of eight phases of the educational programme (from 'being touched' to

18 https://www.hogeschoolrotterdam.nl/onderzoek/projecten-en-publicaties/zorginnovatie/samenhang-in-zorg/betekenisvol-leven-in-de-buurt/resultaten/#flex

'taking responsibility') could be used as a framework for further development of educational programmes, regarding patient's MiL, not only in homecare, but also in other fields of nursing, in vocational training of nurses and in education for social workers. In further development of the educational programme specific attention should be paid to the aspects of care which are most valued by patients, such as showing interest in the person, adapting care to personal wishes, and building long, kind reciprocal nurse-patient relationships. Learning how to balance reciprocity is a topic of specific interest for education. This goes beyond the communication training which are common in vocational training for nurses.

8.4.4 Healthcare management

The benefits of the educational programme, provided by spiritual counsellors, are most important for nurses and patients. In addition, the benefits are interesting for healthcare managers. Firstly, because the programme contributes to good care (according to nurses); Secondly, because, pleasure in work increased for some nurses. Nurses valued the spiritual counsellors as persons who were interested in them as a person and they enjoyed the togetherness with colleagues during the sessions. The education aligned with nurses' personal vision and triggered their playfulness and creativity. Working in accordance with ones values is important for employees: it contributes to MiL [53, 93]. The educational programme contributed to positive development of nurses and teams. These benefits of the educational programme were valued by the management of the care provider where our project was conducted. They embraced the programme and continued and expanded it. Besides, the programme is implemented in nursing homes. Several other (homecare and social care) organisations are interested in the programme. However, implementation of the educational programme is not enough to ensure good care with respect to older patients' MiL. Despite the benefits of the programme, both patients and nurses expressed that the working conditions, during the research period, limited the provision of good care. Besides education, managers in home nursing should realise working conditions that enable both good care with respect to older patients' MiL and nurses' pleasure in work. This includes schedules (time, continuity) that allow nurses to pay attention to the patient as a person and build reciprocal nurse-patient relationships as a basis for good care. MiL should not only be an integral part of the vision of healthcare organisations, as the Standard Existential Questions of Older People already recommended [94], it should, consequently, provide direction for actions, both for nurses and for managers.

8.4.5 Society and policy

As we explained in our introduction, interest in MiL in general, and especially regarding older persons, has been growing in (Dutch) society over the last years. This is reflected in recent publications in the media[19], governmental policy[20] and professional news sites[21]. Our research adds research-based literature which can be used in the underpinning of policy. Our research brings nuance in the image of older persons in society. Older persons are not only vulnerable and dependent on our care; they also provide valuable contributions to others. For instance, respondents in our study cared for an, even older, sister; were valued community leaders; spent time with their grandchildren; were talented card players; advised a nurse in her problems with her upgrowing children; or helped a researcher with her work. Older persons desire to mean something for others [63]. People are throughout life intertwined in many interdependent relationships while finding MiL [13]. Recent initiatives for older, and other, citizens acknowledge this, and emphasise reciprocity, for instance in intergenerational projects[22] or volunteering[23]. Although this thesis shows that healthcare professionals, and indirectly spiritual counsellors, can provide a valuable contribution, MiL of older persons is not a topic that is limited to healthcare. MiL is a multidimensional concept and MIL sources of older persons are extremely broad. Other policymakers, for instance in public space and social care, should be aware of older persons' MiL and consider the impact of their decisions in this respect. In explanation of this statement, this discussion ends, as the introduction started, with examples.

Corinne (appendix 8 Ch 3) is 97 years old and has been single all her life. She had a career in childcare. She is unable to go out on her own. A friend accompanies her every few days. Corinne is still fascinated by the children she sees on her walks. Other days she is alone all day and sits in her chair in front of the window, looking outside for hours, watching the water, ducks, traffic and people passing by. Her apartment has a beautiful view on a well-kept park. Corinne's MiL is fostered by the maintenance of the pleasant environment and the facilities for children in the neighbourhood.

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19 For instance series in de Volkskrant regarding MiL https://www.volkskrant.nl/kijkverder/t/2018/zin-van-het-leven/?referrer=https%3A%2F%2Fwww.google.com%2F and in De Correspondent https://decorrespondent.nl/10876/luisteren-dit-zijn-de-professionals-van-de-zingeving/1115007520-969594c9

20 See for instance: https://www.zorgvoorbeter.nl/nieuws/factsheet-subsidieregeling-geestelijke-verzorging-thuis and Campagne ministerie van VWS: ouderen van grote waarde voor samenleving | Nieuwsbericht | Rijksoverheid.nl

21 For instance https://www.nursing.nl/aandacht-voor-zingeving-door-verpleegkundigen-7-tips/

22 There are many examples, for instancehttps://www.hogeschoolrotterdam.nl/onderzoek/projecten-en-publicaties/zorginnovatie/samenhang-in-zorg/afgeronde-projecten/jong-en-oud-samen-goud/project/#flex orhttps://www.maatjesgezocht.nl/ or https://www.gene-ro.com/coronaspondentie

23 For instance http://www.dementalent.nl/

Romeo (appendix 5 Ch3) is a 90-year old man and almost blind. He lives together with his beloved wife and, although they both have a fragile physical condition, they manage to live their life together, which is of high value to them. However, daily chores demand extremely much energy of Romeo all day. He looks tired. Romeo loves 'reading' audiobooks and listening to opera with his wife, but the load of everyday chores limits him to do so. The couple would benefit from more (instead of less) support in housekeeping: This would leave them more time to enjoy the activities that they love, during the little time they may have together.

8.5 Conclusions

This work contributes to knowledge, practice and education regarding older patient's MiL. Older persons derive MiL from a broad range of sources and they do a lot to retain MiL. For older home care patients, MiL is interwoven in everyday life. Home nurses have a modest, yet important, role in supporting them in this respect and are in a key position to do so, because home nursing is saturated with situations where MiL comes to light. Long, kind, reciprocal nurse-patient relationships and skilled personalised physical care are pivotal in this support. Home nurses benefit from a varied educational programme regarding MiL. It helps them to provide good care and contributes to their pleasure in work and personal growth. In this education the relationship with the educator and experiential learning are crucial. Besides education, homecare managers should realise working conditions that enable good care with respect to older patients' MiL. Furthermore, older persons' MiL should be a concern for policy makers beyond the field of healthcare.

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Summary

Introduction

Meaning in life (MiL) is a subject of growing interest in (Dutch) society. In later life, MiL can be a challenge for older persons, among others, due to loss of dear ones and loss of physical and mental ability. Most older persons in the Netherlands age in place (in their private homes), hence home nurses frequently encounter older patients with MiL issues. According to the Dutch nurse competence profile, MiL issues are principle problems on which nurses should focus. However, nurses in practice feel incompetent in this regard. The scholarly literature provides little support, as it contains multiple gaps regarding: MiL of older home nursing patients; home nursing with respect to older patient's MiL; and education in this regard. Lack of knowledge and competence contributes to nurses' dissatisfaction and may negatively influence patients' health and quality of life. The objective of this thesis is to generate knowledge with respect to the mentioned knowledge-gaps. Additionally, this work contributes to good professional practice and to education with respect to older home nursing patients' MiL.

Part 1: Older persons' MiL

Chapter 2 is a literature review regarding MiL in the (non-specified) population of older persons; chapter 3 is an empirical study which focusses on a specific group of older persons: home nursing patients. This group is particularly relevant, because 90% of Dutch older persons (75+) ages in place and many of them receive home nursing.

Chapter 2 provides insights into the existing literature regarding MiL of older persons through an integrative review. In various academic databases we identified 574 texts, of which 44 met the inclusion criteria. Texts were heterogeneous in type and discipline. Analysis of texts resulted in five themes regarding finding MiL: developmental process, creation of meaning, discovery of meaning, daily meaning, and connection. Older persons find meaning in a *developmental process*, both in continuity and discontinuity of life, and in relation to their cultural values. In the later years *they create* MiL through activities, composing a life story, using character strengths and by various (coping) strategies. MiL can also be found through *discovery*, by silence and contemplation, instead of acting. Only a few authors described *daily meaning*, finding meaning by daily activities. These daily activities may be connected to another (existential) level. Finding meaning is not an individual process. It is a process of *connection*, with self, others, society, or something greater than oneself, e.g. God, the universe.

The selected texts revealed many circumstances that are associated with MiL: health, higher education, higher income, good relational quality, social integration, high everyday competence, employment, marriage, self-compassion, helping others, religiousness.

Multiple sources of MiL were mentioned in the texts, in varied populations. Differences in MiL sources may relate to differences in age or culture. Older persons seem, compared to younger people, to derive less MiL from personal achievements and more from relatedness with others and to something greater than themselves (e.g. God). One source was prevalent: human relationships, especially the relationship with family.

Synthesis of the themes in this integrative review resulted in the representation of a 'River of meaning in later life'. Finding MiL is a process which is like a river, winding its way through the landscape in quiet and turbulent circumstances. Several streams contribute to a river, just as several processes and sources contribute to MiL in connection with the environment. Gaps in the literature were found regarding discovery of MiL, daily meaning, cultural diversity, and studies from a healthcare perspective.

Chapter 3 provides insight into sources (What?) and the process of MiL (How?) of 24 community-dwelling older adults (who received home nursing). Data was gathered in three waves of semi-structured interviews (the first part of 60 interviews). Most respondents had many sources of MIL (What?). Four overarching themes were identified in the analysis: Self, others, environment and living. *Self* was an overarching theme: To live according to one's values was a major source of MiL for all older persons. Using one's character strengths provided them with MiL, for instance, being optimistic, creative or generous. Respondents told about their life and how their beautiful memories stayed a source of MiL in their present life. They regarded their physical and mental abilities and autonomy, 'living my life as I want to', as sources of meaning. *Others* was an overarching theme: Personal relationships were mentioned by all older persons: Relations with spouses, brothers and sisters, children, grandchildren, friends, neighbours, but also with pets, contribute to older persons' MiL. Even dear ones who passed away could still be an important source of MiL in present times. Role fulfilment was important for the respondents, e.g. being a good mother or neighbour. Reciprocity in relationships was pivotal: older adults not only want to receive; they give and help as well. Besides individual relationships, communities, of friends or a parish, were a source of MiL. Half of respondents mentioned religion as MiL source. Home and the *environment* were mentioned as a source of MiL: a comfortable house, the view, convenient shops in the neighbourhood. Furthermore, art, music and media (television, radio). *Living* was the last overarching theme: For many respondents, activities were a source of MiL. Both beginning and finishing the activity was regarded as important for MiL and the activity had to contribute to something valuable. Some respondents experienced daily rhythm or life itself as a source of MiL: waking up in the morning and being able to live another day.

Three processes of retaining MiL were identified (How?) in the analysis of the study: maintaining, adapting and discovering. Many respondents experienced retaining MiL as an increasing challenge due to loss of declining health and loss of dear ones. They *maintained* their MiL through being themselves, going on as they were used to, by taking good care of themselves, and by staying connected to their MiL sources, such as relations, activities and music. Respondents *adapted* continuously to the changing conditions. They accepted help or found creative solutions for themselves. Some explained that this process costs more and more energy and perseverance over time, and has a limit, when pain or exhaustion becomes too much or when preferred roles are hindered. Respondents adapted already to future situations by looking ahead and taking precautions, for instance, by making final arrangements. Finally, respondents found MiL through *discovering*: They reflected about life, 'observed the puzzle' and found connections and meanings they had not seen before. Many described a sense of wonder and openness towards life, which enabled them to discover unexpected meaning in their daily life; while looking out of the window, listening to music, or in unexpected encounters.

Analysis of the interviews at the general level supported the image of meaning in later life as a flowing river (from the literature review- chapter 2), ever-changing by multiple processes, sources and circumstances. Analysis at the individual level (all interviews of one person) resulted in cases which reveal the meaning and interconnectedness of (sub)themes, which were different for every person (see appendices chapter 3). Although our findings (themes) provide relevant knowledge for workers in practice, the most important lesson from this study is that every person is unique with respect to MiL. Therefore, listening in an open, questioning and attentive attitude is most important, as a first step to person-centred care in this respect.

If we compare the empirical work (chapter 3) to the previous literature (chapter 2), we mostly see similarities. Yet, our empirical work adds some interesting differences and nuances to the literature, for instance, the importance of relationships with pets, of home and the environment as MiL sources, and the value of reciprocity in relationships. Our empirical study emphasises, more than the previous literature, that maintaining meaning in later life is a continuing daily process, rather than occurring at intervals.

Part 2: Home nursing with respect to older patients' MiL

Chapter 4 describes how MiL comes to light in daily home nursing. We joined home nurses in their daily rounds and (qualitatively) described observations of 197 home nursing visits. In our (inductive) analysis we identified four main themes: being in a *private environment*, nurse-patient encounter embedded in relationship; personal care; conversation. Home nurses enter the private environment, the patient's house, and may perceive signs and symbols which reveal patient's MiL, for instance photos.

They meet family and pets. *Encounters* with patients in home nursing are frequently *embedded in long-term relationships*. Nurse and patient may know each other for a very long time and the relationship has become reciprocal. Seeing the patient provides a nurse with information about a patient's MiL: is he feeling good, engaged in an activity? We observed nurses who were merely focused on a technical task, such as an injection, but also many nurses who paid attention to the whole person, including MiL, and the environment. Besides verbal communication, non-verbal communication revealed the direction of attention. We saw nurses who integrated MiL in *personal care* by touching the patient with respect and adaptation of care to their values. In *Conversation* patients and nurses discussed many MiL issues, for instance: plans for the day, worries about the future, loneliness and grief. In some visits these conversations had a reciprocal character.

To connect findings from practice with theory about MiL, we added a final step in our analysis, by linking our themes to Derkx' dimensions of MiL. All seven dimensions were recognisable in our observations of daily home nursing visits. We concluded that MIL can be at stake in every situation in home nursing. It may depend on the ability to perceive 'with the heart's eye' (Martinsen) whether the nurse recognises MiL in practice. This implies opening up for what can be seen through two ways of seeing: The first one is feeling touched personally by the patient in their situation ('the other is a person like me'); the second is reflective and understanding ('the other is not me; I might be of help')'. The heart's eye lies in the space and interaction between both ways of perceiving. Although this study reveals how MiL may come to light in daily home nursing, it lacks interpretation of the observed situations by the involved patient (and nurse).

Chapter 5 reveals this patient's perspective. MiL is different for every person. Therefore, care should be attuned to MiL of the individual patient. This chapter describes patients' experiences with to their MiL attuned care. This was discussed in the second part of the 60 interviews with 24 older home nursing patients. Respondents expressed that they did not expect attention nor attunement of nurses to their MiL. They preferred to keep MiL to themselves, regarding MiL as their own quest. From nurses they expected *'simply normal contact'* and *adequate physical care*. Some patients didn't believe that nurses are competent for conversations regarding MiL, and moreover, they experienced that nurses even lack the time for a normal chat. Nonetheless, respondents shared examples of situations where nurses showed to be open to patient's MiL. The *tone* for MiL was already set when the nurse was entering the patient's house. Patients immediately felt if there was space for MiL or not and adapted their behaviour to this space. Respondents appreciated if nurses showed *interest in them as a person*, even if they experienced the contact as superficial. However, they also told about situations where the nurse was only interested in a technical task and they experienced this as denigrating. Patients told about nurses who *recognised hidden needs* or suffering, for instance, pain or

sadness. At the same time, they also expressed that the attention of nurses was blurred by organisational issues.

Respondents also shared experiences of care which was attuned to their MiL. They told about the *long, kind, and especially reciprocal, relationship* with some nurses. They valued nurses who *do what is needed* and provide *skilled personalised care*, because this limits suffering and discomfort. On the other hand, they complained about nurses who were never in time or delivered inadequate technical care. Respondents explained what the consequences are of care that is attuned to their MiL: they enjoyed the nursing visits as a *cheerful moment*, *felt secure and treated as an equal, valuable person*. They had a good day due to good care. Some patients added that attention to MiL restored attention to what is *important in healthcare*. Again, the individual analysis of interviews provided cases. These cases enable in-depth insight of unique nurse-patient interaction in their own contexts and the consequences of nurse's behaviour for the individual patient (see appendices chapter 5).

Part 3: Education regarding nurses' attunement to older paients' MiL

If nurse's attunement to patient's MiL is important, education in this regard is the following step. Related to this PhD, an educational programme was developed and provided to home nurses by spiritual counsellors. The programme consisted of five interrelated modalities: team sessions; coaching on the job; individual consultation; presence in teams; short messages. Aim of the programme was to improve home nurses' sensitivity and competence in attuning care to older patients' MiL.

Chapter 6 evaluates the outcomes of this education from the perspective of the nurses in a mixed methods study. Nurses benefitted from the education in various ways. Firstly, it enabled them to give *good care to patients and this provided nurses with a sense of fulfilment*. Nurses had developed in attentiveness, empathy, attunement to patient's MiL. They emphasised that they prioritised what is important for patients (instead of for the organisation). Furthermore, they referred better to others, if needed, and they cooperated better in their teams. Additionally, many nurses experienced *more pleasure* in their work due to the education, because it enabled them to work more in line with their own vision of what good care consists of. Some nurses mentioned that, due to the education, they enjoyed the surprise and challenge of the interaction with patients more. They also benefitted from the togetherness with colleagues during the education. Finally, some nurses reported *personal growth*; they became more aware of their own MiL, which gave them the strength to do what was important for themselves, like booking a holiday to a special destination.

Although nurses expressed that they benefitted from the education, there were at the same time, critical voices: Many nurses stated that they *already* did what the education aimed to learn them: attune care to patient's MiL. Comparison of examples in the interviews of nurses in subsequent waves provides mixed results about this.

Additionally, some nurses told that they could *insufficiently integrate what they had learned in the care process*. Some nurses reported that they were unable to experience any benefits of the training due to the continuous *pressure of the organisation* on production and efficiency. Nurses were ambiguous regarding the sustainability of the outcomes of the education. Although the majority stated that they had *further developed* in what they learned, even after the education, they stressed, at the same time, *that attention to MiL evaporated* over time. Although the outcomes of education were mixed, many nurses developed sensitivity and competences in attuning care to older patients' MiL, in accordance with the aims of the project. On top of that, nurses learned many things which patients consider as good care (in chapter 5).

Chapter 7 provides a description of the underlying learning-teaching process of the educational programme, which was developed during the project that was related to this thesis. Multiple data collection methods, perspectives and dialogues resulted in a model of eight interrelated learning phases, which are embedded in a supportive relationship with the spiritual counsellor. The learning phases are: being touched; opening-up; awareness of own meaning; broadening and deepening understanding; turning point - awareness of the patient as other; exploring and reflecting; working, practising and reflecting; taking responsibility. The behaviour of the spiritual counsellor facilitated these phases. The first phase, 'being touched', serves as a trigger for learning. The phase 'awareness of the patient as other' is the pivotal phase, because it turns the direction of attention from the nurse to attentiveness to, and understanding for, the patient. This opens the possibility for transforming behaviour of the nurse into attuned care. The relationship with the educator, reflection and experiential learning are crucial in this process. The sketched model can serve as a basis for further development of educational programmes aimed at learning nurses attunement to patient's MiL.

Conclusion

This work contributes to knowledge, practice and education regarding older patient's MiL. Older persons derive MiL from a broad range of sources and they do a lot to retain MiL. For older home nursing patients, MiL is interwoven in everyday life. Home nurses have a modest, yet important, role in supporting them in this respect and are in a key position to do so, because home nursing is saturated with situations where MiL comes to light. Long, kind, reciprocal nurse-patient relationships and skilled personalised physical care are pivotal in this support. Home nurses benefit from a varied educational programme regarding older persons' MiL. It helps them to provide good care and contributes to their pleasure in work and personal growth. In this education the relationship with the educator and experiential learning are crucial. Besides education, homecare managers should realise working conditions that enable good care with respect to older patients' MiL. Furthermore, older persons' MiL should be a concern for policy makers beyond the field of healthcare.

Samenvatting (in Dutch)

Inleiding

Zingeving is een onderwerp dat steeds meer aandacht krijgt in de samenleving, ook in Nederland. Met het ouder worden kan zingeving een uitdaging worden, onder andere door het verlies van naasten en het verlies aan fysieke en mentale capaciteiten. Omdat de meeste ouderen thuis wonen (in hun privéwoning), komen thuiszorgmedewerkers vaak ouderen tegen die zingevingsproblemen hebben. Volgens het Nederlandse beroepsprofiel van de verpleegkundige horen zingevingsvragen tot de kernset van verpleegproblemen. Toch voelen zorgmedewerkers in de beroepspraktijk zich niet competent op dit gebied. De wetenschappelijke literatuur biedt hen weinig steun. Er zijn meerdere lacunes in de academische kennis gevonden; ten aanzien van zingeving door ouderen die thuiszorg ontvangen, verpleegkundige zorg voor thuiswonende ouderen waarbij aandacht is voor zingeving, en onderwijs op dit gebied. Gebrek aan kennis en competenties leidt tot werkontevredenheid bij zorgmedewerkers. Bij patiënten kan dit gebrek aan kennis en competenties (van zorgmedewerkers) een negatieve invloed hebben op hun gezondheid en kwaliteit van leven. Het doel van dit proefschrift is om kennis te genereren ten aanzien van de gesignaleerde kennislacunes en om bij te dragen aan een goede professionele praktijk en aan educatie van zorgprofessionals op dit gebied.

Deel 1: Zingeving door ouderen

Hoofdstuk 2 is een (integratieve) literatuurreview over zingeving en ouderen in het algemeen; hoofdstuk 3 is een empirische studie waarin we ons richten op een specifieke groep ouderen, namelijk ouderen die thuiszorg ontvangen. Dit is een zeer relevante groep, want 90% van de Nederlandse ouderen (75+) zijn thuiswonend en veel van hen ontvangen thuiszorg.

Hoofdstuk 2 biedt inzicht in de bestaande literatuur over ouderen en zingeving. In diverse academische databases vonden we 574 teksten, waarvan er 44 voldeden aan de inclusiecriteria. Deze teksten waren divers in aard en discipline. Analyse van deze teksten resulteerde in vijf thema's ten aanzien van het vinden van zin: ontwikkelingsproces, creatie van zin; ontdekken van zin; dagelijkse zingeving, en verbinding. Ouderen vinden zin in een *ontwikkelingsproces*, in zowel de continuïteit als de discontinuïteit van het leven. Zij verhouden zich hierbij tot hun culturele waarden. Ouderen *creëren* zin door hun activiteiten, het maken van een levensverhaal, het gebruik van hun sterke karaktertrekken en door verschillende coping-strategieën. Zin kan ook worden gevonden door het te *ontdekken*, in stilte

en door contemplatie, in plaats van actief iets te doen. Slechts een paar auteurs schrijven iets over *dagelijkse zingeving*, zin vinden in dagelijkse activiteiten. Deze dagelijkse activiteiten kunnen verbonden zijn met een ander (existentieel) niveau. Het vinden van zin is geen individueel proces. Het is een proces van *verbinding*, met jezelf, anderen, de maatschappij, of iets groters dan jezelf, bijvoorbeeld God of het universum.

In de geselecteerde teksten werden veel omstandigheden genoemd die samenhangen met de ervaring van zin in het leven: goede gezondheid, hoger opleidingsniveau, hoger inkomen, goede kwaliteit van relaties, sociale integratie, ADL-zelfstandigheid, werk, gehuwd zijn, zelfcompassie, het helpen van anderen en religiositeit.

In de teksten werden veel verschillende zingevingsbronnen genoemd, in verschillende populaties. Verschillen in zingevingsbronnen kunnen samenhangen met verschillen in leeftijd of cultuur. Ouderen lijken, in vergelijking met jongeren, minder zin te halen uit persoonlijke prestaties en meer uit hun betrokkenheid met anderen en uit 'het grotere dan henzelf' (zoals God). De meest voorkomende zingevingsbron was: menselijke relaties, vooral de relatie met familie.

Synthese van de thema's in deze integratieve literatuurreview leidde tot de representatie van de 'Rivier van zingeving in het latere leven'. Het vinden van zin in het leven lijkt op een rivier, die zijn weg vindt in het landschap in rustige en in turbulente omstandigheden. Zoals diverse processen bijdragen aan een rivier, in samenhang met de omgeving, zo dragen verschillende processen ook bij aan zingeving. In de literatuur werden leemtes ontdekt ten aanzien van: het ontdekken van zin, culturele diversiteit en studies vanuit het perspectief van de gezondheidszorg.

Hoofdstuk 3 geeft inzicht in de zingevingsbronnen (Wat?) en het proces van zingeving (Hoe?) van 24 thuiswonende ouderen die thuiszorg ontvangen. Data werd verzameld in drie interviewrondes (eerste gedeelte van 60 semigestructureerde interviews) met 24 oudere thuiszorg patiënten. De meeste respondenten hadden veel zingevingsbronnen (Wat?). Uit de analyse kwamen vier overkoepelende thema's naar voren: Zelf, anderen, omgeving en leven. *Zelf*: het gaf alle respondenten zin om het leven te leiden volgens hun eigen normen en waarden. De eigen sterke kanten gebruiken was voor hen belangrijk, bijvoorbeeld optimistisch, creatief of vrijgevig zijn. De respondenten vertelden over hun leven en hoe mooie herinneringen nog steeds een zingevingsbron voor hen bleven. Zij beschouwden ook hun lichamelijke en geestelijke vermogens en autonomie, 'leven zoals ik dat wil', als zingevingsbronnen. *Anderen*: alle ouderen noemden persoonlijke relaties: relaties met echtgenoten/echtgenotes, broers en zussen, kinderen, kleinkinderen, vrienden, buren, maar ook met huisdieren. Zelfs overleden geliefden konden in het dagelijkse leven nu nog een zingevingsbron zijn. De respondenten vonden rolvervulling belangrijk, bijvoorbeeld een goede moeder

of buurman zijn. Wederkerigheid was voor hen cruciaal in relaties: zij willen niet alleen ontvangen, zij geven en helpen ook. Behalve individuele relaties, waren ook gemeenschappen, van vrienden of een parochie, een zingevingsbron. De helft van de respondenten noemde het geloof als zingevingsbron. Het huis en de *omgeving* werden genoemd als zingevingsbron: een prettig huis, het uitzicht, de handige winkels in de buurt. Verder werd kunst genoemd, muziek en de media (TV, radio). *Leven* was het laatste overkoepelende thema: Voor veel respondenten waren hun activiteiten een zingevingsbron. Daarbij werd het van belang gevonden om de activiteit niet alleen te beginnen, maar ook om die te (kunnen) beëindigen. Verder diende de activiteit bij te dragen aan iets waardevols. Sommige respondenten beleefden het dagelijks ritme als een bron van zin, of het leven zelf: 's morgens opstaan en weer een nieuwe dag te kunnen leven.

Hoe houden thuiswonende ouderen zin in het leven? In de interviews werden hiervoor drie processen gevonden: behouden, aanpassen en ontdekken. Voor veel van de respondenten was zingeving een toenemende uitdaging, door het verlies van gezondheid en het verlies van dierbaren. Zij *behielden* zin in het leven door zichzelf te blijven en verbonden te blijven met hun zingevingsbronnen, zoals relaties, activiteiten en muziek. Respondenten *pasten zich voortdurend aan* aan de veranderende omstandigheden. Ze accepteerden hulp en vonden creatieve oplossingen. Sommigen vertelden dat dit proces steeds meer energie en doorzettingsvermogen kostte en dat het ook een grens had, als pijn of uitputting te veel werden, of als favoriete (sociale) rollen werden belemmerd. Respondenten pasten zich bij voorbaat al aan de toekomst aan, door vooruit te kijken en vast maatregelen te treffen, bijvoorbeeld door hun begrafenis alvast te regelen. Tot slot vonden de respondenten zin in het leven door te *ontdekken*: Zij reflecteerden over hun leven, 'observeerden de puzzel' en vonden verbindingen en betekenissen die zij eerder nog niet gezien hadden. Velen beschreven een gevoel van verwondering en openheid ten opzichte van het leven, wat hen in staat stelde om onverwachte betekenissen te ontdekken in hun dagelijks leven; terwijl zij uit het raam keken, naar muziek luisterden, of in toevallige ontmoetingen.

Analyse van de interviews op overstijgend niveau bevestigde het beeld van de 'Rivier van zingeving in het latere leven' (uit de literatuurreview, hoofdstuk 2), steeds veranderend door meerdere processen en omstandigheden. Analyse op het individuele niveau van de interviews (alle interviews van een persoon) resulteerde in casussen. In deze casussen is de betekenis en onderlinge verbondenheid van de subthema's duidelijk, die verschillend is voor elke persoon (zie de appendices bij hoofdstuk 3). Alhoewel de bevindingen van dit onderzoek relevante bevindingen (thema's) opleverden voor de praktijk, is de belangrijkste les dat iedere persoon uniek is ten aanzien van zijn/haar zingeving. Daarom is luisteren, vanuit een open en vragende houding, zo belangrijk, als een eerste stap naar persoonsgerichte zorg op dit gebied.

Als we de empirische studie (hoofdstuk 3) vergelijken met de literatuurstudie (hoofdstuk 2) zien we vooral overeenkomsten. Toch voegt ons empirische onderzoek een aantal interessante verschillen en nuances toe aan deze literatuur, bijvoorbeeld het belang van relaties met dieren, van thuis en de omgeving als zingevingsbronnen, en de waarde van wederkerigheid in relaties. Onze empirische studie benadrukt, meer dan de eerdere literatuur, dat het behoud van zin in het latere leven eerder een continu, dagelijks proces is, dan dat het iets is dat in bepaalde situaties naar voren komt.

Deel 2: Thuiszorg aan ouderen met betrekking tot zingeving

Hoofdstuk 4 beschrijft hoe zingeving aan het licht komt in de dagelijkse thuiszorg aan ouderen. We 'fietsten mee' met thuiszorgmedewerkers in hun dagelijkse routes en beschreven (op kwalitatieve wijze) observaties van 197 zorgmomenten. In de (inductieve) analyse vonden we vier hoofdthema's: In privéomgeving zijn, ontmoeting tussen zorgmedewerker en patiënt ingebed in een relatie, persoonlijke zorg, en gesprekken. Zorgmedewerkers komen in de *privéomgeving*, het huis van de patiënt. Zij kunnen dan allerlei signalen en symbolen waarnemen die de zingeving van de patiënt laten zien. Zij ontmoeten familie en huisdieren. *Ontmoetingen* met patiënten in de thuiszorg zijn vaak ingebed in *langdurige relaties*. De zorgmedewerker en de patiënt kennen elkaar mogelijk al heel lang en de relatie is wederkerig geworden. Het zien van de patiënt geeft de zorgmedewerker informatie over zingeving van de patiënt: voelt deze zich goed, is hij/zij bezig met een activiteit? We observeerden zorgmedewerkers die voornamelijk gericht waren op een technische taak, bijvoorbeeld het toedienen van een injectie, maar ook veel zorgmedewerkers die aandacht besteedden aan de hele persoon, inclusief diens zingeving, en de omgeving. Naast verbale communicatie maakte ook de non-verbale communicatie de focus van de aandacht duidelijk.
We zagen zorgmedewerkers die zingeving integreerden in *persoonlijke zorg* door respectvolle aanraking van de patiënt en het aapassen van de zorg aan diens waarden. In de *gesprekken* kwamen veel zingevingsaspecten aan de orde, zoals de plannen voor de dag, zorgen over de toekomst, eenzaamheid en verdriet. Tijdens sommige zorgmomenten hadden deze gesprekken een wederkerig karakter.

Om dit praktijkonderzoek te verbinden met de theorie over zingeving, hebben we een extra stap toegevoegd in de analyse door onze thema's te linken aan de zingevingsdimensies van Derkx. Alle zeven dimensies waren herkenbaar in onze observaties van dagelijkse thuiszorgmomenten. Wij concludeerden dat zingeving in elke thuiszorgsituatie aan de orde kan zijn. Of de zorgmedewerker zingeving ook herkent in het dagelijkse zorgmoment, kan afhangen van diens vermogen om waar te nemen met 'het oog van het hart' (Martinsen). Dit houdt in: je openstellen voor wat er te zien is middels twee manieren van kijken. De eerste is je persoonlijk geraakt voelen door de patiënt in zijn/haar situatie ('die ander is een persoon zoals ik'). De tweede is reflectief en met begrip waarnemen ('die ander is niet mij, ik kan mogelijk helpen'). 'Het oog van het hart' bevindt zich in de ruimte en interactie tussen deze

twee manieren van waarnemen. Hoewel dit hoofdstuk laat zien hoe zingeving aan de oppervlakte komt in dagelijkse thuiszorg, ontbreekt de interpretatie van de geobserveerde situaties door de betrokken patiënt (en zorgmedewerker).

Hoofdstuk 5 laat juist dit patiënten-perspectief zien. Zingeving is voor ieder mens iets anders. Daarom dient zorg te worden afgestemd op zingeving van de individuele patiënt. Dit hoofdstuk beschrijft ervaringen van patiënten met op hun zingeving afstemde zorg. Dit werd besproken in het tweede deel van de 60 interviews met 24 oudere thuiszorgpatiënten. De respondenten vertelden dat zij niet verwachtten dat zorgmedewerkers aandacht hadden voor hun zingeving, noch dat zij de zorg daarop afstemden. Zij gaven aan zingeving liever voor zichzelf te houden, dit als hun eigen zoektocht te beschouwen. Van zorgmedewerkers verwachtten zij voornamelijk *'Gewoon normaal contact'* en *'goede lichamelijke zorg'*. Sommige patiënten hadden het idee dat zorgmedewerkers niet bekwaam zijn in het voeren van zingevingsgesprekken, en vooral, dat zij niet eens de tijd hebben voor een (gewoon) praatje. Toch deelden respondenten voorbeelden met ons van situaties waarin zorgmedewerkers wel degelijk open stonden voor hun zingeving. De *toon* voor zingeving werd al gezet bij binnenkomst. De patiënten voelden meteen of er ruimte was voor zingeving of niet en pasten hun eigen gedrag hierop aan. De respondenten waardeerden het als zorgmedewerkers *interesse in hen toonden als persoon*, zelfs als zij het contact als oppervlakkig ervoeren. Maar zij vertelden ook over situaties waarin de zorgmedewerker slechts geïnteresseerd was in een technische handeling. Dit vonden zij denigrerend. Patiënten vertelden over zorgmedewerkers die *verborgen behoeftes opmerkten*, of verborgen leed, zoals pijn of verdriet. Maar ook vertelden zij dat de aandacht van zorgmedewerkers was afgeleid door organisatorische issues.

De respondenten deelden ook voorbeelden van zorg die afgestemd was op hun zingeving. Zij vertelden *over lange, vriendelijke en vooral wederkerige relaties* met sommige zorgmedewerkers. Zij waardeerden zorgmedewerkers *die doen wat nodig is* en *vaardige op de persoon afgestemde zorg* boden, want dit beperkte hun lijden en ongemak. Maar zij klaagden ook over zorgmedewerkers die nooit op tijd waren of technisch slechte zorg leverden. De respondenten vertelden wat het gevolg is van zorg die op zingeving is afgestemd: zij genoten van het zorgmoment als een *vrolijk moment,* zij voelden zich veilig en benaderd als een gelijkwaardig persoon. Zij hadden *een goede dag door goede zorg*. Sommige patiënten voegden daaraan toe dat aandacht voor zingeving de *aandacht had hersteld voor wat belangrijk is in de gezondheidszorg*. Ook hier weer, volgden er uit de individuele analyse casussen, die diepgaand inzicht geven in de unieke interactie tussen zorgmedewerker en patiënt in context, en het gevolg daarvan voor de individuele patiënt (zie de appendices bij hoofdstuk 5).

Deel 3: Educatie over afstemming op zingeving

Als het belangrijk is dat zorgmedewerkers hun zorg afstemmen op zingeving van de patiënt, dan is educatie over zingeving een volgende stap. In samenhang met dit promotietraject, werd er door geestelijk verzorgers een educatief programma ontwikkeld en aangeboden aan thuiszorgmedewerkers. Het programma bestond uit vijf samenhangende delen: teamsessies, coaching on the job, individuele consultatie, presentie in teams, en korte berichten. Doel van het programma was om zorgmedewerkers sensitief en vaardig te maken in het afstemmen van zorg op de zingeving met betrekking tot ouderen.

Hoofdstuk 6 evalueert de opbrengsten van deze educatie vanuit het perspectief van de zorgmedewerkers in een mixed methods studie. De thuiszorgmedewerkers hadden op verschillende manieren baat bij de educatie. Op de eerste plaats hielp het hen om *goede zorg te verlenen en dit gaf een gevoel van voldoening*. De zorgmedewerkers ontwikkelden zich in aandacht, empathie, en afstemmen van zorg op de zingeving van de patiënt. Zij benadrukten dat zij na de educatie, prioriteit gaven aan wat belangrijk is voor de patiënt (in plaats van voor de organisatie). Zij verwezen, indien nodig, beter door naar anderen en ze werkten beter samen in hun team. Op de tweede plaats, hadden de thuiszorgmedewerkers *meer plezier* in hun werk door de educatie, omdat het hen in staat stelde meer volgens hun eigen visie op goede zorg te werken. Sommige zorgmedewerkers vertelden dat zij sinds de educatie meer genieten van de verrassingen en uitdaging in de interactie met patiënten. Zij hebben baat gehad van het samen zijn met collega's. Tot slot zijn sommige zorgmedewerkers als *persoon gegroeid*, wat hen de kracht gaf om (ook) te doen wat belangrijk is voor henzelf, zoals een vakantie boeken naar een bijzondere plek.

Hoewel de zorgmedewerkers aangaven dat zij baat hadden bij de educatie, waren er tegelijkertijd ook kritische geluiden: veel zorgmedewerkers gaven aan dat zij al deden wat de educatie hen poogde te leren: zorg afstemmen op de zingeving van de patiënt. Een vergelijking van voorbeelden van de zorgmedewerkers in de verschillende interviewrondes laat hierover verdeelde resultaten zien. Daarnaast waren er zorgmedewerkers die vertelden dat zij hetgeen zij leerden *onvoldoende konden integreren in het zorgproces*. Sommigen gaven aan helemaal geen baat te ervaren van de educatie door de *continue druk van de organisatie* op productie en doelmatigheid. De zorgmedewerkers waren dubbel over de duurzaamheid van de opbrengsten van de educatie. Hoewel de meerderheid aangaf dat zij, zelfs na de educatie, nog verder waren *doorontwikkeld* in wat zij geleerd hadden, benadrukten zij tegelijkertijd dat *aandacht voor zingeving verdampt* na verloop van tijd. Alhoewel de evaluatie van de educatie verdeelde resultaten laat zien, hebben toch veel thuiszorgmedewerkers sensitiviteit en vaardigheden ontwikkeld om zorg af te stemmen op zingeving van patiënten, in overeenkomst met de gestelde doelen van het project. Bovendien is het geleerde grotendeels in overeenstemming met wat patiënten goede zorg vinden (in hoofdstuk 5).

Hoofdstuk 7 beschrijft het onderliggende leer-onderwijsproces van het educatieve programma, dat ontwikkeld werd gedurende het project, samenhangend met dit promotieonderzoek. Meerdere dataverzamelingsmethoden, perspectieven en dialogen resulteerden in een model van acht onderling gerelateerde leerfasen, die zijn ingebed in een ondersteunende relatie met de geestelijk verzorger. De leerfasen zijn: geraakt zijn, zich open stellen, bewust zijn van eigen zingeving, verbreding en verdieping van begrip, kantelpunt – bewust zijn van de patiënt als ander, ontdekken en reflecteren, werken, oefenen en reflecteren, verantwoordelijkheid nemen. Het gedrag van de geestelijk verzorger was faciliterend voor deze fasen. De eerste fase 'geraakt zijn' is een trigger voor leren. De fase 'bewust zijn van de patiënt als ander' is de meest cruciale fase, omdat in deze fase de aandacht wordt verplaatst van de zorgmedewerker zelf, naar aandacht, en begrip, voor de patiënt. Hierdoor opent zich een mogelijkheid voor transformatie van het gedrag van de zorgmedewerker naar afgestemde zorg. De relatie met de geestelijk verzorger, reflectie en ervaringsleren zijn doorslaggevend voor dit proces. Het geschetste model kan als basis dienen voor verdere ontwikkeling van educatieve programma's om zorgmedewerkers te leren zorg af te stemmen op zingeving van patiënten.

Conclusie

Dit werk draagt bij aan kennis, de praktijk en onderwijs ten aanzien van zingeving door ouderen. Ouderen hebben een breed scala aan zingevingsbronnen en zij doen veel om zin te behouden. Voor oudere thuiszorgpatiënten is zingeving verweven met het leven van alledag. Thuiszorgmedewerkers hebben een bescheiden, maar belangrijke rol om hen daarbij te ondersteunen en zij zijn in een sleutelpositie om dit te doen, omdat de thuiszorg verzadigd is met situaties waarin zingeving aan het licht komt. Langdurige, vriendelijke, wederkerige zorgrelaties en vaardige, persoonsgerichte lichamelijke zorg zijn essentieel in deze ondersteuning. Thuiszorgmedewerkers hebben baat bij een gevarieerd educatief programma over zingeving met betrekking tot ouderen. Dit helpt hen om goede zorg te verlenen en het draagt bij aan hun werkplezier en persoonlijke groei. In deze educatie zijn de relatie met degene die de educatie biedt en ervaringsleren cruciaal. Behalve educatie, zouden thuiszorgmanagers arbeidsvoorwaarden moeten realiseren die goede zorg ten aanzien van zingeving mogelijk maken. Bovendien zou zingeving ook een zorg moeten zijn voor beleidsmakers buiten de gezondheidszorg.

The Author

Susan Hupkens was born in 1963 and spent most of her childhood in Arnhem, the Netherlands. After her Athenaeum diploma she chose to follow the practice oriented 'inservice' vocational training for nurses. She graduated as a nurse in 1985 from the Academical Hospital Utrecht (now UMC) and worked there at the hematological department. She worked in several hospitals and as a home nurse in Utrecht and The Hague.

Susan graduated in nurse education from the Hogeschool Midden Nederland in 1990 and worked as a lecturer practitioner in the Westeinde Hospital and in 2013-2014 in Woonzorgcentra Haaglanden (WZH) in the Hague. She was a nurse lecturer for seventeen years in the Frédérique Meyboomschool, and its successors, in Delft and The Hague.

Besides, Susan worked as an aromatherapist in her own practice, from 2002- 2016, in cooperation with several midwives in the Hague. As a board member of the section complementary care of V&VN (the Dutch nurse's professional association) she contributed to professionalisation of complementary nursing in the Netherlands. She was co-editor and author of professional literature and guidelines regarding this subject.

In 2009 she graduated (cum laude) in Public Health (differentiation Health Service Innovation) from Maastricht University and she started as a researcher in the Research Centre Innovations in Care of the Hogeschool Rotterdam, which she combines, since 2013, with education for nurses. Susan has contributed to several practice-oriented studies of this research centre. Most of her work focusses on well-being of older persons and community care.

In 2014 she started the graduate school of the University of Humanistic Studies in Utrecht for this PhD (part-time). Susan is married and has two daughters and a granddaughter. She lives in the Hague.

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Dankwoord (in Dutch)

Op mijn tafel liggen twee dikke, afgesleten, boekjes met aantekeningen. Het ene helemaal vol, het andere met nog maar een paar lege bladzijden. Het zijn mijn logboeken van deze promotieperiode. Ze staan symbool voor de afgelopen jaren. Het waren volle jaren, inspirerend, maar ook intensief. De laatste bladzijden van dít boekje wil ik vullen met woorden van dank aan alle mensen die mij deze jaren hebben gesteund.

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Het schrijven van een proefschrift is toch ook een beetje zolderkamertjeswerk: (te) veel uren maken achter het scherm, eindeloos verbeteren, herschrijven. Hoewel mijn kamer uitkijkt over de duinen en de zee, is het toch wel een eenzame bezigheid.

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Appendices

Appendices chapter 3

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APPENDIX 1 INTERVIEWS AND DURATION

	A1	A2	A3	A4	B1	B2	B3	B4	B5	B6	B7	B8	C1	C2	C3	C4	C5	C6	D1	D2	D3	D4	D5	D6	Freq.
Interview 1	1.11	1.30	1.40	1.20	1.15	1.15	1.37	1.12	1.5	1.5	0.58	1.29	1.02	0.52	0.58	0.54	0.42	0.53	1.09	0.51	1.12	1.13	1.09	1.11	
Interview 2	2.05	1.32	1.31	-	0.59	0.59	1.14	1.06	1.52	1.52	-	1.11	1.04	0.59	0.52	-	-	1.33	1.24	0.32	1.21	1.11	0.48	1.29	
Interview 3	1.17	1.26	0.38	-	-	-	1.27	0.57	1.27	1.27	-	1.29	0.38	1.16	-	-	-	1.12	0.49	-	1.12	1.46	0.53	1.45	

APPENDIX 2 THEMES-PARTICIPANTS MATRIX

What: sources of meaning in life

Themes and subthemes	A1	A2	A3	A4	B1	B2	B3	B4	B5	B6	B7	B8	C1	C2	C3	C4	C5	C6	D1	D2	D3	D4	D5	D6	Freq.
Self																									
Values	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	24
Character strengths	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x			x	x	x	x	x		x	21
Life story	x	x	x	x	x	x	x	x	x		x	x	x	x		x		x	x	x	x		x	x	20
Physical and mental abilities	x	x	x		x	x		x	x	x	x	x	x	x	x			x	x	x	x		x		18
Autonomy	x	x				x		x	x	x	x	x		x	x			x		x	x			x	14
Others																									
Personal relationships	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	24
Community and society	x	x	x	x		x	x	x	x	x		x	x	x			x	x	x		x	x	x	x	19
Religion	x		x				x					x	x	x	x	x	x					x			10
Environment																									
Home and neighbourhood	x		x	x		x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	21
Art and media		x	x	x	x	x	x	x	x	x			x	x				x					x	x	14
Living																									
Activities	x	x	x			x	x	x	x	x	x	x	x	x				x				x	x	x	16
Daily rythm			x	x	x						x	x	x	x						x	x				9
Life itself								x					x	x				x	x		x			x	7

How: The process of retaining meaning in life

Themes and subthemes	A1	A2	A3	A4	B1	B2	B3	B4	B5	B6	B7	B8	C1	C2	C3	C4	C5	C6	D1	D2	D3	D4	D5	D6	Freq.
Maintaining																									
Being myself	x	x	x	x	x	x	x	x	x	x	x	x	x	x		x		x	x		x	x		x	20
Taking care of myself	x	x		x		x	x	x	x	x			x	x				x	x	x	x	x		x	17
Staying connected to MiL sources	x	x	x	x	x	x	x	x	x	x		x	x	x	x	x	x	x	x	x	x	x	x	x	23
Adapting																									
Adapting to conditions	x	x	x	x	x	x	x	x	x	x	x	x	x	x			x	x	x	x	x	x	x	x	22
Community and society	x	x	x		x	x		x	x	x		x	x	x	x		x	x	x				x	x	17
Discovering																									
Reflecting about life	x	x	x	x	x	x	x	x	x	x	x		x	x				x	x	x	x	x	x	x	20
Openness and sense of wonder		x	x			x	x		x	x			x	x	x		x	x		x	x	x	x	x	16

Photo	Laetitia (C1) age 87
	Laetitia is 87 when I first visit her. She has a kind face with soft eyes and always wears beautiful clothes and make-up. She'll tell me her *'beauty secrets'* later. She loves listening to the news on the radio while grooming herself: *'then you always have something to talk about over a cup of coffee.'* (C01.2, C01.3) She tells me she was born in Surinam and spent a happy youth there. Laetitia moved to the Netherlands in the 1970s. She was widowed twice and has been living alone for many years now. She goes out a lot, sometimes with her sister who lives nearby, and together with a group of friends. They meet at many organised activities for the elderly. *'We go everywhere. It's always fun. It is important to go out, to move around.'* (C01.1, C01.2, C01.3) She also likes going out on her own, buying nice food to make herself a good meal. *'I was born alone. I do what I want, eat what I want, go where I want. I don't have a lot of money. I live a happy life.'* (C01.1) The second time I visited her she had been to a traditional Surinamese party on a city square and enjoyed the music. She tells enthusiastically: *'I went by in the afternoon and then in the evening I thought: I want to go again, and I was there till 10 o'clock, relaxing, dancing a bit.'* (C01.2) Her faith is important for her. Laetitia chooses a photo of praying hands. She prays regularly herself. *'When I go out I say A wani fu Gado – in God's will. I ask God to lead me and bring me home safely. He guards and protects me'* (C01.1, C01.2, C01.3) Laetitia thinks of herself as a friendly person: 'I am confident within myself and confident with who I am.' (C01.2) *'I am not a difficult person. I am not jealous. I don't want anything from others. I am like my grandma, a giving person. I always keep some sweets in my bag to offer someone. I like to help others. That's how I am.'* (C01.1, C01.2, C01.3) Although her mobility is declining, she manages with elastic stockings and a walker. *'It is allright. That's how older persons are. I have a little pain here and there. I live healthy.'* (C01.1, C01.2, C01.3) Her family is important to her as well (three daughters, two grandchildren and her three brothers and four sisters). A brother and sister died recently. She likes to spoil her grandchildren. She shows me many pictures of people who are close to her. Her dead sisters and brothers have been inserted into a photo of her and her family. Laetitia thinks back at her life now and then: *'I have led a normal life, I didn't do any evil, I have been an honest person. I have peace of mind.'* (C01.1, C01.2, C01.3). Last week, as more often in recent years, one of her friends died. She realises her death may be near too: *'You never know, death may be around the corner. I am aware of that, it doesn't make me feel sad.'* (C01.3)

Photo: Cuijpers & Vooren, 2015, Vilans

	Source (subthemes)	Process (subthemes)
		Taking care of myself
	Art and media	Staying connected to MiL sources
	Personal relationships	
	Life story	Reflecting about life
	Personal relationships	Staying connected to MiL sources
	Activities	Openness and sense of wonder
	Physical and mental abilities	
	Autonomy	Taking care of myself
	Daily rhythm	
	Community and society	Staying connected to MiL sources
	Art and media	
	Activities	
		Staying connected to MiL sources
	Religion	
	Character strengths	Being myself
	Values	
		Adapting to conditions
	Physical and mental abilities	
		Taking care of myself
	Personal relationships	Staying connected to MiL sources
	Life story	
	Character strengths	Reflecting about life
	Values	
	Life itself	Looking ahead

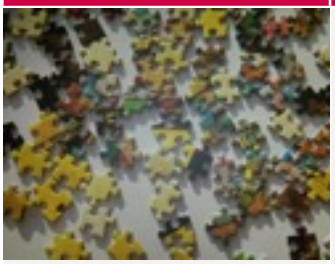
Photo	Willie (B7), age 88
	When I enter the house I see many arrangements that enable Willie in her limited mobility. Her clothes are in the hall, her bed is in the living room, and furniture is placed in such a way that she can easily pass with her walker. Willie knows she is becoming increasingly forgetful. Nurses come to check her medicine daily. But Willie says: *'I don't need that. I've always helped myself. And why not now, now that I'm so old? It is none of their business. I have always been an independent person.'* In our conversation she repeatedly stresses: *'People should not interfere in my affairs'*. Willie lives in a neighbourhood that changed a lot recently. It used to be a Dutch working-class district, but increasing numbers of immigrants have been settling there. Willie complains about the neighbours. *'I miss my old neighbourhood. When you say hello, you hardly get an answer. No, that used to be different. I remember sitting near the central sink, drinking water and gossiping ...'* She smiles. *'But nowadays you don't see anybody around.'* When I ask her if she visits people, she answers that there are community activities in the neighbourhood, but she won't go. *'No matter if all neighbours go drink coffee together, I won't go.'* She looks angry. I ask about her family. Many family members live nearby, but she only sees one nephew, who manages her affairs. He has also arranged a meal service for her. *'Since my husband died, a few years ago, I don't see anybody anymore... I leave it like that, although I don't like it.'* Willie doesn't have children, but is proud to have cared for the children in the house where she worked for many years. *'That was marvellous!'* She has one beloved sister left, who lives in another city. They are both unable to travel, but she calls her now and then. Willie tells she is Catholic, but no longer goes to church. *'It doesn't mean that much to me anymore. You don't see any priests around, and all those terrible stories about the church...'* The only persons that enter her house are the nurses and the housekeeper. *'It's fun when they have time for a cup of coffee,'* she says smiling. Willie always worked as a housekeeper. Her days are still filled with chores. Today she got up at 6 and did the laundry. *'Well, most times I even don't have the time to read the paper... I have other things to do. At the moment the washing machine is working as well. And when that is all set, that feel's good. Yes, it provides me with fulfilment'*. She adds: *'I think I am rather strong, compared to others. I still do all those things.'* She chooses a photo of puzzle pieces. Besides her housekeeping she does puzzles and reads magazines and the newspaper. She goes out to do some shopping now and then. She says: *'I don't do anything I don't want. I just live my life here. I don't have that much...'* (B7.1)

Photo: Cuijpers & Vooren, 2015, Vilans

	Source (subthemes)	Process (subthemes)
		Adapting to conditions
	Character strengths Values	Being myself
	Life story	Reflecting about life
	Life story	Reflecting about life
	Personal relationships	
	Personal relationships	
	Daily rhythm	Being myself
	Physical and mental abilities Activities	
	Autonomy	

Photo	Romeo (B1) age 90
No photo selected. Romeo is almost blind.	A large man (Romeo) opens the door and welcomes me. He walks slowly towards the living room. He bends almost 90 degrees over his walker. All the furniture is placed against the walls. He says he will help his wife out of bed and explains: *'It is literally "the blind leading the blind" here'*. Romeo says he is happy with the good example his father gave him, who used to help at home too. Romeo does most chores: *'I get through the days doing that. When I get up I make coffee, empty the dishwasher and bring a cup of coffee to my wife. She cannot do that anymore. That I can mean something for my wife, that's my fulfilment.'* And he tells tiny details of the daily rhythm, which contribute to this being together. He even sorts out the laundry with a magnifier, together with her. (B1.1 B1.2) *'I used to be religious, when I was younger, but we lost that (explains why). I have always been a self-responsible and critical person. So, in younger years we had the hereafter. But we don't have that anymore. I have been thinking about meaning in life, before you came. MiL is today: that's all there is ... that we can live this life together.'* (B1.1) Although meaningful, he experiences life as *'difficult'*, due to both their deteriorating health conditions. *'Daily life costs energy and strength all day'*. He worries about further decline. Even with the help of their children and homecare it may become too much. (B1.1 B1.2) Between the first and second appointments Romeo was hospitalised. He realises the fragility of the equilibrium. *'However ... I cannot imagine her not being there anymore. We still sleep in two beds against each other. And yes, waking up, while she's not there ... that is something over which I don't have any control whatsoever, yet ...'I realise that if one of us left, the other might need to go to a nursing home, but that will become clear by that time '* (B1.2) He explains that MiL isn't a topic of conversation between the couple. 'We are married 63 years. We know those things from each other. We don't talk about it. But I do experience it.' (B1.2) Romeo tells that the relationship with his children is important for MiL: *'Meaning in life is the pleasure when the children come around. We have such a pleasant relationship with them: more open and affectionate than my father used to have with us.'* He is grateful for the help they provide to them, both practically and psychologically. (B1.1 B1.2) Romeo used to read a lot. Because of his deteriorated sight he cannot do that anymore, or other hobbies. Even the audio books lie *'unread'*, because of the increasing energy and time that daily life demands. However, they go to bed late, to enjoy listening to classical music together. Romeo looks back on a happy life with his wife and as a professional. He used to be active in the community. Things are different now: *'That's a feeling of powerlessness. There is so much trouble in the world, terrorist attacks, etc. You observe, but are aware that there is nothing you can do anymore.'* (B1.2)

	Source (subthemes)	Process (subthemes)
	Physical and mental abilities	Adapting to conditions
	Values	
	Daily rhythm	
	Personal relationships	Staying connected to MiL sources Adapting to conditions
	Life story Character strengths	Being myself
	Personal relationships	
		Adapting to conditions Looking ahead
	Personal relationships	Looking ahead
	Personal relationships	
		Staying connected to MiL sources
	Art and media	
		Staying connected to MiL sources
	Life story	Reflecting about life

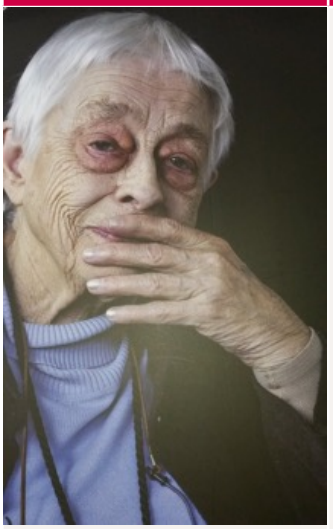
Photo	Ed (A2), age 64
	Despite being the youngest respondent, Ed is severely impaired by his physical condition. A work accident and a limited recovery disabled him in his functioning. He lost two fingers and suffers severe bodily pains. He had to leave his job when he was 47. He used to enjoy a social life at work and in his community. Those are happy memories. Ed lost his first and second wives. *'I have had my full share'* he says. (A2.1) The pain rules Ed's life. He lists many examples of how he adjusts to his condition. 'When I want to cook chili con carne, I plan it a day ahead. I do the shopping the day before, and start early in the afternoon. I take some bowls and cut peppers and leeks, and then I take some rest, because it costs energy. I take breaks and spare my other hand'. 'Sometimes I am pissed off: that I am unable to eat my soup in one go.' He trains his painful legs. 'I'll do anything to firm up those legs.' (A2.1, A2.2, A2.3) Ed's son and grandson visit him now and then. Ed likes to play games with the boy. 'That is important: the pleasure with grandchildren. Simple, to have people around me.' (A2.1, A2.2, A2.3) He also enjoys the recently renewed contact with a schoolmate, who comes by occasionally. They share old stories and his friend gives a hand with practical things, but Ed 'won't ask too much, he has his own life too.' His sister administrates his affairs (A2.2 A2.3) For Ed, to have meaning in life it is important 'to do what I want to do'. Ed used to make beautiful portraits. They cover every spot of his living room walls. The portraits show that he is interested in people who have something special. He loves to go out (in his electric wheelchair), to look around and watch people. 'Going out and shooting those photos, then you do something that means something, you have to see those things.' He chooses a woman's photo. 'That's a portrait that tells something.' (A2.1 A2.2) Ed: 'It is all about respect, accepting someone for who they are. If someone wants to live another way? That's fine. Whether you are fat, tall, tiny, makes no difference to me.' (A2.1 A2.2 A2.3) In the second interview he tells he cannot shoot photos anymore. The camera is too heavy. He suggested small adjustments to the technicians of the wheelchair company, which would enable a stand for the camera, but they were not allowed to do it. It makes him *'angry at all those incompetent people.' 'I feel powerless. If you have been doing that for so many years ... That that has been taken away from me ...'* (A2.2 A2.3) Between the second and third interviews Ed was hospitalised. Although he receives specialised treatment for his pain, his condition has further deteriorated. He is no longer able to do his hobbies. *'That is all lost. My world is getting smaller.'* (A2.3) Ed talks about the neighbourhood. There used to be more contact. Ed misses that. '*Just normal contacts, small-talk, having a cup of coffee ... We used to do things with each other, but that's gone. Many neighbours died recently. People don't have the time, they don't look after each other anymore ...'* (A2.1 A2.2 A2.3) Ed likes watching travel programs on television and makes plans to travel. *'I hope the new treatments will work. What can you do further? Yes, I am happy it's not over. I still want to live a bit more and go places.'* (A2.2 A2.3)

Photo: Cuijpers & Vooren, 2015, Vilans

	Source (subthemes)	Process (subthemes)
	Life story	
		Reflecting about life
		Adapting to conditions
		Taking care of myself
	Character strengths	
		Staying connected to MiL sources
	Personal relationships	
		Adapting to conditions
	Autonomy	
	Physical and mental abilities	
	Art and media	Being myself
	Activities	
	Character strengths	
		Openness and sense of wonder
	Values	
	Community and society	
	Values	
	Art and media	Openness and sense of wonder
		Looking ahead

Photo	Yamini (C4), age 85
Yamini could not choose a photo.	Yamini sits in a comfortable chair by the window: a tiny, frail-looking woman with a pale greyish face, blanket over her knees even though it's warm outside. In the apartment everything is arranged in such a way that a walker can pass easily. Several images of Hindu gods on the wall. The one above Yamini is Ganesha, the god with an elephant head. I'll read later that when you worship this god, obstacles can be taken away. In our conversation Yamini's daughter translates when necessary. Although Yamini came to the Netherlands more than 40 years ago, her Dutch is limited. When she observes the informed consent form, I discover she cannot read or write. We explain before she signs. Yamini was born in Surinam and worked hard as an agricultural worker in a rice plantation when she was young. When I ask her about life in her village, a smile lights her face. Yamini is in very poor health. Her daughter names an impressive list of diseases. She thinks her mother is terminally ill. There have been attempts to move her to a nursing home, but Yamini keeps refusing: she wants to stay where she is, at home. Her main complaint is chronic pain in her joints. Morphine plasters relieve the pain slightly but, since she fell a few times, they had to stop them. When I ask what makes a day meaningful for her, Yamini answers: *'Nothing. Pain, pain, pain.'* According to her daughter, Yamini frequently says: *'Why does God not take me?'* Yamini doesn't eat much anymore. When I show Yamini the photo set so she can choose a picture that tells something about her meaning in life, she hardly pays any attention to it. In my experience, most people find it difficult to choose one of several that apply to them. But for her there doesn't seem to be one that catches her eye. When I ask her if I should stop, she gladly agrees. There is nothing anymore ... When I ask Yamini why there is nothing that's important to her anymore, she answers: *'Difficult, pain, pain. I am not feeling well'*. Then I ask Yamini about earlier days: what was meaning in life for her? She says she loved to go shopping, that her husband bought her nice things, going out ... but that is all over. She sheds a tear. When we talk about visits of her brother, sister and grandchildren Yamini smiles. However, her daughter tells she cannot enjoy these visits like before. She doesn't laugh or chat anymore. The same goes for calls from other relatives. Yamini says: *'Don't call me, don't call me.'* A favourite nurse's name makes her smile again: That special nurse knows exactly how Yamini wants to be cared for. I ask her about the images of gods in the room. She tells that they provide some support. A pandit visits her regularly. Cultural habits are still important for her, like cleanliness.'I always was a clean woman.' (C4.1)

	Source (subthemes)	Process (subthemes)
	Religion	
	Life story	
	Home and neighbourhood	
	Personal relationships	Staying connected to MiL sources
	Religion Values	Staying connected to MiL sources Being myself

Photo	Corinne (D5), age 97
	Corinne stayed single her entire life and had a career in childcare. She loved her work, loved the children. Sometimes times at night she reflects on how things went. Children still fascinate her (she chooses a photo of a girl with a mirror). Although her condition limits activities, she goes out with her walker and a friend every two days, which she highly enjoys, especially looking at children in the supermarket. Two nieces are her family carers. Corinne loves their visits. However, sometimes the home nurses are the only persons she sees that day. *'It is important not to be alone all day. I love (unexpected) visits, conversation. But I leave my nieces free. I don't want to be demanding. They should have fun and enjoy their holidays.'* (D5.1 D5.2 D5.3) She explains that *'meaning in life'* sounds a bit *'loaded'* to her in this period of life. *'When you are so old everything comes towards you. Life trudges on. You just sit and then sit some more. You have to adjust to the day, to the instant that you are in that actual moment. Well, I still live like a princess here.'* And she shows me the bright apartment and beautiful view of the park. (D5.1) Corinne is our oldest respondent, but she loves our talks about meaning in life. Corinne remarks that it feels good to have a dialogue about a *'difficult subject'. 'It is good for me to crack my brains.'* (D5.2 D5.3) In our second interview we talk about the difference between a happy life and a meaningful life. Corinne: *'You have to make your life meaningful yourself. Another person cannot do that for you. Meaning in life is doing or seeing something of worth: tidying up a drawer, having a 'real conversation'* (not chit-chatting), reading a good book or watching something about history on television, for instance.' She explains that this becomes more difficult in old age, because the energy is often lacking to start and finish something. *'They are really different things: Meaning in life is something you have to make yourself and happiness can come your way. For instance when my nieces come by, I don't do anything for that. Only listening and showing interest in them.'* (D5.2 D5.3) On the other hand, it is not a sharp distinction for Corinne: *'Meaning in life is seeing something that attracts or touches you: little ducks in the water when I look out the window, children on my daily walk... That you enjoy something. Like last year on my birthday when we were having lunch with a view over the water, and boats passed by towards Germany. Beautiful view, tasty food. That gives me pleasure and it's meaningful.'* (D5.2 D5.3) Corinne takes interest in staying up to date. She reads the newspaper every day with a special magnifier and watches the news. *'All this misery: attacks with children and abuse in religion. It is a sad time. She wonders what the future will be like. She is curious about the consequences of actual measures.'* I would like to live that back. To live back from the future. I want to see how the measures that we take now work out. That it stops ... Yes, I am hopeful.' (D5.2 D5.3)

Photo: Cuijpers & Vooren, 2015, Vilans

	Source (subthemes)	Process (subthemes)
	Life story	Reflecting about life Staying connected to MiL sources
	Activities Home and neighbourhood Personal relationships	
		Adapting to conditions
		Adapting to conditions
	Home and neighbourhood	
	Physical and mental abilities	
	Values	
	Activities Art and media	Staying connected to MiL sources Adapting to conditions
		Staying connected to MiL sources
	Home and neighbourhood	Openness and sense of wonder
	Community and society Art and media	Staying connected to MiL sources Adapting to conditions Looking ahead

Appendices chapter 5

Appendix 1	Interview guide
Appendix 2	Analysis of participant D4
Appendix 3	Analysis of participant A3
Appendix 4	Analysis of participant B4
Appendix 5	Analysis of participant C6
Appendix 6	Analysis of participant B5
Appendix 7	Analysis of participant C5

Appendix 1 Interview guide

Topic	Interview 1	Interview 2	Interview 3
Introduction	Aim, information, informed consent	Aim, information, informed consent	Aim, information, informed consent
Background data	Age, gender, marital status, living arrangement, cultural background, religion, highest educational level, self-rated health	Self-rated health	Self-rated health
Current situation		How are you at the moment? Important changes since last interview?	How are you at the moment? Important changes since last interview?
MiL	Questions about respondent's MiL *(not this paper)*	Questions about respondent's MiL *(not this paper)*	Questions about respondent's MiL *(not this paper)*
Relationship with nurses	Can you tell me something about your relationship with nurses?	Can you tell me something about your relationship with nurses? Last time you told ..... The same? / Changed? Example? Explain?	Last time you told ..... The same? / Changed? Example? Explain? Do I understand correctly that ....
Recognising MiL?	Do you feel that nurses are interested in you? How? Do you think that nurses are aware of your MiL (or: what is important for you in life?) How do you notice this?	Do you feel that nurses are interested in you? How? Do you think that nurses are aware of your MiL How do you notice this? Last time you told ..... The same? / Changed? Example? Explain?	Last time you told ..... The same? / Changed? Example? Explain? Do I understand correctly that ....
Expectations	Can you tell me what you expect in this regard? Competence?		

Topic	Interview 1	Interview 2	Interview 3
Attuning?	Can you tell a recent example in which the nurse was attuned to your MiL (to what is important for you in life)? (Ask details: Can you tell me more about it? What? Where? Who? How? Behaviour? Feeling? What mattered to you? Etc.) Ask for another example.	Can you tell a recent example in which the nurse was attuned to your MiL? (Ask details: Can you tell me more about it? What? Where? Who? How? Behaviour? Feeling? What mattered to you? Etc.) Last time you told ..... The same? / Changed? Example? Explain?	Last time you told ..... The same? / Changed? Example? Explain? Do I understand correctly that ....
Value/ competence	Can you tell me what you value in this respect? Do you miss something? Competence?	Can you tell me what you value in this respect? Do you miss something? Competence? Last time you told ..... The same? / Changed? Example? Explain?	Last time you told ..... The same? / Changed? Example? Explain? Do I understand correctly that ....
Consequence	What was the consequence for you?	What was the consequence for you? Last time you told ..... The same? / Changed? Example? Explain?	Last time you told ..... The same / Changed? Example? Explain? Do I understand correctly that ....
Final question	Is there something you want to add regarding the subject of this conversation?	Is there something you want to add regarding the subject of this conversation?	Is there something you want to add regarding the subject of this conversation?
Finishing interview	Any questions? Thank you	Any questions? Thank you	Any questions? Thank you

Appendix 2 Analysis of participant D4

Analytical questions	Participant D4 (age 76-80)
Introduction 1. What is at stake for the aged person?	Participant D4 lives in an apartment with a lovely terrace, covered with flowers. He lives alone since the death of his partner, years ago. He has five children. They maintain good relationships. Participant D4 suffers from severe progressive Parkinson's disease which limits his speech, movement and energy. He regularly feels sad about his deteriorating health condition. Participant D4 explains that meaning is *'like the weather: there are good and bad days.'*
a. What are MiL sources for the aged person?	1a. Participant D4's MiL sources are: • Human relationships: the community in the apartment building, in church and his family. *'It is important to live in a community where one can count on one another.'* • Nature. He loves to observe the birds in his aviary and care for the plants on his terrace. *'Life is so wonderful!'* Both nature and community connect him to the universe, to something bigger. For Paul this relates with (protestant) faith. • Doing craftwork: making things. *'To do those pieces of work; that's my life.'* (D4.1, D4.2, D4.3)
1b. How does the person retain MiL?	Participant D4 rarely talks about his worries regarding the deteriorating health condition and the future. He rather picks up some work to do. He tells that whenever he talks about it, he tries not to be pessimistic and to search for the humour in a situation. Participant D4 is a reflective person. He keeps pondering *'about the puzzle-pieces of life'* and also about the meaning of his actual life. Nature keeps him wondering: *'Enjoy the last sunbeam of the day.' 'That little bird can be sitting right next to your shoe!'* Furthermore, he tries to mean something for others, e.g. he takes care of the cat of his son now and then and visits sick neighbours.*'You have to be attentive to others.'* This also applies to the home nurses. He loves to ask them: *'Are you busy or do you want a coffee?'* (D4.1, D4.2, D4.3)
1c. What does he/she expect from the nurse?	Participant D4 expects that nurses are well-trained, skilful and trustful. He expects them to keep to their agreements or, at least, call if this is not possible. He expects them to have some *'basic interest'* in him. *'When I feel that they solely come to pour that drop into my eye and put on those elastic stockings, only for the bare fact of doing this, it feels denigrating to me. I would like them to approach me with a basic interest in me.'*(D4.1, D4.2, D4.3)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Participant D4 doubts this. Due to temporary staff he experiences most contact as superficial. On the other hand he tells about two nurses who do recognise it when he is feeling low. *'They have this personal attention.'* (D4.3)

Analytical questions	Participant D4 (age 76-80)
3. How does the nurse respond to the patient (attunement to MiL)? a. to the struggle, concern, vulnerability, need or pain of the aged person?	Participant D4 is annoyed by the fact that he never knows when the nurses come. *'I hate waiting, you know. It has a high impact on my day. I can read the newspaper but it feels obligatory. And then gradually the day is slipping away. And that makes me dissatisfied again because I wasted my time. I have suggested that they provide a prognosis regarding the estimated time they'll come but it had no result...' Although nurses come on time when he wants to go to church, he can never be sure about appointments. Participant D4 tells about the impact the nurses'* mood has on him: *'They are like the weather: When they are in a bad mood they are unable to enter joyfully. And I won't react too much. But if they enter with good cheer, it gives me a boost like: Cheer-up! Let's go for it.'* On bad days Participant D4 is a bit more silent: he doesn't want to transfer his bad mood to the nurses. A few nurses, who remarked changes in his condition, asked follow-up questions. Participant D4 suggests that they could do this more. Participant D4 tells that nurses take over a bit more on a bad day. He highly appreciates this.
b. to the strength and resilience of the aged person?	Participant D4 enjoys when the well-known nurses visit him, because they can talk about broader subjects, subjects that interest both, e.g. the birds, children, work. *'You become more interested in each other and that is reciprocal.'*He especially appreciates continuing a conversation. *'There are nurses who come back to a conversation we had three weeks ago! Then I conclude: they listened to me with attention, they took the effort to remember it and continue the conversation. And then I feel very happy.'* When Participant D4 was visiting an ill neighbour, two nurses accidentally came by, while he was making tea for her. The relation between Participant D4 and the nurses has become more equal since then. He explains: *'That's what it is like when you are in care. You can encounter each other. And it doesn't matter whether you are caring or cared for.'* (D4.1, D4.2, D4.3)

Analytical questions	Participant D4 (age 76-80)
4. Does the care offered do well to the patient?	Yes and no.
a. If yes: what is the consequence?	Participant D4 emphasises that the physical help he receives is *'an enormous support'* for him: *'They complement my handicaps which enables me to make something of my day.'* This especially valuable on a bad day: *'Taking over a bit more than usually then feels well for a human being.'* He appreciates the reciprocal personal contact with nurses in long-standing relationships and especially the encounter as equal human beings. It feels good to be able to mean something for nurses as well. Benefit for healthcare: Participant D4 emphasises that attention for MiL is important in healthcare, not only for nursing but also for management. *'Well, I think that the higher you come in the organisation, the less focus there is on this aspect [MiL] and on emotions. And that is important for the people who give those trainings: that these very tiny spiritual notes are most important in the big picture.'*
b. If not: what is the consequence?	When the nurses are not coming on time the day slips away. When nurses are entering grumpy it has a negative impact on his mood. Participant D4 doesn't invest in the relationship with temporary staff. *'I can tell a lot of things but there is no consequence to it.'* (D4.1, D4.2, D4.3)
Additional remarks	Participant D4 loved to participate in the study. He was looking forward to our talks. He remarked that it contributed to his MiL: *'to participate in something that may bring forward something good.'* (D4.1, D4.3)

Analytical questions	Participant A3 (Age 76-80)
Introduction 1. What is at stake for the aged person?	Participant A3 lives with his dog in the city centre in an old house. He tells me his life story. He divorced 16 years ago. He has no kids. Beside the marital problems, other family relations were troublesome as well. Participant A3 had a few good friends. However, between our first and second interview his last four friends, including his best friend, died. He says: *'Now I have nobody anymore, nobody who comes around here, nobody who puts her arms around me.'*Participant A3 had cancer some years ago. The cancer was cured but the therapies resulted in a fragile health status which limits his activities. Therefore home nurses assist Participant A3 with daily care.
a. What are MiL sources for the aged person?	Participant A3 wears a necklace with three pendants which reveal his most important MiL sources: • A pendant with the emblem of his favourite soccer club. Participant A3 watches every match on television. It is a club which is supported by many working class people. Participant A3 emphasises: *'I am a normal person, a working- person'*. Participant A3 worked as a housekeeper till his retirement and he is proud of that. • A pendant of his favourite animal, a dog. Participant A3's dog is his most important friend. *'He is my everything. He is my child, a prop and stay to me. He comes to me when I am sad. He makes me live. He is getting old. I always ask the Lord: Could I please stay a little longer, for him?'* • The last pendant is an angel. It symbolises his faith (Roman Catholic). To live a morally good life is most important to him. *'Everything in life is predesignated. You have to walk the right path which means being there for others.'* Participant A3's mother was his shining example in Christian virtues (and Mary). Participant A3 tells that he is, as his mother, a person who loves people: generous and providing help to others. He regrets not being able to go to church anymore due to his physical condition. (A3.1, A3.2, A3.3)
1b. How does the person retain MiL?	Faith enabled Participant A3 to survive difficult periods in his life. He tells he has come to terms with his past. He prays daily. He stresses that his faith provides him with strength, trust and positivity. He won't share his troubles with others. *'I keep my sorrow to myself. You cannot share it; it wouldn't help. Every person has his own path in life.'* He emphasises he always *'goes on with his daily chores'* when times get rough. *'Don't complain, don't think about it so much.'* Participant A3 arranged a mobility scooter, so he will be able to *'walk'* his dog, when his physical condition may deteriorate. He also made last arrangements, to safe his sister work. (A3.1, A3.2, A3.3)

Analytical questions	Participant A3 (Age 76-80)
1c. What does he/she expect from the nurse?	Participant A3 doesn't expect nurses to pay attention to MiL and he prefers not to share his sorrow. Participant A3 believes nurses' only task is the physical care. However, Participant A3 is confident with the care he receives. '*You know, you shouldn't bother others with your grief and worries. You just shouldn't ...you know: they have their own family. They are there for their work. They don't have the time to sit and talk. They come to dó something. They help me taking a shower; they dry and rub me in with body lotion. They even dry the shower stall'* Furthermore, Participant A3 thinks nurses won't understand, because they don't share religious backgrounds. (A3.1, A3.2, A3.3)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Although Participant A3 doesn't perceive nurses' recognition, the behaviour of the some nurses shows that they notice and understand the grief and loneliness of Participant A3. They visit Participant A3 during lunchtime. (A3.2, A3.3)
3. How does the nurse respond to the patient (attunement to MiL)?	Although Participant A3 doesn't share much with nurses, some nurses try to ask follow-up questions. *'I always tell them that I am fine. And they say: you always say you're fine. And then I respond: complaining doesn't help.'*
a. to the struggle, concern, vulnerability, need or pain of the aged person?	Participant A3 told to some of the nurses about his recent loss. *'I told them about the loss of my last friends... eh... and they sympathised with me but you know: they have their own family. So I keep it as much as possible to myself'* Conversation didn't go any deeper and Participant A3 didn't want to bother the nurses. Lunch visits of nurses can be regarded as a response to the perceived loneliness of Participant A3. Some of the nurses even walk the dog, when Participant A3 had a serious flu, which was most important to him. Participant A3 tells that one of the nurses had proposed him to go to a (community) dinner in a nearby school and had suggested to ask a few neighbours. Participant A3 enjoyed the evening and was happy with the suggestion of the nurse. Participant A3 tells about the temporal personnel: He won't allow them to help his taking a shower. *'I am not going to undress for an unknown person! I just told I did it myself already.'*
b. to the strength and resilience of the aged person?	Participant A3 experiences the lunch visits as an opportunity to be a generative person: *'Sometimes when they have a free hour they come to my home. I tell them: come to me. I'll make you tea, coffee, whatever you want. And then they eat their lunch sandwich here and I really enjoy that.'* He daily provides fruit and specific drinks to the nurses because he knows they love it. Participant A3 also buys a personal Christmas gift for them. *'You have to be friendly and interested in them too.'* He highly enjoys the stories of the nurses during daily care. (A3.2, A3.3)

Analytical questions	Participant A3 (Age 76-80)
4. Does the care offered do well to the patient?	Yes and no.
a. If yes: what is the consequence?	Participant A3 enjoys the lunch visits of well-known nurses. The relationship feels equal and reciprocal to him. Comparable to Participant A3 in his younger years, the nurses need to work to make a living. *'I am a working person, just like them.'* He tells about the lunch visits: *'Then you have different conversations. More about what's on their mind. And they say to me:You are just like a mom to us. And then we're joking around.'* Participant A3 appreciated nurse's suggestion to go to the dinner and he is currently making plans to go again together with his neighbours.
b. If not: what is the consequence?	The care of temporary staff doesn't feel well. Participant A3 is not cared for as good as normally and he misses the reciprocal contact with the trusted nurses. (A 3.2, A3.3)
Additional remarks	

Appendix 4 Analysis of participant B4

Analytical questions	Participant B4 (Age 91-95)
Introduction 1. What is at stake for the aged person?	Participant B4 looks younger than his age but his condition is fragile, due to severe heart failure which limits activities. The self-made paintings on the wall are from years ago. Participant B4 is unable to go out and as a result he has no contact with neighbours. During our conversations he repeats himself many times. However, Participant B4 tells that he's content that his *'mind is still working well.'* Although he claims that he is not a talkative person, he shares many stories with me. Participant B4 had a career in a company for beauty products and he loves to tell about that. He also tells about his private life: *'I didn't have an easy life. My partner was untrue. My partner was in jail several times and transmitted me a venereal disease. I was longing for a happy, warm family life but I didn't have that...'* Participant B4 had one son. Participant B4 worked hard and did everything to prevent his son from following the bad example of his parent. His son became *'an honest guy'* and he was proud of him. Unhappily his son died when he was 43 years old. *'I dream of him every night.'* He tells his dream: *'I dream that I am on my bike and he, a little boy, is sitting behind me. I worked during lunch breaks, so I prepared sandwiches for my son and kept them fresh between two plates... and when he went back to school he passed by and waved behind the shop-window and I waved back'*.The relationship with his daughter-in-law is warm. His grandchildren don't visit him. Sometimes Participant B4 calls them. Home nurses come by four times a day. Participant B4 says: *'They come to look after me because I am very old and have nobody. They check on me.'* And he adds *'I am doing fine but the most beautiful thing would be to peacefully close my eyes.'*
a. What are MiL sources for the aged person?	Although life wasn't easy for Participant B4, he is at peace with the way he lived it. MiL sources are: • Happy memories of his son and his work. • His own personality. Participant B4 is a self-conscious person and he is satisfied with what he achieved. He sees himself as a kind person who can interact well with people and as a strong, self-reliant person: *'Sometimes you have to jump into the deep. Life's not a bed of roses. There was nobody to catch me, I all did it by myself... I am strong. That's what life made of me. I am a go-getter. I want to have a good life and most of all: I wanted a good life for my son.'* • The relationship with his daughter-in-law: *'She is a gem. When my son was dying, he asked her to care for me, and she does so very well! That comforts me.'* • Everyday life. *'I take life as it is. I have my puzzle-books, the television. And the girls (home nurses) come by.'* (B4.1, B4.2, B4.3)
1b. How does the person retain MiL?	Participant B4 accepts old age and its limitations. *'That's logical when you are so old.'*He does exercises every day and makes sure he looks good. *'I keep on taking care of myself as I always did.'* Participant B4 relies on himself. He tells he never asks help from others. *'I cope with everything myself. I always say: I am fine'*. However, at night dreams and thoughts keep him awake. Participant B4 tells: *'I don't want to think too much about these things. I turn to my puzzle-books and the television.'* (B4.1, B4.2, B4.3)

Analytical questions	Participant B4 (Age 91-95)
1c. What does he/she expect from the nurse?	Participant B4 accepts that the nurses visit him four times a day. He explains: *'They have to do that because I am so old.'* He expects them to be polite but he doesn't expect them to have attention for MiL. He thinks nurses are not capable to discuss MiL. *'The girls are so young. They are a bit shy. I have to keep the conversation going. They are not able to discuss such a matter.'* (B4.2)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Participant B4 thinks that the contact is too short to notice MiL aspects. *'They come to watch if you are not dead. The contact is too short to form an opinion of such a thing (as MiL).'*However, nurses who stay a little longer with Participant B4 possibly notice his loneliness and grief and also his strength. (B4.1, B4.2)
3. How does the nurse respond to the patient (attunement to MiL)?	Participant B4 tells that all nurses are very kind and polite towards him.
a. to the struggle, concern, vulnerability, need or pain of the aged person?	Participant B4 tells he doesn't want attention for his worries and sorrow. *'I am a closed person. I don't want to talk about the past with everybody. I am not pitiable!'*
b. to the strength and resilience of the aged person?	Participant B4 tells that the home nurses like to come with him. *'The girls always say: it is so cosy with you.'* Participant B4 believes this is a result of his long experience as a manager. *'They can rest here for a little while. I can relate to them, start a light conversation with them, because I worked with people all my life'* (B4.1, B4.2, B4.3)
4. Does the care offered do well to the patient?	Yes. Participant B4 says: *'I couldn't wish better.'*
a. If yes: what is the consequence?	It feels safe for Participant B4 to know that the nurses are watching over him. Furthermore he appreciates the kind contact with the nurses.It confirms him in his quality to interact with people. *'Of course I enjoy it that they say: it is cosy with you. You know, that's because I worked with people all my life'* and he tells another example from his job.
b. If not: what is the consequence?	(B4.1, B4.2, B4.3)
Additional remarks	

Appendix 5 Analysis of participant C6

Analytical questions	Participant C6 (Age 81-85)
Introduction 1. What is at stake for the aged person?	Participant C6 and his partner moved from Suriname to the Netherlands in the sixties. Participant C6 worked for labour subcontractors as a welder. The couple had three children. Two of them died very young. Participant C6's partner died, only 49. He shows me a photo of an elegant young person. Participant C6 tells he doesn't think a lot about his losses. *'Those are things which have to happen. Everything is written already. Our lives are predesignated. And therefore you can live as you wish. Nobody has to tell another how to live. I am free.'* Participant C6's son lives in a city far from Rotterdam. He calls now and then but they don't see each other frequently. A friend comes by now and then to cook and do the shopping for Participant C6. Participant C6 has severe diabetes. He used to control and inject himself but due to deteriorating vision he is unable to do this anymore. Therefore nurses visit him four times a day. His foot has a dirty wound, which is dressed by the home nurses. Participant C6 suffers from pain in his back.
a. What are MiL sources for the aged person?	Participant C6's MiL sources are: • Going out and meeting friends. At the time of the first interview, pain limits Participant C6's mobility. He says *'When I am in pain, that day is nothing for me. I am cursing in Surinam... I stay inside and talk to nobody... Not being able to go out, is the worst thing that can happen to me.'* Between the first and second interview one of his toes was amputated and pain in his back diminished. He is going out again and meeting with friends. *'A good day is when I am talking with other people about what happened long time ago and laughing about that.'* Participant C6 is proud to have friends from all over the world. • Social engagement. Participant C6 talks a lot about society, history, especially from Suriname, and actual news. He is very aware of differences among people (Dutch-Surinam, men-women). He emphasises values as solidarity and equality. *'We are all people and we have to help each other.'* • Music. Participant C6 listens to music all day. He used to play guitar but he gave it away to a niece. *'We, Latin-Americans, have music from Cuba and Jamaica. We are rhythmic people. That's great to play!'* (C6.1, C6.2, C6.3)
1b. How does the person retain MiL?	Participant C6 perceives himself as a sociable person. *'I talk with everybody.'* He is used to tell stories and making a lot of jokes, also during our conversations. He follows the news on the radio. *'When you hear the news you can talk with friends about it.'* Participant C6 used to be a person who did everything himself. *'I don't like to ask people things.'* He adapts his habits to his actual condition, for instance, in order to walk bigger distances, Participant C6 walks with the support of a bike. He is pondering to learn how to use different instruments so he can manage his diabetes himself again. In the third interview Participant C6 tells he is considering going to a nursing home. (C6.2, C6.3

Analytical questions	Participant C6 (Age 81-85)
1c. What does he/she expect from the nurse?	Participant C6 expects from nurses that they keep an *'appropriate distance between man and woman'*. Furthermore he expects nurses to do what he cannot do himself anymore and watch a bit over him. He expects them to perform their work according to *'normal standards'* and ads that he cannot assess this, because it is not his profession. (C6.1, C6.2, C6.3)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Participant C6 experiences nurses as attentive. Participant C6 tells an example of an experience when his glucose was low. The nurse who visited him immediately understood the situation. Furthermore Participant C6 tells stories about nurses who ask him if they can do anything for him. Participant C6 thinks they do this because they notice that he is not able to do it himself anymore. Whether nurses perceive other aspects of his MiL is not clear from Participant C6's perspective. Participant C6 answers: *'I cannot know what they perceive.'* (C6.1, C6.2, C6.3)

Analytical questions	Participant C6 (Age 81-85)
3. How does the nurse respond to the patient (attunement to MiL)?	Although Participant C6 would rather be independent of home nurses, he appreciates the care they provide.
a. to the struggle, concern, vulnerability, need or pain of the aged person?	Participant C6 says: *'They do their work well: fast and well ... When they dress my wound they are very careful not to hurt me. That's humane. And they bind my slippers onto my feet, so bacteria don't get into my wound, because I cannot see it. They are caring.'* With some nurses of permanent staff relations are closer. They help Participant C6 with administration and mail which is difficult for him to do himself, due to limited vision and mobility. He is grateful for that. 'Some people say that people are malicious nowadays... but I can rely on those trusted nurses. They do it out of love for me...Those things are solidarity, no matter who you are.' The nurse who noticed that Participant C6 had a hypo reacted adequately: she assisted him to a chair and made some lemonade for him.
b. to the strength and resilience of the aged person?	Participant C6 perceives himself as a sociable person. He enjoys the relationship with permanent staff members. *'They are young and free, some are Dutch, one is Antillean and there's a Cape Verdean. I believe I had luck with this group. We have a chat and some ask if they can do something for me. I appreciate that.'* There is one special nurse. She shares Participant C6's love for music. *'When she comes she always asks: shall we put the volume a bit higher? Yes, with her... we laugh together and enjoy the music.'* Participant C6 loves his freedom and independence. Sometimes it is difficult for him to be at home on time for the nursing visits. He tells that nurses call him when he is not there. They don't complain. They change their schedule and visit him later. (C6.1, C6.2, C6.3)

Analytical questions	Participant C6 (Age 81-85)
4. Does the care offered do well to the patient?	Yes, the offered care feels good, although visits limit his freedom.
a. If yes: what is the consequence?	The fact that nurses look over him and notice when something is wrong makes Participant C6 feels secure. Because he doesn't like to ask anything from another, Participant C6 appreciates that nurses notice things which are difficult to accomplish for him and offer him help. The relationship with nurses and the personalised, skilled care are of great value to Participant C6. *'That's humaneness!'*
b. If not: what is the consequence?	Although Participant C6 appreciates the home nurses highly, the four daily visits limit his freedom: *'My life organisation has changed. I cannot go where and whenever I want, because I have to be home for them.'* (C6.1, C6.2, C6.3)
Additional remarks	

Appendix 6 Analysis of participant B5

Analytical questions	Participant B5 (Age 71-75)
Introduction 1. What is at stake for the aged person?	Participant B5 was a successful entrepreneur until his stroke, two years ago. He and his partner had to be persistent to be admitted to intensive rehabilitation therapy but succeeded. Participant B5 has reached a high level of independence after his stroke, due to the specialised therapies and intensive exercise. Home nurses visit the couple once a day to assist Participant B5 with bathing and grooming. Although he is proud of what he accomplished, the - partial - independence annoys him, for instance not being allowed to drive a car or to play tennis anymore. He keeps searching for, and achieving, further improvements. His partner is a great support for Participant B5, both physically and mentally. Participant B5 perceives himself as a society-critical person. He is worried about recent transitions in elderly care and the future of young people. The couple has a full agenda: they are active community members in the neighbourhood where they live.
a. What are MiL sources for the aged person?	Participant B5 lives a dynamic life. Sources for Mil are: • Looking back on a life which he regards as successful: *'I had a tremendous life. I had several companies, saw the whole world. I had the luck to meet good people.'* • Independence. • Being there for others in the community, especially those in vulnerable conditions. *'I hate injustice. I hate indifferent, incompetent people... We want to be there for others, to make the community more liveable.'* • His partner. Participant B5 regrets that most attention went to his health last years. *'MiL is for me: doing things together with [name partner].'* (B5.1, B5.2, B5.3)
1b. How does the person retain MiL?	Participant B5 exercises every day and does as much as he can by himself, also in daily care. He tells he is open to others, especially when they are in trouble. Participant B5 experiences himself as a doer and a fighter, who can accomplish things because of his character and experience. *'I am a fighter... I want to show that you can accomplish a lot by will power.'* Furthermore he enjoys life, his achievements of the past and his present life with his partner. (B5.1, B5.2, B5.3)
1c. What does he/she expect from the nurse?	Because he has an active life it is very important for Participant B5 that nurses come on time.He expects them to do their work with pleasure. *'If they enter the house with pleasure, we have pleasure in them being here.' Participant B5 thinks 'nurses don't have the psychological knowledge to discuss MiL.'* (B5.1, B5.2, B5.3)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Since organisational transitions started, nurses are occupied with organisational troubles. Participant B5 notices that this limits their space to be open to patients. *'The nurses are being jerked around. Those changes in the organisation are an excuse for other procedures here. And [name nurse] has to explain all that to us, in her free time. But that has nothing to do with us. That's not our business. We listen to them but it distracts from what they come for. But most of all, it limits the pleasure they have in their work. And that is important to us too.'* (B5.2, B5.3)

Analytical questions	Participant B5 (Age 71-75)
3. How does the nurse respond to the patient (attunement to MiL)?	Participant B5 mentions that there is a big difference between nurses. He and his partner maintain cordial relations with the permanent staff but he complains about the temporal staff. As an entrepreneur he doesn't understand why management did replace nurses, while the team was functioning well.
a. to the struggle, concern, vulnerability, need or pain of the aged person?	Nurses seldom come on time. When Participant B5 had a hospital appointment they were more than an hour late. *'I do as much as I can by myself. I had to be in the hospital on time. The taxi will not wait. It intrudes in my life when they are too late. I was there sitting and waiting, and they even didn't call to say they were late.'* It was not the first time. The uncertain time of visits of the nurses is also inconvenient for his partner: she feels she has to adapt to nurses' schedule, unable to plan when to use the bathroom and get dressed. In the second interview Participant B5 mentions a special nurse of the permanent staff. In an unexpected difficult situation, she came immediately, in her free time, and did everything that was needed. *'These few are toppers. When you call them that something is wrong, they come immediately. No bullshit: Just being there when they are needed.'*
b. to the strength and resilience of the aged person?	Participant B5 had to explain to new and temporal staff that he wants to do himself as much as he can, to regain his capabilities. *'And then they open the bathroom door many times: "can I wash your back?" (irritated) No, I do it myself, don't you understand!? Some of them were terrible. I prohibited some of them to come again.'* Participant B5 and his partner feel the pressure of permanent staff, due to organisational change, and they serve as an outlet for them. *'You just feel that when you know each other well... And sometimes they tell a little bit about that... And we listen. I understand they need a way to vent their feelings. I hope they feel relieved afterwards. That is no problem for us '* (B5.2, B5.3)

Analytical questions	Participant B5 (Age 71-75)
4. Does the care offered do well to the patient?	Yes and no
a. If yes: what is the consequence?	Participant B5 enjoys the contact with permanent staff. When they do their job with pleasure it influences his day. They provide the care well and if they are on time he can carry on in his active life and mean something for others. A few nurses are special ones: he knows he can count on them.
b. If not: what is the consequence?	Although Participant B5 and his partner experience that they are *'a sounding board for them'*, he believes that nurses' attention is distracted from their principal focus -the relation with patients- and their pleasure in work, when nurses are occupied with organisational problems. Furthermore, Participant B5 is limited in the life he wants to live, when nurses don't respect his independence, or don't come on time. However, he doesn't blame the nurses for this but the healthcare organisation. *'I was used to care independently for myself and my partner all my life. And when they don't come on time I lose part of my life. We don't blame those nurses we know. It's taken away by the policy of an organisation. It makes me feel curtailed…'* (B5.2, B5.3)
Additional remarks	Participant B5 gladly wanted to participate in the study. He hoped it contributes to improvements in healthcare.

Analytical questions	Participant C5(Age 66-70)
Introduction 1. What is at stake for the aged person?	Participant C5 grew up in Turkey in the mountains. His partner went to the Netherlands as a labour immigrant and he followed several years later. The couple had five children and thirteen grandchildren. Four children live nearby. The children and grandchildren share the care for their parent, as they had done before, together with Participant C5, for their other parent before he died. They maintain warm relationships. Participant C5 suffers from terminally metastased cancer.He had several operations and treatments, both in Turkey and the Netherlands. Pain and exhaustion limit activities. However, the family hopes there will be time to enjoy another summer in the beloved mountains in Turkey, where the climate is beneficial for him. Home nurses visit Participant C5 once a day to dress a radiation wound on his shoulder which is very painful. Participant C5's Dutch is limited but he has a very expressive face. Her children assist him during our conversation.
a. What are MiL sources for the aged person?	Participant C5's MiL sources are: • Faith (Islam). In the room is a picture of Mekka. He tells he went to Hadj when he was younger.Living as a good Moslim is important to him. He adds: *'Being a good Muslim is not slaughtering other people. Good Muslims help others and bring about peace...It is not good to focus on differences. All people are brothers: black, Dutch, Turks...'* • His children and grandchildren. Participant C5 is happy being surrounded by family. *'I am happy to have five children who all love me. They are always there. Whenever I feel sick they comfort me. I pray to Allah that all people may have such good children.'* • Nature. Participant C5 loves flowers, plants, birds. He loved gardening. His current condition limits this but he still enjoys being outside or watching the garden from inside. (C5.1)
1b. How does the person retain MiL?	Living as a good Muslim. Praying provides him with peace in mind. For Participant C5 being a good Muslim also involves being kind to others. He always has been a welcoming person and still is. Besides family, neighbours visit him frequently. He donates to charity, like the cancer fund.Participant C5 loves to look out of the window on the gardens below. He also liked to feed the birds on his balcony, although his daughter asked him not to do so because of the dirt they produced. When children and grandchildren take him out in a wheelchair he enjoys this highly. (C5.1)
1c. What does he/she expect from the nurse?	Participant C5 and his children) mainly expect skilled physical care of the nurses. Participant C5's children emphasise that care on other domains than the physical is unwanted; they care for it all. (C5.1)
2. Does the nurse recognize the person's MiL (and the way he/she deals with it)?	Participant C5 and his children notice that the nurses of permanent staff know how to behave towards him. They don't think that nurses recognise MiL, because they don't ask and Participant C5 doesn't tell. It is private. (C5.1)

Analytical questions	Participant C5(Age 66-70)
3. How does the nurse respond to the patient (attunement to MiL)?	Depending on the nurse. Participant C5 and his children are more positive about permanent than temporal staff.
a. to the struggle, concern, vulnerability, need or pain of the aged person?	The dressing of the wound can be very painful. Permanent staff members know exactly how to do this in order to let it be bearable for Participant C5. However, he also had bad experiences with nurses who were not skilled to dress the wound *'It was so painful! I was screaming out, crying and trembling.'*
b. to the strength and resilience of the aged person?	The family system is strong: After the bad experiences the family consulted the family doctor. Now there is an appointment with the homecare organisation that only experienced nurses are allowed to dress the wound. Participant C5 stresses several times that the nurses of permanent staff are *'all good women, very sweet'* and he smiles. He has two special ones. They have known him for several years. They are cheerful. They take time to chat, have a drink and make a little joke with him. The family invited them on the engagement party of Participant C5's granddaughter. (C5.1)
4. Does the care offered do well to the patient?	Yes, nowadays it does, although Participant C5 had some bad experiences in the past.
a. If yes: what is the consequence?	If nurses know how to treat the wound and do it carefully, it doesn't hurt and Participant C5 saves energy for the rest of the day. Participant C5 feels cheered up when the two favourite nurses visit him.
b. If not: what is the consequence?	When the dressing of the wound was not done properly it caused a lot of pain.He was stressed by the situation and couldn't sleep or eat anymore. Participant C5's daughter tells that Participant C5 lost 15 kilos during that period. (C5.1)
Additional remarks	Participant C5 was interviewd one time. His children stressed that due to his prognosis they didn't want more interviews: they rather saved Participant C5's energy for happy moments. Participant C5 agreed.

Susan Hupkens

At home with meaning

Older persons' meaning in life, good home nursing and nurse education

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Meaning in life (MiL) is a subject of growing interest in (Dutch) society. In later life, MiL can be a challenge for older persons, among others, due to loss of dear ones and loss of physical and mental ability. Most older persons in the Netherlands age in place (in their private homes), hence home nurses frequently encounter older patients with MiL issues.

This thesis consists of three parts:
Part 1 sheds light on older person's MiL: What are sources for MiL and how do older persons maintain MiL? Our research shows that many older persons have multiple sources for MiL and do a lot to maintain it. They adapt continuously to their changing circumstances.

Part 2 focusses on home nursing: How does MiL come to light in home nursing and (how) could nurses support older persons' MiL? Although MiL may be highly recognisable in many aspects of daily home nursing, attention for, and attunement to patient's MiL is a delicate process in which the nurse-patient relationship plays an important role. Organisational factors may facilitate or hinder in this respect.

Part 3 evaluates an educational programme which was provided by spiritual counselors to home nurses in order to improve sensitivity and competence in attuning care to older patients' MiL. Besides the outcomes of the education this last part of the thesis focusses on the underlaying learning-teaching process of the education.

This thesis will be of particular interest to those practicing, governing, or researching (home)care for older persons, and to educators who teach nurses regarding MiL.

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