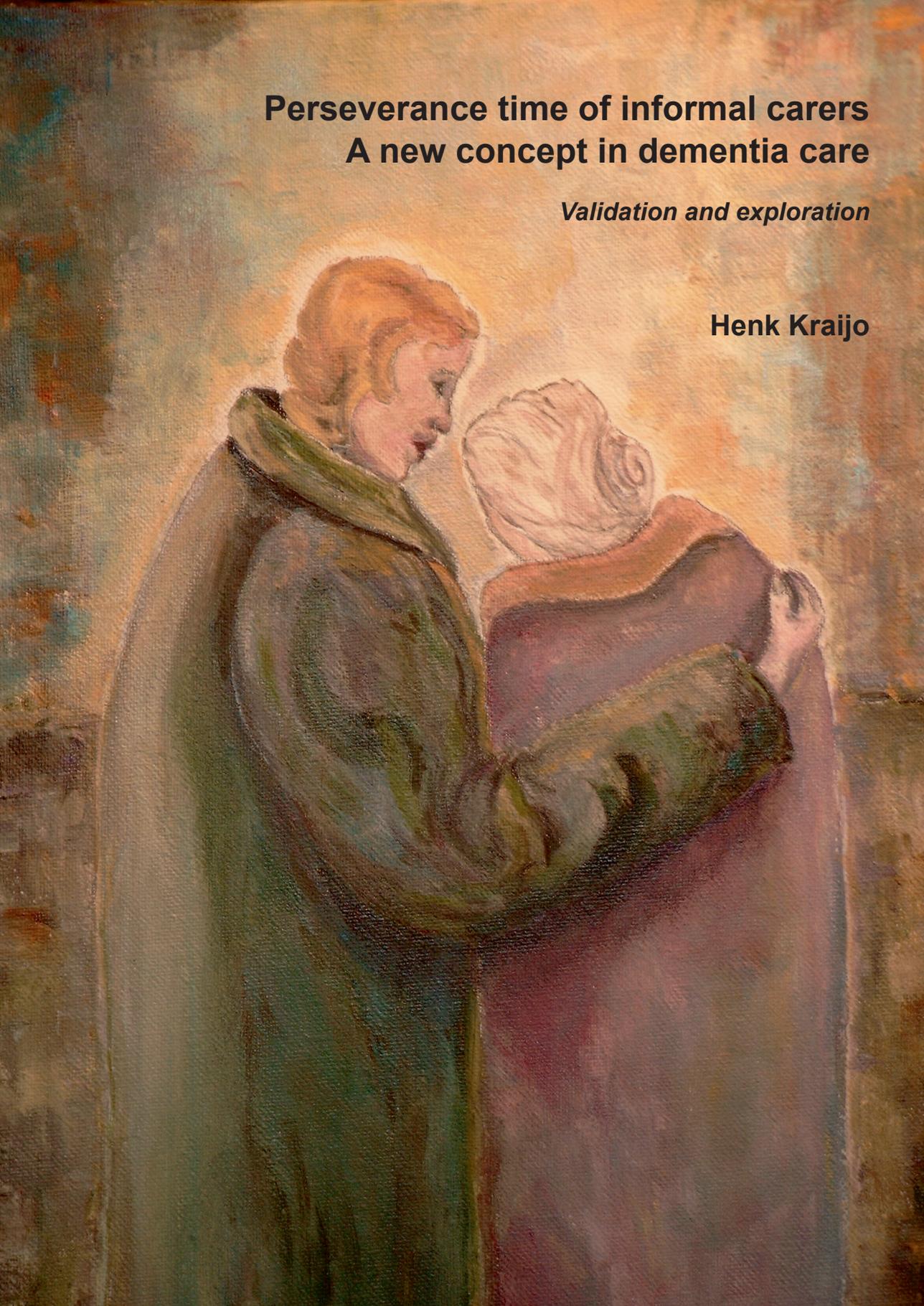


**Perseverance time of informal carers
A new concept in dementia care**

Validation and exploration

Henk Kraijo



Perseverance time of informal carers

A new concept in dementia care

Validation and exploration

Henk Kraijo

Cover painting by: Jannie Kraijo-Holleman
Printed by: Gildeprint – The Netherlands

The production costs of this dissertation were co-funded by:
Vivium Zorggroep, Thuiszorg Gooi en Vechtstreek, HilverZorg,
and Amaris Zorggroep.

Title:
Perseverance time of informal carers
A new concept in dementia care

Utrecht University, Julius Centre
Thesis University Utrecht
ISBN 978-90-393-6231-0

© Henk Kraijo and co-authors

Perseverance time of informal carers
A new concept in dementia care

Validation and exploration

Volhoudtijd van mantelzorgers
Een nieuw concept voor dementiezorg

Validering en exploratie

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht
op gezag van de rector magnificus, prof.dr. G.J. van der Zwaan,
ingevolge het besluit van het college voor promoties
in het openbaar te verdedigen op

vrijdag 13 maart 2015 des middags te 12.45 uur

door

Hendrik Kraijo

geboren op 4 juli 1947 te Rotterdam

Promotoren: Prof.dr. A.J.P. Schrijvers
Prof.dr. W.B.F. Brouwer

Copromotoren: Dr. J.R.J. de Leeuw
Dr. N.J.A. van Exel

Aan mijn vrouw Jannie

Beoordelingscommissie:

Prof.dr. J.J.M. van Delden

Prof.dr. R. Huijsman

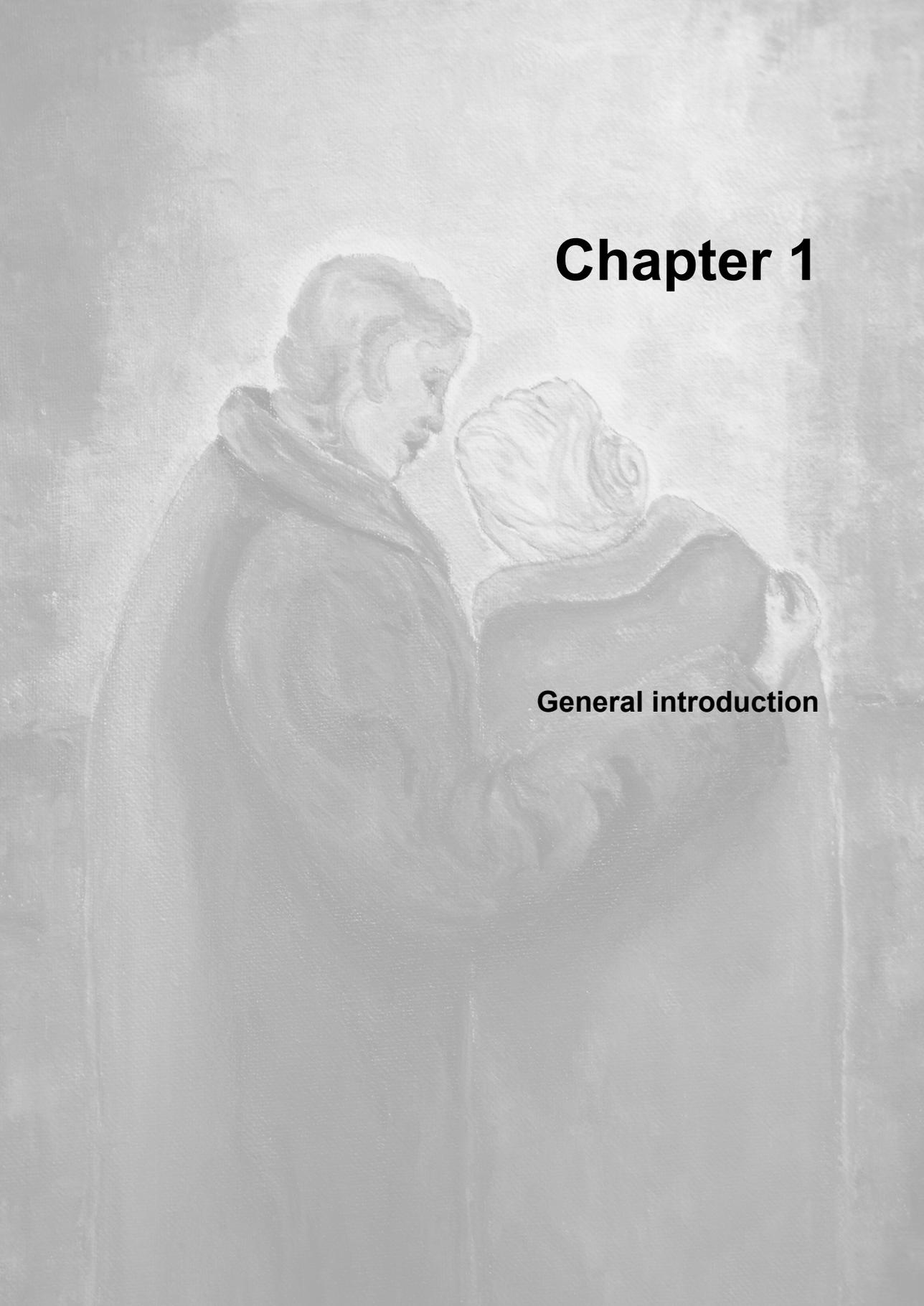
Dr. M.A. Koopmanschap

Prof.dr. M.J. Schuurmans

Prof.dr. N.J. de Wit

CONTENTS

1. General introduction	9
1.1. Context of the study	11
1.2. Dementia and caregiving	12
1.3. Perseverance time: origin, definition, and purpose	14
1.4. Research questions and structure of the thesis	16
2. Perseverance time of informal carers of persons with dementia: validation of a new concept and measure to initiate transition of care at home to nursing home care.	21
3. Perseverance time of informal carers for relatives with dementia: results of a two year follow-up study.	45
4. Coping with caring: Profiles of caregiving by informal carers living with a person with dementia. Appendix: Profiles of caregiving in longitudinal perspective.	71
5. How spouses evaluate Nursing Home Placement of their partner with dementia: a study about the end of perseverance time.	103
6. Right Time Transition of persons with dementia to a nursing home in informal cares' point of view: A longitudinal study of perseverance time.	123
7. General discussion and conclusion	145
7.1. Main findings	148
7.2. Limitations and methodical considerations	154
7.3. Implications for practice	157
7.4. Future research	160
7.5. General conclusion	162
• <i>List of references</i>	167
• <i>Summary</i>	179
• <i>Samenvatting</i>	187
• <i>Dankwoord</i>	197
• <i>Over de auteur</i>	199



Chapter 1

General introduction

1.1. Context of the study

Dementia is a syndrome that generally affects the elderly, and can be caused by a number of disorders that affect memory, thinking, behaviour, and the ability to perform everyday activities [Borsje et al., 2014]. Alzheimer's disease is the most common type of dementia. Typically, dementia is progressive illness in nature and, in the absence of a cure, persons with dementia deteriorate over time until they die.

In the World Alzheimer Report (2010) it was estimated that, in 2010, some 35.6 million persons were suffering from dementia worldwide. Moreover, it indicated that this number was expected to increase to 65.7 million by 2030, and to 115.4 million by 2050 due to the ageing of populations and the fact that dementia is especially prevalent among the elderly. Such projections indicate the need to anticipate this steep increase in the prevalence of dementia in order to remain able to provide timely and sufficient care. Often, the care for persons with dementia starts at home, where informal and formal care may be combined (when the severity of the disease is still in an early phase), but mostly ends with an admission to a nursing home (when the disease becomes too severe). In light of the increasing numbers of persons with dementia, it is expected that the demand for formal and informal care for these persons will also increase sharply.

The World Health Organization has contributed to awareness of this problem. In 2012 it published the report '*Dementia: a public health priority*', which encouraged countries to prepare themselves for this by developing and strengthening policies aimed at enhancing dementia care. This should ultimately improve the social well-being and quality of life of those living with dementia as well as their informal carers.

National governments also appear to be increasingly aware of the important challenges they face in light of the increase in dementia prevalence. The Obama administration, for example, stimulated Alzheimer's research by investing 156 million dollars in 2014 and 2015.¹ Action is also being undertaken in the European Union, where 26 European countries in cooperation with Canada are working together in the Joint Programming Initiative on Neurodegenerative Diseases

¹ United States Department of Health and Human Services, 7 February 2012

(JPND). Initiatives have also been launched at national level. In the Netherlands, for example, the government initiated the 'Master plan for Dementia', which includes plans for integrated registration of persons with dementia, an e-health portal, and a research programme [Dutch Ministry of Health, Welfare, and Sport, 2013]. The national research programme is focussed on prevention and cure of dementia, and on quality of life and care for persons with dementia as well as for their informal carers.

Increasingly, informal care is recognized as being highly important within the context of the care for persons with dementia. However, the burden of this informal care is also being increasingly demonstrated and recognized. In light of the projected increase in the prevalence of dementia, it is crucial to further investigate the role and impact of informal care in dementia. This thesis aims to contribute to the knowledge in this area. The central aim of this thesis is to investigate the perseverance time (defined in 1.3) of informal carers of persons with dementia living at home.

1.2. Dementia and caregiving

Dementia has a profound effect on the daily lives of persons with dementia and their informal carers. Informal care is a collective term for all non-professional care and support provided to a relative or friend.² This may vary from temporary practical support to 'full-time' long-term care for an ill partner. A defining characteristic of informal care is that, in contrast to voluntary work, this care emanates from a personal and/or emotional tie with the person who is in need of help [Brouwer et al., 1999].

The decision whether and to what extent informal care is provided depends on numerous factors, including the skills, expertise, and available time of the informal carer, anticipated period of care need and material and immaterial appreciation, and mutual trust [Mundt et al., 1997; Marcén et al., 2011]. In addition to these factors, cultural influences also play a role in determining the amount of informal

² Informal care can be defined as care provided to persons suffering from chronic illness or who have a disability or other long-term health care needs by someone outside a professional or formal network (Eurocarers, a European association working for carers: www.eurocarers.org).

care provided [Dilworth-Anderson et al., 2002; Pinquart et al., 2005; Donovan et al., 2011]. While one may think of the decision to provide informal care as a conscious choice, this may be perceived differently by those facing this 'choice' or its effects. The perceived freedom of choice to provide informal care appears to decrease with the strength of the relationship with the person in need of care [Gitlin et al., 1999].

The availability of informal care is also affected by socio-demographic factors, such as size and composition of families, increased (female) participation in the labour market, and geographical dispersion of families [Colombo et al., 2011]. Trend studies suggest that the availability of informal care will decrease in the coming decades [Mesthenos et al., 2005; Gaymu et al., 2008; Sadiraj et al., 2009]. However, at the same time, the demand for informal care is likely to increase due to the ageing of populations and the increase in the number of the chronically ill [Ferri et al., 2005], whose demand for care is not likely to be matched by budgets for formal care. Therefore, policymakers are increasingly aware that it is pivotal to make optimal use of the available informal carers, and to facilitate their contribution through support programmes in local communities [Kodner et al., 2006; Vreugdenhil et al., 2011].

Also for persons with dementia, informal carers are typically important as providers and coordinators of care, especially in the advanced stages of the disease when these persons can no longer organize their own care. In the Netherlands, in 2007, two out of three persons with dementia were living at home [Sadiraj et al., 2009]. To a large extent, these persons with dementia were cared for by informal carers [Bakker et al., 2013]. Generally, this is also the preferred care setting for both persons with dementia and their carers [Grunfeld et al., 1997]. Nonetheless, the impact of informal care on the lives, health, and well-being of carers can be substantial [Raine et al., 2004]. Moreover, different carers may experience the burden of care differently – even when performing similar tasks. Overburdening carers may result in losses of health and well-being [Bobinac et al., 2010; Bobinac et al., 2011; Schulz and Beach, 1999], and eventually result in an increased demand for formal care (including institutionalization). The progressive nature of dementia and the associated symptoms may add to this. Many informal carers have difficulties coping with the behavioural changes of the persons with dementia, and experience emotional stress [Peeters et al., 2007].

The study presented here of the perseverance time of informal carers of relatives with dementia living at home must be seen against this complex background. There is an increasing number of persons with dementia, and both the need and the desire to have relatives care for these persons in the home environment. At the same time, though, there is decreasing availability of formal and informal care, and providing care to persons with dementia can place a great burden on informal carers. This creates a difficult and pressing problem.

1.3. Perseverance time: origin, definition, and purpose

In 2002, the concept of perseverance time originated from concerns regarding the increasing burden placed on informal carers, which were amplified by a growing lack of places in nursing homes [Dutch National Board of Health, 2002]. This raised questions about the extent to which informal carers could continue to provide care, and whether they would be able to articulate and predict their perseverance time. If it would be possible to elicit their perseverance time, this could help to prevent the overburdening of carers and subsequent crisis situations that might arise from this and result in emergency institutionalizations. This could be achieved by providing timely and appropriate support at home to persons with dementia and their informal carers, based on the carers' estimations of perseverance time.

We defined the concept of perseverance time as the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia; the length of this period of time is influenced by a combination of factors.

A first step in developing an instrument for measuring perseverance time was the investigation into whether informal carers are able to understand and relate to the concept of perseverance time. During interviews in panel sessions with about 30 informal carers of persons with dementia (which were held within the context of the Dutch National Dementia Programme 2004–2008), carers were asked about persevering with their care tasks. This question resulted in a diversity of answers regarding their ability to persevere with this care, and the

impression that informal carers thought the question about perseverance time is recognizable [Kraijo, 2006].

In this thesis, we will therefore introduce and evaluate a measure of perseverance time, which intends to quantify the length of time that informal carers expect to be able to continue performing their current care tasks. This measure thus also provides an indication of the end of the informal caregiving period. The perseverance time measure was also developed to be useful in the daily practice of caring for persons with dementia. For instance, it could be useful for having timely discussions between formal care providers and informal carers about the decision on when to end informal care in order to avoid negative consequences for informal carers, and facilitate more optimal use of their inputs in the care for their relative with dementia.

To this end, the perseverance time measure is operationalized in a very direct fashion by asking informal carers of persons with dementia the following question: 'If the informal care situation stays as it is now, how long will you be able to cope with the care?'³

The perseverance time of informal carers of persons with dementia living at home is the subject of study in this thesis, also in relation to the actual 'end of caring' (that is, the institutionalization of the person with dementia).

The overall research question is to explore the feasibility, validity, and added value of perseverance time, both as a concept and as a measure within the context of decision making in dementia care.

Before we began our main study, we tested both the concept and the measure of perseverance time in a pilot with ten informal carers of persons with dementia living at home. We asked these carers to complete a pilot questionnaire for the longitudinal study. This contained the perseverance time question as well as a range of other questions, based on previous research in the field of informal care [e.g. Van Exel et al., 2004; Brouwer et al., 2006]. In the pilot, the perseverance time measure (including the answer categories) proved to be both understandable

³ As will be discussed more extensively in the following chapters, informal carers are then offered a number of answer categories and can select the one that applies best to their situation.

and relevant. This thesis will present the results of the subsequent studies into perseverance time.

1.4. Research questions and structure of the thesis

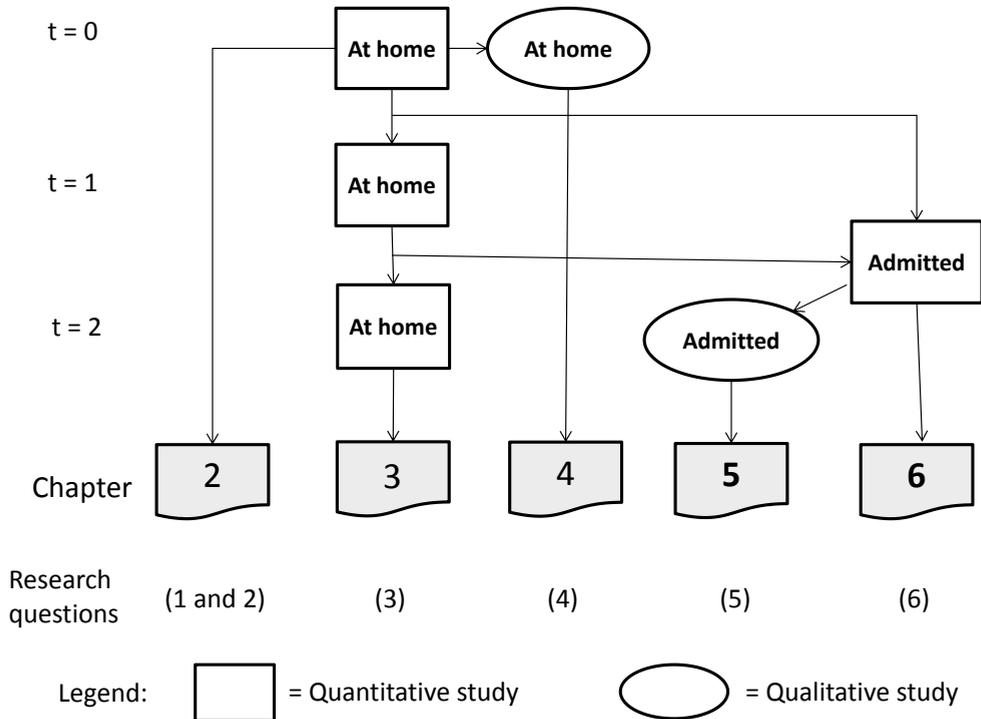
To meet the overall aim of this thesis, we will address the following research questions:

1. What is the feasibility and convergent validity of perseverance time?
2. Which characteristics of the informal carer, the person with dementia, and the care situation are associated with perseverance time? (content validity)
3. To what extent is perseverance time indicative of observed perseverance time? (predictive validity)
4. Can different profiles of caregiving be distinguished, and how do these relate to perseverance time?
5. How do spouses experience the decision to place their partner with dementia in a nursing home?
6. How is the timing of placing persons with dementia in nursing homes related to the perseverance time of their informal carers?

To address these questions, a longitudinal study was designed in which 223 informal carers for persons with dementia from the Gooi and Vechtstreek region in the Netherlands were followed for a period of two years. Ethical approval for this study was obtained from the medical ethics committee of University Medical Centre Utrecht (protocol number 07-189/C; 26 July 2007).

Figure 1 depicts the possible developments of caregiving situations included in the sample during the two-year follow-up study, and relates them to the different research questions and chapters.

Figure 1. Flow chart sample development related to chapters and research questions of this thesis.



In research question 1, we addressed the feasibility and the convergent validity of the perseverance time measure. At the start of the two-year follow-up study ($t = 0$), we investigated whether participants were able to respond to the measure, and how their indicated perseverance time was associated with a number of instruments measuring caregiver burden and well-being. The results of this study are reported in Chapter 2.

In research question 2, we addressed the content validity of the perseverance time measure by exploring associations with characteristics of the informal carer, the person with dementia, and the care situation. The results of these investigations are reported in Chapter 2.

In research question 3, we explored the predictive validity of perseverance time by looking at whether perseverance time was indicative of observed

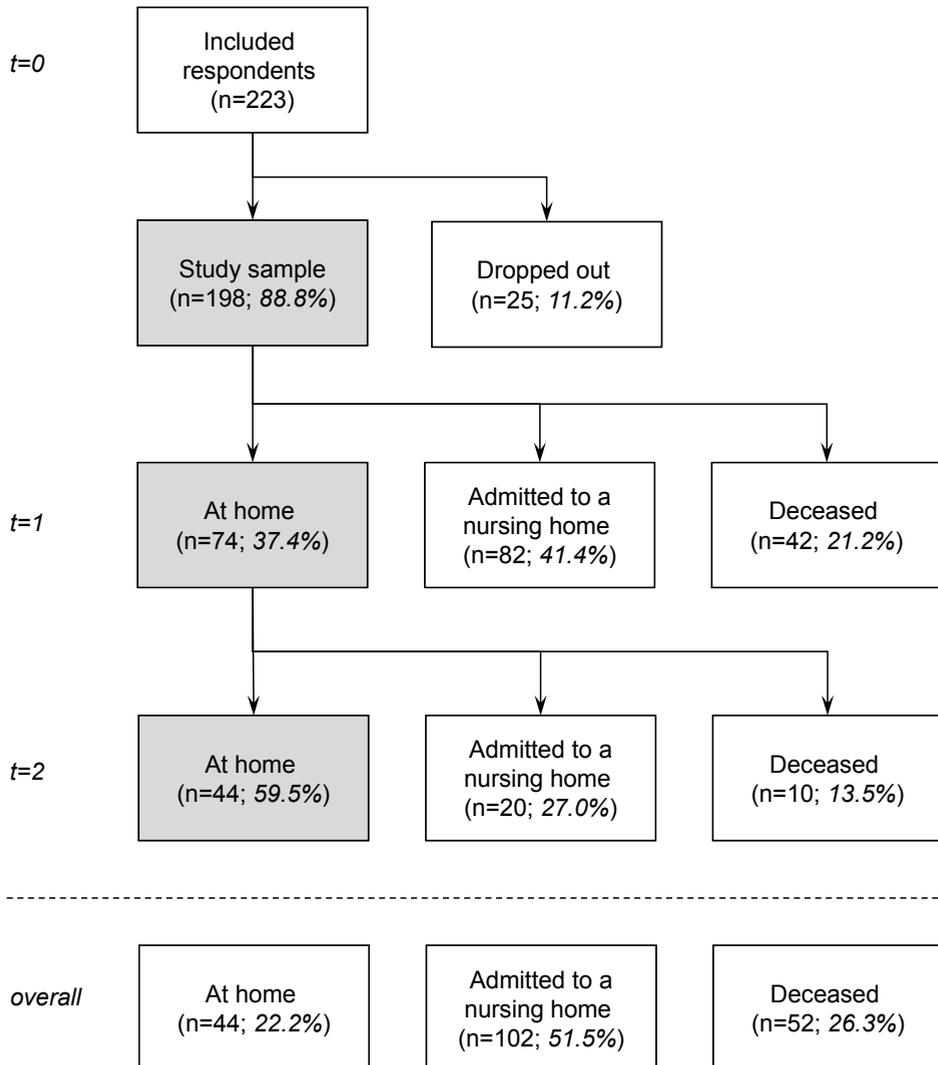
perseverance time during the two-year follow-up. In a longitudinal cohort study, we use multiple questionnaires to investigate how the care situations of persons with dementia developed over time; which characteristics of informal carers, persons with dementia, and care situations were associated with the person with dementia living at home at $t = 1$ or $t = 2$ (i.e. observed perseverance); how the perseverance time of carers developed over time; and whether reported perseverance time was indicative of the observed timing of admissions. The results are reported in Chapter 3.

In research question 4, we investigated how informal carers experienced their caregiving situation, identified different caregiver profiles, and related these to perseverance time. The results are presented in Chapter 4.

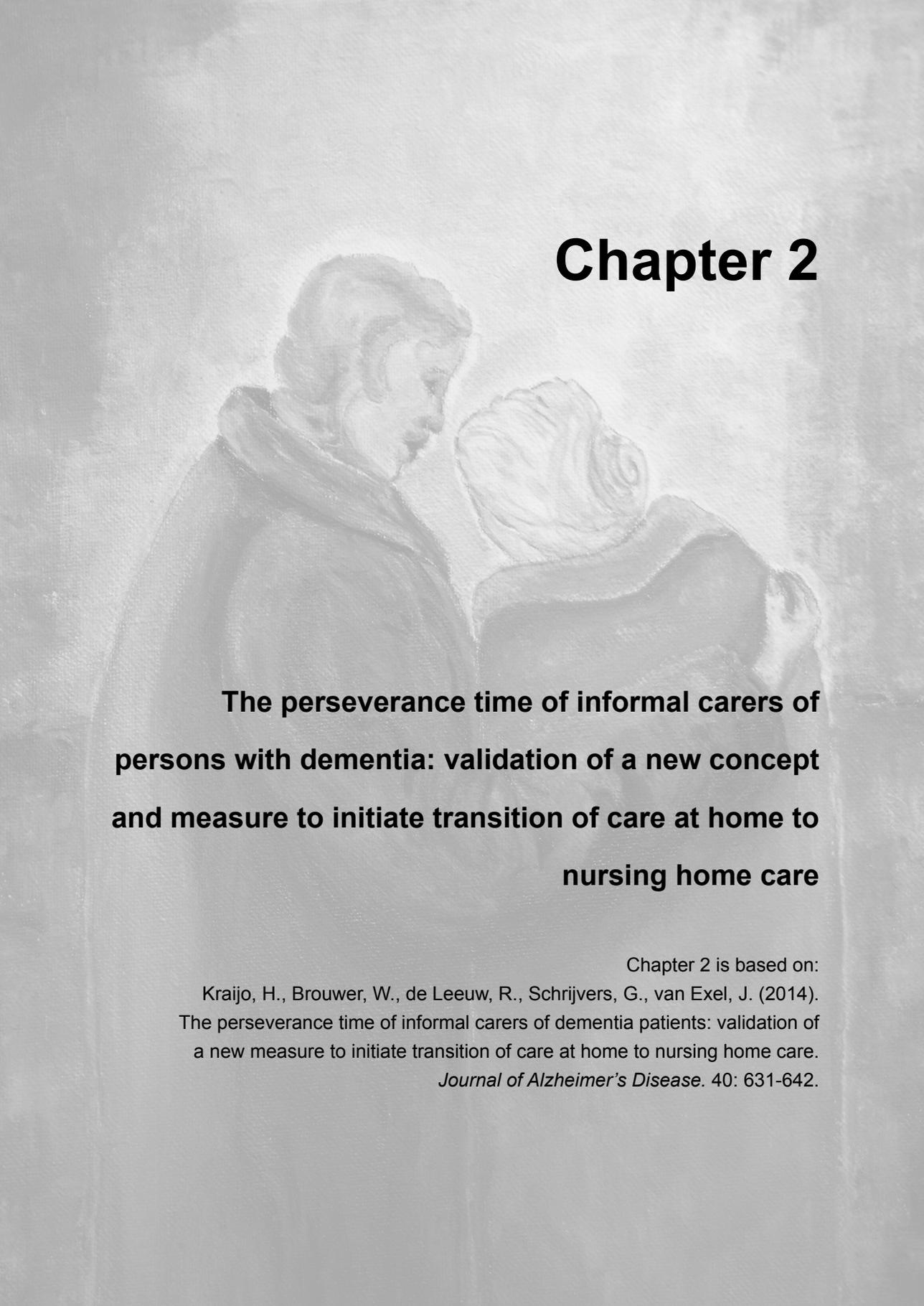
In research question 5, we looked at how spouse evaluated the decision to place their partner in a nursing home. We interviewed them about their experiences with regard to the observed end of their perseverance time and explored with them whether the admission took place at the appropriate moment. The results are presented in Chapter 5.

In research question 6, we investigated how the timing of admission to a nursing home related to the perseverance time of their informal carer. We did so by seeking insight into the caregiving situation before and after the admission to a nursing home, with particular attention to differences between informal carers living at home with their relative with dementia and informal carers living apart from them. These results are reported in Chapter 6.

Figure 2 shows the sample we used to answer the subsequent research questions. A sample of 223 informal carers caring for a person with dementia living at home were included at baseline ($t = 0$). Over the course of the 2-year follow-up, 25 dropped out, 102 persons with dementia had been admitted to a nursing home, and 52 had died. After 1 year, 74 persons with dementia were still living at home; after 2 years, this was 44 persons.

Figure 2. Development of care situations during the two-year follow-up

Finally, in Chapter 7 we discuss the findings from the different studies in relation to each other and to current literature. We also draw some conclusions regarding the feasibility, validity, and added value of perseverance time, both as a concept and a measure within the context of decision making in dementia care.



Chapter 2

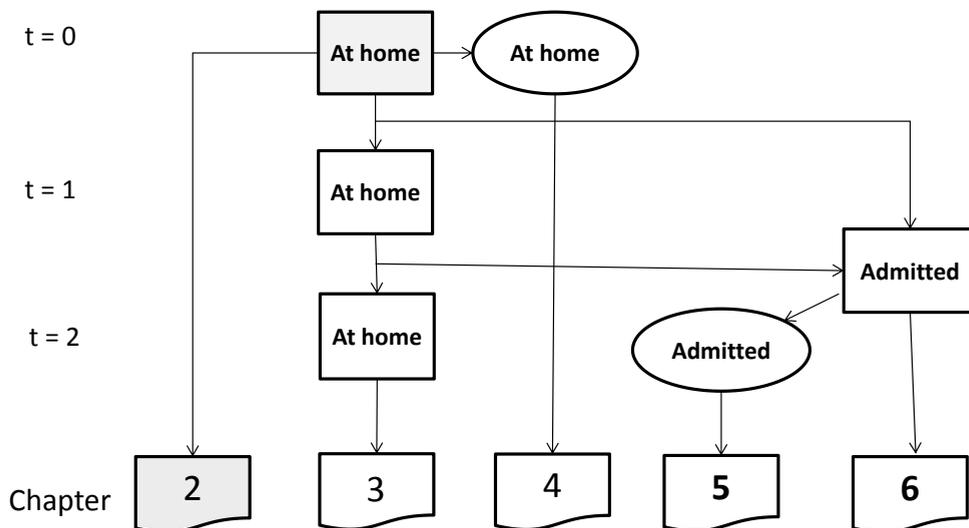
The perseverance time of informal carers of persons with dementia: validation of a new concept and measure to initiate transition of care at home to nursing home care

Chapter 2 is based on:

Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., van Exel, J. (2014).
The perseverance time of informal carers of dementia patients: validation of
a new measure to initiate transition of care at home to nursing home care.

Journal of Alzheimer's Disease. 40: 631-642.

Flow chart related to Chapter 2



Research questions:

1. What is the feasibility and convergent validity of perseverance time?
2. Which characteristics of the informal carer, the person with dementia, and the care situation are associated with perseverance time? (content validity)

ABSTRACT

Background

Health care systems aim to involve as much informal care as possible and persons with dementia prefer to stay home as long as they can. In this context, perseverance time - the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia - is an important concept.

Objective

The aim of this study was to introduce the concept and measure of perseverance time and validate it in a sample of informal carers of persons with dementia living at home.

Methods

Data were collected from 223 informal carers of persons with dementia. Convergent validity was assessed by looking at associations of perseverance time with validated instruments for measuring subjective burden (CSI, CarerQoI-7D and SRB) and happiness (CarerQoI-VAS). Content validity was evaluated by performing multivariate correlations between perseverance time and characteristics of persons with dementia, informal carers and care situations.

Results

Correlation coefficients between perseverance time measure and the measures of burden CSI, SRB, and CarerQoI-VAS were -0.46, -0.63 and 0.23 ($p < 0.01$), respectively. Health of the person with dementia, informal carer living apart from the person with dementia, and male gender of informal carer were positively associated with perseverance time; need for supervision, intensity of informal care provision, and reductions in working hours and hobbies in order to be able to provide care negatively.

Conclusions

Perseverance time is helpful in monitoring need for support and planning the transition of care from home to nursing home. This study provides a first indication of its validity, but replication is necessary.

BACKGROUND

Informal care is the care and support provided to persons with dementia by persons from their social environment, normally in a non-professional or non-commercial capacity. This can vary from temporary practical support to full time care for an ill partner. In most countries informal care constitutes a large part of the total care provided to persons with dementia, especially those with chronic illnesses, disability, and other (aging-related) long lasting health problems or care needs. Increasingly, the importance and impact of informal care is recognized, not only for persons with dementia and carers but also for the health care sector. Given the rising pressure on health care budgets and the desire of persons with dementia to stay at home as long as possible, increasing the involvement of informal care has become an important policy objective in many health care systems. Dementia is a good example in this context, in particular because the number of persons with dementia is expected to double in the coming 20 years [Ferri et al., 2005]. When devising policies to increase the involvement of informal care, the positive effect of reducing the need for formal care must be balanced with potential negative effects on informal carers. This balance can, and increasingly is, influenced by support programs for which there is an apparent need amongst informal carers [e.g. Peeters et al., 2010; Kraijo et al., 2012; Van Exel et al., 2006]. Many such programs have been developed and evaluated in terms of their effectiveness and efficiency [e.g. Smits et al., 2007; Vernooij-Dassen et al., 2000 and 2004; Acton et al., 2001; Cooper et al., 2007; Spijker et al., 2009; Callahan et al., 2011; Andr n et al., 2008; Grossfeld-Schmitz et al., 2010].

Nonetheless, the crucial question that remains is how long the informal carers of persons with dementia can provide care in a sustainable fashion. This question is becoming more important now that trend studies suggest that while the demand for informal care is expected to increase together with the prevalence of dementia, [Ferri et al., 2005] the supply of informal care is expected to decrease in coming decades [Mesthenos et al., 2005; Gaymu et al., 2008; Sadiraj et al., 2009]. Important reasons for this include changes in the average size and composition of families as well as trends of increasing (female) participation in the labour market, geographical dispersion of families, and individualisation in many societies [Agree et al., 2009]. It is unlikely that

the formal health care sector can fully accommodate this increase in demand for dementia care. Hence, it need not surprise that in many countries seek the reliance on informal care will rise.

In this context, it must be recognized that the objective burden (i.e., the tasks performed and the amount of time spent on these tasks) and the subjective burden (i.e., the strain perceived from performing these tasks) of informal care can be substantial [Brouwer et al., 2004; De Vugt et al., 2006]. Dementia is an illustrative example of an illness in which informal carers may experience considerable burden due to the prolonged and intense character of the informal care situation [Clyburn et al., 2000; Razani et al., 2007; Lilly et al., 2011; Annerstedt et al., 2000; Maslach et al., 1981; Almborg et al., 1997; Yilmaz et al., 2009].

Investigating how long informal carers of persons with dementia can be expected to continue providing care in a sustainable way, then becomes an important issue. For instance, the objective and subjective burden of informal care, and the health of the informal carer, and the person with dementia, appear to be important determinants of nursing home admissions, [Luppa et al., 2008; Gaugler et al., 2009; Coehlo et al., 2007] and thus for how long informal carers can reasonably continue providing informal care. In the context of dementia it is also important to consider the progressive nature of the illness and, like the person with dementia, the increasingly higher age of informal carers.

Here we propose and validate a measure that directly asks informal carers how long they expect to be able to persevere with the current informal care, using the concept of perseverance time (PT). This measure can be used to determine the capacity of informal carers to continue care, particularly in the context of chronic illnesses. If informal carers can give a reasonable indication of how long they will be able to persevere with the care, then any necessary support could be offered more timely and tailor-made, admission to a nursing home could be better planned, and crisis situations more often prevented. Thus, such a measure could help getting informal carers optimally involved in the total care for persons with dementia. We tested the concept and measure of PT among Dutch informal carers of persons with dementia because of the chronic and progressive nature of the illness and the associated importance of timely interventions. The concept of PT was operationalized by asking informal carers of persons with dementia the following question:

“If the informal care situation stays as it is now, how long will you be able to cope with the care?”

This study concerns a first investigation of the added value of this concept for research and policy making, and therewith for informal carers. The primary aim of this study is to gather insight into the feasibility and validity of perseverance time.

METHODS

Research population

The informal carers participating in this study were recruited between September 2007 and March 2008, in co-operation with the assessment agency of the Dutch Exceptional Medical Expenses Act in the Gooi and Vechtstreek region, the Netherlands. There is no formal registration of informal carers in the Netherlands, but regional assessment agencies have a registry of diagnosed persons with dementia living at home who receive formal help. The assessment agency sent a letter to the home address of all the persons in their registry diagnosed with dementia, directed ‘To the primary informal carer of [name person with dementia]’. The letter explained the purpose of our study and why the assessment agency supported the study by sending out this letter. In addition, the letter explained that their decision to participate in the study was voluntary and would not affect formal care provision to their relative with dementia in any way, that anonymity of data from questionnaires returned was guaranteed (and how), and that we would assume that by returning the questionnaire they gave permission to use the data they provided for the purpose of this study (as described in the letter). Attached to the letter were a questionnaire and a stamped return envelope, with the address of the assessment agency. After four and eight weeks a reminder was sent.

The investigators periodically received bundles of completed questionnaires from the assessment agency. Therefore, the information available for this study was the data provided by informal carers through our questionnaire, exclusive of identifying information of respondents (i.e., their names and addresses) and persons with dementia (i.e., data from the registry of the assessment agency).

Measuring instruments

The intake questionnaire for the longitudinal study was based on earlier research among informal carers [Van Exel et al., 2004; Brouwer et al., 2006; Al-Janabi et al., 2010] and consisted of a comprehensive set of questions about the informal carer, the person with dementia and the informal care situation (see table 1). Beside the objective burden in terms of duration and intensity of the informal care, questions were also asked about the consequences that informal carers experience in giving the informal care to their relatives with dementia and what their need for support is.

In order to measure the health of the persons with dementia and the informal carers, use was made of a visual analogue scale (VAS) upon which informal carers could indicate how they experience their health and that of their relative with dementia on a scale that runs from 0, worst conceivable health to 10, best conceivable health. In addition, informal carers indicated whether the persons with dementia had co-morbidities (no/yes) and, if so, whether they thought these were mild, moderate or severe. In order to measure the care dependency, measurements were taken with a VAS that runs from 0, fully self-sufficient to 10, fully dependent.

In order to measure the subjective burden, use was made of three validated instruments, the Caregiver Strain Index (CSI) [Robinson, 1983], Self-Rated Burden (SRB) [Van Exel et al., 2004], and the CarerQol [Brouwer et al., 2006; Hoefman et al., 2011; Hoefman et al., 2011]. The CSI consists of 13 items that refer to problems informal carers can experience (see figure 1) and has a simple sum score of 0, no burden, to 13, problems in all 13 items. A score of 7 or higher is defined as substantial burden. The SRB concerns a VAS on which informal carers indicate how burdensome they experience the informal care; the scale runs from 0, not at all straining, to 10, much too straining. The CarerQol-7D, the first part of the CarerQol, consists of seven dimensions (five negative and two positive), registering the informal care experience on a three point scale (see figure 2). The CarerQol-VAS is a valuation component that measures quality of life with a VAS on which informal carers can indicate their happiness; the scale runs from 0 (i.e., completely unhappy) to 10 (i.e., completely happy).

Furthermore, the question about PT was included. Informal carers were asked *“If the informal care situation stays as it is now, how long will you be able to cope with the care?”*, with answer categories: less than one week; more than one

week, but less than one month; more than one month, but less than six months; more than six months, but less than one year; more than one year, but less than two years; more than two years. PT in months is determined by taking the middle of the category in the first five answer categories (for example 3.5 months for the category 'more than one month, but less than 6 months') and was arbitrarily set at 30 months in the (open-ended) sixth category 'more than two years'.

To identify the need for support, informal carers were asked if they had need for: support with informal care tasks; emotional support; and/or respite care.

Statistical analyses

The convergent validity of PT, that is, the extent to which PT is related to constructs to which it theoretically should be, was assessed by looking at bivariate associations between PT and already validated outcome measures for subjective burden (CSI, SRB, CarerQoL-7D) and happiness (CarerQoL-VAS). We expected thereby that PT is statistically significantly and negatively associated with subjective burden (CSI, SRB, and the five negative dimensions of the CarerQoL-7D) and positively with the two positive dimensions of the CarerQoL-7D and happiness (CarerQoL-VAS). Correlations of size smaller than 0.1 were considered as trivial; 0.1–0.3 as small; 0.3–0.5 as moderate; 0.5–0.7 as high; 0.7–0.9 as very high; >0.9 as nearly perfect [Hopkins, 2010].

The content validity of PT was evaluated by performing binary logistic regression analyses between PT (dichotomised at three levels: >6 months; >1 year; >2 years) and characteristics of informal carers, persons with dementia, and the informal care situation. For all continuous variables linear as well as non-linear associations were tested. We expected thereby that PT is statistically significantly and negatively associated with characteristics that represent a more demanding informal care situation.

Statistical analyses were conducted with SPSS 17.0.

RESULTS

Of the 602 questionnaires sent 292 envelopes were returned (gross response rate 49%). Non-participation was caused by administrative issues with the addresses used, like for instance undeliverable envelopes because of moving house. Other reasons mentioned included: relatives admitted to a nursing home, deceased, or receives no informal care, and carer regards participation too burdensome. After further examination of the 292 responses, 69 of the returned questionnaires turned out to be inadmissible for the study because of empty envelopes, (largely) incomplete questionnaires, no case of dementia, or questionnaires (retrospectively) completed by carers of persons with dementia already admitted to a nursing home or deceased. Consequently, 223 informal carers were included in the study (net response rate 37%; which compares well to previous studies in this population – e.g. [Van Exel et al., 2004; Van Exel 2006]).

Table 1 shows the characteristics of the included informal carers and the persons with dementia they take care of. The average age of the persons with dementia was 81 years (range 51-97), 54% were women and 62% had a partner. The health of the person with dementia was valued by informal carers with a mark of 5.8 (on a scale of 0-10). Informal carers had the feeling that something was not right with the relative with dementia on average two years prior to the final diagnosis of dementia. In case of three quarters of the person with dementia there was co-morbidity. The care dependency of persons with dementia was considerable, valued at 7.0 (on a scale of 0-10). A little over half of the persons with dementia could easily be left alone for a few hours, 23% for no more than one hour, while 22% needed continuous supervision. The informal carers were on average 66 years of age (range 29-93) and 66% were women. More than half of the informal carers (54%) were the partner of the relative with dementia, in the remaining cases they usually took care of their parent (in law). In 57% of the cases the informal carer and the dementia person with dementia lived in the same house. In addition to the responsibility for the person with dementia 11% of the informal carers had children living at home and 30% a paid job. Health and happiness were valued respectively at 7.3 and 6.3 (on a scale of 0-10).

The duration of the informal care was on average 3.1 years, and the intensity amounted to on average 38 hours per week spread over on average 5 days per week (see table 2). Almost three quarters of the persons with dementia

received additional professional care at home, 62% made use of day care and 24% also received help from other informal carers. Of the informal carers who were employed, 25% had decided to work less to be able to (continue to) provide informal care. In addition, 40% of the informal carers had given up a hobby and 40% of those who did voluntary work decided to reduce this commitment.

Table 1 Sample characteristics (n=223)

Characteristics		N (%)	Mean	SD	Range
<i>Persons with dementia</i>					
Age	Years		81.2	6.7	51-97
Gender	Female	120 (53.8)			
	Male	103 (46.2)			
Marital status	Married/having a partner	139 (62.3)			
	Single	84 (37.7)			
Health status (VAS 0-10)	VAS (0-10)		5.8	1.9	0-10
Co-morbidities	No	49 (22.0)			
	Mild	44 (19.7)			
	Moderate	86 (38.6)			
	Severe	44 (19.7)			
Supervision	Needs constant supervision	50 (22.4)			
	Can be left alone for one hour at the very most	51 (22.9)			
	Can be left alone for a couple of hours easily	122 (54.7)			
Care dependence	VAS (0-10)		7.0	2.4	0-10
Time since suspicion of dementia	Years		5.1	2.8	1-18
Time since diagnosis of dementia	Years		3.3	2.3	1-16
<i>Informal carers</i>					
Age	Years		66.4	13.4	29-93
Gender	Female	146 (65.5)			
	Male	77 (34.5)			
Marital status	Married/having a partner	187 (83.9)			
	Single	36 (16.1)			
Children at home	No	198 (88.8)			
	Yes	25 (11.2)			
Education level	Low	28 (12.6)			
	Middle	131 (58.7)			
	High	64 (28.7)			
Employed	No	155 (69.5)			
	Yes	68 (30.5)			
Health status	VAS (0-10)		7.3	1.6	0-10
Well-being (CarerQol)	VAS (0-10)		6.3	1.9	0-9

Characteristics		N (%)	Mean	SD	Range
Relationship					
Person with dementia is	Partner	121 (54.3)			
	Parent (in-law)	86 (38.6)			
	Other (family) relationship	16 (7.2)			
Living together	No	95 (42.6)			
	Yes	128 (57.4)			

Table 2 Burden of the care giving situation (n=223)

		N (%)	Mean	SD	Range
Objective burden					
Duration of informal care giving	Years		3.1	2.1	0.5-16
Intensity of informal care giving	Days per week		4.8	2.7	0.5-7
	Hours per week		37.7	40.9	1-126
Formal care at home	Yes; Hours per week	163 (73.1)	11.6	13.5	1-125
Formal day-care away from home	Yes	139 (62.3)			
Support by other informal carers	Yes; hours per week	118 (52.9)	8.7	10.8	1-84
Private home help	Yes; hours per week	65 (29.1)	6.9	16.0	1-126
Adjustments					
- Adjusted working hours	Yes if working	17 (25.0)			
- Reduced volunteer work	Yes if they do	22 (43.1)			
- Abandoned hobbies	Yes if they had one	73 (39.9)			
Subjective burden					
Caregiver Strain Index (CSI)	Score (0-13)		7.7	3.1	0-13
- substantial strain	% CSI score ≥ 7	148 (66.4)			
Self-Rated Burden (SRB)	VAS 0-10		5.8	2.2	0-10
Desire for additional support					
Help with care giving activities	Yes	101 (45.3)			
Emotional support	Yes	38 (17.0)			
Respite	Yes	77 (34.5)			
None	Yes	35 (15.7)			

The burden experienced was 7.7 on the CSI and 5.8 on the SRB. Two thirds (66.4%) of the informal carers felt overburdened (CSI score ≥ 7); of the partners 85% felt overburdened, of the informal carers who lived in the house with the relative with dementia 84% felt overburdened.

The scores on the items of the CSI (figure 1) shows that 87% of the informal carers indicate that: 'it is painful to see that he/she has become a different person' (item 10), and that 50% or more of the informal carers indicated 9 of the 13 items as a problem area, especially those items that refer to emotional burden [Acton et al., 2001; Cooper et al., 2007; Spijker et al., 2009] and the effect on daily life (Van Exel et al., 2006; Smits et al., 2007, Vernooij-Dassen et al., 2000 and 2004; Callahan et al., 2011; Andrén et al., 2008]. The scores on the seven dimensions of the CarerQol (figure 2) show that many informal carers experience some to a lot of problems in the relationship with the person with dementia, the combining of daily activities with providing informal care and with their own physical and mental health. Nevertheless, the largest proportion of informal carers experience satisfaction in caring for the relative with dementia (88%) and support from the immediate circle of persons around the informal carer. Informal carers of persons with dementia experience little financial problems as a result of providing informal care, as also evident from CSI item 13.

Figure 1 Problems experienced with care giving (CSI) and association with PT

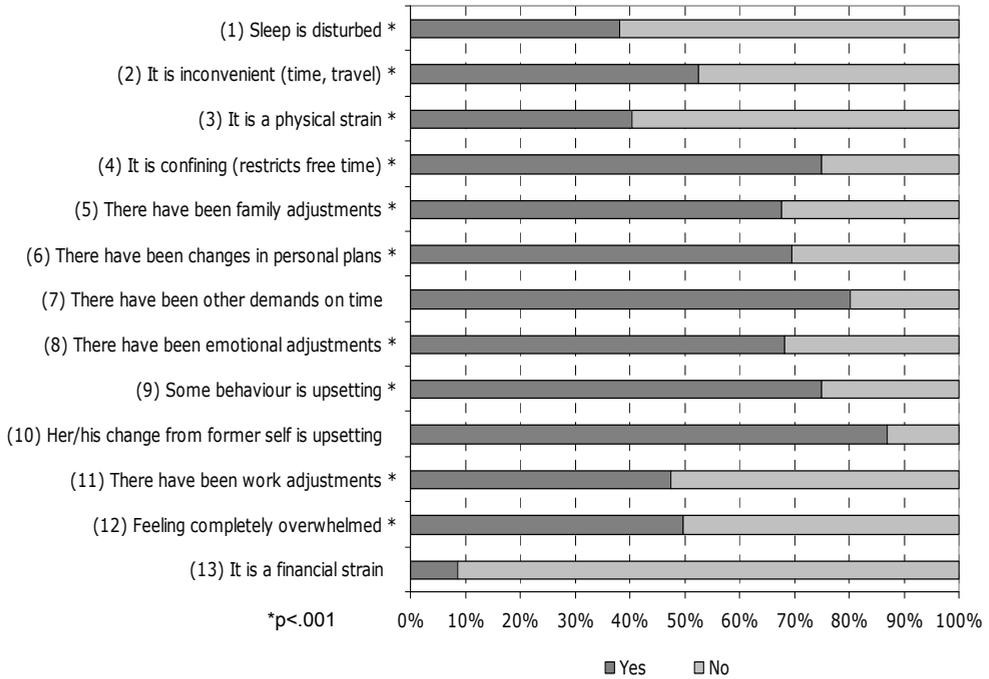
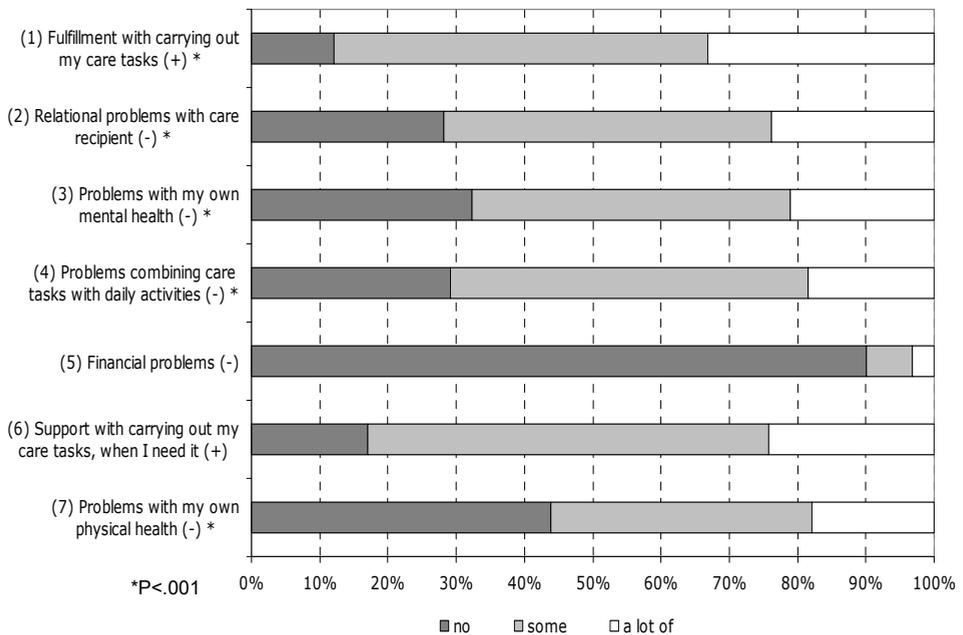
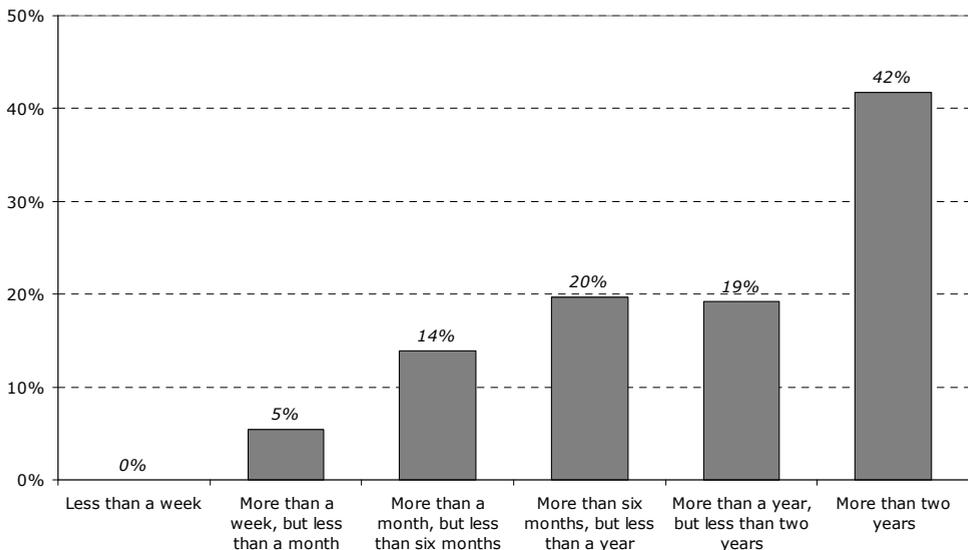


Figure 2 Problems of care giving situation (CarerQol-7D) and association with PT



The PT stated by informal carers was considerable despite the high burden experienced (figure 3). The average PT in months was 18.3 (SD 11.0). A little over four out of ten informal carers indicated they would be able to cope with the informal care as it was at the time of completing the questionnaire for longer than two years. However, approximately one out of five informal carers did not see themselves coping for longer than six months with the current informal care situation, five percent even no longer than one month.

Figure 3 Perseverance time



Of all informal carers 84% indicated to have a need for additional support to be able to persevere longer with the informal care task, whereby especially practical support (45%) and respite (35%) were mentioned, while 16% indicated not to have any need for additional support.

In table 3 the associations are presented between PT, subjective burden, and happiness. The average scores in the different categories of PT as well as the correlations show that lower subjective burden and higher care-related quality of life are associated with longer PT. In addition, PT is significantly associated with 10 of the 13 items of the CSI (figure 1), and five of the seven dimensions of the CarerQol (figure 2). The association with happiness (CarerQol-VAS) is less strong and seems to exist especially at lower PT-scores. These results show that the convergent validity of PT can be classified as moderate with CSI, good with SRB, but poor with happiness.

Table 3 Mean scores of outcome measures CSI, SRB, and CarerQol-VAS according to perseverance time category and correlations with perseverance time in months

	CSI score	SRB score	CarerQol VAS score
<i>Perseverance time category</i>			
▪ Less than six months	10.1	8.0	5.5
▪ More than six months, but less than a year	8.5 **	6.8 **	6.1 *
▪ More than a year, but less than two years	7.5	5.7	6.6
▪ More than two years	6.4	4.5	6.6
<i>Perseverance time in months</i>			
Spearman correlation coefficient	-.46 **	-.63 **	.22 *

*p<.01; **p<.001

Table 4 presents the statistically significant ($p < .10$) correlations between PT (in months) and the characteristics of persons with dementia, informal carers and the informal care situation from table 1 and 2. PT was positively associated with masculine gender, health and happiness of the informal carer, and having children living at home. PT was negatively associated with care dependence of the persons with dementia, age of the carer, being partner of the relative with dementia, living in the same house as the relative with dementia, and all measures of objective and subjective burden. These findings were largely confirmed by the multivariate analyses.

Table 4 Statistically significant associations of perseverance time (PT) with characteristics of persons with dementia, informal carers, and care situation.

Characteristics		N	PT (months)	Oneway Anova (p < 0.10)
Persons with dementia				
Care dependence	≤ 7	111	20.0	0.020
	> 7	112	16.6	
Informal carers				
Gender	Female	146	17.0	0.048
	Male	77	20.7	
Age	< 65	99	20.0	0.035
	≥ 65	124	16.9	
Children at home	No	198	17.8	0.049
	Yes	25	22.4	
Health status	≤ 6	59	14.7	0.024
	> 6	164	19.6	
Well-being	≤ 6	103	15.4	0.030
	> 6	120	20.8	
Relationship				
Relative with dementia is partner	No	102	20.3	0.011
	Yes	121	16.6	
Living together	No	95	20.4	0.092
	Yes	128	16.7	
Objective burden				
Intensity of informal care giving (days/week)	≤ 5 days/week	96	20.4	0.017
	> 5 days/week	127	16.7	
Intensity of informal care giving (hours/week)	≤ 32 hour/week	142	20.5	0.000
	> 32 hours/week	81	14.3	
Adjusted working hours (if working)	Not adjusted	51	21.3	0.096
	Less or stopped working	17	16.2	
Abandoned hobbies (if they had one)	No	110	20.3	0.000
	Yes	73	14.4	
Subjective burden				
Caregiver Strain Index (CSI)	≤ 6	75	23.3	0.000
	> 6	148	15.7	
Self-Rated burden (SRB)	≤ 6	123	23.8	0.000
	> 6	100	11.4	

Table 5 presents the results of three binominal models with PT as dependent variable (dichotomized as: more than six months (yes/no); more than one year (yes/no); more than two years (yes/no)). Explaining variables were the characteristics of persons with dementia, informal carers, and the informal care situation presented in tables 1 and 2.

The results of these analyses however show that different categories of PT were associated with different sets of characteristics. First, a PT of more than six months was associated positively with the health of the person with dementia, the level of education of the informal carer, and with the degree of satisfaction; it associated negatively with the intensity of the informal care, whether the informal carer has a partner, and whether the informal care comes at the expense of sacrificing hobbies. Second, a PT of more than one year depended a great deal on preceding variables, but also for example on the masculine gender of the informal carer and if the person with dementia is not a single parent (in law) of the informal carer (positive). Finally, a PT of more than two years (i.e., no limit indicated to PT) gives a slightly deviating picture and was associated especially with masculine gender of the informal carer, person with dementia being the married/living together, parent (in law) of the informal carer (positive), and giving up of hobbies (negative). Fulfilment from care giving increased the odds of a PT of more than two years.

Table 5 Binary logistic models for perseverance time

Characteristics		Perseverance time					
		>6 months		>1 year		>2 years	
		O.R.	p	O.R.	p	O.R.	p
Persons with dementia							
Age	Years	0.98		0.97		0.96	
Gender	Male	1.01		1.71		1.92	
Supervision	Can be left alone (one hour at the most)	2.36		0.97		1.30	
	Needs constant supervision	1.10		0.61		1.03	
Health status	VAS (0-10)	1.45 ***		1.23 **		1.06	
Informal carers							
Age	Years	1.03		1.01		1.03	
Gender	Male	0.88		3.24 **		2.75 **	
Marital status	Married/having a partner	5.69 **		2.49 *		1.42	
Children at home	Yes	0.29		0.54		0.87	
Education level	Middle	2.77		2.85 *		2.46	
	High	5.08 *		1.95		3.10	
Employed	Yes	0.87		1.39		1.00	
Health status	VAS (0-10)	0.09 *		0.73		0.56	
	Squared	1.19 *		1.04		1.05	
Relationship							
Relative with dementia is	Partner	0.72		1.33		0.58	
	Parent (in-law), single	2.42		2.32		1.35	
	Parent (in-law), Married/ having a partner	2.25		5.74 *		7.26 **	
Objective burden							
Duration of informal care giving (years)	Years	1.11		0.97		0.95	
Intensity of informal care giving	Hours per week	0.91 ***		0.95 **		0.98	
	Squared	1.00 ***		1.00 **		1.00	
Formal care at home	Yes	0.82		0.72		0.59	
Formal day-care away from home	Yes	1.30		0.78		0.95	
Support from other informal carers	Yes	1.47		0.80		0.90	
Support from private home help	Yes	1.08		1.08		1.27	
Carer adjusted working hours	Yes	0.39		0.45		0.94	
Carer reduced volunteer work	Yes	1.59		4.01 **		0.62	
Carer abandoned hobbies	Yes	0.31 **		0.31 ***		0.32 ***	
Carer has some fulfilment from care giving		3.29 *		4.65 ***		2.54	
Carer has a lot of fulfilment from care giving		8.26 ***		7.84 ***		4.51 **	
Constant		334.03		0.08		0.43	
Nagelkerke R ²		0.39		0.37		0.27	
Percentage correctly classified		83.4		78.5		70.0	

***p<0.01; **p<0.05; *p<0.10

DISCUSSION

This study introduced the concept of perseverance time (PT), defined as the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia, and operationalized in a very direct fashion by asking informal carers how long they are able to cope with the current care? This concept and measure may be useful in determining the optimal involvement of informal carers in the total care for persons with dementia, and in facilitating a timely and smooth (perhaps phased) transition of the care at home from informal carers to nursing home care. The necessity to attempt involving informal care optimally is emphasised by the fact that the growth of the nursing home capacity is not keeping pace with the growth of the number of persons with dementia [Peeters et al., 2010]. Making PT explicit could thus help in offering timely and better support in the home environment so that informal carers are able to persevere with the care for longer (assuming that postponing the admission of the person with dementia is desired by the informal carer), and initiating the mostly inevitable transition to nursing home care at a time that is suitable for the informal carer and the person with dementia.

PT is a new concept and therefore no previous data are available for comparison. In this study we found that the PT measure is understandable for informal carers and that they are capable (and willing) to indicate how long they are able to continue current care. This confirms previous findings in an interview setting [Kraijno et al., 2012] and can be viewed as supporting the feasibility of PT in this context.

We measured PT in the circumstance '*when the care giving situation stays as it is now*'. Without this addition the question would be meaningless (and even painful) because dementia has a progressive course, and carers often are the (also aged) partners of the relative with dementia. Health care professionals must, therefore, understand the answer to the PT question against this background. In principle, it can be expected that the actual PT will usually be shorter than the indicated PT, as the care situation is likely to change (to the worse) and caring will become more straining than it is at the moment of PT measurement.

We studied the convergent validity of PT by investigating associations with validated measures for caregiver burden, happiness and care-related quality of life. Two measures of subjective burden (CSI and SRB) were associated

significantly with PT. A reason for the stronger correlation of PT with the SRB than with the CSI may relate to the fact that CSI provides an unweighted sum score of perceived problems in caring, while the SRB is an overall (subjectively weighted) assessment of the care situation, in which positive experiences may also be included. Informal carers possibly also included and weighed these different elements to come to an overall assessment in answering the question of PT. The chosen outcome measure for happiness (CarerQoL-VAS) associated significantly with PT but less strongly than with the measures for subjective burden. An explanation for this can be that happiness is a much broader concept, whereby more life domains than only the informal care situation are taken into consideration. The content validity of PT appeared fair to good for the categories more than half a year and more than one year and declined for a PT of more than two years. Examining determinants of PT showed a marked resemblance with known determinants of subjective burden: the health status of the person with dementia and the informal carer and the objective burden of the informal care situation [Acton et al., 2001; Lilly et al., 2011; Hoefman et al., 2011; Van Exel et al., 2005]. Nevertheless, it is important to note that PT is conceptually different from subjective burden. Both PT and subjective burden measures ask carers to consider the positive and negative aspects of caring (although, with a few exceptions, [Van Exel 2004; Al-Janabi et al., 2010] most burden measures focus on the negative aspects only). However, on top of that, PT asks carers to assess how long they can continue functioning at the current level of burden. Therefore, PT aims to provide more than an indication of the balance between care demands and caring capacity at one particular point in time. Rather, in order to determine the future need for support, it aims to look forward in time and to assess perseverance in a carer-centred manner. Regular assessment of PT could therefore be helpful in signalling carers' need for (extra) support to enable the care at home to continue, or to start planning the transition from care at home to nursing home care.

We found men to report a longer PT, less burden and higher happiness than women in this study. These findings resemble those from earlier research [Almberg et al., 1997; Yilmaz et al., 2009; Yee et al., 2000; Gallicchio et al., 2002; Akpınar et al., 2011]. A pro-active attitude by professionals may thus be necessary to offer timely support for female carers. However, at this stage it is first of all important to further study the validity of PT, also in longitudinal studies, in order to determine how stated PT related to actual PT.

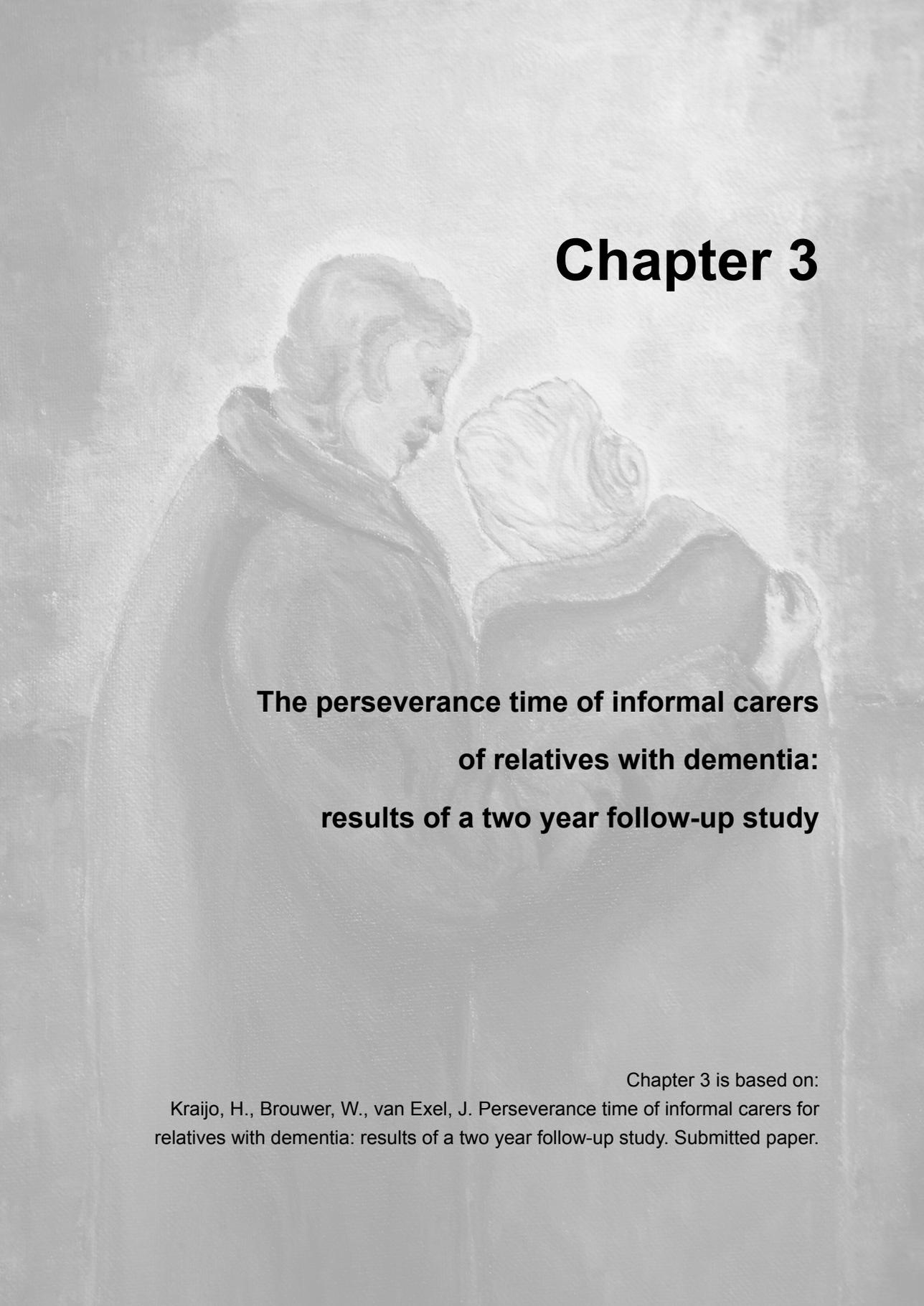
Contrary to what one might expect, informal carers who had reduced working time still indicated a lower PT than informal carers who did not. Similar effects were also found in reduction of other forms of social participation, such as voluntary work and no longer having time for hobbies. Adjustment of work and social participation therefore may be rather a signal for need of extra support, than an outlook for increasing PT. The interaction between providing informal care and work and social participation appears an important area for further research.

Although the first results regarding the feasibility and validity of the concept of PT are encouraging, caution is warranted given a number of limitations of this study. The sample of this study was small and possibly selective, although there is no reference data for a representative sample of carers (of persons with dementia or others). In any case, the level of burden in the sample was considerable when compared to other studies using the same measures (e.g., higher than in case of children with craniofacial malformations [Payakachat et al., 2011], patients with rheumatoid arthritis [Brouwer et al., 2004] and stroke patients [Van Exel et al., 2005], similar to patients with Muscular Dystrophy [Pangalila et al., 2012]) and, like in other studies [Schneider et al., 1999; Campbell et al., 2008], particularly high among persons providing care to their partner with dementia. Furthermore, the PT question had six answer categories, of which the last one (i.e., 'more than two years') was open-ended. Given the answering pattern (see Figure 3), adjustment of the answer categories should be considered. The lowest two categories have hardly been selected by respondents. It may of course be that carers with such low PT are less likely to participate in a survey, but that these categories do have significance when used in the field by case managers, for instance. In addition, the mean PT value in months derived from these categorical answers should be interpreted with some caution because it is particularly dependent on the value chosen for the last category (i.e., 'more than two years'; mean PT was 18.3 months if 2.5 years was chosen for this category, but 30.8 or 55.8 in case 5 or 10 years was chosen. All associations presented in Table 4 were also statistically significant for PT based on 5 and 10 years, except for 'adjusted working hours'). Future studies may consider asking respondents choosing this category to provide an indication of their PT. In addition, the sample of this cross-sectional study was limited in terms of numbers, scope, and geography. At the least, this affected the choice of statistical techniques

(and explains the reliance on dichotomization and logistic regression). Moreover, the potentially large group of informal carers of persons not formally diagnosed with dementia was not involved in this research. Larger, longitudinal studies are required to investigate whether our results can be generalised. Studying PT in other (chronic) disease areas would be valuable as well.

CONCLUSION

Concluding, perseverance time provides a direct way of investigating how long informal carers can continue providing informal care and can thus be helpful in signalling need for extra support or planning the transition from care at home to nursing home care. Recently, one of the health insurance companies in the Netherlands has added perseverance time to their monitoring toolkit for case managers in dementia care, exactly for this purpose. However, this first study is insufficient to claim feasibility or validity of the concept and more research is required to confirm these findings, also in informal carers of different patient populations, and to study the accuracy and policy relevance of estimated perseverance time in daily practice.

A grayscale painting of a man and a woman in winter coats, with the man looking at the woman. The man is on the left, wearing a dark coat and a hat, looking towards the woman on the right. The woman is wearing a dark coat and a hat, looking away from the man. The background is a textured, light gray.

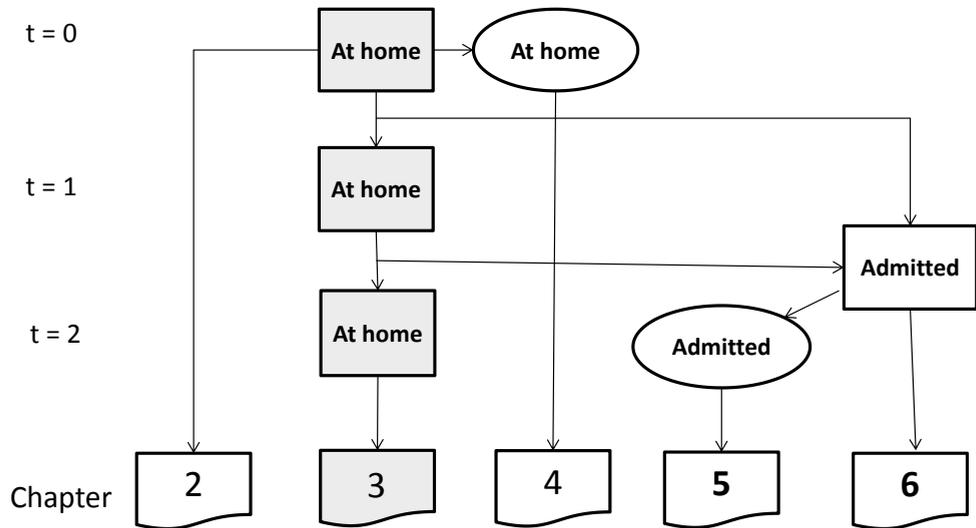
Chapter 3

The perseverance time of informal carers of relatives with dementia: results of a two year follow-up study

Chapter 3 is based on:

Kraijo, H., Brouwer, W., van Exel, J. Perseverance time of informal carers for relatives with dementia: results of a two year follow-up study. Submitted paper.

Flow chart related to Chapter 3



Research question:

To what extent is perseverance time indicative of observed perseverance time?
(predictive validity)

ABSTRACT

Background

In light of the projected increase of people with dementia in the next decades and the related demand for informal care, an important question is how much and how long informal carers can be expected to provide care in a sustainable way. This study aimed to investigate the perseverance time of informal carers for people with dementia.

Methods

A two year longitudinal cohort study was conducted. Data about the care situation, the impact of caregiving on carers and their need for support, and the anticipated and realized perseverance time was collected from informal carers of people with dementia living at home using questionnaires. The data were analysed using bivariate analyses.

Results

223 carers of people with dementia were included in the study, of which 25 dropped out during follow-up. The results showed that after one year 74 of 198 patients were still living at home and after two years 44 of 198 patients. Variables associated with this outcome were identified. When informal carers anticipated their perseverance time was less than one year, it was indicative of actual perseverance time.

Conclusions

Perseverance time provides a fair indication of the expected end of informal care. Its accuracy appears best when carers indicate a limited rather than an unlimited perseverance time. Although more research is required to support these findings, perseverance time may be considered as a useful additional instrument in health policy and clinical practice for monitoring need for support and planning the transition of care from home to nursing home.

BACKGROUND

Informal care is the care and support provided to patients by persons from their social environment, normally in a non-professional and non-commercial capacity. The care can vary from temporary practical support to full time care for an ill partner [Kraijo et al., 2014]. Informal care is an important part of total care in many disease areas, especially in cases of chronic illness. One of the crucial questions regarding informal care is how long an informal carer is able to provide informal care in a sustainable fashion. This question is becoming more important now that trend studies suggest that the supply of informal care will decrease in coming decades, while at the same time the demand is growing [Mesthenos et al., 2005; Gaymu et al., 2008; Sadirai et al., 2009]. Important reasons for the declining supply of informal care include: changes in the average size and composition of families; increasing (female) participation in the labour market; increasing geographical dispersion of families, and increasing individualisation in society [Agree et al., 2009]. These social trends coincide with an expected increase in the demand for informal care due to an ageing population and an increase in the number of chronically ill patients. For example, in many countries the number of persons with dementia is expected to double over the next decades [Ferri et al., 2005]. For reasons of labour scarcity and limited health care budgets, it is unlikely that the formal health care sector can fully accommodate this increase in demand. Hence, many governments seek to increase the involvement of increasingly scarce informal carers.

The potential for doing so is not unlimited, however, because the objective and subjective burden of informal care can be substantial. Dementia is an illustrative example of an illness in which informal carers may experience substantial burden, due to the prolonged and intense character of the informal care situation, but also the progressive nature of the illness and the usually relatively high age of carers. Many studies have shown that the impact of providing informal care to persons with dementia can be profound [Maslach et al., 1981; Almborg et al., 1997; Annerstedt et al., 2000; Razani et al., 2007; Yilmaz et al., 2009; Lilly et al., 2011]. Therefore, in order to know how much and how long informal carers can be expected to provide care in a sustainable way, it is important for policy makers to understand what determines carers' perseverance time [Kraijo et al., 2014] and how carers can be supported to continue providing care and so help decrease the demand for formal health care and delay nursing home admission.

There is increasing research attention for informal care. For example, several studies have investigated the coping capacity and strategies of carers [Graham et al., 1997; Kneebone et al., 2003; Li et al., 2012] or interventions aimed at reducing burden and depression in carers [Acton et al., 2001; Garcia-Alberca et al., 2012], in order to identify factors that may help prolong the duration of caregiving. An important concept in this context is carer resilience [Ross et al., 2003; Gaugler et al., 2007; Coon, 2012; Windle et al., 2012]. Several studies have shown that informal carers can be assisted in coping with the demands of informal care, thus lowering their perceived burden [Annerstedt et al., 2000; Arai et al., 2002; Gaugler et al., 2007]. Other studies have looked at attitudes of informal carers regarding caregiving, respite care and institutionalisation [Peeters et al., 2010; Kraijo et al., 2012; Van Exel et al., 2007; Van Exel et al., 2006]. All this research has improved our understanding of the caregiving process for relatives with dementia [Penrod et al., 2007; Zabalegui et al., 2008; Connor et al., 2008].

Another important branch of research investigated the predictors of nursing home admission [Gaugler et al 2009; Luppá et al., 2010]. Predicting admissions in individual cases, however, remains difficult [Durme et al., 2012], while good timing of admissions is very important for different reasons, including that patients and informal carers generally prefer care at home for as long as possible [Grunfeld et al., 1997; Verbeek et al., 2012] and the increasing scarcity of nursing home capacity [Peeters et al., 2010].

Loeb [2005] argued that an important step in addressing perseverance of informal carers would be the development of an instrument capable of measuring that perseverance. Recently, such a measure was proposed and validated [Kraijo et al., 2014]. In that study, the concept of perseverance time (PT) was operationalized by asking informal carers of persons with dementia the following question: *“If the informal care situation stays as it is now, how long will you be able to cope with the care?”* The findings indicated that informal carers understood this line of questioning well and that PT was useful to provide an indication of the time they expect to be able to continue care in light of the care situation and the burden this entails. An instrument capable of measuring perseverance time may help policy makers and practitioners to support those carers who expect a short PT and can help in planning timely admissions, when unavoidable.

In this Chapter, we report the results of a longitudinal study of anticipated and realized perseverance time of informal carers of persons with dementia. A sample of informal carers of persons with dementia described in [Kraijo et al., 2014] was followed during a two year period. We registered PT using the proposed instrument [Kraijo et al., 2014] next to a number of characteristics of persons with dementia, their informal carers and the caregiving situation. The aim of this study was to (i) investigate how care situations of persons with dementia developed over time, (ii) which informal carer, person with dementia and care situation characteristics were associated with the person with dementia living at home after one and two years, (iii) how PT of informal carers developed over time, and (iv) whether PT answers were indicative of actual admission to a nursing home.

The structure of this Chapter is as follows. First, we describe the methods used. Then, we describe the results of our study. Finally, these results are discussed and conclusions are drawn

METHODS

Sample

This study is a follow-up of the sample of informal carers of persons with dementia, described in Chapter 2. The informal carers participating in this study were recruited between September 2007 and March 2008, in co-operation with the assessment agency of the Dutch Exceptional Medical Expenses Act in the Gooi and Vechtstreek region, near Amsterdam, The Netherlands. There is no formal registration of informal carers in the Netherlands, but regional assessment agencies have a registry of diagnosed persons with dementia living at home receiving formal help, for instance home care. The assessment agency sent a letter to the home address of all the persons in their registry diagnosed with dementia, directed 'To the primary informal carer of [name person with dementia]'. The letter explained the purpose of our study and why the assessment agency supported the study by sending out this letter. In addition, the letter explained that their decision to participate in the study was voluntary and would not affect formal care provision to their relative with dementia in any way, that anonymity of data from questionnaires returned was guaranteed (and how), and that we

would assume that by returning the questionnaire they gave permission to use the data they provided for the purpose of this study (as described in the letter). Attached to the letter were a questionnaire and a stamped return envelope, with the address of the assessment agency. After four and eight weeks a reminder was sent.

The investigators periodically received bundles of completed questionnaires from the assessment agency. Therefore, the information available for this study was the data provided by informal carers through our questionnaire, exclusive of identifying information of respondents (i.e., their names and addresses) and persons with dementia (i.e., data from the registry of the assessment agency).

Informal carers who agreed to participate in the study received a follow-up questionnaire one year (t=1) and –if applicable- two years (t=2) after completing the first questionnaire (t=0). The data collection procedure at t=1 and t=2 was as described above for t=0.

Measures

The follow-up questionnaire was an abbreviated version of the baseline questionnaire used in [Kraijjo et al., 2014], which consisted of a comprehensive set of questions about the informal carer, the person with dementia, and the informal care situation (e.g., objective and subjective burden of care, need for support, adjustments in work and other activities). This questionnaire was largely based on the iMTA valuation of informal care questionnaire (iVICQ) [Hoefman et al., 2011] and was described in more detail elsewhere [Kraijjo et al., 2014]. Some key outcome measures for this longitudinal study are highlighted below. In follow-up surveys, we reduced the length of the baseline questionnaire in order to promote response, and focussed on the key outcome measures for this study.

The health status of persons with dementia and carers was measured using a visual analogue scale (VAS) ranging between 0 (labelled 'worst conceivable health') and 10 ('best conceivable health'). Care dependency of the person with dementia was assessed using a VAS ranging between 0 (labelled 'fully self-sufficient') and 10 ('fully care-dependent').

The subjective burden of care was assessed with two short and validated instruments: the Caregiver Strain Index (CSI) [Robinson, 1983] and Self-Rated Burden (SRB) [Van Exel et al., 2004]. The CSI consists of 13 items describing problems informal carers can experience. Respondents are asked to indicate

whether they experience these problems (answer categories: no / yes) and a simple sum score is computed. This score ranges between 0, indicating no burden, and 13, indicating the carer experiences strain on all 13 problem areas. A CSI score of 7 or higher is defined as substantial burden.[Sullivan, 2003] The SRB is a VAS on which informal carers are asked to indicate how burdensome they experience the informal care to be. The scale ranges between 0 (labelled 'not at all straining') and 10 ('much too straining').[Van Exel et al., 2004]

Moreover, PT was assessed by asking informal carers: "*If the informal care situation stays as it is now, how long will you be able to cope with the care?*"; with answer categories: less than a week; more than a week, but less than a month; more than a month, but less than six months; more than six months, but less than one year; more than one year, but less than two years; more than two years (see figure 2) [Kraijio et al., 2014]. PT in months was estimated by taking the centre value of a category (e.g., 9 months for the category 'more than six month, but less than one year'). For the (open-ended) fourth category 'more than two years', the value was arbitrarily set at 30 months.

Statistical analyses

Descriptive statistics of all variables are presented in mean and standard deviation for continuous variables and in percentages for categorical variables. Differences between sub-groups were tested using ANOVA in case of continuous variables and Chi-square in case of categorical variables. Differences between two points in time were tested using the paired sample T-Test. Statistical analyses were conducted with SPSS 20.0.

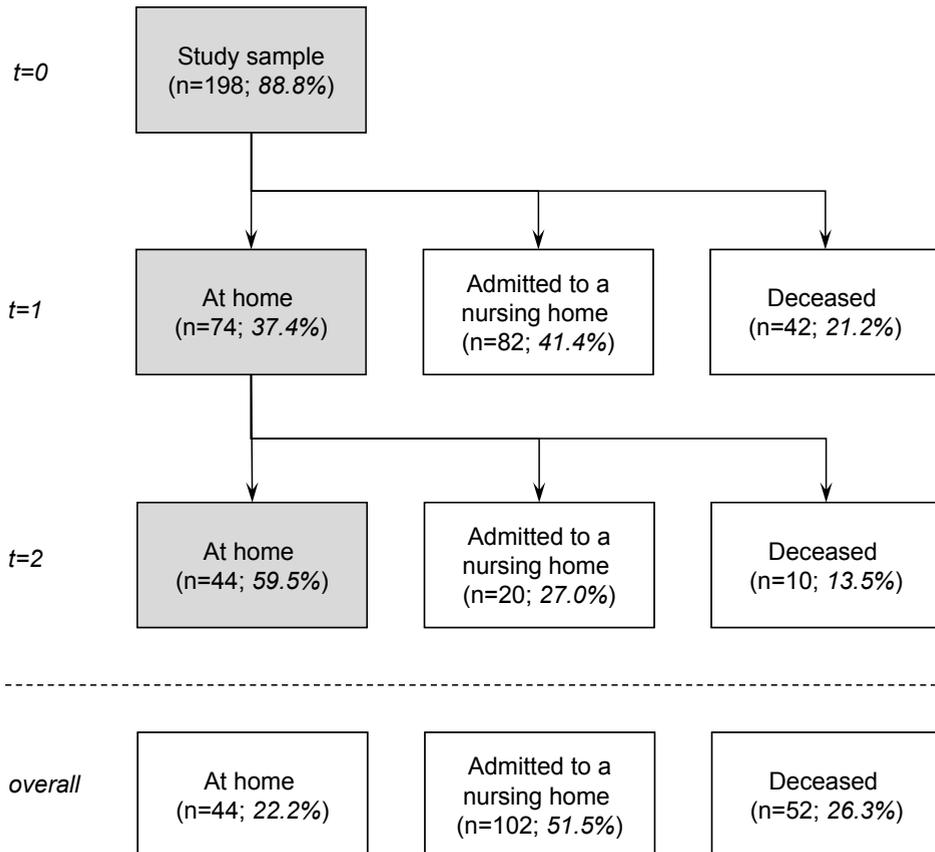
RESULTS

Sample

As described elsewhere Chapter 2, 223 informal carers were included in this longitudinal study at baseline. During the two-year follow-up 25 informal carers dropped out because of non-response (after reminders). At baseline (t=0), this subgroup of informal carers reported significantly higher burden of care (CSI score 7.9 vs. 6.5 ($p<.05$); SRB score 6.0 vs. 4.8 ($p<.05$)) and they were more often identified as being substantially strained (CSI score ≥ 7 : 69% vs. 48%;

$p < .05$) than the informal carers retained for this follow-up study. Therefore, the sample for the longitudinal analysis presented here consisted of 198 informal carers of persons with dementia living at home at $t=0$ (Figure 1). At baseline, 42% of carers expected to persevere in caregiving (at least) throughout the two-year follow-up period (Figure 2).

Figure 1 Development of care situations during the two year follow-up



Development of care situations

Figure 1 shows how the 198 care situations developed throughout the two-year follow-up. After one year 74 persons with dementia (37.4%) still lived at home, while this reduced to 44 (22.2%) persons with dementia after two years. About half of the persons with dementia (n=102; 51.5%) was admitted to a nursing home during the follow-up period, the majority within one year from inclusion in this study, and about a quarter (n=52; 26.3%) had died. In this context it is relevant to note that persons were diagnosed with dementia on average 3.2 years (S.D. 2.4; range 1-16) before inclusion in our sample and that the survival period after diagnoses commonly varies between 3 and 9 years [Bianchetti et al., 2001; Wolfson et al., 2001].

Figure 2 Perseverance time at base line

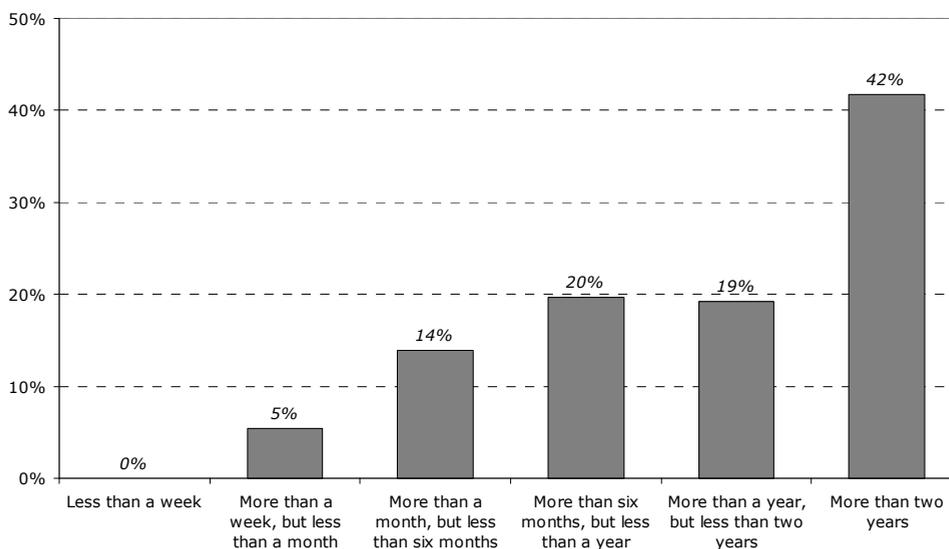


Table 1 presents descriptive statistics of the characteristics of persons with dementia, their informal carers, and the caregiving situation.

The average age of persons with dementia at baseline was 81 years (range 60-97) and about half were women; these values did not change considerably among persons with dementia retained during follow-up. 36% of persons with dementia were single and 33% lived alone; these percentages slightly decreased among those who were still living at home at t=1 and t=2. The average health

of the persons with dementia was valued at 5.8 (range 0-10), and co-morbidity was reported in 78% of persons with dementia; the proportion of persons with dementia without co-morbidities clearly declined over time in the person with dementia group still living at home. Almost half of the persons with dementia needed (constant) supervision and the average care dependence score was considerable at 7.0 (range 0-10).

The average age of informal carers was 67 years (range 35-93), over half was aged 65 or more, and two out of three were women. A minority of the carers was single or had children under the age of 18 co-residing with them, 29% was employed; the proportion of carers with a job decreased considerably during follow-up among carers for persons with dementia still living at home. Informal carers rated their health at 7.3 (range 0-10) and their happiness at 6.4 (range 1-9). More than half of the carers (55%) were the partner of the relative with dementia, and 59% of the persons with dementia lived in the same house as the carer; both proportions clearly increased among those continuing to live at home during follow-up.

Carers reported they had been providing informal care to the person with dementia for 3.2 years on average (range 0-7) and that their current task was intensive, taking up a substantial part of their time: 38.6 hours a week (range 1-126) spread over 4.8 days (range 1-7). At baseline, 74% of the persons with dementia received formal care at home, 63% received day-care away from home and about half received support from other informal carers than the primary carer (i.e., the respondent). During follow-up, the proportion of persons with dementia living at home receiving formal care increased, while the proportion receiving support from other informal carers decreased. In order to persevere in caregiving, a substantial proportion of carers reported they had adjusted their working hours or social activities. For the majority of carers the burden of the caregiving situation was substantial, and only 15% of carers expressed no desire for additional support with their care responsibilities. During follow-up, the proportion of carers of persons with dementia living at home reporting substantial strain or desire for support with their care giving decreased considerably.

Table 1 Sample and care giving situation characteristics; mean (SD) or %

Characteristics		Persons with dementia living at home		
		t=0 (n=198)	t=1 (n=74)	t=2 (n=44)
Persons with dementia				
Age	Years	81.3 (6.6)	81.8 (6.8)	82.1 (7.3)
Gender	Female (%)	53.0	50.0	50.0
Marital status	Single (%)	36.4	29.7	29.5
Lives alone	Yes (%)	32.8	27.0	25.0
Health status	VAS (0-10)	5.8 (1.9)	5.0 (1.7)	5.5 (1.6)
Comorbidity	No	21.7	14.9	9.1
	Mild	18.7	25.7	20.5
	Moderate	39.9	45.9	43.2
	Severe	19.7	13.5	27.3
Supervision	Needs constant supervision	22.7	17.6	20.5
	Can be left alone for one hour at the very most	23.2	39.2	27.3
	Can be left alone for a couple of hours easily	54.1	43.2	52.3
Care dependence	VAS (0-10)	7.0 (2.4)	7.1 (2.0)	7.2 (2.0)
Informal carers				
Age	Years	66.6 (12.9)	69.6 (12.8)	70.3 (12.5)
	65 Years or older (%)	56.5	64.9	63.6
Gender	Female (%)	67.2	63.5	63.6
Marital status	Single (%)	16.7	17.6	15.9
Children at home	Yes (%)	9.6	9.5	9.1
Education level	Low	12.1	10.8	11.4
	Middle	60.6	62.2	54.5
	High	27.3	27.0	34.1
Employed	Yes (%)	28.8	21.6	18.2
Health status	VAS (0-10)	7.3 (1.6)	6.7 (1.8)	6.9 (1.5)
Well-being	VAS (0-10)	6.4 (1.8)	6.4 (2.0)	6.4 (1.8)
Relationship				
Relative with dementia is:	Partner	55.0	64.9	65.9
	Parent (in-law)	37.4	28.4	25.0
	Other (family) relationship	7.6	6.8	9.1
Co-residents	Yes (%)	58.6	67.6	70.5

Characteristics		Persons with dementia living at home		
		t=0 (n=198)	t=1 (n=74)	t=2 (n=44)
Objective burden				
Duration of care giving	Years	3.2 (2.2)	4.2 (2.5)	5.4 (2.8)
Intensity of care giving	Days per week	4.8 (2.8)	5.5 (2.5)	5.3 (2.6)
	Hours per week	38.6 (41.5)	42.3 (42.9)	34.2 (34.4)
Formal care at home	Yes (%)	73.7	91.9	93.2
	Hours per week, if yes	8.5 (13.2)	5.8 (6.6)	11.4 (21.6)
Formal day-care away from home	Yes (%)	63.1	64.9	59.1
Support by other informal carers	Yes (%)	54.5	44.6	45.5
	Hours per week, if yes	9.0 (11.2)	7.2 (5.6)	10.4 (9.8)
Adjustments:	Adjusted working hours (if applicable ^a)	24.6	6.3	25.0
	Reduced volunteer work (if applicable ^b)	40.8	20.0	9.1
	Abandoned hobbies (if applicable ^c)	41.7	41.9	38.6
Subjective burden				
Caregiver Strain Index	Score (0-13)	7.9 (3.0)	7.0 (3.5)	6.6 (2.7)
Substantial strain	% CSI-score \geq 7	68.7	56.8	50.0
Self-Rated Burden	Score (0-10)	6.0 (2.2)	5.5 (2.4)	5.6 (2.1)
Perseverance time	Months	17.8 (11.1)	20.0 (10.5)	22.1 (9.3)
Desire for additional support				
Help with care giving activities	Yes (%)	44.4	47.3	25.0
Emotional support	Yes (%)	17.2	12.2	25.0
Respite	Yes (%)	35.9	18.9	36.4
None	No (%)	15.2	35.1	38.6

Note: ^a number of respondents employed: n=57 (t=0); n=16 (t=1); n=8 (t=2). ^b number of respondents doing volunteer work: n=49 (t=0); n=15 (t=1); n=11 (t=2). ^c number of respondents with a hobby: n=168 (t=0); n=136 (t=1); n=44 (t=2).

Variables associated with observed perseverance

Table 2 highlights the differences in characteristics of persons with dementia, informal carers, and the caregiving situation at baseline (t=0) between the subsamples of persons with dementia still living at home and those admitted to a nursing home at t=1.

The 74 persons with dementia still living at home after one year on average were younger, more often male and less often single. They more often had comorbidity, but less often needed constant supervision and their care dependence was lower. The mean age of the carers of these relatives with dementia was slightly higher and they were less often employed. Persons with dementia still living at home more often were the partner of the carer, less often their parent (in-law), and more often co-resided with the carer. The intensity of the care task was somewhat higher, but the carer less often had made adjustments to work or hobbies in order to provide care. On average, the subjective burden of care, measured with either CSI or SRB, was lower, and their reported PT was higher. More than 3 out of 4 carers for persons with dementia still living at home at t=1 anticipated to be able to cope with the care task for at least a year at baseline (t=0), provided the informal care situation stayed as it was, while this was less than half for carers for relatives with dementia admitted to a nursing home. Persons with dementia who had died before t=1 (not shown in table) more often had severe comorbidity (33.3% vs. 16.0%; $p < .05$) and on average had a lower health status (5.3 vs. 6.0; $p < .05$) at t=0; no significant differences were observed in objective or subjective burden of the care situation.

Table 2 Differences in characteristics of the care situation at t=0 between persons with dementia living at home and admitted to a nursing home at t=1

Characteristics		t=0		t=1	P
		Total (n=156)	Home (n=74)	Nursing home (n=82)	
Persons with dementia					
Age	Years	81.2	80.0	82.4	**
Gender	Female (%)	56.4	50.0	62.2	*
Marital status	Single (%)	37.2	29.7	43.9	**
Lives alone	Yes (%)	32.7	27.0	37.8	n.s.
Health status	VAS (0-10)	6.0	5.9	6.1	n.s.
Comorbidity	Yes (%)	76.3	82.4	70.7	*
Needs constant supervision	Yes (%)	22.4	14.9	29.3	**
Care dependence	VAS (0-10)	7.0	6.5	7.4	**

Characteristics		t=0		t=1		P
		Total (n=156)	Home (n=74)	Nursing home (n=82)		
Informal carers						
Age	Years	66.5	68.6	64.6		*
Gender	Female (yes)	64.1	63.5	64.6		n.s.
Marital status	Single (yes)	18.6	17.6	19.5		n.s.
Children at home	Yes (%)	10.3	9.5	11.0		n.s.
Education level	High (%)	27.6	27.0	28.0		n.s.
Employed	Yes (%)	30.1	21.6	37.8		**
Health status	VAS (0-10)	7.3	7.2	7.4		n.s.
Well-being	VAS (0-10)	6.5	6.5	6.6		n.s.
Relationship						
Relative with dementia is partner	Yes (%)	53.8	64.9	43.9		***
Relative with dementia is parent (in-law)	Yes (%)	37.8	28.4	46.3		**
Co-residents	Yes (%)	58.3	67.6	50.0		**
Objective burden						
Duration of care giving	Years	3.2	3.2	3.2		n.s.
Intensity of care giving	Days per week	4.8	5.2	4.5		*
	Hours per week	35.2	37.0	33.7		n.s.
Formal care at home	Yes (%)	69.9	71.6	68.3		n.s.
Support by other informal carers	Yes (%)	51.9	45.9	57.3		n.s.
Adjustments:	Adjusted working hours (if applicable ^a)	19.1	0.0	29.0		***
	Reduced volunteer work (if applicable ^b)	44.7	40.0	47.8		n.s.
	Abandoned hobbies (if applicable ^c)	41.0	32.3	48.6		**
Subjective burden						
Caregiver Strain Index		7.7	7.1	8.2		**
Self-Rated Burden		6.0	5.6	6.4		**
Perseverance time						
Perseverance time	Months	18.3	22.2	14.8		***
	> 2 Years (%)	41.0	54.1	29.3		***
	> 1 Year (%)	62.2	78.4	47.6		***
	> 6 Months (%)	80.1	94.6	67.1		***

Note: *p < 0.10; **p < 0.05; ***p < 0.01; n.s. = not significant. ^a number of respondents employed: n=47 (total); n=16 (home); n=31 (nursing home). ^b number of respondents doing volunteer work: n=38 (total); n=15 (home); n=23 (nursing home). ^c number of respondents with a hobby: n=134 (total); n=62 (home); n=72 (nursing home).

Not many statistically significant differences were observed in characteristics at t=1 between persons with dementia living at home at t=2 (n=44) and those who were admitted to a nursing home (n=20) or had died (n=10). The main differences (not shown in table) concerned the subjective burden of the care situation: the CSI score was lower (6.2. vs. 8.2; $p < .05$), SRB score was lower (4.8 vs. 6.6; $p < .001$) and reported PT in months was higher (24.3 vs. 13.7; $p < .001$) for those still living at home. Moreover, 86.4% of the informal carers for persons with dementia still living at home at t=2 anticipated to be able to cope with the care task for at least another year at t=1, provided the informal care situation stayed as it was at baseline, while this was 40% for the other carers ($p < .001$).

Anticipated PT

Figure 2 shows PT at baseline. A small proportion of carers for included persons with dementia (5%) anticipated they could cope with the caregiving situation for less than a month, if it stayed as it was, while a large proportion (42%) indicated they would cope for at least the duration of the two-year follow-up.

A very similar response pattern to the PT question was observed at t=1 among the 74 carers of persons with dementia still living at home, namely 0.0%, 1.4%, 12.2%, 18.9%, 20.3% and 47.3% for the six answer categories in figure 2, respectively. This was again the case at t=2 (n=44): 0.0%, 0.0%, 6.8%, 13.6%, 27.3% and 52.3%, respectively.

Anticipated PT and observed perseverance

Table 3 compares anticipated and realized PT. When making this comparison, it must be emphasised that while anticipated PT was asked under the assumption that the care situation would not change, this inevitably did change in reality. Still, Table 3 shows that a large proportion of the carers who indicated their PT was less than a year at t=0, anticipated this correctly (90.2% of the 41 carers with $PT < 6$ months; 69.2% of the 39 carers with $6 \text{ months} < PT < 1 \text{ year}$; i.e., 80.0% in aggregate). Similar numbers were observed at t=1 (i.e., 90.0% and 64.3%, respectively; 75.0% in aggregate). These proportions were lower when only persons with dementia admitted to a nursing home were considered (and deceased relatives excluded from % realized PT). Figure 3 provides full details on the comparison between anticipated and realized PT.

Carers who indicated their PT was between 1 and 2 years (baseline) also largely anticipated this correctly, as 79.5% of the corresponding persons with

dementia no longer lived at home at t=2. Note, however, that a considerable number of these relatives already were admitted at t=1. A majority of carers who indicated their PT was at least 2 years (baseline) did not realize their anticipated PT, as only 35.4% of the corresponding relatives still lived at home at t=2. Overall, it appears that carers who indicated a limited PT (more) often anticipated their PT correctly, in particular for shorter PT intervals.

Table 3 Anticipated and realized perseverance time during 2-year follow-up

	Baseline						t=1	
	Home after 1 year (t=1)		Home after 2 years (t=2)		Home after 1 year (t=2)		N	% realized PT* (% PT cat.)
	N	% realized PT* (% PT cat.)	N	% realized PT* (% PT cat.)	N	% realized PT* (% PT cat.)		
Perseverance time								
- less than 6 months	41	4 (9.8%)	90.2% / 65.9%	3 (7.3%)	n.a.	10	1 (10.0%)	90.0% / 80.0%
- between 6 months and 1 year	39	12 (30.8%)	69.2% / 41.0%	5 (12.8%)	n.a.	14	5 (35.7%)	64.3% / 35.7%
- between 1 year and 2 year	39	18 (46.2%)	n.a.	8 (20.5%)	79.5% / 51.3%	15	10 (66.7%)	n.a.
- more than 2 years	79	40 (50.6%)	n.a.	28 (35.4%)	35.4%**	35	28 (80.0%)	n.a.
Perseverance time > 1 year								
- No	80	16 (20.0%)	80.0% / 53.7%	n.a.	n.a.	24	6 (25.0%)	75.0% / 54.2%
- Yes	118	58 (49.2%)	49.2%	n.a.	n.a.	50	38 (76.0%)	76.0%
Perseverance time > 2 years								
- No	119	n.a.	n.a.	16 (13.4%)	86.6% / 58.8%	n.a.	n.a.	n.a.
- Yes	79	n.a.	n.a.	28 (35.4%)	35.4%**	n.a.	n.a.	n.a.

Note: * realized PT incl. / excl. deceased persons with dementia. ** living at home

Figure 3 Anticipated and realised perseverance time (expected path based on PT at t=0 shaded in grey)

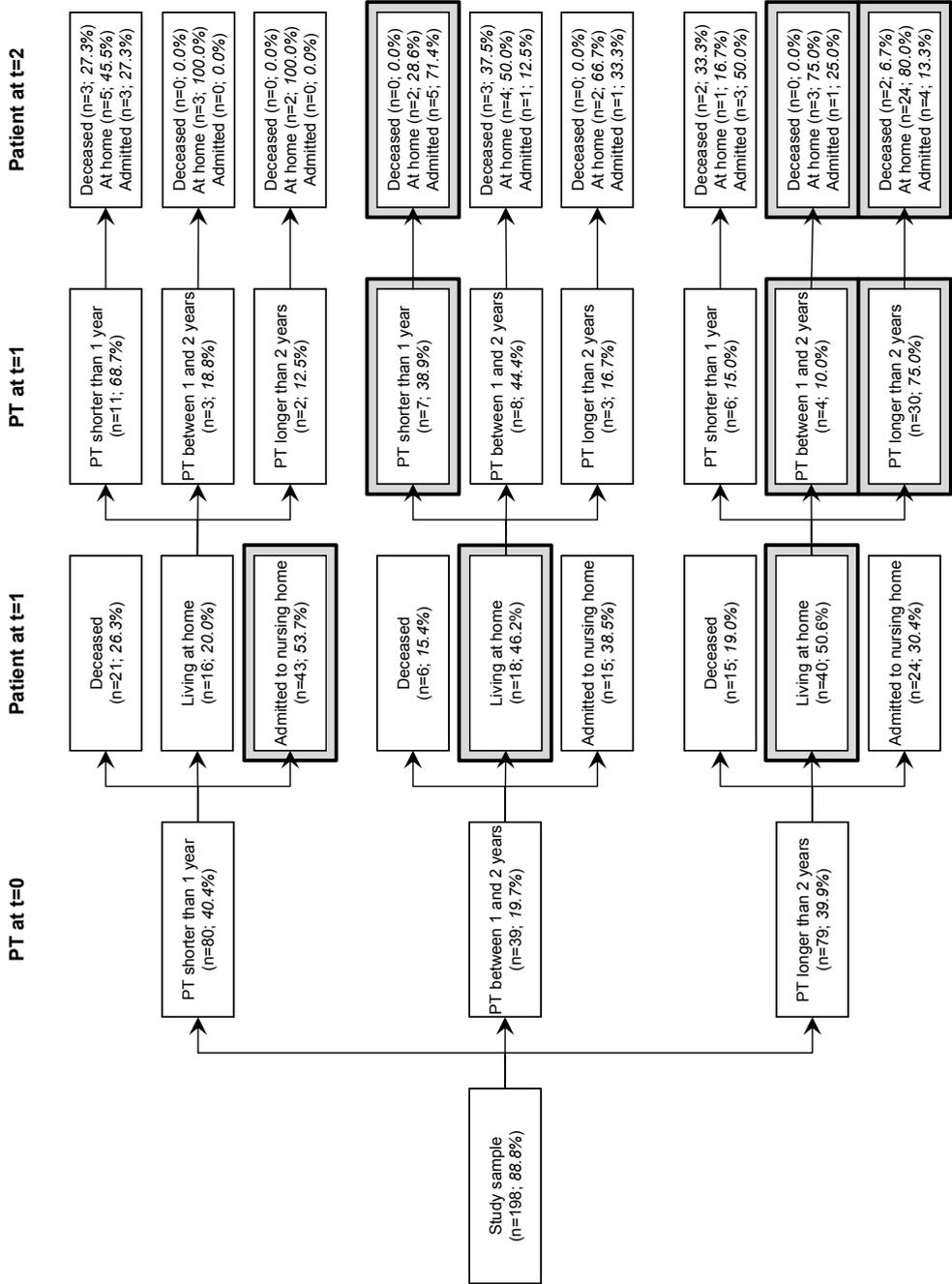


Table 4 shows associations between anticipated PT and characteristics of persons with dementia, their informal carers, and the caregiving situation at baseline. Carers for female persons with dementia, with a slightly higher health and lower care dependence more often indicated a PT of longer than 1 year. This was also the case among carers who were younger, male, employed, healthier and happier. Those providing care to their partner or co-residing with the person with dementia less often expected to cope for longer than a year, as did those with more intensive care tasks or who had abandoned their hobbies in order to provide care. In general, carers experiencing higher strain from their care task more often indicated a PT shorter than one year.

Table 4 Associations between anticipated and realized perseverance time at t=0 with characteristics of the care situation at t=0; mean or %

Characteristics		Anticipated PT			Realized PT >1 year		
		<1 year (n=80)	>1 year (n=118)	p	Yes (n=58)	No (n=60)	p
Persons with dementia							
Age	Years	82.0	80.9	n.s.	79.8	82.0	*
Gender	Female (%)	45.0	58.5	**	56.9	60.0	n.s.
Marital status	Single (%)	31.3	39.8	n.s.	34.5	45.0	n.s.
Lives alone	Yes (%)	28.7	35.6	n.s.	31.0	40.0	n.s.
Health status	VAS (0-10)	5.5	6.0	**	6.0	6.1	n.s.
Comorbidity	Yes (%)	81.2	76.3	n.s.	82.8	70.0	*
Needs constant supervision	Yes (%)	27.5	19.5	n.s.	12.1	26.7	**
Care dependence	VAS (0-10)	7.5	6.7	**	6.2	7.2	**
Informal carers							
Age	Years	68.8	65.1	**	67.3	62.9	*
Gender	Female (%)	75.0	61.9	**	58.6	65.0	n.s.
Marital status	Single (%)	18.8	15.3	n.s.	19.0	11.7	n.s.
Children at home	Yes (%)	6.2	11.9	n.s.	12.1	11.7	n.s.
Education level	High (%)	26.3	28.0	n.s.	27.6	28.3	n.s.
Employed	Yes (%)	22.5	33.1	*	24.1	41.7	**
Health status	VAS (0-10)	6.9	7.6	***	7.5	7.7	n.s.
Well-being	VAS (0-10)	5.9	6.7	***	6.7	6.7	n.s.
Relationship							
Relative with dementia is partner	Yes (%)	65.0	48.3	**	58.6	38.3	**
Relative with dementia is parent (in-law)	Yes (%)	28.7	43.2	**	34.5	51.7	**
Co-residents	Yes (%)	67.5	52.5	**	62.1	43.3	**

Characteristics		Anticipated PT			Realized PT >1 year		
		<1 year (n=80)	>1 year (n=118)	p	Yes (n=58)	No (n=60)	p
Objective burden							
Duration of care giving	Years	3.4	3.1	n.s.	4.8	4.0	n.s.
Intensity of care giving	Days per week	5.5	4.4	***	4.9	4.1	n.s.
	Hours per week	44.7	34.5	*	33.4	35.5	n.s.
Formal care at home	Yes (%)	73.8	73.7	n.s.	69.0	78.3	n.s.
Support by other informal carers	Yes (%)	55.0	54.2	n.s.	48.3	60.0	n.s.
Adjustments:							
- Adjusted working hours (if applicable ^a)		33.3	20.5	n.s.	0.0	32.0	**
- Reduced volunteer work (if applicable ^b)		38.9	41.9	n.s.	38.5	44.4	n.s.
- Abandoned hobbies (if applicable ^c)		56.5	31.3	***	29.2	33.3	n.s.
Subjective burden							
Caregiver Strain Index (CSI)		9.3	7.0	***	6.5	7.4	n.s.
Self-Rated Burden (SRB)		7.4	5.0	***	4.9	5.1	n.s.

Note: *p < 0.10; **p < 0.05; ***p < 0.01; n.s. = not significant. ^a number of respondents employed: n=18/39/14/25, respectively. ^b number of respondents doing volunteer work: n=18/31/13/18, respectively. ^c number of respondents with a hobby: n=69/99/48/51, respectively.

Regarding the realization of an anticipated PT > 1 year (n=118), carers more often anticipated their PT correctly in case they provided care to a relative with dementia who was younger, had comorbidity, did not need constant supervision or was less care dependent. Carers who were older, not employed, provided care to their partner or co-resided with the person with dementia also more often realized their PT > 1 year. In addition, carers who had adjusted their working hours in order to persevere in providing care less often realized their anticipated PT > 1 year.

DISCUSSION

This paper reported a longitudinal study of informal carers of persons with dementia, in which the focus was on describing the development of the care situation over a two year follow-up period and the anticipated and observed perseverance time of their informal carers. In our sample of 198 informal carers, only 74 were still living at home after 1 year and this dropped to 44 after two years. Directly asking informal carers about their expected perseverance time (PT) showed that informal carers who indicated a relatively short, limited PT (i.e. less than 1 year) in 80% of the cases predicted their PT correctly (or 53.7% excluding deceased persons with dementia). For those carers indicating a long PT, the predictive accuracy was less favourable.

Before highlighting some implications of our findings, a number of limitations of this study need to be noted. First of all, we used a relatively small sample (198 informal carers) from one region in the Netherlands. Although we have no reason to expect that this selection influenced our results, further investigation of perseverance time of carers in other and potentially larger samples, regions and countries remains important. Second, the drop out in the follow-up study was selective. Especially highly burdened carers dropped out, which may have influenced our findings. Investigating perseverance time in this group remains pivotal, since it can be expected that the chance of admission of persons with dementia in this group may be especially high. Third, we used only one patient group; persons with dementia. Given the nature of this disease, this has led to a specific sample (e.g. elderly patients, relatively old carers, deterioration of health in patients, etc.). Given demographic and epidemiological projections, as well as the demand of formal and informal care of persons with dementia, knowledge regarding (the carers of) this patient group is extremely relevant. Still, investigating perseverance time in other patient groups is important as well and the here presented results may not be generalizable to other diseases. Fourth, the measure of PT we used explicitly asks about perseverance time under the assumption that the caregiving situation remains 'as it is now'. This was done to avoid the influence of (unrealistic) projections of the future health of the person with dementia in the estimation of perseverance time and to have an indication of the current severity of the caregiving burden. However, it must be emphasised, that, certainly for diseases like dementia, with its progressive

nature, this assumption is very unlikely to hold. Hence, the indicated PT may be an overestimation of true perseverance time (e.g. if the person with dementia deteriorates over time and the increased care demands are not fully met by others) or an underestimation (e.g. if the support in caring increases more over time than the demand for care). One may expect indicated PT in contexts like dementia most often to be an overestimation of actual perseverance time, given the deterioration of persons' with dementia health over time.

Taking these limitations into consideration, we suggest future studies should try to generate more insight in the changes in caregiving situations between measurements, investigate PT at the time of admission of the person with dementia in relation to the main reason for admission, and add an open-ended follow-up question to the PT answering categories asking carers to provide a more precise estimate of their perseverance time.

Notwithstanding these limitations, our results have some important implications. First, informal carers expecting a relatively short, limited perseverance time often predict this fairly accurately. This means that if informal carers indicate that perseverance time is limited (i.e. less than a year), formal care could anticipate either by increasing formal support at home (to increase perseverance time) or by facilitating timely admission to a nursing home. For carers expecting a PT of longer than one or two years, the accuracy is lower. This may have to do with the fact that the caregiving situation did not remain stable and became more burdensome over time, thus reducing PT. Our results imply that, while persons with dementia of carers who indicate a PT of less than a year are indeed at considerable risk of being admitted within that timeframe, relatives of carers indicating a PT of more than a year may still be admitted relatively soon. In other words, a short PT appears to be a better predictor than a long PT. Further investigation of why some carers overestimate their PT (apart from deterioration of persons' with dementia health) remains important.

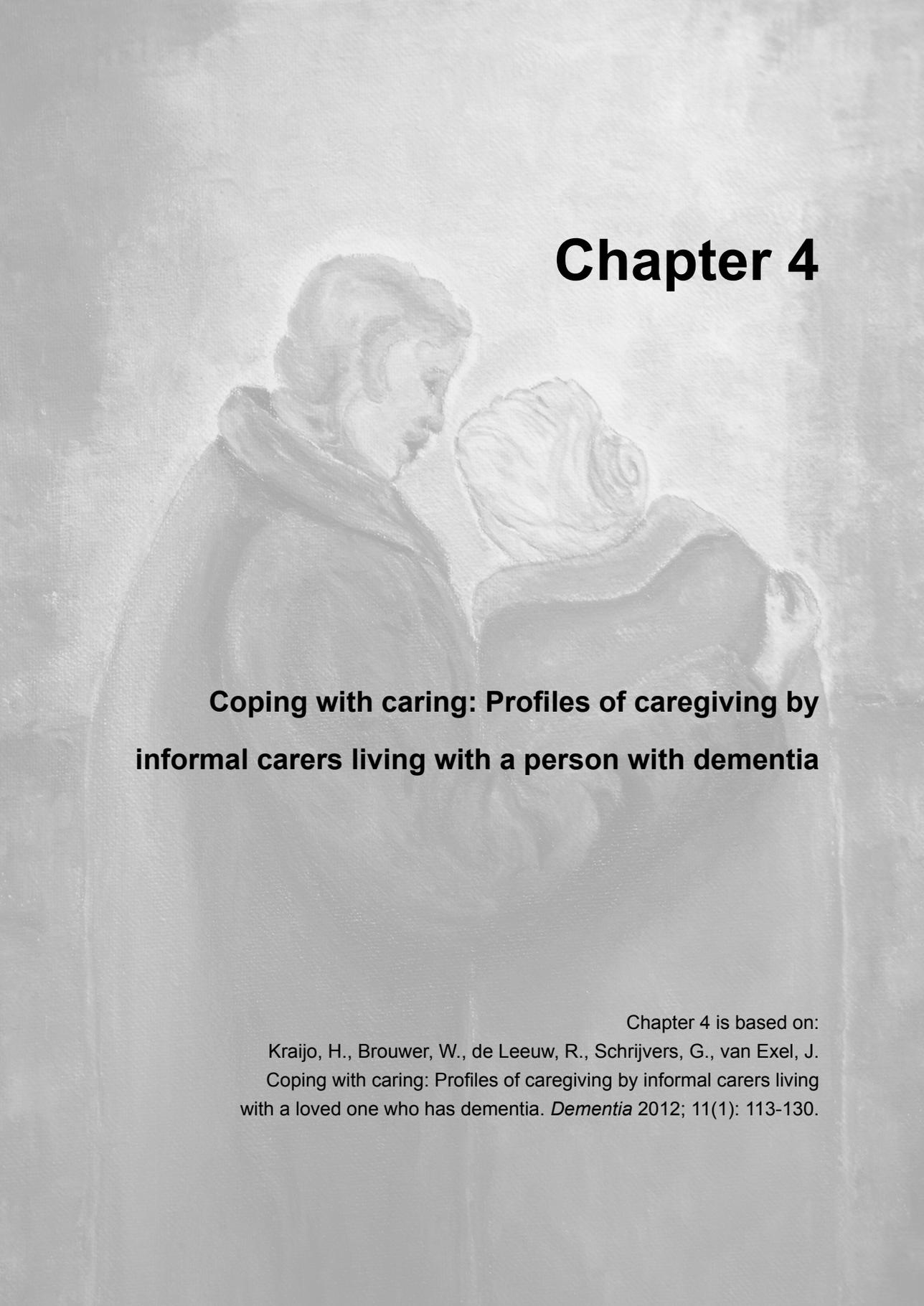
Previous longitudinal studies [Garity, 1997; Gaugler et al.,2000] documented how informal carers for persons with dementia adapt to their role. In our study, as Figure 3 also shows, a part of the informal carers adjusted their perseverance time upwards over time. Several indicated the same anticipated perseverance time at the different measurement moments. In some cases this may relate to an adaptation process of informal carers, which helps them to continue caring beyond points in time or levels of burden they (or practitioners) had a priori

expected to be possible [Pot et al., 2001; Timmermans et al., 2005]. Measuring Pt may help to quantify and gain more insight in adaptation processes.

Moreover, more research could be focused on the tension between caregiving (for a dementing relative) and participation in social activities and work, and on work productivity [Durme et al., 2012]. In this study informal carers indicated to have sacrificed unpaid or paid working hours and hobbies because of the informal caregiving situation. This may achieve a prolonged stay at home of the person with dementia. Policies facilitating such a trade-off, for instance through paid leaves of absence, may support informal carers to prolong or intensify caring activities. Such policy options should be further explored [Van den Berg et al., 2006; Koopmanschap et al., 2008].

CONCLUSION

Informal care is important in the context of diseases such as dementia. One of the key questions, also in light of the projected increase of persons with dementia and related demand for informal care, is how to predict and influence perseverance time of informal carers. Directly measuring PT proved possible and for carers indicating a short, limited PT appears to have clear predictive accuracy. PT may thus be helpful in monitoring need for support and planning the transition of care from home to nursing home. This should, however, be further investigated and confirmed in other samples and contexts. If confirmed, PT may be a useful instrument in research of informal care and may directly facilitate health care policy and planning by allowing timely support of carers and facilitating timely admissions of persons with dementia to a nursing home.

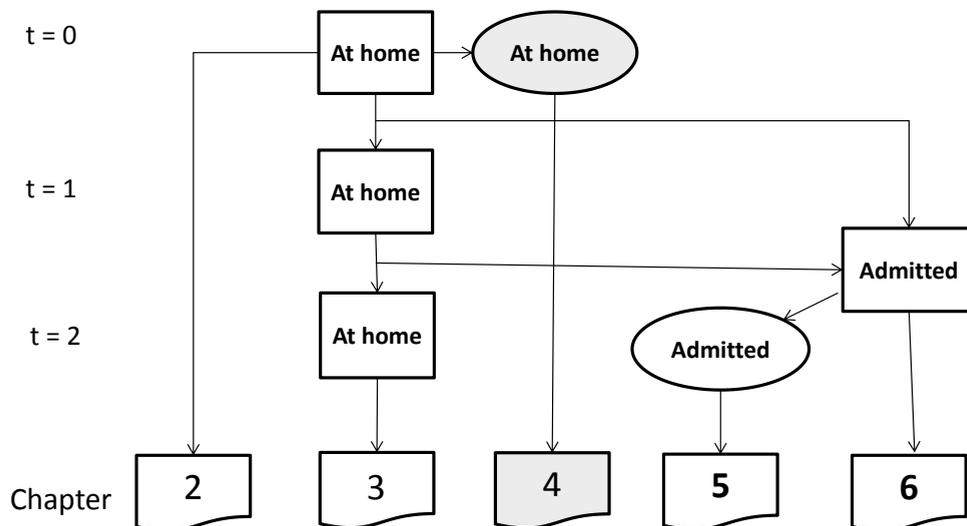


Chapter 4

Coping with caring: Profiles of caregiving by informal carers living with a person with dementia

Chapter 4 is based on:
Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., van Exel, J.
Coping with caring: Profiles of caregiving by informal carers living
with a loved one who has dementia. *Dementia* 2012; 11(1): 113-130.

Flow chart related to Chapter 4



Research question:

Can different profiles of caregiving be distinguished, and how do these relate to perseverance time?

ABSTRACT

Background and aim

While the number of persons with dementia in the Netherlands will double in the next 25 years, there are no plans to expand the capacity of residential care facilities for these persons. This will almost inevitably lead to an increase in the burden placed on informal carers. We investigated how informal carers living with a relative with dementia experience their caregiving situation.

Method

Fifty-three carers ranked a structured set of opinion statements covering a representative range of aspects of caregiving. By-person factor analysis was used to uncover patterns in the rankings of statements.

Results

Five distinct profiles of caregiving were identified that provide information on the various care situations that can occur, the needs and dilemmas that these carers face, and the subjective burden and perseverance time of the carers.

Conclusion

The findings contribute to the development of interventions for the support of informal carers.

INTRODUCTION

In line with projections in many other countries, the number of persons suffering from dementia in the Netherlands is expected to double during the next 25 to 40 years. It is estimated that the prevalence of persons with dementia of 65 years and older will increase from 1 in 93 to 1 in 44 inhabitants. In terms of the proportion of active against inactive persons in society, this implies an increase of 1 person with dementia per 63 working population to 1 per 27 population [De Lange & Poos, 2007; Ferri et al., 2005; Wancate et al., 2003; Wimo et al., 2003 and 2009].

At present in the Netherlands, two out of three persons with dementia live at home. These persons with dementia are largely cared for by informal carers. The informal carers all experience the burden of care differently – 22% see this as a light task, 58% as moderate and 20% as very demanding. Furthermore, 77% of informal carers find it difficult to cope with the behavioural changes of the dementing person they are caring for and approximately 50% feel themselves under a great deal of emotional stress due to this fact [Peeters et al., 2007].

In 2002, the Health Council of the Netherlands concluded that the supply and demand of facilities and services for persons with dementia in the Netherlands was not balanced. In order to answer the ever increasing needs regarding this issue, the Health Council advised the government to increase residential capacity by approximately 2% each year between 2001 and 2010. Without this expansion, it is estimated that the percentage of persons with dementia who will be able to get a place in a residential setting will decrease from 35% to 29% [Health Council of the Netherlands, 2002]. However, at the time, the government did not choose to expand capacity but to stimulate collaboration between care providers at regional level. This move was aimed at achieving improvements in care and services for persons with dementia and their informal carers in a non-residential setting.

Therefore, policy for the next few years in the Netherlands will encompass the stimulation of care in non-residential settings without extra resources for dementia care [Bussemaker, 2008]. Without any additional policy in this area, the tension between care supply and demand will certainly shift towards informal carers and their subjective burden of care will almost certainly increase considerably.

The purpose of this study is to investigate how informal carers experience their personal caregiving situation and which needs and dilemmas they face. For this purpose we use Q methodology. Because this is a fairly novel method in the field, the next section starts with an introduction of the method, followed by a more detailed description of how the current study was carried out.

The explorative study presented in this paper is part of a larger longitudinal study (2007-2010) into the perseverance time of informal carers living with someone with dementia and its most important determinants. The results from this larger study will help in the development of specific, demand-driven interventions aimed at supporting informal carers in their task.

METHOD

Research method

Q methodology combines elements of qualitative and quantitative research methods and provides a scientific base to study the perceptions, preferences and opinions of persons regarding a certain subject. This type of research is relatively new to the field of health care but has been widely used in other areas of policy research during the last 70 years [Stephenson, 1935; Brown, 1980]. The following studies in health care have been published recently: Tielen et al., 2008; Kreuger et al., 2008; Van Exel et al., 2007, 2006; Baker, 2006; Bryant et al., 2006; Risdon et al., 2003; Stenner et al., 2000.

In a Q methodological study, respondents are asked to rank a set of opinion statements. This method of ranking enables the respondents to give their opinion and attitude towards the subject being studied [Cross, 2005; Smith, 2001; Watts, 2005, Van Exel & de Graaf, 2005]. William Stephenson (1935), who was the founder of Q methodology, introduced the method as an inversion of conventional (by-item) factor analysis, in the sense that Q correlates persons instead of tests - correlation between individual rankings of statements then indicates similar viewpoints. Significant clusters of correlations can be identified through by-person factor analysis, described as common viewpoints, and individual respondents can be mapped to these viewpoints. Therefore, Q methodology is used to describe a population of viewpoints and not – as is the case in conventional factor analysis – a population of persons [Risdon et al., 2003]. Only a small research population

is needed because the aim is to reveal the commonly shared viewpoints and not the size of the population that subscribes to these viewpoints (Bryant et al., 2006; Risdon et al., 2003; Smith, 2001).

Our study was conducted in three steps described below.

Step 1: Collecting and selecting statements

The first step consisted of collecting a set of opinion statements that typically represented the situation of informal carers living with someone with dementia – this is known as the Q-set. In order to design the Q-set, informal carers were asked in a series of five panel interviews about how they experience their own care situation, including which problem areas and dilemmas they have to face. These interviews were conducted by using fourteen problem areas⁴ which carers of persons with dementia may encounter over time and as defined by the Dutch National Dementia Programme [Landelijk Dementie Programma (LDP); Peeters, van Beek & Francke, 2007]. The stories that the participants told the panel were an important component for the design of the Q-set. As well as this reference material, an earlier Q methodological study on the attitudes of informal carers regarding respite care [Van Exel et al., 2007] was examined as well as the questionnaire “Problems and wishes of informal carers of persons with dementia” (freely translated from the Dutch) [Van der Poel & van Beek, 2006].

From these sources, two authors [Kraijo & Van Exel] collected and structured opinion statements that related to the most important themes surrounding informal care for persons with dementia (see table 1) – this was done by using an iterative process. Subsequently, a representative set of statements was selected. The final Q-set consisted of 36 statements from informal carers living with someone with dementia. These 36 statements were then numbered randomly and printed onto cards that fitted into the slots on the response sheet (see figure 1). The Q-set was tested by five informal carers and then approved as the definitive version without any further changes being made.

⁴ The fourteen problem areas are: the feeling that something isn't right; what exactly is going on and what may help; afraid, angry and confused; totally alone in the situation; avoiding contact; physical care; danger; carer also has health problems; loss; it's all too much; giving up and losing control; through good and bad times; bad communication with health professionals & resistance to admission [Peeters, van Beek & Francke, 2007].

Table 1 The statements according to theme

Statement	Nr
Motivation for providing informal care	
• I feel as if it is my duty to care for him/her.	19
• Taking care of him/her gives me a good feeling.	24
• I would feel guilty if I had to hand over his/her care to someone else.	32
• I would feel ashamed if I had to hand over his/her care to someone else.	8
Problem areas for the informal carer (burden/strain, strength)	
<i>Physical/mental</i>	
• Caring for him/her is physically demanding.	33
• Caring for him/her is emotionally demanding.	17
• I can cope well with his/her care.	7
• I am worried that unsafe situations may occur around the house as a result of his/her behaviour.	5
<i>Practical/financial</i>	
• We are not very well off financially because I am the carer.	34
• It is difficult to set your own boundaries and stand up for yourself.	1
• I can deal well with his/her behavioural changes that have resulted from the dementia.	31
<i>Relational/social</i>	
• Because I have to take care of him/her, I have less time for other activities.	28
• I have less contact with other persons because of his/her dementia.	30
• I avoid contact with other persons because of his/her dementia.	10
• I feel lonely.	4
Support experienced by carers (other carers, family, social environment, organisations; information, availability, access)	
<i>Informal</i>	
• My social environment understands well what it means to be able to care for him/her.	6
• My social environment leaves the task of caring for him/her up to me.	14
• If I need help then I can always ask someone in my social environment.	16
<i>Formal</i>	
• Healthcare professionals do not involve me when they make decisions about his/her care.	26
• The healthcare professionals take my concern for him/her seriously.	27
• It is clear to me how the care for persons with dementia is organized.	9
• The healthcare professionals do have time for me.	18
• If I have a question about his/her care, then I know where to go.	35

Statement	Nr
Inclination towards and obstacles felt in asking for support in the care	
• He/she wants preferably for me to provide the care.	2
• I want to keep control over his/her care situation.	11
• I don't have any problem asking for help if I think that I need it.	13
• I am apprehensive about him/her being admitted to residential care.	29
• I would like to hand over his/her care to someone else.	25
Need for support/respite care (social environment and institutions; social, emotional, practical)	
• I appreciate it when someone asks me how I am myself.	12
• I appreciate it when someone asks me if I can carry on caring for him/her like this.	20
• I would like to have a regular respite break each week when I can get away and do something else.	36
• I would like to have a holiday.	21
• I would like a permanent contact person who I can ask for advice if necessary.	22
• I would like to have a focal liaison point e.g. a professional who can help me organise all kinds of practical things involved in the care process.	3
• I would like to be better prepared for what is going to happen in the future so that I will know how to react to situations.	15
• I would like to know for certain that there would be a place in residential care should it be needed in the future if caring for him/her at home is no longer possible.	23

Figure 1 Response sheet

LEAST AGREE	←-----→							MOST AGREE
1	2	3	4	5	6	7	8	9

Step 2: The implementation of the study

The informal carers who participated in this study were recruited from the database of 223 carers living at home with a relative with dementia and who were taking part in the previously mentioned longitudinal study into perseverance time. Out of the 223 informal carers, 124 (56%) were living in the same house as the person with dementia. From these 124 carers, 53 (43%) agreed to take part in our study. Participants and non-participants did not differ in terms of age, health status and the principal variables of concern for this study - subjective burden of caring and perseverance time. Female informal carers more often agreed to participate than male informal carers, as did higher educated carers as compared to lower educated informal carers ($p < .01$).

The interviews were conducted in the homes of the carers by the first author of this paper. After first sorting the statements into three categories (agree, neutral, disagree) the informal carers then ranked the statements according to a scale of agree the least to agree the most using the response sheet provided (see figure 1). Any comments given by the informal carers during and following the sorting of the statements were carefully noted down. Regarding the two statements at either end of the scale – those representing the very least or the very most in agreement – the participants were asked to describe their motivation clearly. This material was then used later to help in the interpretation of the results and also used as quotes in the description of the profiles (*in italics* in the results section).

Step 3: The Q analysis

The individual rankings of statement were subsequently analysed using by-person factor analysis, with the aim of identifying a number of corresponding ways in which the informal carers ranked the statements⁵. For the resulting factors (i.e. profiles of caregiving) a weighted average ranking of the statements was compiled based on the rankings of the carers associated with the factor and the corresponding correlation coefficients as weights. These compiled rankings of statements, representing how an informal carer with a correlation coefficient of 1 with a factor would have ranked the statements, were used to describe the profiles concerned according to characteristic and distinguishing statements.

⁵ The dedicated software can be downloaded at www.lrz-muenchen.de/~schmolck/qmethod.

A statement is considered characteristic for a profile whenever it scores a -4, -3, + 3, + 4 in the compiled ranking. A statement is considered distinguishing whenever the score of the statement statistically significantly differs from those in the other profiles ($p < .01$). The compiled rankings for each profile are given in table 3. Together with the explanations from informal carers to their ranking of the statements, these form the base for the description of the profiles.

Additional data

The interviews for this study were conducted at the time of inclusion of the respondent in the longitudinal study into perseverance time of informal carers for a relative with dementia. As part of the longitudinal study, respondents completed an extensive questionnaire concerning their care situation. Here we use selected data from this questionnaire concerning characteristics of the informal carers, their relative with dementia and the care situation.

Regarding the care situation, the questionnaire included questions about subjective carer burden and perseverance time. Burden was assessed using two measures, the Self-Rated Burden (SRB) scale [Van Exel et al., 2004] and the Caregiver Strain Index [Robinson, 1983]. The SRB is a visual analogue scale ranging between 0 ('not at all straining') and 100 ('much too straining') on which carers were asked to indicate the overall subjective burden of caregiving. The CSI comprises 13 items referring to the stressors in caring, each completed yes/no, with the yes answers summed to give an overall strain score. Perseverance time was measured using the following question: "*If the informal care situation stays as it is now, how long will you be able to cope with the care?*" (answer options: less than six months; more than six months but less than one year; more than one year but less than two years; more than two years).

RESULTS

Fifty-three informal carers living with a relative with dementia participated in this study. The characteristics of these carers, their relative with dementia and, the care situation are set out in table 2.

The analysis of the individual rankings resulted in a five factor solution. In other words, five profiles of caregiving by living with a relative with dementia

could be differentiated regarding their perception towards their individual care situation. Together, the five profiles account for 50% of the variance in the 53 individual rankings of statements. The profiles are presented in sequential order of increasing subjective burden as indicated by the carers associated with each profile. In the description of the profiles, the numbers of the statements are given between parenthesis (see table 3) and the quotes from the carers concerned are given in italics.

Table 2 Sample characteristics (n = 53)

Characteristics		%	Mean (SD)
<i>The informal carer</i>			
Gender	Female	50.0	
Age	Years		74.4 (8.4)
Educational level	Low	19.2	
	Middle	42.3	
	High	38.5	
Health status	VAS (0-10)		6.9 (1.6)
Well-being	VAS (0-10)		5.9 (1.8)
<i>The person with dementia</i>			
Gender	Female	48.1	
Age	Years		78.8 (7.7)
Health status	VAS (0-10)		5.7 (2.0)
Comorbidity		78.8	
Degree of comorbidity	Slight	19.5	
	Medium	46.3	
	Severe	34.1	
Care dependence	VAS (0-10)		7.7 (2.1)
<i>Relationship</i>			
	Partner	94.2	
<i>Objective burden</i>			
Care by main informal carer	Hours per week		56.6 (42.0)
Care by other informal carers		36.7	
Professional care at home		88.2	
Supervision	Continuous supervision required	17.3	
	Can only be alone for a maximum of 1 hour	38.5	
	Can be alone for a couple of hours	44.2	

Characteristics		%	Mean (SD)
Subjective burden			
Self-Rated Burden (SRB)	VAS (0-10)		5.7 (2.2)
Caregiver Strain Index (CSI)	Score (0-13)		8.8 (2.5)
Perseverance time			
	< 6 months	12.2	
	> 6 months < one year	16.3	
	> 1 year < 2 years	18.4	
	> 2 years	53.1	
	Months		21.1(10.5)

Profile 1

These informal carers are able to cope well, both physically and emotionally with their task (7, 17, and 33). *'The care required is still fairly limited and can be carried out without too much difficulty'*. They are able to cope with the behavioural changes of the relative with dementia (31), are not afraid of unsafe situations occurring (5) and do not avoid contact with others as a direct result of their relative's dementia (10). These informal carers have the least need for a regular respite break in which they can get away from the care situation (36). In addition, these carers do not want to hand the care over to someone else (25). *'If she will suffer from that, then so will I.'* Whilst in one way they see it as their duty to care for their relative with dementia (19) and are apprehensive about them being admitted to residential care (29), they also admit to thinking that their relative wants and prefers to be cared for by them (2). Moreover, these informal carers (more than those in the other profiles) do get satisfaction i.e. feel good about caring for their relative with dementia (24). They appear to know their way around the world of care well (35) and need to be reassured that a place in residential care would be available for their relative should it be needed in the future if care at home is no longer possible (23). *'If I think about the future, then I get a kind of panicky feeling, so knowing that residential care is a possibility reassures me again'*. As far as the future is concerned, these informal carers want to remain in control of the care given (11). Informal carers with this profile are able to cope well with the care they are giving.

Profile 2

This group of informal carers can cope reasonably well with the care (7). However, they also indicate clearly that they need support (3, 22) and reassurance that things will be OK in the future. For example, they would like to have a focal liaison point for advice and a health professional who can organise all kinds of practical things that are involved with the care process (3). The need for support stems from the informal carer's wish to remain in control of the care for their relative (11, 25). *'Being so close to my partner means that I know a lot about him, especially his emotional side and that's why I want to decide when, where and what is going to happen'*. Whilst informal carers in this group do not feel that healthcare professionals pay them enough attention, they do want to be able to ask advice on how to deal better with the behavioural changes that result from the dementia (22, 31, and 5). They also indicate that they would like to have regular (monthly) respite breaks in order to rebuild their energy levels (36). *'Just a day and night once or twice a month would be nice - to be able to visit the grandchildren'*. They want to carry on caring for their relative as long as possible and see this as their duty (19). They are apprehensive about an admission to residential care (29). *'It would be difficult for me to live my own life again. I think I would walk around feeling sorry for myself'*. However, they do want to have reassurance regarding an available place in residential care should the time come that the person can no longer be cared for at home (23). With this group, fortunately that time has not yet arrived. Caring for the relative is not physically demanding (33) and there is no fear of unsafe situations occurring (5).

An informal carer with this profile wants support in order to carry on giving the care but at the same time wants to keep control over the situation.

Table 3 Compilation of scores per profile

Statements	Profile				
	1	2	3	4	5
1 Sometimes it is difficult to set your own boundaries and stand up for yourself.	-2	-1	+1	+1	-1
2 He/she wants preferably for me to provide the care.	+2	0	+2	0	+1
3 I would like to have a focal liaison point e.g. a professional who can help me to organise all kinds of practical things involved in the care process.	-2	+4**	-2	-2	+1**
4 I feel lonely.	-2	-3	-4	0*	-2
5 I am worried that unsafe situations may occur around the house as a result of his/her behaviour.	-3	-2	-4	-1	0**
6 My social environment understands well what it means to care for him/her.	+1	+2	+4**	-3**	-2**
7 I can cope well with his/her care.	+4**	+1*	-1	0	-3**
8 I would feel ashamed if I had to hand over his/her care to someone else.	+1	-1	-1	+1	-3**
9 It is clear to me how the care for persons with dementia is organized.	-1	-1	-1	0	-1
10 I avoid contact with other persons because of his/her dementia.	-3	-2	-3	-4	-2
11 I want to keep control over his/her care situation.	+3	+2	+2	+2	-1**
12 I appreciate it when someone asks me how I am myself.	+1	0	+1	+1	+2
13 I don't have any problem asking for help if I think that I need it.	+1	0	+2	-2**	+2
14 My social environment leaves the task of caring for him/her up to me.	0	0	-2**	+2**	-1
15 I would like to be better prepared for what is going to happen in the future so that I will know how to react to situations.	-1	0	-1	-1	0
16 If I need help then I can always ask someone in my social environment.	0	+1	+3**	-3**	0
17 Caring for him/her is emotionally demanding.	+4**	0**	+2*	+3	+4
18 The healthcare professionals do have time for me.	+1	-1*	0	+1	+1
19 I feel as if it is my duty to care for him/her.	+3	+3	+3	+3	+3
20 I appreciate it when someone asks me if I can carry on caring for him/her like this.	0	-1	+3	+1	+1
21 I would like to have a holiday.	-1	-2	-2	-1	+1**
22 I would like a permanent contact person who I can ask for advice if necessary.	-1	+3**	-1	-1	+1**

Statements	Profile				
	1	2	3	4	5
23 I would like to know for certain that there would be a place in residential care should it be needed in the future if caring for him/her at home is no longer possible.	+2	+2	0	-1	+4**
24 Taking care of him/her gives me a good feeling.	+2	+1	+1	+1	-2**
25 I would like to hand over his/her care to someone else.	-2	-4	-3	-4	-1**
26 Healthcare professionals do not involve me when they make decisions about his/her care.	0	+1	0	-2*	0
27 The healthcare professionals take my concern for him/her seriously.	+2	+1	0	0	+2
28 Because I have to take care of him/her, I have less time for other activities.	-1	-2	+1**	+4	+3
29 I am apprehensive about him/her being admitted to residential care.	+3	+4	+4	+4	0**
30 I have less contact with other persons because of his/her dementia.	-1	-1	-3**	+3**	0
31 I can deal with his/her behavioural changes that have resulted from the dementia.	+1*	-3	0*	-3	-3
32 I would feel guilty if I had to hand over his/her care to someone else.	0	+2	-1	+2	-4**
33 Caring for him/her is physically demanding.	-4*	-3*	+1**	-1	-1
34 We are not very well off financially because I am the carer.	-3	-4	-2	-2	-4
35 If I have a question about his/her care, then I know where to go.	+4**	+1	0	0	+3
36 I need to have a regular respite break each week when I can get away and do something else.	0*	+3	+1	+2	+2

Note: Distinguishing statements are marked as follows *p<.05; **p<.01.

Profile 3

These informal carers find their task physically demanding (33). *'Sometimes I'm on the go 24 hours a day'*. In spite of this, it is the emotional demand that weighs the most (17). *'Seeing my husband's sadness and the helplessness that seems to pour out of him – and the fact that I can't help him at all'*. They sometimes find it difficult to set boundaries and make room for their own activities (28). Family and friends understand perfectly well what it is to be a carer for someone who is suffering from dementia (6). In this profile, more than other informal carers, these persons do perceive the support they get from their social environment (6, 16). *'Everyone asks how he is and they also understand my situation'*. Out of all the informal carers, these persons have the least feeling of being on their own (14). Informal carers in this situation do not find it difficult to ask family and friends for help (13). *'If it's really necessary I can always ask my neighbours or one of the children for help'*. Therefore they do not feel isolated (4). They have good and supportive contacts in their own social environment (10, 30). *'I am not ashamed of the situation and take him everywhere with me'*. However, in spite of the support from their environment, these informal carers do not want to hand over the care to anyone else (25). *'If I did that I would feel as though I was leaving him in the lurch'*. They experience fulfilling their task for as long as possible as a duty (19). They are apprehensive about an admission to residential care (29) because of the negative image that this carries. They want to save their relative from admission if at all possible. *'I wouldn't want that to happen to him. I think that he would deteriorate even further if he was admitted to a care home'*. Moreover, they are apprehensive about an admission because their relative prefers to be taken care of by them (2) and because they would be missed so much if they were not the one giving the care.

An informal carer with this profile experiences the task of providing care as quite demanding but has a lot of support from his/her environment.

Profile 4

In this profile, the persons in the direct social environment of the carers do not understand very much about the situation (6). *'Nobody understands properly because they only see him for a few hours at a time'*. This is why informal carers in this profile can only expect a little help and support from their family and friends (16). Whilst they do not avoid making contact with others themselves (10), there

is less contact with others (30) as a direct result of the dementia. *'We have a lot less contact with other persons due to the advanced incontinence'*. All of the above leaves these informal carers with the feeling that they cannot depend on persons in their social environment when they need support themselves (13, 16). These informal carers find the task of caring for someone with dementia very demanding (17) indeed. *'Together with my wife, I cry a lot about the situation that has arisen and all the grief and sadness that goes with it'*. They find it very difficult to cope with the behavioural changes that have resulted from the dementia (31). These carers feel as if the burden of care has been left to them alone by persons in their environment much more than the informal carers in other profiles (14). *'Because he can't join in with social activities anymore and is not much fun to be with, nobody wants to do anything with him'*. Therefore, with these informal carers, loneliness comes to the foreground the most (4). Moreover, due to the time pressure of providing the care itself, these informal carers have less time to focus on other activities (28). They do not readily ask for help from professional organisations because they have experienced a lack of being consulted on care decisions for their relative in the past (13). They would welcome a regular respite break in their care task each week (36). In spite of the seriousness of the situation and the sense of duty to take care of their dementing relative, these informal carers still don't want to hand over the care to someone else (25). *'When you have shared everything together for 58 years, I just see it as my duty to take care of her'*. They are even apprehensive about a future admission to residential care (29) *'I know he would be very unhappy there. He is dreading that himself'*.

An informal carer with this profile experiences the task of caregiving as very demanding and does not receive much support from family and friends.

Profile 5

Informal carers in this profile are actually barely able to keep up their task of providing their relative with care (7). *'I am extremely tired and hardly ever have any time for myself'*. They find it very difficult to cope with the behavioural changes that have resulted from the dementia (31). *'The person you loved so much is not there anymore and the person who is there - well you just feel sorry for them and take care of them'*. Of all the informal carers, these are the ones who worry the most about unsafe situations occurring (5). *'I have to keep an eye on him all*

the time'. They experience caring for the person with dementia as emotionally demanding (17). *'Slowly and surely you start to suffer yourself'*. Caring for your relative no longer gives you any satisfaction (24) *'I see caring for him as my duty but it produces feelings of frustration rather than any good feelings'*. They find it regrettable that family and friends do not seem to appreciate just what being an informal carer entails (6). The uncertainty, doubt and strain are expressed in a need for support in many areas, including a focal point for advice and regulatory matters (3, 22). *'The care itself is heavy enough'*. In addition, whilst there is a real desire for a short break or holiday, it actually is essential in order for the informal carer to carry on with the care task. However, in spite of everything these informal carers still see it as their duty to carry on with the care (19). *'That's the promise you make when you marry'*. Of all informal carers, these are the persons who want to keep control of the care task the least (11) and who are also the least apprehensive about admission of their relative to a residential care setting (29). *'I think that now, after all these years it will be a relief for me when I can live my own life again without my partner'*. These informal carers have already reached the stage where they would no longer be ashamed or feel guilty if they had to hand over care to someone else (8, 32). These informal carers have an express need for a guarantee that, should they need it there would be a place available for their relative in residential care (23). *'I need a lot of reassurance that he will be temporarily admitted to residential care if there comes a time that I can't cope any more – but nobody gives me that reassurance'*. However, this certainly doesn't mean that they are looking forward to their relative being placed in a care home. *'That would mean the end of our marriage. I would have to totally rethink my whole life – everything I do. I suppose you could say that admission is the same as death in many ways'*.

An informal carer with this profile is overtaxed and can barely cope with providing the care for their dementing relative that is required.

Similarities between the profiles

A number of striking similarities between the five profiles have been observed. Whilst informal carers consider caring for their relative with dementia as their duty (19) most of them also say it makes them feel good (24). The majority of informal carers want to keep control of the care their relative receives as much as possible (11) and are apprehensive about admission of the person to

residential care (29). In spite of this, in general the need for respite care scores relatively high (36). Contrary to what is often thought about informal carers of persons with dementia, they do not avoid contact with their social environment (10). Financial aspects hardly play a role in the whole scenario (34).

In general, the need for reassurance felt by informal carers is that there must be a safety net in place if a time comes when it will be needed (23).

Profiles and background characteristics

The number of informal carers who took part in this study is insufficient for giving any indication of the prevalence of the profiles among carers living with a relative with dementia or for generalising the associations between profiles and background characteristics of the care situation. A number of striking relationships between the profiles and data of the informal carers (see table 2) are given here as hypotheses for further study.

It is clear that there is a strong positive association between the profiles and the caregiver burden as measured with the SRB ($r_s = 0.601$; $p < 0.01$) or the CSI ($r_s = 0.527$; $p < 0.01$) scale and the perseverance time ($r_s = -0.410$; $p < 0.05$) as indicated by the informal carers. The informal carers in profile 1, for example, indicated a lower burden (3.2 on SRB; 5.4 on CSI) and a longer perseverance time (27.6 months) than those in profile 5 who clearly reported a higher burden (7.3 on SRB and 10.2 on CSI) and a shorter perseverance time (14.6 months).

A short summary has been made for each profile outlining the principal characteristic and distinguishing characteristics - please see figure 2 below. These summaries will be used in further research to study how often the profiles occur in a larger sample of informal carers and the relationship between the profiles and the characteristics of informal carers, persons with dementia and the care situation itself.

Figure 2 Summary of the profiles and scores for measuring prevalence.

Profile 1. I can cope well with caring for my relative, both physically and emotionally. I can also deal well with the behavioural changes that have resulted from the dementia. I don't feel the need to get away from things at present. If I did have a question about the care, I would know where to go.

Not at all Not really A little bit Well Very well

Profile 2. I can cope reasonably well with the caregiving. I don't find the caregiving physically demanding, and I can manage the situation reasonably well emotionally. While the health care professionals don't have a lot of time for me, I really do need someone who can give me advice and organize practical things for me. I want to continue to provide care for as long as I can, and that's why I need reassurance about certain things – for example, that it's possible to get away from the situation now and again.

Not at all Not really A little bit Well Very well

Profile 3. I find the caregiving physically, and especially emotionally, demanding. Luckily, if I need help, I can always ask one of my family or friends. They really understand what it means to take care of him/her, and they help and support me whenever necessary. Thanks to their support, I'm also able to do my own things.

Not at all Not really A little bit Well Very well

Profile 4. I find the caregiving emotionally demanding. I have much less contact with my family and friends due to my relative's dementia. I often have the feeling that it's all my responsibility. Those around me don't really understand what it means to be a carer in this situation, and they're all too happy to leave everything to me. That's why I find it hard to ask for help when I actually really need it. The health care professionals don't take me seriously, either.

Not at all Not really A little bit Well Very well

Profile 5. I can't really cope with the care anymore. I don't feel good about the situation anymore, and I sometimes worry that unsafe situations might arise. I wouldn't be ashamed or feel guilty if I had to hand over the care to someone else. Although I'm not really looking forward to an admission to residential care, I do need to know for certain that there will be a place available if I can't cope at home anymore. I would really welcome the chance to have a break so I can recharge my batteries.

Not at all Not really A little bit Well Very well

DISCUSSION

This study produced five distinctive profiles relating to informal carers living with a person with dementia. A short summary ordered by registered subjective burden would be as follows: informal carers who cope well with providing care; informal carers who would like to receive help in providing the care but who want to remain in control of the care process; informal carers who find it quite demanding to keep up the level of care needed but who do receive a lot of help and support from their family and friends; informal carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends; informal carers who can hardly cope with providing the care for their relative with dementia that is required.

The profiles show that informal carers experience a number of dilemmas in their task of caring for a relative with dementia. Therefore, some attention will be paid to these dilemmas and their implications in this discussion section.

From the interviews, it became clear that informal carers want to retain control of the care process for their relative for as long as possible and that they really do not want to hand over the care to others. However, they also indicated an express need for reassurance that there would be a place available in residential care should the need arise – read here that the person can no longer be cared for at home. This dilemma is kept alive by the fact that whilst persons realise only too well that handing over the care will be unavoidable at some point, they also know that they want to put this moment off for as long as possible [Van Exel, de Ruiter & Brouwer, 2008].

Moreover, informal carers indicate that their relative with dementia only wants to be cared for by them and sometimes by them alone. For this reason, the informal carers want to carry on with their task – after all, they have promised, in sickness and in health to look after each other until death. However, there comes a moment when they want to share the care with someone else. This is not always a truly sincere thought but has to do with self-protection and the ability to carry on caregiving for longer. Reaching a decision to hand over care is often accompanied by feelings of guilt and shame. However, this is not always the case as sometimes persons just resign themselves to the fact that they can have no control over how the disease progresses and that they will not always be able to care for their relative themselves.

Throughout the whole disease process, informal carers seem to wrestle with a varying complexity of feelings – resistance, anger, sadness, powerlessness, acceptance, acquiescence etc. – that have to do with the unavoidable but gradual phases of realisation that they have to say goodbye to their relative. Changes in personality, admission to residential care and death are recognisable breaking points in these personal relationships. Uncertainty, unavoidability and losing control over the situation are all things which take over the informal carer's life.

The balance between caregiver strain and caregiver strength is characterised by the degree to which persons experience satisfaction when providing informal care. Caring for your life partner can be a very satisfying experience and can be the incentive needed to continue with providing informal care. But, that incentive can be severely damaged when changes in personality/character occur. Feelings of estrangement then take over. The very demanding emotional situation which, on the one side is the commitment to the relative and on the other side, the separation that is taking place due to the dementia, starts a phase in which special attention and support for the informal carer is needed.

Informal carers do not avoid contact with their environment as a result of their relative's dementia. However, when behavioural changes and incontinence become a reality, then it becomes more and more difficult for persons to maintain contact with their social environment. This is also a sign that priority should be given to an offer of respite care to the informal carer.

At this point, attention, understanding and empathy for the informal carers by persons in their social environment are important and function as support for the informal carers. If there is no understanding from the person's social environment, including direct family members, then it may be necessary to focus more on helping family and friends to understand the situation better.

One of the images that comes to the foreground from earlier typing of dilemmas is that of the carer who needs but does not ask for support or at least not without difficulty [Van Exel, de Graaf & Brouwer, 2007]. However, this dilemma is not recognised when healthcare professionals work on a demand-driven basis. What happens then is the omission of early signalling and offers of support. For these carers, a mild form of assertive outreach in the care offers them a chance of temporary support – which is just what they need in order to carry on with their task longer. A trusted representative who can offer professional advice to informal carers regarding dementia and who can support them in organising all

kinds of practical things involved in the care is a possible answer to this problem.

Although the number of respondents included in this study is sufficient for the purposes of Q methodology and no substantial selection bias was found between participants and non-participants from the larger longitudinal study, some concerns regarding the population of study need mentioning. A common feature of research among informal carers is that carers who experience very low or very high burden are under-represented. Those with very low burden often do not identify or report themselves as informal carers and therefore are difficult to trace, while those who are very strained by their care situation are not able or less willing to participate in any type of research. It is difficult to say whether the omission of these respondents has influenced our results – the profiles seem to represent care situations varying from no strain at the one end to substantial strain on the other, perhaps with the exception of more extreme, crisis situations that may occur in the last phase before admission of the person with dementia to a residential setting. Considering that the wider purpose of our project is to inform the development of interventions to support carers in their task, this issue appears to be of limited concern. In any case, the data that will be gathered during the follow-up study will inform about the prevalence of the profiles in a wider population of carers for a relative with dementia and thus also reveal whether specific groups are ill-represented by these profiles. Because the follow-up study is longitudinal, we will also be able to investigate whether informal carers move between profiles over time and how this relates to the progression of their relative's dementia.

In addition, this study has been conducted among carers living in the same house as the person with dementia. The Q-set was developed on the basis of opinion statements from carers regardless of the physical distance that separates them from the dementing person. Further research should show whether the profiles described in this paper also apply to carers who are not living in the same house as the person with dementia.

The profiles were presented in sequential order of subjective caregiver burden. We found that the profiles were also associated with the perseverance time as indicated by the informal carers. This provides a first indication of the relevance of the concept of perseverance time as an indicator of how informal carers cope with their caregiving situation and the type of support they need to be able to

carry on. The profiles are therefore considered an important starting point for a longitudinal follow-up study investigating the perseverance time of carers and its determinants, in which the prevalence of the profiles will also be identified (see summary of the profiles in figure 2).

CONCLUSION

The results of this study will contribute to the development of more specific, demand-driven interventions for the support of informal carers living with a relative with dementia.

APPENDIX TO CHAPTER 4

Profiles of caregiving in longitudinal perspective

INTRODUCTION AND AIM

In chapter 4 we described five profiles of caregiving by informal carers living at home with their dementing relative, mostly their partner: (profile 1) carers who cope well with providing care, (profile 2) carers who would like to receive help with providing care, but who want to remain in control of the care process, (profile 3) carers who find it quite demanding to maintain the level of care needed, but who get a lot of help and support from their family and friends, (profile 4) carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends, and (profile 5) carers who can barely cope with providing the care required by their relative with dementia. In this appendix we explore the adherence of informal carers from the longitudinal cohort study discussed in Chapter 3 to these five caregiving profiles, as well as the associations of adherence to these profiles with several characteristics of the caregiving situation. We investigated if it is feasible for informal carers to typify their care situation using the profiles, and we wondered if the profile-scores are associated with perseverance time in a longitudinal perspective.

METHODS

The sample of the longitudinal cohort study consisted of 74 informal carers at $t=1$ and 44 informal carers at $t=2$. Details of the sample and drop-out during the year follow-up period were presented in Chapter 3, table 1.

Adherence to the five profiles of caregiving was measured using the questionnaire presented in Figure 1 in Chapter 4. Respondents were presented with abbreviated descriptions of the five profiles of caregiving discussed in Chapter 4, in a fixed order, increasing in subjective burden of the caregiving situation but varying in other aspects (e.g., receiving support). Informal carers used 5-point Likert-type scales to indicate how well each profile described their own caregiving situation. This question was included in the written questionnaire used in the longitudinal cohort study and was administered at $t=1$ and $t=2$. Changes in adherence over the one year follow-up period were computed by subtracting adherence at $t=1$ from adherence at $t=2$. These scores were categorized into three categories: 'lower' (if score ($t=2$) < score ($t=1$)), 'same' (if score ($t=2$) = score ($t=1$)) and 'higher' (if score ($t=2$) > score ($t=1$)). Adherence to

the profiles was explored using descriptive statistics and Spearman correlations ($p < .10$).

Associations of adherence scores to the five profiles with health of care giver and care recipient, objective burden (caregiving hours per week), subjective burden (Caregiver Strain Index and Self Rated Burden), perseverance time, happiness (CarerQoL-VAS), and still living at home after one year (at $t=2$) were explored using Spearman correlations ($p < .10$). These measures are described in detail in Chapter 2.

RESULTS

All respondents provided adherence scores to all five profiles of caregiving at $t=1$ as well as at $t=2$. Figure 2 shows the adherence scores of informal carers to the five profiles at the two measurement moments. Mean scores at $t=1$ were 3.4, 2.9, 3.0, 2.6 and 2.6, respectively, and at $t=2$ were 3.5, 3.0, 3.0, 2.7 and 2.9. Carers who dropped-out of sample during the one year follow-up period scored statistically significantly ($p < .05$) lower at $t=1$ on profile 1, representing lower burden care situations, and higher on profiles 4 and 5, representing higher burden care situations.

At $t=1$, a higher adherence score on profile 1 was associated with lower scores on profiles 4 and 5, a higher score on profile 2 was associated with higher scores on profiles 3, 4 and 5, and a higher score on profile 4 was associated with a higher score on profile 5.

Data at $t=2$ showed a similar pattern; a higher adherence score on profile 1 was associated with a higher score on profiles 2, a higher score on profile 2 was associated with higher scores on profiles 3, 4 and 5, a higher score on profile 3 was associated with higher scores on profiles 4 and 5, and a higher score on profile 4 was associated with a higher score on profile 5.

Comparing scores at $t=1$ and $t=2$, a higher adherence score on profile 1 at $t=1$ was associated with a higher score on profile 1 at $t=2$ and a lower score on profile 4 at $t=2$, a higher score on profile 2 at $t=1$ was associated with a higher score on profile 4 at $t=2$, a higher score on profile 3 at $t=1$ was associated with higher scores on profiles 3, 4 and 5 at $t=2$, a higher adherence score on profile 4 at $t=1$ was associated with a higher score on profile 4 at $t=2$, and a higher score on profile 5 at $t=1$ was associated with higher scores on profile 5 at $t=2$.

Figure 2 gives further insight into the changes in adherence over the one year follow-up period. The figure shows that adherence scores changed upwards and downwards for all profiles. Notably, large majorities of 65-80% gave lower or same scores to profiles 1, 2 and 3 at t=2 as compared to t=1, whereas about 80% gave same or higher scores to profiles 4 and 5. This indicates that one year later carers associated themselves more strongly with “carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends” and “carers who can barely cope with providing the care required by their relative with dementia”.

A higher adherence score on “carers who cope well with providing care” (profile 1) was associated with higher health and happiness of the carer, lower objective burden, lower need for support, lower subjective burden on CSI and SRB scales, and higher perseverance time.

A higher adherence score on “carers who would like to receive help in providing the care but who want to remain in control of the care process” (profile 2) was associated with higher health of the informal carer, higher objective burden and higher subjective burden on SRB.

A higher adherence score on “carers who find it quite demanding to maintain the level of care needed but who get a lot of help” (profile 3) was associated with lower health of the person with dementia and higher need for support.

A higher adherence score on “carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends” (profile 4) was associated with lower health and happiness of the carer, higher objective burden, less help from other informal carers, higher need for support, higher subjective burden on CSI and SRB scales, and lower perseverance time.

Finally, a higher adherence score on “carers who can barely cope with providing the care required by their relative with dementia” (profile 5) was associated with lower happiness of the carer, higher objective burden, higher subjective burden on CSI and SRB scales, and lower perseverance time.

DISCUSSION

This explorative study showed that it was feasible to inform informal carers for a person with dementia to describe their caregiving situation using the five profiles

developed on the basis of the results of Chapter 4, and carers' responses provided some interesting insights.

First, the relations between adherence scores on the five profiles of caregiving at each of the measurement moments as well as between the two measurement moments were plausible. Informal carers giving higher scores to profiles representing lower burden care situations provided lower scores to those representing higher burden situations, vice versa, both at t=1 and t=2 as well as at t=2 compared to t=1.

Second, the changes in adherence scores between the two measurement moments indicate that as caregiving time progresses, on average, carers give lower scores to profiles representing lower burden care situations and higher scores to the profiles representing higher burden situations. In other words, informal carers seem to indicate that in one year their ability to cope with their caregiving situation decreased.

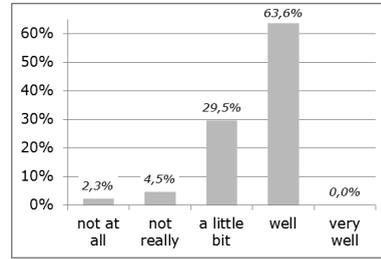
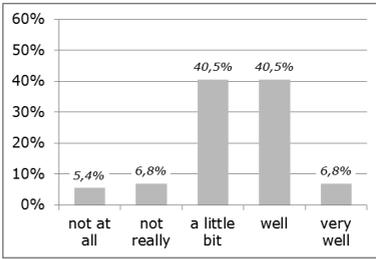
Third, univariate association showed that a higher adherence score on profile 1 at t=1 was associated with higher odds of the person with dementia still living at home at t=2, while higher scores on profiles 4 and 5 were associated with significantly lower odds.

Finally, the associations between adherence scores and measures of burden of the caregiving situation confirm the findings from Chapter 4, which suggested that profiles of caregiving 1 to 5 represent consecutively increasing levels of burden, associated with decreasing perseverance time.

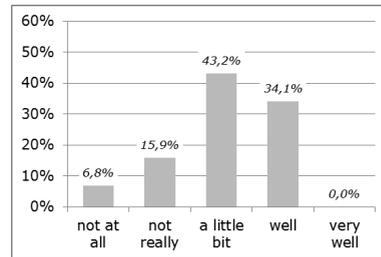
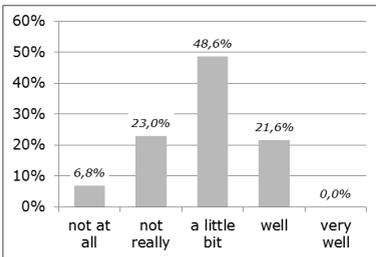
Although these findings seem plausible, it is important to note that they are based on a sample of limited size and on written questionnaires. The feasibility and validity of the five profiles of caregiving for typifying caregiving situations needs to be studied further before conclusions can be drawn about their value for use in practice. For instance, it might be useful in addition to the score per profile to ask informal carers which profile fits the most. Nonetheless, this study was embedded in a larger longitudinal cohort study and the results seem encouraging enough to recommend researchers and practitioners to consider an approach as presented in Chapter 4 and in this appendix to generate more insight in the care situations they analyse or work with. Such insight can, for instance, be helpful in conducting more subgroup sensitive research and develop better monitoring systems and more personalized support programmes for informal carers.

Figure 1 Adherence to the profiles of caregiving at t=1 (left) and t=2 (right)

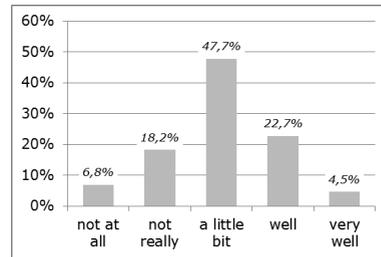
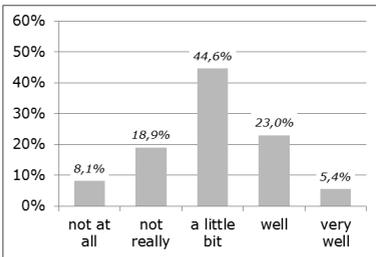
Profile 1: Carers who cope well with providing care



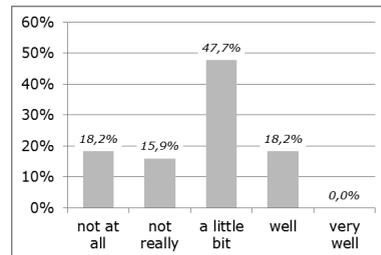
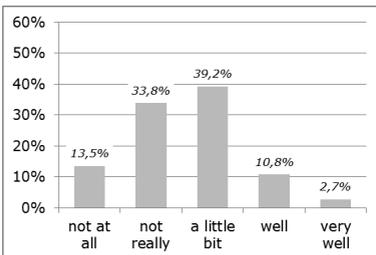
Profile 2: Carers who would like to receive help with providing care but who want to remain in control of the care process



Profile 3: Carers who find it quite demanding to maintain the level of care needed but who do get a lot of help and support from their family and friends



Profile 4: Carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends



Profile 5: Carers who can barely cope with providing the care required by their relative with dementia

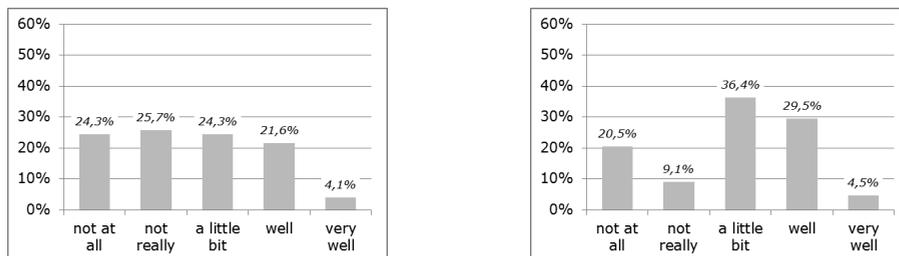
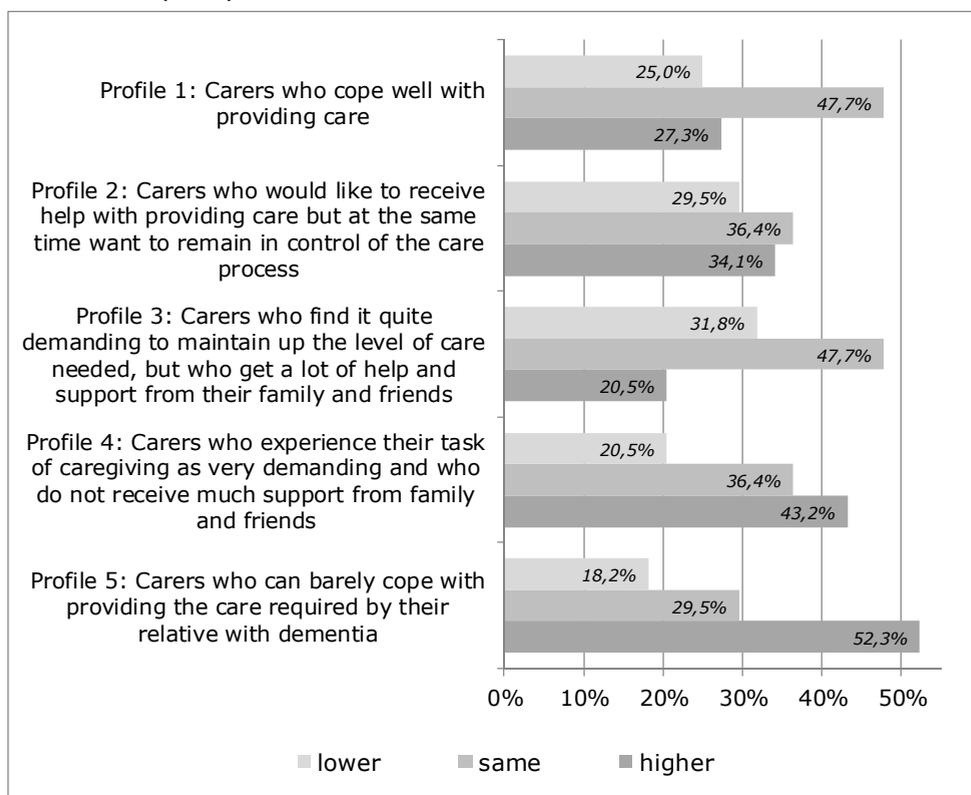
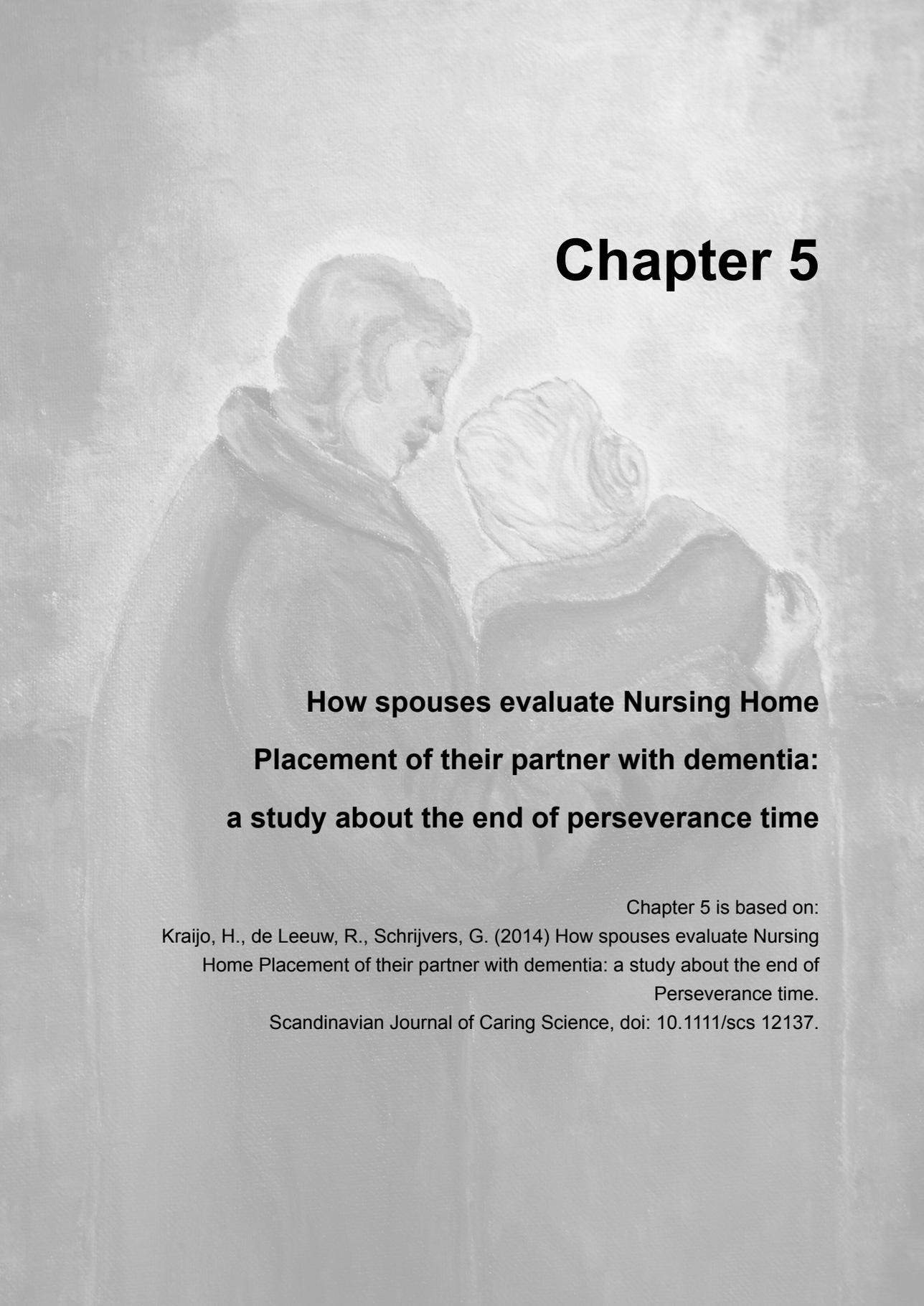


Figure 2 Difference in adherence scores to profiles of caregiving between t=2 and t=1 (n=44)



Note: the bar 'higher' means that those informal carers have given a higher adherence score to that profile of caregiving at t=2 than at t=1, which means that this profile of caregiving describes their caregiving situation at t=2 better than at t=1.



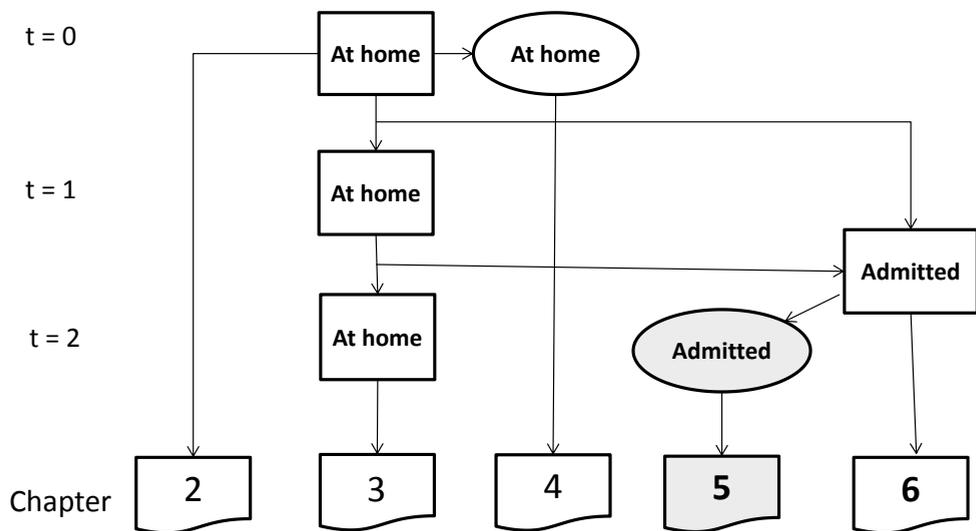
Chapter 5

How spouses evaluate Nursing Home Placement of their partner with dementia: a study about the end of perseverance time

Chapter 5 is based on:
Kraijo, H., de Leeuw, R., Schrijvers, G. (2014) How spouses evaluate Nursing
Home Placement of their partner with dementia: a study about the end of
Perseverance time.

Scandinavian Journal of Caring Science, doi: 10.1111/scs.12137.

Flow chart related to Chapter 5



Research question:

How do spouses experience the decision to place their partner with dementia in a nursing home?

ABSTRACT

Aim

This study was about the final decision by spouses to have their partner with dementia placed in a nursing home. The central question was whether the admission took place in the right time in their point of view.

Method

Fourteen partners of persons with dementia evaluated the nursing home placement. They were interviewed at home using a semi-structured questionnaire. Grounded theory was used to explore the process of decision making. In addition to the interviews quantitative data were used from a two-year follow-up study.

Results

Results underline that the placement decision had to be made in phases over time. The first decision is about placement of the relative on a waiting list and the second decision is about the actual placement in a nursing home once a place becomes available. This second and final decision often had to be taken under time pressure in order to avoid a place in the nursing home being left empty. If they had been given more time and space to reconsider their admission decision, most partners said they could have had continued providing home care longer. During the investigation the following classification in timeliness of the admission emerged: Placement was at the right time, too early, too late, or out of control.

Conclusion

It may be helpful for informal and formal carers to focus on perseverance time in considering placement or prolonged support at home. Placement at an appropriate time may lead to a higher degree of well-being of informal carers before and especially after the admission.

INTRODUCTION

Having one's partner with dementia put on a waiting list for placement in a nursing home is an important and difficult decision. After making this decision, spouses' lives are heavily influenced by the thought of this placement in the near future and its consequences, i.e. permanent separation. In addition, there is the ever-present and unavoidable reality that the death of one's partner is nearing. This situation places an extremely heavy burden on partners of persons with dementia [Meiland et al., 2001; Mittelman et al., 2007; Kraijo et al., 2012].

A lot of research has been carried out about the determinants of nursing home placement [Pruchno et al., 1990; Cohen et al., 1993; Coehle et al., 2007; Chang et al., 2010]. A complex combination of variables related to the characteristics of informal carers, persons with dementia, and the wider context, has varying degrees of influence on the admission decision [Vaugh, 2009; Noël-Miller, 2010; Mc. Donnell et al., 2013].

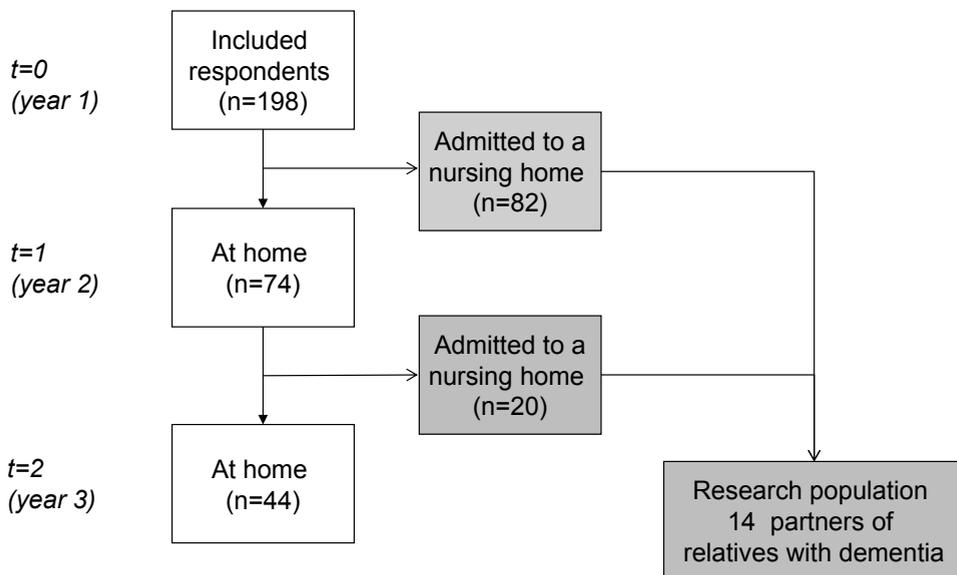
Nursing home waiting lists are used in the Netherlands, as well as in other countries [Morin et al., 2007; Meiland et al., 2002; Fjeltun et al., 2009]. The existence of waiting lists means that, inevitably, the decision by informal carers to place a relative in a nursing home, is made in phases over time. The first decision is to place the person with dementia on a waiting list for a nursing home, mostly based on a decision by the insurance authorities. The second decision is the final decision for placement when, over the course of time, a place in a nursing home becomes available. In the papers we read [Ducharme et al., 2012; Caldwell et al., 2014] it is assumed that the first decision included automatically the final decision. Therewith time for informal carers to reconsider the final decision remains out of view. This issue of phasing of the placement decision seems to be underexplored in its consequences for persons with dementia and their informal carers. Research about decisions of home-care entry are mainly focused on the first admission decision [Corcoran, 1994; Davies et al., 2003; Caron et al., 2006; Söderberg et al., 2012; Abendroth et al., 2012]. At the moment of this study, as far as we know, there was no literature about the difference in phasing in decision-making by the informal carers. In this study, we focus on the final decision for placement in a nursing home.

The central focus of this study was the timeliness of placement from the viewpoint of the partners of persons with dementia in order to provide indications

of optimal use of informal care and nursing home capacity as well [Jansson W. et al., 2001; Jansson I. et al., 2009; Lin et al., 2011; Verbeek et al., 2012].

This retrospective study is part of a longitudinal study of perseverance time of informal carers of persons with dementia living at home (see figure 1). Perseverance time is defined as *the period of time informal carers indicate that they can continue care for their dementing relative under current conditions* [Kraijo et al., 2014]. We examined how partners of persons with dementia feel afterwards about their final admission decision to place their partner in a nursing home and if the admission took place at the right time in their point of view.

Figure 1. Flow chart Longitudinal study Perseverance time, Sub collection: Admission Population



METHOD

Study population

The informal carers of persons diagnosed with dementia, participating in the longitudinal study, were recruited in co-operation with the assessment agency of the Dutch Exceptional Medical Expenses Act in a region near Amsterdam. The assessment agency sent a letter to the home address of all the persons with dementia, directed 'To the primary informal carer of [name person with dementia]'. The letter explained the purpose of our study. In addition, the letter explained that: 1. their decision to participate in the study was voluntary 2. anonymity of data from questionnaires returned was guaranteed (and how), and 3. by returning the questionnaire they gave permission to use the data they provided for the purpose of this study (as described in the letter).

Figure 1 shows that during the longitudinal study 102 persons with dementia were admitted to a nursing home including 47 persons with dementia with a spouse as informal carer. Forty-three of them participated in a previous study investigating profiles of informal carers [Kraijer et al., 2012]. After a personal request by phone 22 of them were willing to give their consent for this second and separate study. The most important reason for not participating of four spouses was the desire to close a stressful period. Finally 14 spouses participated in this study. We have chosen for spouses of persons with dementia because they are day and night permanently involved in caring for their relatives. We also selected them on the basis of urgency of the admission and whether the placement was necessary in connection with their own health or the health of their partner with dementia. Finally we also tried to realise a gender equal distribution. This selection should lead to a variety of considerations taken into account in making the final admission decision.

Theoretical setting

In performing and analysing the interviews we chose an interpretative view: people define their situation in their daily interaction with one another and from their surroundings [Boeije, 2005; Baarda, 2006]. This choice appeared to be the most suitable in studying the social reality of informal carers of persons with dementia. The grounded theory approach [Glaser et al., 1967; Strauss, 1987] supposed to lead to the emergence of categories in perspective of the research

question of timeliness of the final decision of nursing home placement. Those categories of care situations can/should be used as building blocks for designing a model for decision making of admission to a nursing home. In this study we used a parallel nested strategy. That means that we used some of the earlier collected data of the quantitative longitudinal study. From that study, we obtained more information about subjective burden, measured by the Self Rated Burden [Van Exel et al., 2004], well-being, measured by the CarerQoL-VAS [Brouwer et al., 2006]. We compared those variables at two different times. At the first moment the relative with dementia was still living at home. The second moment in time was one year later. Between those moments the relative with dementia has been admitted to a nursing home (see table 1).

Table 1 Care situation of the participants (N = 14)

14 spouses	1	2	3	4	5	6	7	8	9	10	11	12	13	14
<i>Care situation before the admission of the partner with dementia</i>														
Persons with dementia														
Age (years)	79	78	85	87	89	78	82	70	74	79	82	77	86	73
Co-morbidities (Y=yes, N=no)	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y	Y
Care dependence (VAS 0-10)	8	9	8	9	9	8	8	10	10	9	7	10	10	7
Spouses														
Age (years)	72	78	79	83	75	79	79	74	73	57	74	83	87	72
Gender (M=male, F= female)	F	M	F	M	F	M	F	M	M	F	F	M	M	M
Self-rated burden (VAS 0-10)	6	8	6	8	7	5	8	8	4	7	8	5	5	5
Well-being (VAS 0-10)	8	5	4	9	8	7	4	7	6	7	3	7	5	7
Admission														
Because of the health of D or S ¹	S	D	D	S	D	D	S	S	D	S	S	D	D	D
<i>Care situation after the admission of the partner with dementia</i>														
After admission														
Self-rated burden (VAS 0-10)	6	6	4	10	4	7	8	5	6	3	6	4	5	4
Well-being (VAS 0-10)	6	4	6	0	7	5	4	3	3	4	7	4	3	6
Perseverance time ²	3	1	1	3	3	3	1	3	4	4	4	4	1	4
Interview time after admission (months)	19	24	25	22	26	24	25	15	25	23	15	16	18	22

1) D=Partner with dementia; S=spouse

2) 1 = < one week, 2 = > one week < one months, 3 = > one month < six months and 4 = > one year

Data collection and processing

The interviews took place about eighteen months after the admission of their partner to a nursing home, were audio recorded, literally transcribed and processed into anonymous thematic reports. The reports were returned to the spouses for their approval. The evaluation of the definitive decision for admission by the informal carers was focused on the timeliness of placement. During the semi-structured interviews, the question on the timeliness of placement was formulated on the basis of questions in text box 1, worked out in a checklist for use at the end of the interview. In this way a uniform basis for constant comparison was ensured.

Textbox 1

- At the time of institutionalization, could you have continued to manage caring and/or did you want to manage for a longer period of time?
- Which persons or agencies were important to you when you were making the decision about placement?
- Do you think placement came at the appropriate time?
- Were there any circumstances beyond your control that influenced your decision?

A standardised approach to report the source data was chosen, i.e. citations were modified only for readability. Each interview was processed before the next interview took place. This way of working was conducive to a concentrated focus on each next interview. The transcripts reports approved by the informal carers (member's check) formed the basis for the analysis. The first author did all the interviews and was familiar with the theme of this study because of his experience as former CEO of several care organizations.

Analyses

Data analyses were carried out using the constant comparative method in order to discover a relevant classification. Transcribed interviews were analysed line by line and analytical notations were made resulting in a thematic reports (coding). In this way the comparative analyses were carried out. Data were analysed by using WinMax 98. In support of the analysis, short summaries of events and evaluations have been drawn up which focus on the limits of perseverance time.

As result of this analytical process we should be able to explore the decision process by informal carers of admitting a relative with dementia to a nursing home. The analytic process can be characterised as an iterative process of action learning and discovery, supported by the discussions in the authors group. After fourteen interviews virtually no new points of view or experiences emerged from the interviews.

RESULTS

Characteristics of the study population

Table 1 shows an overview of quantitative data of the fourteen spouses. Almost all of the partners and their husbands were around 70 to 80 of age. The situation of the relatives with dementia before placement was characterised by high care dependence and co-morbidity.

In the period after nursing home placement the burden of care reduced and at the same time spouses felt less happy. A quote may explain how un-happy feelings showed up:

“I have cared for her for a period of sixty years and wanted to take care for her much longer. So, after the admission I felt guilty about it because I had to leave caring to others. That is what me makes very unhappy. Moreover I was convinced that I could have persevere longer in caring for my wife”.

At the time of placement: How did the informal carer act?

Before placement most of the spouses had indicated that they wanted to care for their partner at home for as long as possible. Some spouses did not have that wish any longer, which seemed to be related to the high level of burden they experienced due to severe co-morbidity and of incontinency of their partners.

“At the end my children said to me: Mam you will go under yourself. I really could not persevere any longer at the end and that all gave me the decisive to accept the admission of my husband”.

The majority of the spouses indicated afterwards that they were not ready for placement when it occurred. In retrospect, they thought they could have managed caring for their partner at home for longer than they did. Sometimes the situation was beyond their control, for instance when the informal carer had to be admitted into a hospital. Placement was unavoidable at that time.

“I could have coped for longer if she hadn’t had a brain infarction. At a certain point in time they said to me “you can’t go on any more”. I thought about it as a great shame of course. But that is the way it is”.

In the majority of the cases spouses reported they were able to manage longer because there was no direct need to place their partner in a nursing home in their point of view. They nonetheless did allow it to happen. In the opinion of the informal carers, the reason for this was especially the perceived urgency to accept the placement in a nursing home when a place was offered.

Which persons or agencies played a role in making the decision?

The involvement of relevant care facilities with informal carers and persons with dementia was largely limited to the logistic preparations for placement. Time and space for informal carers to (re)consider carefully their decision was not provided in the protocols of the nursing homes.

When asked who was most influential in the placement decision, some spouses answered that they had made the decision in consultation with their family or general practitioner. In other cases they felt that the nursing home or hospital had put them under pressure to agree to the placement. The motive for this to their opinion was that the place that had come free should be taken as soon as possible for financial reasons.

“All of a sudden it all went too quickly. We were told: “You can say yes now but if you don’t then it could be a very long time before you can do it again”. So indeed I gave permission for her to be placed’. Interviewer: What did you think about the situation? ‘Well, you are confronted with the facts, aren’t you? And you cannot oversee the consequences, but if it is put like that – she can be placed tomorrow but if you say no then it may be years before it’s possible again. That’s how they put it to you”.

Some spouses said that the hospital had a dominant influence. The hospital wanted a transfer to a nursing home as quickly as possible in order to avoid an expensive hospital bed being blocked by a nursing home patient.

In one situation the decision was a joint one that had been made in advance by the carer and his partner with dementia. They had decided that they wanted to stay together for as long as possible. When the situation became untenable, it was the partner of the person with dementia who decided to apply for a crisis placement.

“A completely untenable situation. My wife was also very sad because she realised only too well then it was all going wrong. She actually understood that she didn’t understand”.

In the majority of the cases a kind of case manager was able to offer support but after the partner had been put on a waiting list for a nursing home, case management offered by the home care organization was often terminated, and in one case taken over by the nursing home.

The spouses had the opinion that the effectiveness of case management was mainly determined by the quality of communication by the case manager. They found that case management loses its effectiveness if communication is strictly business-like and predominantly supply-orientated.

“I really could not communicate with my case manager. She knew very well what I have to do and what I don’t have to do. So I told her that she will come to a better understanding when she took over for a month”.

A calamity often proved to necessitate an emergency placement. In these cases there were no alternative options, because, for example, the person with dementia had had a brain haemorrhage and placement had become unavoidable. However, sometimes the policy of the nursing home was so forceful that the informal carers had no other option than to agree with placement (see text box 2).

Textbox 2

Placement was necessary as the informal carer had to have a knee operation followed by a period of rehabilitation in a convalescent home. The nursing home did not want to extend the temporary placement and confronted the informal carer with the choice of either returning home or permanent placement. Thus, this 'situation beyond control' was to some extent created by the nursing home. In the citation below, the informal carer interprets how her partner with dementia experienced the situation.

"We tried again when I was able to walk a bit. He came to lunch and said "Why do I have to leave? I'm not going to set the place on fire." Oh it was awful".

Overall evaluations of timeliness by spouses: a classification

During the interviews it appears that the partners of persons with dementia were able to classify in retrospect the placement in: at the right time, too early, too late, or beyond their control.

Some spouses indicated to have experienced a **situation beyond their control**. This resulted either from somatic calamities (in one case a broken hip in the other a brain infarction) or from the policy of the nursing home. The other cases resulted in a differentiated picture of what the partners of persons with dementia thought about the timeliness of the placement.

A small minority of spouses thought that the placement was **at the right time**. When the nursing home offered the place, the informal carer was no longer able to cope with the situation at home.

"I had one evening to make the decision. It was very tough. I didn't feel pressurised because I had the option. I knew it would happen sooner or later. But it was at such a short notice". Interviewer: Were you prepared for it? "Yes, I was prepared for it".

Another group of spouses thought that placement came **too early**, and said that the admission could have been postponed or possibly even avoided. They thought they could have cared for their partner at home for longer. The structure of the placement process had a lot to do with the fact that placement nevertheless took place.

Interviewer: Did you **want to** go on in caring for your partner? *“Yes, I did actually. I really didn’t want him to go there. On the other hand, they offered us a place and I had to say yes, I couldn’t say no because you do not know what would happen then, and his incontinence was getting worse. It was a real bother. After you get them clean again you think “well that’s that sorted out” and then all is well again and you have a nice cup of coffee or something. Now and again we used to go for a walk, here and around the house. We could still sometimes enjoy ourselves when he was still at home. It wasn’t unpleasant but his care was very demanding”.*

Interviewer: **Could** you have continued to cope with more care at home? *“Yes, may be I could”.*

This shows that there is continuous tension between ‘willing’ and ‘being able to’. ‘Willing to’ is almost always present, from the moment that persons with dementia are on the waiting list, ‘being able to’ is almost never proactively facilitated by homecare organizations or nursing homes.

In a minority of cases the spouses said that placement came **too late** and a crisis placement became necessary. Due to the scarcity of crisis beds, these placements were not at the nursing home of their first choice but in another care facility. These informal carers said that they had been severely overburdened for quite a long time.

The following case history (see textbox 3) illustrates that these situations are not always unambiguous.

Textbox 3

A 60-year-old woman cared for her 82-year-old husband who was suffering from vascular dementia. Following temporary placement for observation he deteriorated so much that an adjustable bed had to be placed in the living room, much more care was required and his problems increased. Someone from the home care services came in each morning to give care. During and after admission for observation his dementia worsened. He enjoyed all the attention but he was not aware that there was anything wrong with him.

“My husband is a champion in ignoring things. He will never admit that he is ill. For example he will say: “I went for a long walk today”. He hasn’t been able to walk for two years now. On the other hand he never feels content. He just wants to go home. His personality is still there. As the family says: “He may have dementia but he is not backward”[during his working life he was a medical specialist].

She felt she was carrying a very heavy burden. It was only after her brother-in-law saw that she could no longer cope and insisted upon it, that she started the placement procedure.

Two years after placement, she made the following evaluation when answering the question if she could have coped any longer.

“Asking for help is always difficult. Moreover, it is really difficult to explain exactly what sort of help you are looking for. Persons sometimes say to me, “come on, speak up and say what you want”.

There was a case manager but one who did not fit. They simply did not get along.

“I was not assertive enough to telephone the organisation and ask them to send another case manager, preferably a woman”.

Only after attending a course with other informal carers did she realise how much use a good case manager could be. Someone you can turn to and who understands the situation. She wished that she had had someone like that. Then she would have coped for longer.

This case history is double charged: The crisis situation could have been avoided if the case manager's guidance had been more effective. Placement could perhaps have been postponed to a later date. From this point of view, placement was too early and might have been avoided altogether by providing home nursing. On the other hand, placement was actually too late when considering the severely stressed situation that she found herself in which necessitated another family member organising the placement.

DISCUSSION AND IMPLICATIONS FOR PRACTICE

This study about the final admission decision of partners of persons with dementia placed in nursing homes underlines that the nursing home placement decision is taken in phases over time. The first decision is to place the person with dementia on a waiting list for a nursing home. The second and final decision is about the actual placement and is taken by informal carers when a place in a nursing home becomes available. That is the very moment for decision making by the informal carers. The admission process was mainly started because of a purely administrative reason instead of desirable careful assessment of carer capacity.

The classification of the final admission decision of the informal carers in: at the right time, too early, too late or out of control, generated knowledge on placement practices and the effects they have on the (over)burdening of informal carers, and on the timeliness of placement. Special attention for the category 'too late' and 'out of control' could help to prevent possible crisis situations. In general, a more informal carer oriented admission process stimulates that the admission takes place at an appropriate time by tuning mutual expectations to one another.

During the waiting list period there was discontinuity in support by a case manager. In most cases the formal carer of the home care organization wrongly assumed that the support of the informal carer was taken over by the nursing home where the person with dementia was placed on the waiting list. Such miscommunication between two care organization causes discontinuity in caring. These experiences underline the need of cooperation between the home care organization and the nursing home. The most effective appointment seems to be that the nursing home takes over the case management at the

moment the person with dementia is placed on the waiting list. The knowhow and expertise of the nursing home is than available from that moment and can be used to support the informal carers and the persons with dementia as well. Some interviewees suggested that more help from an adequate case manager might have helped to postpone institutionalization. This needs to be tested in future research. Although positive results have been reported before [Vernooij-Dassen et al., 2004], a systematic review of randomised controlled studies did not confirm the effectiveness of case management [Pimouguet et al., 2010]. It is important to consider the right conditions for effective case management [Verkade et al., 2010] such as coordination of the support and a client orientated approach.

This study has shown that the timeliness of placement may be viewed differently by the nursing home and the informal carer, based on their different viewpoints and aims. Including informal carers in the decision-making about nursing home placement of their relative with dementia would avoid the situation in which placement is delayed or takes place too early. The number of out-of control situations would be also reduced, or at least they probably would be noticed at an earlier stage. Strang et al. (2006) plead for the 'full incorporation into care' of informal carers. Schoenmakers et al. (2009) are of the opinion that informal carers should have a key role to play in decisions about placement of their relatives in a nursing home.

If the aim is to increase the perseverance time of informal carers, it seems important to better monitor their willingness and ability to continue informal care provision. The perseverance time of informal carers could, for instance, be prolonged if the transition from home to nursing home would be moderated by providing quick access to support at home when in need and waiting time guaranties for when perseverance time has run out [Van Exel et al., 2008]. This may also facilitate early diagnosis of excessive burden of informal carers. Cooperation between ambulant and intramural institutions can prevent discontinuity in support of the informal carers. Time and space for informal carers to (re)consider their decision for admission of their relative with dementia could be facilitated by nursing homes and can provide a placement in appropriate time for the informal carers and for the nursing home as well.

Placement at an appropriate time may lead to a higher degree of well-being of the informal carers before and especially after the admission and resource savings can be realized by prolonging support in the homecare situation.

Strengths, limitations and further research

The strength of this study is the mix of quantitative and qualitative data. We see congruence between both. Another strength is that we distinguish the two following steps in decision making of admission to a nursing home: The first decision is about placement of the relative on a waiting list and the second decision is about the actual placement in a nursing home once a place becomes available. The awareness of that difference makes it easier to find bottle necks in the admission process.

Fourteen partners of persons with dementia living at home were asked about their experiences of placement from the perspective of perseverance time. The interviews took place about eighteen months after the admission, a period of assumed acceptance by the informal carers of the admission of their partners. Partners said they could remember events surrounding the placement 'as if they only happened yesterday'. That phenomenon is usual regarding major emotional life events [Cocenas-Silva et al., 2012; Schmidt, 2012]. Nevertheless there may be some memory bias.

Although the results of this study primarily refer to partners of a person with dementia, it is expected that other groups of informal carers would also appreciate timely placement. Previous research has shown that persons with dementia remain at home longer if they are cared for by their partner [Vernooij-Dassen, 1996]. This study has shown that targeted support and time for reconsidering the admission decision can enable informal carers to persevere in caring for their relative with dementia. We expect that placement for those who cared for by informal carers can be postponed by appropriate support. Further research is necessary to test this hypothesis. Indeed, the social and societal context of this group of informal carers is very different from that of cohabiting partners of persons with dementia living at home [Pot et al., 2001; Nieboer et al., 2010].

The results of this study based on the experiences of informal carers should be a moral obligation to develop a shared decision model for admission of care at home to nursing home care.

CONCLUSION

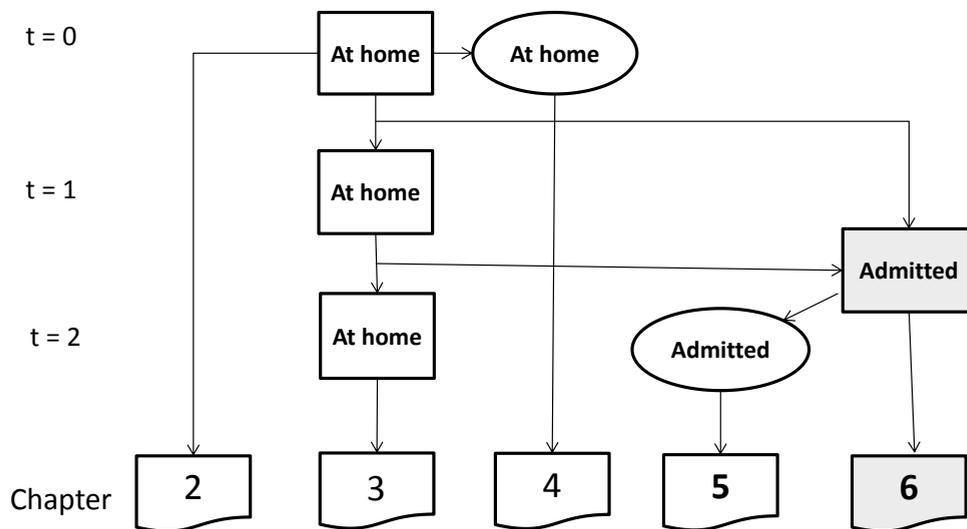
Nursing home placement decisions are made in phases over time. Spouses indicated they could have kept on giving care for a longer period of time if they had been given more time and space to make their final decision about the admission of their partner. It may be helpful for informal and formal carers to focus on perseverance time in considering placement or prolonged support at home. Policy agreement between ambulant and intramural institutions can prevent discontinuity in supporting informal carers. Placement at an appropriate time may lead to a higher degree of well-being of the informal carers before and especially after the admission.

Chapter 6

**Right Time Transition of persons with dementia
to a nursing home in informal cares' point of view:
A longitudinal study of perseverance time**

Chapter 6 is based on:
Henk Kraijo, Rob de Leeuw, Guus Schrijvers. (2014) Right Time Transition of
persons with dementia to a nursing home in informal cares' point of view:
A longitudinal study of perseverance time. Submitted paper.

Flow chart related to Chapter 6



Research question:

How is the timing of placing persons with dementia in nursing homes related to the perseverance time of their informal carers?

ABSTRACT

Introduction and aim

This study answers the question: Could informal carers have persevered in caring if the transition to a nursing home of their relative with dementia had not taken place at that particular time?

Method

Before and after transition 88 informal carers completed a questionnaire with items about their actual care situation. Associations between perseverance time and characteristics of the care situation were explored by bivariate and multivariate analyses. The recent validated measure of perseverance time was used to answer the research question.

Results

Half a year after the admission 53% of the informal carers reported that they could have persevered longer in caring for their relative with dementia if the admission to the nursing home had not taken place at that time.

Perseverance time was associated positively with characteristics of informal carers: male gender, health, and still feeling an informal carer after admission. Perseverance time associated negatively with living in the same house with the relative with dementia and subjective burden. Crisis situations associated positively with retrospective perseverance time.

Conclusion

Monitoring care situations by perseverance time appears to be helpful to provide timely support and transition to a nursing home at an appropriate time for informal carers. To achieve that goal it is useful to start a timely discussion between formal and informal carers based on cooperation agreements between home care facilities and the nursing home.

INTRODUCTION

Admission to a nursing home is a major and emotional event in the life for both a person who is admitted and for the immediate family involved. This applies in particular to admissions that are irreversible such as in case of dementia and should therefore be surrounded by intensive care and support [Sury et al., 2013]. Research has been performed to look for determinants for nursing home admission of persons with dementia [Pruchno et al., 1990; Hope et al., 1998; Smith et al., 2001; Coehlo et al., 2007; Gaugler et al., 2010]. To support informal carers in their wish to continue care as long as possible [Van Exel et al., 2008] it is desirable to study the way in which informal carers can be supported [Rosa et al., 2010]. Many interventions have been devised to support informal carers to do this [Acton et al., 2001; Vickrey et al., 2006; Cooper et al., 2007]. It is also important that the informal carers personally indicate by themselves how long they think they will be able to persevere in caring. The term *Personal case management* [Vernooij-Dassen et al., 2004] symbolises their wish for self-management. In the Netherlands was no instrument available for planning and evaluation of the admission process by informal carers of persons with dementia [Wierdsma et al., 2011].

Therefore we developed and validated the concept of *perseverance time* (PT) of informal carers of persons with dementia [Kraijjo et al., 2014]. In a longitudinal study the predictive value of PT was tested [Kraijjo et al., 2014] and it appeared that informal carers were able to make a reasonable indication of the end of their caring capacities. Relatively little attention is paid to the experiences of informal carers of the admission of their relative with dementia. [Garity, 2006; Strang et al., 2006; Gaugler et al., 2009]. A qualitative study showed how spouses experiences the moment of admission in the perspective of their PT [Kraijjo et al 2014]. In that study it appeared that those spouses often had to be taken the final admission decision under time pressure in order to avoid a place in the nursing home being left empty. They found that if they had been given more time and space to reconsider their admission decision, most partners said they could have had continued providing home care longer.

The present quantitative study answers the research question: Could informal carers still have persevered in caring if the admission to a nursing home of their relative with dementia had not taken place at that particular time. It also examines

in what way their hindsight PT was related to characteristics of the person with dementia, informal carers and of the care situation. The expectation was that the answers to that research question could provide incentives to improve the effectiveness of the transfer care process.

METHOD

Sample

The informal carers participating in this study were recruited in co-operation with the assessment agency of the Dutch Exceptional Medical Expenses Act in a region near Amsterdam. There is no formal registration of informal carers in the Netherlands, but regional assessment agencies have a registry of diagnosed persons with dementia living at home receiving formal help, for instance home care. The assessment agency sent a letter to the home address of all the person with dementia in their registry diagnosed with dementia, directed 'To the primary informal carer of (name person with dementia)'. The letter explained the purpose of our study, why the assessment agency supported the study by sending out this letter, and how anonymity of data from questionnaires returned was guaranteed. Attached to the letter were a questionnaire and a stamped return envelope, with the address of the University. In order to stimulate response a reminder was sent after four weeks. By sending in the questionnaire informal carers confirmed their participation in this longitudinal study.

Questionnaires

Informal carers included in the study received two follow-up questionnaires from the University after one year (t=1) and two years (t=2). One questionnaire to participate in the longitudinal study and another questionnaire for the informal carers of relatives with dementia who were admitted to a nursing home. The first follow-up questionnaire was an abbreviated version of the baseline questionnaire, which consisted of a comprehensive set of questions about the informal carer, the person with dementia and the informal care situation (e.g., objective and subjective burden of care, need for support, adjustments in work and other activities). The questionnaire for informal carers of relatives with dementia who had been admitted consisted of questions about the reason for the admission,

their own health status, burden and well-being after the admission, how they experienced the admission and to what extent they were involved in the care of their relative in the nursing home.

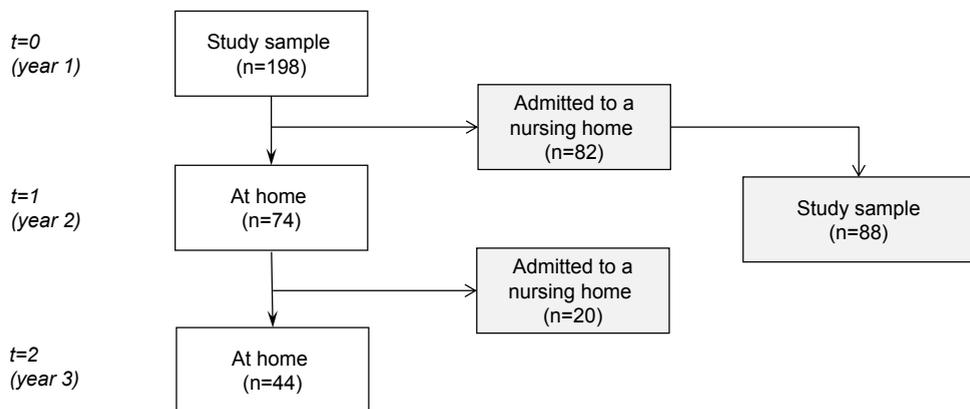
Figure 1 shows that during the longitudinal study 102 persons with dementia were admitted to a nursing home. We compared care situations at two different times. At the first moment the relative with dementia was still living at home. The second moment in time was one year later. Within that year the relative with dementia has been admitted to a nursing home.

Subjective burden was measured with the Caregiver Strain Index (CSI) [Robinson, 1983; Sullivan, 2003] and the Self-Rated Burden (SRB) [Van Exel et al., 2004]. The CSI consists of 13 items that refer to problems informal carers can experience and has a sum score of 0, no burden, to 13, problems in all 13 items. A score of 7 or higher is defined as substantial burden [Brouwer et al., 2006]. The SRB concerns a visual analogue scale (VAS) on which informal carers indicate how burdensome they experience the informal care; the scale runs from 0, not at all burdensome, to 10, too burdensome. Well-being was measured with the CarerQoI-VAS [Brouwer et al., 2006; Hoefman et al., 2011]. This scale runs from 0, not at all happy, to 10, completely happy. Health of the persons with dementia and the informal carers was measured with a VAS that runs from 0, worst imaginable health, to 10, best imaginable health. Care-dependency is also measured with a VAS that runs from 0, full self-reliance, to 10, full dependency. Informal carers of admitted relatives with dementia were asked for how long they could still have persevered if the admission had not taken place (not one day longer; one or two days; more than two days, but less than one week; more than one week, but less than one month; more than one months, but less than six months; more than six months, but less than one year; more than one year but, less than two years, and more than two years). Perseverance time in months is determined by taking the middle of the category in the first seven answer categories (for example 3.5 months for the category 'more than one month, but less than 6 months') and was arbitrarily set at 30 months in the (open-ended) sixth category 'more than two years'.

Statistical analyses

Descriptive statistics of all variables are presented in mean and standard deviation and range. Difference between sub samples were explored by Chi²-analyses (ordinal variables) and by one-way ANOVA (continuous variables). Statistical analyses were conducted with SPSS 20.0. Multivariate analyses were presented for two different models

Figure 1. Flow chart longitudinal study perseverance time, sub sample: admission population



RESULTS

The response rate of the 102 informal carers of admitted persons with dementia was 86.3%. The most important reason for non-response was the desire of informal carers to close a stressful period.

Table 1 shows the sample characteristics of the 88 participating informal carers half a year before admission of their relative with dementia. The relatives with dementia were aged 80-plus with a high score of comorbidity and care dependence. The informal carers had a mean age of 65 years and were in relatively good health. The following sub-samples are recognizable: Informal carers living at home with their relative with dementia (mostly spouses: 92%) and those who are living elsewhere (mostly children: 88%). Another relevant sub-sample is: the persons with dementia living alone, because their situation seems to be extra vulnerable.

Table 1 Sample characteristics average half a year before admission (n=88)

Characteristics		N (%)	Mean (sd)	Range
Persons with dementia				
Age	Years	88	81.6 (6.5)	64 – 93
Gender	Female	55 (62.5)		
	Male	33 (37.5)		
Marital status	Married/having a partner	53 (60.2)		
	Single	35 (39.8)		
Living alone	Yes	31 (35.2)		
	No	57 (64.8)		
Health status	VAS (0-10)	88	6.2 (1.9)	1 – 10
Co-morbidities	Yes	64 (72.7)		
	No	24 (27.3)		
Supervision	Needs constant supervision	20 (22.7)		
	Can be left alone for one hour at the very most	19 (21.6)		
	Can be left alone for a couple of hours easily	49 (57.7)		
Care dependence	VAS (0-10)	88	7.6 (2.0)	1 – 10
Informal carers				
Age	Years	88	65.4 (13.2)	35 – 87
Gender	Female	56 (63.6)		
	Male	32 (36.4)		
Marital status	Married/having a partner	71 (80.7)		
	Single	17 (19.3)		

Characteristics		N (%)	Mean (sd)	Range
Children at home	Yes	9 (10.2)		
	No	79 (89.8)		
Education level	Low	10 (11.4)		
	Middle	57 (64.7)		
	High	21 (23.9)		
Employed	Yes	29 (33.0)		
	No	59 (67.0)		
Health status	VAS (0-10)	88	7.3 (1.5)	3 – 10
Well-being	VAS (0-10)	88	6.5 (1.7)	1 – 9
Relationship				
Relative with dementia is	Partner	43 (48.9)		
	Parent (in-law)	39 (44.3)		
	Other (family) relationship	6 (6.8)		
Living together	Yes	47 (53.4)		
	No	41 (46.6)		

Table 2 indicates the burden of the care giving situation half a year before admission. In general the situation can be characterized as a full-time job for informal carers with different adjustments in order to persevere in caring for their relative with dementia. Of them, 72% felt overburdened (CSI \geq 7) and almost all informal carers (90%) desired additional support.

Table 2 Burden of the care giving situation average half a year before admission (n=88)

Characteristics		N (%)	Mean (sd)	Range
Objective burden				
Intensity of informal care giving	Days per week	88	4.8 (2.6)	0 – 7
	Hours per week	88	36.1 (36.4)	2 – 126
Formal care at home	Yes; Hours per week	68 (77.3)	8.1 (12.3)	0 – 100
Support by other informal carers	Yes; Hours per week	47 (53.4)	8.8 (12.7)	1 – 84
Adjustments	Adjusted working hours	7 (8.0)		
	Reduced volunteer work	10 (11.4)		
	Abandoned hobbies	31 (35.2)		
Subjective burden				
Caregiver Strain Index (CSI)	Score (0-13)	88	8.2 (2.9)	1 – 12
	-Substantial strain Score \geq 7	64 (72.7)		
Self-Rated Burden (SRB)	VAS (0-10)	88	6.4 (2.0)	1 – 10
Desire for additional support				
	Yes	79 (89.8)		
	No	9 (16.2)		

Table 3 shows the sample characteristics half a year after admission of the person with dementia. The amount of crisis admissions was 35%. These admissions were the result of an unpredicted bad health situation of the person with dementia (84%) or informal carer (16%). Afterwards the experience of the admission as such appeared more positive for the informal carers than expected before the admission. Nearly all informal carers were still involved in caring for their relatives in the nursing home (99%) and 47% of them perceived themselves still as an informal carer. Most informal carers (86%) who visited their relative with dementia gave practical support. A small percentage of the informal carers performed volunteer work in the nursing home. Self-Rated Burden after admission (4.3) was lower than the burden before the admission (6.4). However the degree of health and well-being remained virtually the same. Informal carers indicated that they could have persevered in caring at home for average six more months. We defined a 'right-time' placement in cases where informal carers reported a retrospective perseverance time of less than one month (= 47%). This implies that in 53% of the cases, admission could have been postponed.

Table 3 Sample characteristics average half a year after admission (n=88)

Characteristics		N (%)	Mean (sd)	Range
Admission				
Planned admission due the health of the person with dementia	Yes	45 (51.1)		
Planned admission due the health of the informal carers	Yes	12 (13.6)		
Crisis admission due unpredicted bad health person with dementia	Yes	26 (29.5)		
Crisis admission due unpredicted bad health informal carer	Yes	5 (5.7)		
Experiences of the admission by informal carers				
Dread of the admission by the person with dementia	Yes	33 (37.5)		
	No	55 (62.5)		
Dread of the admission by the informal carer	Yes	60 (68.2)		
	No	28 (31.8)		
Admission was better than expected by the person with dementia	Yes	32 (36.4)		
	No	56 (63.6)		
Admission was better than expected by the informal carer	Yes	47 (53.4)		
	No	41 (46.6)		
Involvement informal carer after admission				
They felt still informal carer	Yes	42 (47.7)		
	No	46 (52.3)		
Visiting their relative with dementia	Yes	76 (86.4)		
	No	12 (13.6)		
Gave practical support in the nursing home	Yes	39 (44.3)		
	No	49 (55.7)		
Doing voluntarily work	Yes	6 (6.8)		
	No	82 (93.2)		
No involvement	Yes	1 (1.1)		
	No	87 (98.9)		
Burden and well-being after admission				
Self-Rated Burden (SRB)	VAS (0-10)		4.3 (2.1)	0 – 10
Well-being	VAS (0-10)		6.2 (2.0)	0 – 9
Health status	VAS (0-10)		6.9 (1.7)	0 – 10
Perseverance time after admission (retrospective)				
Not one day longer		9 (10.2)		
One or two days		5 (5.7)		
> two days < one week		6 (6.8)		
> 1 week < one month		21 (23.9)		
> one month < six months		24 (27.3)		
> six months < one year		10 (11.4)		
> one year < two year		5 (5.7)		
> two years		8 (9.1)		
Months			5.9 (8.9)	0 – 30

Table 4 presents the associations between perseverance time in months and the characteristics before admission of persons with dementia, informal carers, care situation, the nature of the admission, and the perception of their role as informal carer. Perseverance time was associated positively with the characteristics of the person with dementia: feminine gender and living alone and the following characteristics of the informal carers: having a partner, being employed, well-being, a parent relationship and still feeling an informal carer after admission. PT was associated negatively with the person with dementia having a partner and the following determinants of the carer: age, living together with the relative with dementia, and subjective burden.

The mean PT value in months is particularly dependent on the value of 30 months for the last category. If 48 months was chosen for this last open-end category all associations presented in table 4 were also statistically significant for perseverance time. We defined a 'right-time' placement in cases where informal carers reported a retrospective perseverance time of less than one month (= 47%). This would imply that in 53% of the cases, admission could have been postponed.

Table 4 Statistically significant associations of perseverance time (PT) with characteristics of relatives with dementia, carers and care situation.

Characteristics		N	PT (months)	Oneway Anova ($p < 0.05$)
Relatives with dementia				
Gender	Female	55	6.8	0.027
	Male	33	4.3	
Married/having a partner	Yes	53	3.9	0.000
	No	35	9.0	
Living alone	Yes	31	9.9	0.000
	No	57	3.7	
Informal carers				
Age	≥ 65	44	3.3	0.001
	< 65	44	8.5	
Married/having a partner	Yes	71	6.2	0.008
	No	17	4.7	
Employed	Yes	29	11.1	0.000
	No	59	3.3	
Well-being	≥ 7	48	7.6	0.024
	< 7	40	3.9	
Relationship				
Relative with dementia is partner	Yes	43	2.5	0.000
	No	45	9.2	
Parent (in-law)	Yes	39	8.8	0.006
	No	49	3.6	
Living together	Yes	47	2.4	0.000
	No	41	9.9	
Subjective burden				
Caregiver Strain Index (CSI)	≥ 7	64	4.2	0.021
	< 7	24	10.4	
Self-Rated burden (SRB)	≥ 7	44	3.9	0.005
	< 7	44	7.9	
After admission				
Admission because of the health of the informal carer	Yes	17	4.7	0.024
	No	71	6.2	
Still feeling an informal carer	Yes	42	8.1	0.017
	No	46	3.9	

Table 5 presents the results of multivariate analyses based on two binary logistic models with retrospective PT as dependent variable (dichotomized as: more than one week (yes/no) and, more than one month (yes/no)). Independent variables were the characteristics of informal carers, the care situation, the admission status and the experiences of informal carers half a year after the admission.

A perseverance time of more than one week was associated positively with the following characteristics of the informal carer and the care situation: a parent relationship with the relative with dementia, health, and still feeling and informal carer after the admission; it was associated negatively with: living in the same house with the relative with dementia, and subjective burden.

A perseverance time of more than one months was associated positively with the male gender, and the health of the informal carer; it was associated negatively with living in the same house with the relative with dementia.

In both models crisis admission associated positively with retrospective perseverance time.

Table 5 Binary logistic models for retrospective perseverance time

Characteristics		Perseverance time			
		> one week		> months	
		O.R.	p	O.R.	p
Informal carers					
Age	Years	0.04		0.03	
Gender	Male	0.92		0.71	**
Marital status (married/having a partner)	Yes	0.94		0.75	
Care situation / relationship					
Relative with dementia is parent (in law)	Yes	1.74	*	1.22	
Living together with the relative with dementia	Yes	1.54	**	1.10	***
Admission					
Crisis admission	Yes	0.85	***	0.62	**
Admission because of		1.06		0.72	
- the health of the informal carer					
- the health of the relative with dementia					
Experiences after admission					
Self-Rated Burden (SRB)	VAS (0-10)	0.20	*	0.14	
Health status	VAS (0-10)	0.33	**	0.19	**
Well-being	VAS (0-10)	0.22		0.18	
Still feeling an informal carer	Yes	0.86	*	0.61	
Constant		4.67		3.53	
Nagelkerke R ²		0.51		0.44	
Percentage correctly classified		83.0		73.9	

***p<0.01; **p<0.05; *p<0.10

The care setting appeared to be relevant in relation to the retrospective perseverance time. The care setting can be characterized by the following items that were highly associated ($p < 0.01$) to each other: living together, person with dementia is married/ having, care recipient is partner and or parent (in law). Therefore it is interesting to explore all possible other statistical significant differences between informal carers living at home with their relative with dementia and those who were living elsewhere. Table 6 presents those differences.

Some remarkable results were: Informal carers living elsewhere cared in 31 cases (75%) for relatives with dementia living alone; Ninety three percent of the informal carers living together with their relative felt overburdened and in 87% there was a child-relationship with the person with dementia (mostly daughter (in law) 83%); Informal carers living elsewhere gave twice as much practical support after the admission (61%) than carers who lived in the same house with their relative (29%). The retrospective perseverance time of informal carers who lived at home with their relative with dementia was 2.4 months; for the elsewhere living informal carers this perseverance time was 9.9 months. Related to the research question of this study, it appeared that there was a significant difference of the Right time Placement (based on the definition of a retrospective $PT < \text{one month}$) between the two categories of informal carers.

Table 6. Care setting and characteristics before and after admission

Characteristics		Total n=88	Care setting Informal carers		p ¹
			In home n=47	Elsewhere n=41	
Relatives with dementia					
Age	Years	81.6 (6.5)	79.2 (6.8)	84.4 (4.8)	**
Gender	Female (%)	62.5	51.1	75.6	*
Dementing relative lives alone	Yes (%)	35.2	0.0	75.6	**
Marital status: married/having a partner	Yes (%)	60.2	91.5	24.4	**
Supervision: needs constant supervision	Yes (%)	22.7	27.7	17.1	**
Informal carers					
Age	Years	65.4 (13.2)	74.5 (10.0)	55.0 (7.5)	**
Age	≥ 65 (%)	50.0	85.1	9.8	**
Gender	Female (%)	63.6	48.9	80.5	**
Health status	VAS (0-10)	7.3 (1.6)	7.0 (1.5)	7.6 (1.6)	*
Children at home	Yes (%)	10.2	0.0	22.0	**
Employed	Yes (%)	33.0	6.4	63.4	**
Well-being	VAS (0-10)	6.5 (1.7)	5.9 (2.0)	7.1 (1.4)	**
Relationship					
Relative with dementia is partner	Yes (%)	48.9	91.5	0.0	**
Relative with dementia is parent (in-law)	Yes (%)	44.3	6.4	87.8	**
Objective burden					
Intensity of informal care giving	Days per week	4.8 (2.6)	6.5 (1.4)	2.8 (2.2)	**
	Hours per week	36.1 (36.4)	55.0 (39.5)	14.5 (13.9)	**
Adjusted working hours	Yes (%)	8.0	2.1	14.6	*
Abandoned hobbies	Yes (%)	35.2	46.8	22.0	*
Subjective burden					
Caregiver Strain Index (CSI)	1-13	8.2 (2.9)	9.6 (2.3)	6.5 (2.6)	**
Substantial strain: CSI ≥7	Yes (%)	72.7	93.6	46.8	**
Self-Rated Burden (SRB)	VAS (0-10)	6.4 (2.0)	6.8 (2.1)	5.7 (2.1)	**
After admission					
Admission because of unpredicted bad health of the informal carer	Yes (%)	19.3	31.9	4.9	**
Dread of admission by the person with dementia	Yes (%)	37.5	27.7	48.8	**
They still felt informal carer	Yes (%)	47.7	36.2	61.0	**
Gave practical support	Yes (%)	44.3	29.8	61.0	**
Well-being	VAS (0-10)	6.9 (1.7)	5.5 (2.0)	7.0 (1.7)	**
Perseverance time	Months	5.9 (8.9)	2.4 (5.0)	9.9 (10.9)	**
Right Time Placement (PT < one months)	Yes (%)	46.7	63.8	24.8	**

1) * p < 0.05; ** p < 0,01

DISCUSSION

Main results

This quantitative study confirmed the fact that informal carers could still have persevered in caring if the admission to a nursing home of their relative with dementia had not taken place at that particular time [Kraijo et al., 2014]. We defined a 'right-time' placement in cases where informal carers reported a retrospective perseverance time of less than one month (= 47%). This would imply that in 53% of the cases, admission could have been postponed.

This study contributes to the specific knowledge about experiences of informal carers in the transition phase of their relative with dementia from living at home to a nursing home. There were many differences between informal carers living together with their relative with dementia (mostly partners) and those living elsewhere [Pot et al., 2001; Schneider et al., 1999; Norton et al., 2010]. The differences in perseverance time can be an indication of respectively under or over estimation of their care possibilities. Professional attention of that phenomenon by the formal carers can be helpful in monitoring the care situation. We therefore recommend more research based on the concept of perseverance time with a focus on those two groups of informal carers.

Limitations

This study was limited in terms of numbers, scope, and geography. Follow-up research on a larger scale is therefore desirable.

Informal carers could have overestimated their possibilities to continue their care for their relative with dementia. Complex feelings of loss, guilt, shame, blame, and regret are likely to influence the way they answered. Nonetheless their answers should be interpreted as an important signal for nursing homes to realise a more informal carer friendly admission process.

Care setting

Caregiving by informal carers living together with their relative with dementia (mostly partners) can be characterized as a fulltime job with a high level of subjective burden. Nevertheless these informal carers wanted to persevere in caring as long as possible to postpone the admission of their partner to a nursing home because that would mean a permanent divorce from each other.

The abandoning of their hobbies were signals for approaching the end of their perseverance time [Kraijo et al., 2014]. Such signals of decreasing social participation should be taken seriously by professionals in order to provide timely support or consider earlier admission.

Characteristics of the care situation of the informal carers living elsewhere is in general typical for the differences between two generations: mostly the daughter (in law) is the main informal carer. The overburdening of these carers stems from a combination of care for their parent (in law), their own household and having a job. On the other hand they have more possibilities of respite of the caring task. The tendency to overestimate their capabilities is present in their optimistic perception of their perseverance time. That could also be their pitfall and should be discussed in a monitoring conversation by the formal carer. Only in the care situation of the elsewhere living informal carers it occurs that the relative with dementia lives alone. That situation is fragile and requires extra attention.

After the admission to the nursing home, informal carers living elsewhere gave significantly more practical support to their relative with dementia than the in home living carers. It illustrates that the caregiving of those informal carers was more or less the continuation of the care situation at another place. Informal carers living with their relative with dementia experienced the admission as a total change of the care situation. The high amount of overburdening they reported before the admission makes it understandable that they wish to transfer most of the care to the formal carers in the nursing home.

Integrated care

Reflecting on the literature of integrated care [Van Exel et al., 2008; Norton et al., 2010; Olson et al., 2013; Davis et al., 2000; Ryan et al., 2000] it appeared that transition to another care facility is one of the Achilles heels of integrated care programmes [Latour et al., 2007]. The fact that informal carers in this study indicated that they could have persevered in caring if the admission had not taken place at that time, indicates that the transition process was not appropriate in the view of the informal carers. The results of this study underline the conclusion [Groenewoud et al., 2009] that a transition programme for persons with dementia and their relatives should include timely discussion of the possibilities of informal carers.

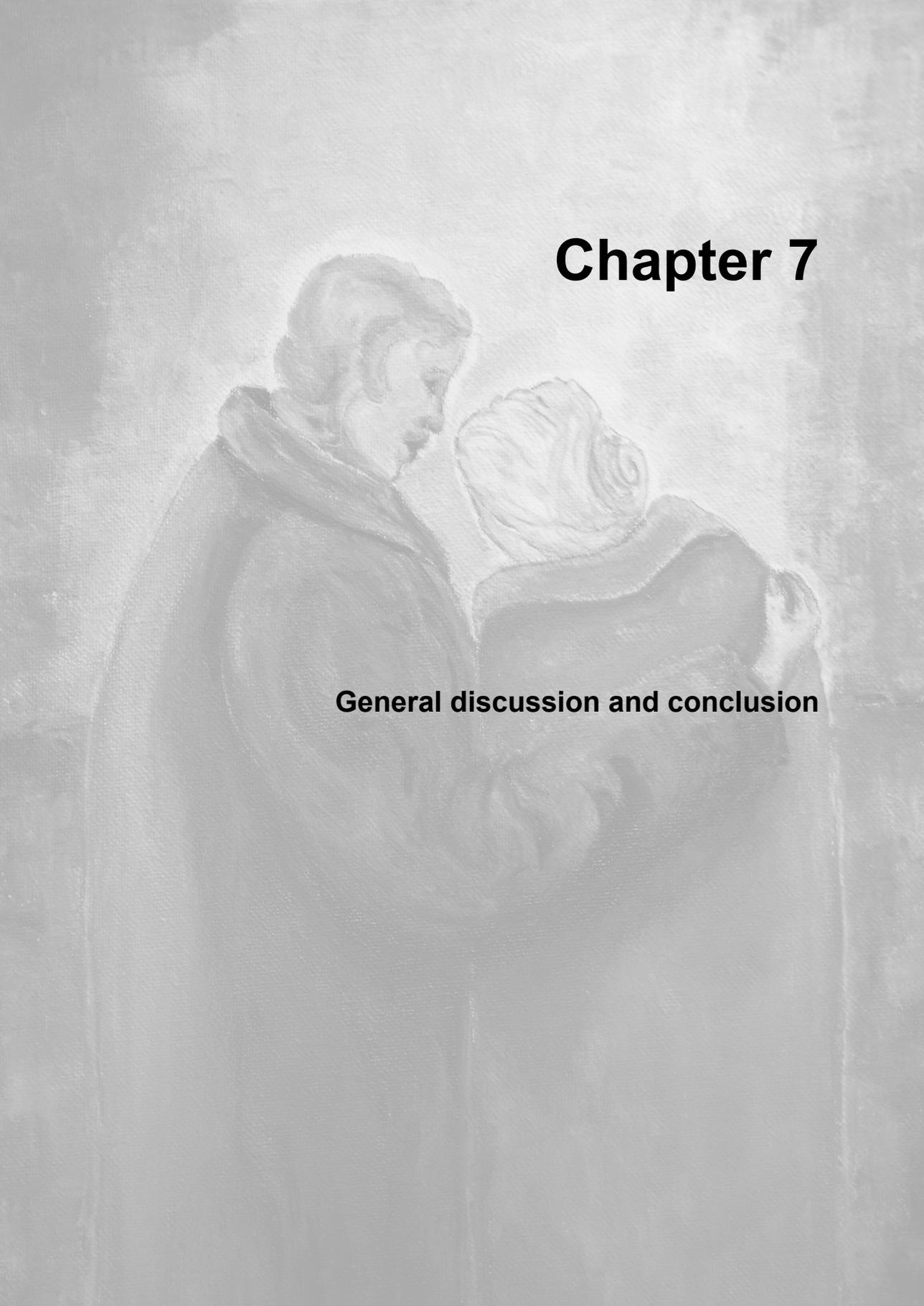
Timely and periodical deliberation about perseverance time with informal carers can stimulate a demand oriented way of supporting informal carers so that the admission can take place at a suitable time. This statement was supported by the available perseverance time of informal carers after the admission, this time could have been used to postpone the admission. Research by Andrén [2008] concluded that the time of admission can be delayed by psychosocial support of informal carers. On the other hand this support included also the possibility of an earlier admission than thought by the informal carer. Monitoring PT by formal carers might be helpful to prevent crisis situations. We advise to add perseverance time to the toolkit for case managers in dementia care. Further research and analysis of the nature of crisis situations is necessary to find more issues to prevent crisis admissions.

CONCLUSION

Monitoring perseverance time appears to be helpful to provide timely support for informal carers so that the admission to a nursing home can take place at an appropriate time. To achieve that goal it is useful to start a timely discussion between professionals and informal carers based on cooperation agreements between home care facilities and the nursing home.

Chapter 7

General discussion and conclusion



GENERAL DISCUSSION AND CONCLUSION

Dementia has a profound effect not only on the daily lives of those who suffer from it, but also on the daily lives of their informal carers. Informal care may range from temporary practical support to ‘full-time’ long-term care for an ill friend or family member. A defining characteristic of informal care is that, in contrast to voluntary work, this care emanates from a personal and/or emotional tie with the person who is in need of help.

There is an increasing number of persons with dementia. At the same time, though, there is a decreasing availability of formal and informal care. This is due to several developments, such as the increased labour participation of women and the geographical dispersion of families. Moreover, providing care to persons with dementia can place a great burden on informal carers. Maintaining sufficient levels of informal care within this context is a difficult and pressing policy issue. One of the challenges is to make optimal use of existing informal care capacity. Within this context, the perseverance time of informal carers could prove helpful. We therefore developed the concept of perseverance time as the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia, the length of this period of time is influenced by a combination of factors (described in Chapter 1).

We hypothesized that the perseverance time of informal carers could provide a direct way of investigating how long informal carers can continue to provide care. Therefore, the perseverance time measure was operationalized in a direct fashion by asking informal carers of persons with dementia the following question: ‘If the informal care situation stays as it is now, how long will you be able to cope with the care?’

If it were possible to elicit the perseverance time of informal carers, this could help to prevent the overburdening of informal carers and crisis admissions to a nursing home by providing timely and appropriate support at home. The joint aim of the studies presented here was to explore the feasibility, validity, and added value of perseverance time within the context of decision making in dementia care.

7.1. Main findings

To address the main aim of this thesis, a longitudinal study was designed. For a period of two years, we followed 223 informal carers of persons with dementia living at home. To validate and explore the concept of perseverance time, we carried out several quantitative (Chapters 2, 3, and 6) and qualitative (Chapters 4 and 5) studies to find the answers to the following research questions:

Research question 1 (Chapter 2):

What is the feasibility and convergent validity of perseverance time?

In Chapter 2, we tested the feasibility and validity of the concept of perseverance time in a sample ($n = 223$) of informal carers of persons with dementia living at home. During the study it became apparent that the perseverance time measure was understandable for informal carers. They were able and willing to indicate how long they expected to be able to continue current care.

The convergent validity of the perseverance time measure with subjective burden measured by the Caregiver Strain Index (CSI) and the Self-Rated Burden (SRB) was reasonably strong. Happiness (CarerQoL-VAS) was significantly associated with perseverance time, but less strongly than subjective burden.

It is important to note that perseverance time is conceptually different from subjective burden. Both measures ask carers to consider the positive and negative aspects of caring. However, in addition to this, the perseverance time measure also asks carers to assess *how long* they can continue functioning at the current level of burden. Therefore, the perseverance time measure aims to provide more than an indication of the balance between care demands and caring capacity at one particular point in time. Rather, in order to determine the future need for support, it aims to look forward in time and assess perseverance in an informal carer-centred manner. Regular assessment of perseverance time could therefore help to identify carers' need for support (or additional support) to enable the care at home to continue, or to start planning a timely transition from care at home to nursing home care.

Research question 2 (Chapter 2):

Which characteristics of the informal carer, the person with dementia, and the care situation are associated with perseverance time? (content validity)

In Chapter 2, the content validity of perseverance time was tested in a sample of 223 informal carers by performing multivariate analyses in which perseverance time was related to characteristics of the persons with dementia, the informal carers, and the care situation.

The results of these analyses showed that different categories of perseverance time were associated with different sets of characteristics. First, a perseverance time of more than six months was associated positively with the health of the person with dementia, the level of education of the informal carer, and with the degree of satisfaction; it associated negatively with the intensity of the informal care, whether the informal carer has a partner, and whether the informal care comes at the expense of sacrificing hobbies.

Second, an expected perseverance time of more than one year was associated with the same variables, but also with others, such as being associated positively with male gender of the informal carer, whether the person with dementia had a partner, and whether the person with dementia was a parent (or parent-in-law) of the informal carer.

Finally, an expected perseverance time of more than two years showed the following associations: it was positively associated with male gender of the informal carer, the person with dementia having a partner/living together, and the person with dementia being a parent (or parent-in-law) of the informal carer, and negatively associated with giving up hobbies in order to provide care.

Research question 3 (Chapter 3):

To what extent is perseverance time indicative of observed perseverance time? (predictive validity)

To answer this research question, we noted whether the person with dementia (n = 198) was still living at home after one and two years. This enabled a

comparison between indicated (at $t = 0$) and observed perseverance time after one ($t = 1$) and after two ($t = 2$) years. Table 3 in Chapter 3 compares anticipated and observed perseverance time. When making such a comparison, it must be emphasized that while the question about anticipated perseverance time was asked under the assumption that the care situation would not change, it inevitably always did. Still, Table 3 shows that a large proportion of the carers who indicated that their perseverance time was less than one year at $t = 0$ anticipated this correctly (90.2% of the 41 carers with perseverance time < 6 months; 69.2% of the 39 carers with 6 months < perseverance time < 1 year). Similar numbers were observed at $t = 1$ (i.e. 90.0% and 64.3%, respectively). Figure 3 in Chapter 3 provides full details on the comparison between anticipated and realized perseverance time. It appeared that informal carers who indicated a limited perseverance time of less than one year were able to make a reliable prediction of actual perseverance time. For instance, of all informal carers who indicated a perseverance time of less than one year (at $t = 0$), 80% of the persons with dementia were no longer living at home within that year because they had been admitted (67% at $t = 1$) or had died (33% at $t = 1$).

Research question 4 (Chapter 4):

Can different profiles of caregiving be distinguished, and how do these relate to perseverance time?

In Chapter 4, we used Q-methodology to distinguish carer profiles. A subsample of 53 informal carers was presented with a representative set of statements covering aspects of informal caregiving for someone with dementia, and these carers were asked to rank these statements. This method of ranking enables the respondents to give their opinion about and attitude towards caregiving.

We identified five distinct profiles: (1) Carers who cope well with providing care, (2) Carers who would like to receive help with providing care, but at the same time want to remain in control of the care process, (3) Carers who find it quite demanding to maintain the level of care needed, but who get a lot of help and support from their family and friends, (4) Carers who experience their task of caregiving as very demanding and who do not receive much support from family

and friends, (5) Carers who can barely cope with providing the care required by their relative with dementia.

These profiles also show that informal carers experience a number of dilemmas in performing their care tasks. Moreover, we found a strong association between the identified profiles and the perseverance time indicated by the informal carers. Carers in Profile 1, for example, indicated a longer perseverance time (27.6 months) than those in Profile 5 (14.6 months). In the appendix to Chapter 3, we confirmed that the profiles differed significantly from each other in terms of perseverance time. In this appendix, Figure 1b illustrates the differences in profile scores of informal carers at home at $t = 1$ and $t = 2$ ($n = 44$). After one year of caregiving, a trend from Profile 2 to 4 and 5 and from Profile 4 to 5 can be observed.

Research question 5 (Chapter 5):

How do spouses experience the decision to place their partner with dementia in a nursing home?

Fourteen partners of persons with dementia were interviewed in order to evaluate the nursing home placement. They were interviewed at home using a semi-structured questionnaire. Based on grounded theory, we used the constant comparative method to explore the process of decision making regarding nursing home placement. This study showed that this decision was taken in two distinct steps. The first step entailed the decision to place the person with dementia on a waiting list for a nursing home. The second step related to the decision of actual placement. This decision was normally taken by informal carers when a place in a nursing home became available. Informal carers experienced placement as coming at the right time, too early, too late, or as the result of a crisis situation.

This study generated knowledge on placement practices (in the Dutch context) and its effects on the burdening (and overburdening) and perseverance time of informal carers. If an aim of policy is to increase the perseverance time of informal carers, it would seem important to better monitor their willingness and ability to continue informal care provision. Admission processes that are oriented towards informal carers may ensure that admissions take place at the right time, and make this process easier.

Research question 6 (Chapter 6):

How is the timing of placing persons with dementia in nursing homes related to the perseverance time of their informal carers?

To answer this research question in Chapter 6, we examined the informal care situation before and after the transition of the person with dementia to a nursing home in a sub-sample of 88 persons. Six months after the admission, informal carers reported that they could have persevered in providing care for another six months on average if the admission had not taken place. Partners of persons with dementia were better able to predict the end of their perseverance time than other informal carers.

Retrospective Perseverance time was associated positively with characteristics of informal carers: male gender, health, and still feeling an informal carer after admission. Perseverance time associated negatively with living in the same house with the relative with dementia and subjective burden. Crisis situations associated positively with the retrospective perseverance time.

To answer the research question, we defined a 'right-time' placement in cases where informal carers reported a retrospective perseverance time of less than one month (= 47%). This would imply that in 53% of the cases, admission could have been postponed.

Having discussed now the six research questions we come now to a short answer to the overall research question.

The joint research question the studies presented here is to explore the, feasibility, validity, and added value of perseverance time, both as a concept and as a measure within the context of decision making in dementia care.

Our operationalization of the concept of perseverance time was understandable for informal carers. The convergent and content validity of the instrument appeared to be reasonably strong. This study validated both the concept and the measure of perseverance time for the first time.

The results of these studies suggest that perseverance time may help with decision making to prevent the overburdening of informal carers, to provide timely support, and to prevent crisis admissions to nursing homes. Nonetheless, we emphasize the need for future research in order to replicate these findings.

7.2. Limitations and methodological considerations

Sample

The sample of this cross-sectional study was limited in terms of numbers, scope, and geography. Larger, longitudinal, studies are required to investigate whether our results can be confirmed and also generalized to other settings. This thesis is on informal care within the context of dementia. Studying perseverance time within the context of other chronic diseases would be valuable as well.

In our study we made no distinction between different types of dementia, and we used limited variables to characterize dementia. For further research we recommend specific instruments such as the Clinical Dementia Rating scale [Hughes et al., 1982] and the Neuropsychiatric Inventory Questionnaire [Cummings et al., 1994]. It could be interesting to investigate how the staging and symptoms of dementia are associated with perseverance time. This might also provide more clues for preventing the overburdening of informal carers and persons with dementia.

Formal carers were not involved in this study, and were not asked to estimate the perseverance time of the informal carers they supported. In practice, it could be useful to match the informal carer's estimate of perseverance time with the estimate of a formal carer (also in interactions between the two) in order to provide appropriate support.

Identifying informal carers of persons with dementia for scientific research can be difficult, especially because they are not registered in the databases of health care facilities or insurance companies. Often, they can only be approached through persons with dementia, who (at least when they are in the more advanced stages of dementia) may be listed in such databases. The response rate in informal care research is often low, and may be even lower when using this indirect approach to carers. It would be helpful if health care facilities would also register the main informal carer of the person with dementia. This is important not only for scientific research, but can also prove helpful in practice and result in better management of the care situation.

In this study we focussed primarily on following, over time, informal carers who care for their relatives with dementia living at home. Our sampling strategy resulted in a sample of informal carers of persons with dementia who had been diagnosed with dementia three years earlier on average. Hence, we expected

that the included carers would be caring for persons in relatively advanced stages of dementia. This may explain why a high proportion of the study population was admitted to nursing homes or died. This course made it possible to investigate differences in care situations between persons with dementia living at home and persons admitted to a nursing home. We did not specifically examine the situations of informal carers of persons with dementia who died during the two-year follow-up study. This remains an important area for future research.

The study on profiles of caregiving described in Chapter 4 was conducted in a subsample of carers who lived in the same house as the person with dementia. However, the Q-set was developed on the basis of opinion statements from carers, regardless of the living arrangements. Further research should show whether the profiles described in Chapter 4 also apply to carers who are not living in the same house as the person with dementia.

Methodology

The perseverance time of informal carers can be operationalized and explored in several ways. In our study, perseverance time was operationalized in a very direct way by asking informal carers of persons with dementia how long they expected to be able to cope with their current care tasks. Importantly, the question about perseverance time was asked under the assumption that respondents would consider the period they could continue to provide care '*if the caregiving situation remains as it is now*'. We considered the addition of this assumption to be important within the context of a progressive illness such as dementia. Without this description, the answers would be more difficult to compare because of different expectations regarding the progression of the illness and what this would imply for caregiving. Still, health care professionals must consider the indicated perseverance time against the background of this question. In principle, the actual perseverance time can usually be expected to be shorter than the observed perseverance time, as the care situation is likely to worsen over time and the caregiving will put more of a strain on carers as a consequence. Therefore, if used in practice, it would be advisable for health care professionals to monitor and carefully interpret perseverance time.

In our study, perseverance time was measured by several answer categories ended with the open-ended answer category of 'more than two years'. A more precise estimate of the perseverance time in that last category (e.g. an estimate in months) could be an alternative that could further distinguish between informal

carers in this category. However, the information value of this precision is unclear, since we found the 'predictive value' of this answer category to be low. Hence, at this stage of development of the instrument, we recommend the use of the same answer categories for perseverance time to allow comparisons across studies and to confirm the validity of the perseverance time measure used here in further research.

In Chapter 5, 14 partners of persons with dementia were asked about their experiences with placing their relative with dementia in a nursing home from the perspective of perseverance time. The interviews took place about 18 months after the admission, which may be considered to be relatively late and may introduce recall bias. While partners indicated having a good recollection of the event (i.e. they could remember events related to the placement 'as if they happened only yesterday'), we consider the timing of the interview to be a limitation of our study. Hence, to minimize recall bias, we recommend that future studies evaluate placements sooner after the actual event.

In Chapter 6, informal carers could have overestimated their possibilities to continue their care for their relative with dementia. Complex feelings of loss, guilt, shame, blame, and regret are likely to influence the way they answered. Nonetheless their answers should be interpreted as an important signal for nursing homes to realise a more informal carer friendly admission process.

To study the convergent validity of the perseverance time measure in Chapter 2, subjective burden, measured by the SRB, showed a stronger correlation with perseverance time than the subjective burden, measured by the CSI. This may be explained by the fact that the CSI provides an unweighted sum score of perceived problems in caring, while the SRB is an overall (subjectively weighted) assessment of the care situation that may also include positive experiences. Happiness was significantly associated with the perseverance time measure, but less strongly than with subjective burden. An explanation for this may be that happiness is a much broader concept than perseverance time.

7.3. Implications for practice

Although formal carers did not participate in this study, the instrument and results presented here may be useful for health care practice. We will discuss some of the potential uses and implications here, without attempting to be exhaustive. Moreover, we would like to stress that more research is needed before large-scale applications of the perseverance time instrument can be recommended.

Perseverance time and profiles of informal carers

The perseverance time question may help to address the current and future needs of informal carers, the availability of timely support to prevent overburdening, and timely admissions to nursing homes. It can provide formal carers with an indication of the urgency with which additional support should be arranged. Especially when respondents indicate a perseverance time of less than a month, this appears to signal a need for support. Most of the crisis admissions took place within a perseverance time of less than six months. The monitoring of perseverance time by formal carers may be a useful tool for preventing crisis situations.

The predictive value is less clear when respondents indicate a perseverance time of more than two years, and, once again, it would be worthwhile to further investigate the caring capacities of the individuals involved. When a perseverance time of less than one year is indicated, our results suggest that actual admission to a nursing home (or the death of the person with dementia) indeed often takes place within a year.

Moreover, the caring profiles we developed may help to assess actual care situations. The profile of an individual care situation can be assessed by inviting the informal carer to complete the response sheet (see Chapter 4).

Differences between care settings

Care settings can differ, with important implications for burden and perseverance time. For instance, the informal carers in this study who lived with their relative with dementia (usually partners) were heavily involved in caregiving ('caregiving round the clock'), had fewer opportunities for respite, gave up more hobbies, and felt overburdened more frequently than informal carers who lived elsewhere. Informal carers who lived elsewhere (usually the children of persons with

dementia) were more frequently employed and had more opportunities for respite, which may make the care less burdensome. Informal carers who lived with their relative with dementia seemed better able to predict the end of their perseverance time than other informal carers.

Social participation

Informal carers sometimes reduced their paid working hours so they could provide care. Contrary to what one might expect, informal carers who had adjusted their working time downwards still indicated a lower perseverance time than informal carers who had not. Similar effects were also found for reductions in other forms of social participation, such as voluntary work and hobbies. Therefore, such adjustments may indicate a need for extra support rather than increased perseverance time. In this study, giving up hobbies or working hours seemed to indicate that the end of their perseverance time was approaching, and professional carers should therefore heed these signals so that they can provide timely support for informal carers. The interaction between providing informal care and social participation appears to be an important area for future research.

Admission process

This study suggests that nursing home professionals may view the timeliness of admissions differently than informal carers. Greater involvement of informal carers in the decision-making process regarding the nursing home placements of their relatives with dementia may be a way to avoid placements that are viewed as coming too late or too early. A particularly important goal is to avoid crisis admissions, which have a strong impact on persons with dementia and carers.

Cooperation between home care organizations and nursing homes can prevent discontinuity in the support given to informal carers. Nursing homes should provide informal carers with the time and space to consider (or reconsider) their decisions regarding the admission of their relative with dementia; this could lead to more placements that are considered to be timely.

While it is not surprising to find a reduction in the subjective burden of informal care after admission, it is important to emphasize that in this study we also found a (limited) decrease in well-being and perceived health after admission. The latter effects appear to reveal something about the impact the admission of the

person with dementia has on informal carers. Future research could investigate whether such effects could be mitigated (for example, by nursing homes) by providing support to informal carers after admission. Also, carers often continue to be involved in the care for their relative after admission [Hoefman et al., 2011]. Nursing homes may welcome the participation of informal carers in nursing home care and this could have a positive influence on the well-being of informal carers, but this needs to be investigated further.

Implementation

Because of the practical significance of perseverance time mentioned here, an insurance company in the Netherlands has added perseverance time to their monitoring toolkit for case managers in dementia care to improve the quality of life of persons with dementia and their informal carers [Kroon, 2013]. We recommend that future research should evaluate the use and contribution of perseverance time in practice.

7.4. Future research

This thesis we introduced the new concept of the perseverance time of informal carers in dementia care. Although the first results regarding the feasibility and validity of perseverance time were encouraging, caution is warranted in generalizing these results, given the afore mentioned limitations of the studies presented here. As we mentioned earlier, our results remains to be confirmed in new studies.

Specifically, in addition to the issues referred to above, we recommend the following areas for future research:

- Larger, longitudinal, studies are required to investigate whether our results can be generalized to dementia care and other chronic diseases.
- We recommend performing a follow-up study to investigate the relationship between perseverance time and the stages and symptoms of dementia. This may provide more information that could help to prevent such things as the overburdening of informal carers.
- In our study, we operationalized the concept of perseverance time in a very direct way by asking informal carers how long they expected to be able to continue their current care tasks. It would be interesting to investigate the impact of different types of support on the caregiving and skills of informal carers, and by extension, the impact this has on their perseverance time.
- We recommend that an additional study using Q-methodology be conducted among informal carers who do not live in the same house as the person with dementia. Profiles of caregiving for these informal carers could help to improve the support provided to them, thus preventing overburdening.
- Previous longitudinal studies (such as Pot et al., 1995; Garity, 1997; Gaugler et al., 2007) have documented how informal carers of persons with dementia may adapt to their role. This phenomenon can be characterized as an '*informal carer trap*' (in Dutch: '*mantelval*') [Timmermans et al., 2005]. The concept of perseverance time may be able to help quantify this adaptation process. Follow-up studies are needed to create more awareness of and knowledge on this adaptation process and its consequences for caregiver burden and perseverance time.
- In our study, most of the crisis admissions in nursing homes took place in situations where the indicated perseverance time was less than six months.

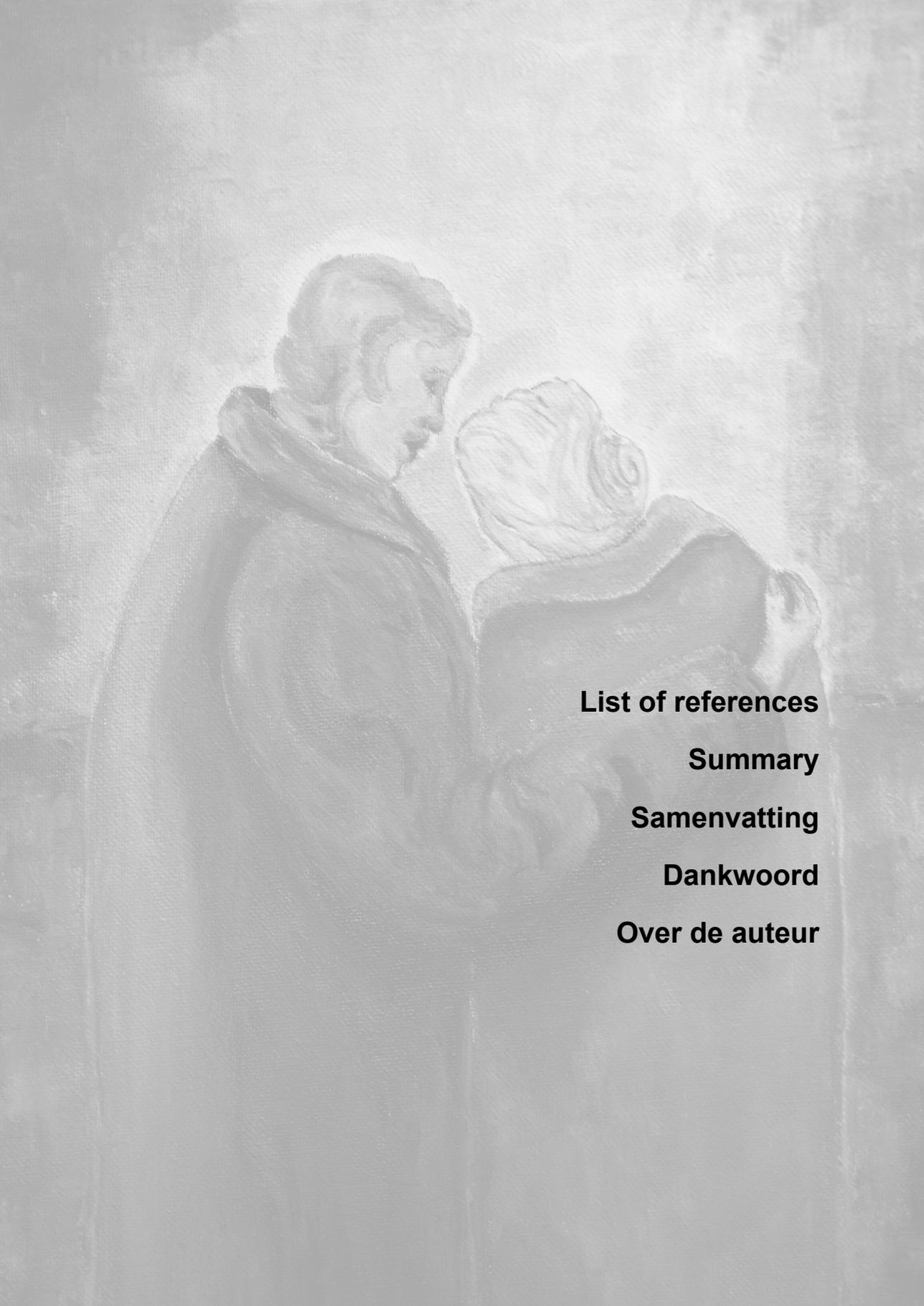
Monitoring of perseverance time by health care professionals could help to prevent such situations. Future studies could be aimed at increasing knowledge on crisis admissions (in relation to perseverance time).

7.5. Conclusion

The overall research question of this thesis was to explore the feasibility, validity, and added value of perseverance time, both as a measure and as a concept within the context of decision making in dementia care. Because of the limitations of the studies presented here and the fact that this thesis has presented only the first explorations of these issues, this thesis cannot provide definitive answers to the related research questions. Still, our results suggest that both feasibility and validity of perseverance time as a concept and as a measure are favourable within the context of informal care for persons with dementia. The way we chose to operationalize perseverance time provided a direct way of investigating how long informal carers can continue their current informal care tasks. In addition to its relevance for research in the field of informal care, the measure may also prove useful in practice in providing timely support to informal carers.

In closing

The basic motivation for this thesis was to develop both a concept and a measure that could help to predict when informal carers of persons with dementia would no longer be able to provide this care, with the aim of preventing overburdening and crisis situations that lead to emergency admissions of persons with dementia. While many questions remain unanswered, we hope that this thesis will contribute to this ultimate goal.



List of references

Summary

Samenvatting

Dankwoord

Over de auteur

LIST OF REFERENCES

- Abendroth, M., Lutz, B.J., Young, M.E. (2012). Family caregivers decision process to institutionalize person with Parkinson's disease: A grounded theory study. *International Journal of Nursing Studies*, 49: 445-454.
- Acton, G.J., Kang, J. (2001). Interventions to Reduce the Burden of Caregiving for an Adult With Dementia: A Meta-Analyses. *Research in Nursing & Health*, 24: 349-360.
- Agree, E.M., Glaser, K. (2009). Demography of Informal Caregiving. *International Handbook of Population Aging*, 1(4): 647-668. Springer, Dordrecht.
- Akpinar, B., Küçükgülü, Ö., Tener, G. (2011). Effects of Gender on Burden Among Caregivers of Alzheimer's Patients. *Journal of Nursing Scholarship*, 43(3): 248-254.
- Al-Janabi, H., Frew, E., Brouwer, W. van Exel, J. (2010). The inclusion of positive aspects of caring in the Caregiver Strain Index: Test of feasibility an validity. *International Journal of Nursing Studies*, 47: 984-993.
- Almberg, B., Grafström, M., Winblad, B. (1997). Caring for a demented elderly Person-burden and burnout caregivers relatives. *Journal of Advanced Nursing*, 25: 109 – 116.
- Andrén, S., Elmståhl, S. (2008). Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 month. *Scandinavian Journal Caring Science*, 22: 98-109.
- Annerstedt, L., Elmståhl, S., Ingvad, B., Samuelsson, S. (2000). Family caregiving in dementia. An analyses of the caregiver's burden and "breaking-point" when home care becomes inadequate. *Scandinavian Journal of Public Health*, 28: 23-31.
- Arai, Y., Zarit, S.H., Sugiura, A., Washio, M. (2002). Patterns of outcome of caregiving for the impaired elderly: a longitudinal study in rural Japan. *Ageing & Mental Health*, 6(1): 39-46.
- Baarda, D.B., de Goede, M.P.M., Teunissen, J. (2005). Basisboek Kwalitatief Onderzoek. 2^egeheel herziende druk. Stenfert Kroeze. 2005; ISBN 90 207 3179 3.
- Bailey, G. (2014). Personalization and Dementia: A guide for Person- Centred Practice. HAS-Press, ISBN 978 1 84905 379 2.
- Baker, R.M. (2006). Economic rationality and health and lifestyle choices for people with diabetes. *Social Science & Medicine*, 63(9): 2341-2353.
- Baker, K.L., Robertson, N. (2008). Coping with caring for someone with dementia: Reviewing the literature about men. *Ageing and Mental Health*, 12(4): 413-422.
- Bakker, C., de Vugt, M.E., van Vliet, D., Verhey, F.R.J., Pijnenburg, Y.A., Vernooij-Dassen, M.J.F.J., Koopmans, R.T.C.M. (2013). The Use of Formal and Informal Care in Early Onset Dementia: Results From the Need YD Study. *American Journal of Geriatrics Psychiatry*, 21(1): January 2013.
- Berg van den, B., Brouwer, W., van Exel, J., Koopmanschap, M., van den Bos, G.A.M., Rutten, F. (2006). Economic valuation of informal care: Lessons from the application of the opportunity costs and proxy good methods. *Social Science and Medicine*, 62: 835-845.

- Bianchetti, A., Trabucchi, M. (2001). Clinical aspects of Alzheimer's disease. *Aging*, 13(3): 221-230.
- Boeijs, H. (2005). *Analyseren in kwalitatief onderzoek*. Meppel: Boom. ISBN 978 90 850 6078 9.
- Bobinac, Ana., Van Exel, N. Job. A., Rutten, Frans F.H., Brouwer, Werner. B.F. (2010). Caring for and caring about: Disentangling the caregiver effect and the family effect. *Journal of health Economic*, 29: 549-556.
- Bobinac, Ana., Van Exel, N. Job. A., Rutten, Frans F.H., Brouwer, Werner, B.F. (2011). Health Effects in Significant Others: Separating Family and Caregiving Effects. *Medical Decision making*, 31: 292-298.
- Borsje, P., Wetzels, R.B., Lucassen, P.L.B.J., Pot, A., Koopmans, R.T.C.M. (2014). Neuropsychiatric symptoms in patients with dementia in primary care: a study protocol. *BMC Geriatrics*, 14: 32
- Brown, S.R. (1980). *Political subjectivity: Applications of Q-methodology in political science*. Yale University Press.
- Brown, S.R. (1993). A primer on Q-methodology. *Operant Subjectivity*, 16(3/4): 91-138.
- Bussemaker, J. (2008). Zorg voor mensen met Dementie. *Brief Staatssecretaris VWS van 17 juni 2008, kenmerk: DLZ/KZ-U-2853804*.
- Bryant, L.D., Green, J.M. & Hewison, J. (2006). Understanding of Down's syndrome: A Q-methodological investigation. *Social Science & Medicine*, 63(5): 1188-1200.
- Brouwer, W.B.F., Van Exel, N.J.A., Koopmanschap, M.A., Rutten, F.F.H. (1999). The validation of informal care in economic appraisal; a consideration of individual choice and social costs of time. *International Journal of Technology Assessment in Health Care*, 15(1): 147-160.
- Brouwer, W.B.F., van Exel, N.J.A., van den Berg, B., Dinant, H.J., Koopmanschap, M.A., van den Bos, G.A.M. (2004). Burden of Caregiving: Evidence of Objective Burden, and Quality of Life Impacts on Informal Caregivers of Patients With Rheumatoid Arthritis. *Arthritis & Rheumatism (Arthritis Care & Research)*, 51(4): 570-577.
- Brouwer, W.B.F., van Exel, N.J.A., van Gorp, B., Redekop, W.K. (2006). The CarerQol instrument: A new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. *Quality of Life Research*, 15: 1005-1021.
- Caldwell, L., Low, L-F, Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *International Psychogeriatrics*, 26(3): 413-424.
- Callahan, C.M., Boustani, M.A., Weiner, M., Beck, R.A., Livin, L.R., Kellams, J.J., Willis, D.R., Hendrie, H.C. (2011). Implementing dementia care models in primary care settings: The Aging Brain Care Medical Home. *Aging and Mental Health*, 15(1): 5-12.
- Campbell, P., Wright, J., Oyebode, J, Job, D, Crome, P., Bentham, P., Jones, L., Lendon, C. (2008). Determinants of burden in those who care for someone with dementia. *International Journal of Geriatric Psychiatry*, 23: 1078-1085.

- Caron, C.D., Ducharme, F., Griffith, J. (2006). Deciding on Institutionalization for a relative with Dementia: The most Difficult Decision for Caregivers. *Canadian Journal on Aging*, 25(2): 193-205.
- Chang, Y., Schneider, J.K. (2010). Decision-Making Process of Nursing Home Placement Among Chinese Family Caregivers. *Perspectives in Psychiatry*, 46(2): 108-118.
- Clyburn, L.D., Stones, M.J., Hadjistavropoulos, T., Tuokko, H. (2000). Predicting Caregiver Burden and Depression in Alzheimer's Disease. *Journal of Gerontology*, 55B(1): S2-S13.
- Cocenas-Silva, R.; Bueno, J.L.O., Droit-Volet, S. (2012). *Memory and Cognition*. 40(2): 161-167.
- Coehlo, D.P., Hooker, K., Bowman, S. (2007). Institutional placement of persons with dementia: what predict occurrence and timing? *Journal of Family Nursing*, 13: 253-277.
- Cohen, C.A., Gold, D.P., Schulman, K.I., Wortley, J.T., McDonald, G., Wargon, M. (1993). Factors determining the decision to institutionalize dementing individuals. A prospective study. *Gerontologist*, 33(6): 714-720.
- Corcoran, M.A. (1994) Management Decisions Made by Caregiver Spouses of Persons With Alzheimer's Disease. *The American Journal of Occupational Therapy*, 28(1): 38-45.
- Cross, R.M. (2005). Exploring attitudes: the case for Q-methodology. *Health Education Research*, 20(2): 206-213.
- Coehlo, D.P., Hooker, C., Bowman, S. (2007). Institutional Placement of persons With Dementia; What Predicts Occurrence and Timing. *Journal of Family Nursing*, 13(2): 253-277.
- Colombo, F. et al. (2011). Help Wanted? Providing and Paying for Long-Term Care. *OECD Health Policy Studies*, OECD Publishing. <http://dx.doi.org/10.1787/9789264097759-en>.
- Connor, K.I., McNeese-Smith, D.K., Vickrey, B.G., Servellen van, G.M., Chang, B.L., Lee, M.L., Vassar, S.D., Chodosh, J. (2008). Determining Care Management Activities with Mastery and Relationship Strain for Dementia Caregivers. *The American Geriatric Society*, 56(5): 891-897.
- Coon, D.W. (2012). Resilience in family caregiving. *Annual review of Gerontology and Geriatrics*, Chapter 12: 231-249.
- Cooper, C., Balamurali, T.B.S., Selwood, A., Livingston, G. (2007). A systematic review of intervention studies about anxiety in caregivers of people with dementia. *International Journal of Geriatric Psychiatry*, 22: 181-188.
- Cummings, J.L., Mega, M., Gray, K., Rosenberg-Thompson, S., Carusi, D.A., Gornbein, J. (1994). The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology*, 44: 2308-2314.
- Davies, S., Nolan, M. (2003) 'Making the best of things': relatives' experiences of decisions about care-home entry. *Aging and Society*, 23(4): 429-450.
- Dilworth-Anderson, P., Williams, I.C., Gibson, B.E. (2002). Issues of Race, Ethnicity and Culture in Caregiving Research: A 20-Year Review (1980-2000). *The Gerontological Society of America*, 42(2): 237-272.
- Mc. Donnell, E, Ryan, A. (2013). Male caregiving in dementia: A review and commentary. *Dementia*, 12(2): 238-250.

- Donovan, R., Williams, A., Stajduhur, K., Brazil, K., Marchall, D. (2011). The influence of culture on home-based family caregiving at end-of-life: A case study of Dutch reformed family care givers in Ontario, Canada. *Social Science & Medicine*, 72: 338-346.
- Ducharme, F., Couture, M., Lamontagne, J. (2012). Decision-making process of family caregivers regarding placement of a cognitive impaired elderly relative. *Home health Care Services Quarterly*, 31(3): 197-218.
- Durme van, T., Macq, J., Jeanmart, C., Gobert, M. (2012). Tools for measuring the impact of informal caregiving of the elderly: A literature review. *International Journal of Nursing Studies*, 49: 490-504.
- Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., et al. (2005). Alzheimer's Disease International. Global prevalence of dementia: a Delphi consensus study. *Lancet*, 366(9503): 2112-7.
- Ferri, C.P., Prince, M., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., et al. (2005). Global Prevalence of Dementia: a Delphi consensus study. *The Lancet*, 366: 2112-2117.
- Fjelltun, A., Hendriksen, N., Norberg, A., Gilje, F., Norman, H.K. (2009). Functional levels and nurse workload of elderly awaiting nursing home residents: a comparative study. *Scandinavian Journal of Caring Science*, 23: 736-747.
- Garcia-Alberca, J.M., Vruz, B., Lara, L.P., Carrido, V., Lara, A., Gris, E. (2012). Anxiety and depression are associated with coping strategies in caregiving of Alzheimer's disease patients: results from the MALAGA-AD study. *International Psychogeriatrics*, 24(8): 1325-1334.
- Garity, J. (1997). Stress, learning style, resilience factors, and ways of coping in Alzheimer family caregivers. *American Journal of Alzheimer's Disease*, 12: 171-178.
- Garity, J. (June 2006). Caring for a Family Member with Alzheimer's Disease: Coping with Caregiver burden Post-Nursing Home Placement. *Journal of Gerontology and Nursing*, 39-48.
- Gallicchio L., Siddiqi N., Langenberg P. (2002). Gender difference in burden and depression among informal caregivers of demented elders in the community. *International Journal of Geriatric Psychiatry*, 17: 154-163.
- Gaugler, J.E., Davey, A., Pearli, L.I., Zarit, S.H. (2000). Modelling caregiver adaption over time. The longitudinal impact of behaviour problems. *Psychology and Aging*, 15: 437-450.
- Gaugler, J.E., Kane, R.L., Kane, R.A., Rosalie, M.D., Kane, A., Clay, T., Newcomer, R. (2003). Caregiving and Institutionalization of Cognitively Impaired Older People: Utilizing Dynamic Predictors of Change. *The Gerontologist*, 43(2): 219-229.
- Gaugler, J.E., Kane, R.L., Newcomer, R. (2007). Resilience and Transition From Dementia Caregiving. *Journal of Gerontology: Psychological Sciences*, 62B (1): 38-44.
- Gaugler, J.E., Pot, A.M., Zarit, S.H. (2007). Long-term Adaption to Institutionalization in Dementia Caregivers. *The Gerontologist*, 47(6): 730-740.
- Gaugler, J.E., Yu, F., Krichbaum, K., Wyman, J.F., (2009). Predictors of Nursing Home Admission for Persons with Dementia. *Medical Care*, 47: 191-198.

- Gaugler, J.E., Mittelman, M.S., Hepburn, K., Newcomer, R. (2010). Clinically significant changes in burden and depression among dementia caregivers following nursing home admission. *BMC-Medicine*, 8(85).
- Gaymu, J., Ekamper, P., Beets, G. (2008). Future trends in health and marital status: effects on the structure of living arrangements of older Europeans in 2030. *European Journal Aging*, 5: 5-17.
- Gezondheidsraad. (2002). Dementie. Den Haag: Gezondheidsraad, publicatie nr. 2002/04.
- Gitlin, L.N., Corcoran, L., Winter, L., Boyce, A., Marcus, S. (1999). Predicting Participation and Adherence to a Home Environmental Intervention among Family Caregivers of Persons with Dementia. *Family relations*, 48(4): 363-372.
- Glaser, B.G., Strauss, A.L. (1967). The discovery of grounded theory: *Strategies for qualitative research*. New York: Aldine De Gruyter.
- Graham, C., Ballard, C., Sham, P. (1997). Carers' knowledge of dementia, their coping strategies and morbidity. *International Journal of Geriatric Psychiatry*, 12: 931-936.
- Groenewoud, H., Lange de, J. (2009). Key issues in transitional care for people with dementia and their caregivers facing institutionalization. *International Journal of Integrated Care*, 9: 31 December 2009.
- Grossfeld-Schmitz, M., Donath, C., Holle, R., Lauterberg, J., Ruckdaeschel, S., et al. (2010). Counsellors contact dementia caregivers-predictors of utilisation in a longitudinal study. *MBC Geriatrics*, 10: 24.
- Grunfeld, E., Glossop, R., McDowell, I., Danbroek, C. (1997). Caring for elderly people at home: The consequences to caregivers. *Canadian Medical Association Journal*, 157(8): 1101-1105.
- Health Council of The Netherlands. The Hague: Health Council of The Netherlands. (2002); Publication 2002/04E. ISBN 90-5549-453-4.
- Hoefman, R.J., van Exel, N.J.A., Foets, M., Brouwer, W.B.F. (2011). The impact of informal care in the context of institutionalised patients. *Aging & Mental Health*, 15(8): 1018-1027.
- Hoefman, R.J., van Exel, N.J.A., de Jong, S.L., Redekop, W.K., Brouwer, W.B.F. (2011). A new test of the construct validity of the CarerQol instrument: measuring the impact of informal caregiving. *Quality Life Research*, 20: 875-887.
- Hoefman, R.J., Van Exel, N.J.A., Brouwer, W.B.F. (2011). iMTA Valuation of Informal Care Questionnaire (iVICQ). Version 1.0 (December 2011). Rotterdam: iBMG / iMTA, 2011. [retrieved from www.bmg.eur.nl/english/imta/publications/manuals_questionnaires/ on 10/11/2012].
- Hoefman, R., van Exel, J., Rose, J., van de Wetering, L., Brouwer, W. (2014). A Discrete Choice Experiment to obtain a tariff for valuing informal care situations measured with the CarerQol instrument. *Medical Decision Making*, 34: 84-96.
- Hope, T., Keene, J., Gedling, K., Fairburn, C.G., Jacoby, R. (1998). Predictors of Institutionalization for people with dementia living at home with a caregiver. *International Journal of Geriatric Psychiatry*, 13: 682-690.
- Hopkins, W.G. (2010). A new view of statistics: effect magnitudes. Retrieved from <http://www.sportsci.org/resource/stats/effectmag.html>.

- Hughes, C., Berg, L., Danziger, W., Coben, L.A., Martin, R.L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry*, 140: 566-572.
- Jansson, W., Nordberg, R.N., Grafström, R.N.T. (2001). Patterns of elderly spousal caregiving in dementia care: an observational study. *Issues and innovations in the nursing practice*: 804-811.
- Jansson, I., Pilhammar, E., Forsberg, A. (2009). Obtaining a Foundation for Nursing Care at the Time at the Time of Patient Admission: A Grounded Theory Study. *The Open Nursing Journal*, 3: 56-64.
- Jedeloo, S., Van Staa, A., Latour, J.M., Van Exel, N.J.A. (2010). Preferences for Health and Self-Management among Dutch Adolescents with Chronic Conditions: a Q-Methodological Investigation. *International Journal of Nursing Studies*, 47(5): 593-603.
- Kneebone, I.I., Martin, P.R. (2003). Coping and caregivers of people with dementia. *British Journal of Health Psychology*, 8: 1-17.
- Kodner, D.L. (2006). Whole-system approaches to health and social partnership for the frail elderly: an exploration of North American models and lessons. *Health and Social Care in the Community*, 14(5): 384-390.
- Koopmanschap, M.A., Van Exel, N.J.A., van den Berg, B., Brouwer, W.B.F. (2008). An Overview of Methods and Applications to Value Informal Care in Economic Evaluations of Healthcare. *PharmacoEconomics*, 26(4): 269-280. *in the Community*, j1365-2524.
- Kraijo, H. (2006). Mantelzorgers vertellen hun verhaal. Deelrapportage in het kader van het Landelijk Dementie Project 2004-2008.
- Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., van Exel, J. (2012). Coping with caring: Profiles of caregiving by informal carers living with a loved one who has dementia. *Dementia*, 11(1): 113-130.
- Kraijo, H., Brouwer, W., de Leeuw, R., Schrijvers, G., van Exel, J. (2014). The perseverance time of informal carers of dementia patients: validation of a new measure to initiate transition of care at home to nursing home care. *Journal of Alzheimer's Disease*, 40: 631-642.
- Kraijo, H., Brouwer, W., van Exel, J. (2014). Perseverance Time of informal carers for relatives with dementia: results of a two year follow-up study. Submitted paper.
- Kraijo, H., de Leeuw, R., Schrijvers, G. (2014). Right Time Transition of dementia patients to a nursing home in informal carers' point of view: A longitudinal study of perseverance time. Submitted paper.
- Kraijo, H., de Leeuw, R., Schrijvers, G. (2014). How spouses evaluate Nursing Home Placement of their demented partner: a study about the end of perseverance time. *Scandinavian Journal of Caring Science*, doi: 10.1111/scs 12137.
- Kreuger, L., van Exel, N.J.A. & Nieboer, A. (2008). Needs of persons with severe intellectual disabilities: a Q-methodological study of clients with severe behavioural disorders and severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 21(5): 466-476.
- Krista Kroon. (2013). Werken in netwerkketens: De winst voor de patiënt. *Achmea periodiek*, (05) juni 2013.

- Kruse, B.G. (2006). The Meaning of Perseverance. Caregiving Stories of Courage Furring Recent Hurricanes. *Journal of Hospice and palliative Nursing*, 8(6): 338-345.
- Lange de, J. &, Poos, M.J.J.C. (2007). Neemt het aantal mensen met dementie toe of af? In: Volksgezondheid Toekomst Verkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM, <<http://www.nationaalkompas.nl>>.
- Latour, H.M., van der Windt, A.W.M., de Jonge, P., Riphagen, I.I., de Vos, R., Huyse, F.J., Stalman, W.A.B. (2007). Nurse-led case management for ambulatory complex patients in general health care: A systematic review. *Journal of Psychosomatic Research*, 62: 385-395.
- Li, R., Cooper, C., Bradley, J., Shulman, A., Livingstaon, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: A systematic review and meta-analyses. *Journal of Affective Disorders*, 139: 1-11.
- Lilly, M.B., Robinson, C.A., Holtzman, S., Bottorf, J.L. (2011). Can we move beyond burden and burn-out to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia Canada. *Health and Social Care in the Community*, j1365-2524.
- Lin, M., MacLillan, M., Brown, N. (2011). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, 11(2): 181-197.
- Loeb, J.S. (2005). Perservance: Analyses of a Concept with Utility for Caregivers Research. *Journal of Theory Construction & Testing*, 9: 21-25.
- Luppa, M., Luck, T., Brähler, E., König, H.H., Riedel-Heller, S.G. (2008). Prediction of Institutionalization in Dementia. *Dementia and Geriatric Cognitive Disorders*, 26: 65-78.
- Luppa, M., Luck, T., Weyerer, S., König, H., Brähler, E. (2010). Prediction of institutionalization in the elderly. A systematic review. *Age and Aging*, 39: 31-38.
- Marcén, M., Molina, A.J. (2011). Informal caring-time and caregiver satisfaction. *Eur. J Health Econ*. 2001; published on line DOI: 10.1007/s10198-011-0322-2.
- Maslach, C., Jackson, S.E. (1981). The measurement of experienced burnout. *Journal of occupational behaviour*, 2: 99 – 113.
- Meiland, F.J.M., Dance, J.A.C., Wendte, J.F., Klazinga, N.S., Gunning-Schepers, L.J. (2001). Caring for relatives with dementia – Caregiver experience of relatives of patients on the waiting list for admission to a psychogeriatric nursing home in The Netherlands. *Scandinavian Journal Public Health*, 29: 113-121.
- Meiland, F.J.M., Dance, J.A.C., Wendte, J.F., Gunning-Schepers, L.J., Klazinga, N.S. (2002). Urgency coding as a dynamic tool in management of waiting list for psychogeriatric nursing home care in The Netherlands. *Health Policy*, 60: 171-184.
- Mesthenos, E., Triantafillou, J. (2005). Supporting Family Carers of Older People in Europe. The Pan-European Background Report. *Eurofamcare*, internet at <http://dnb.ddb.de>.
- Mittelman, M.S., Roth, D. L., Clay, O.J., Haley, W.E. (2007). Preserving Health of Alzheimer Caregivers: Impact of a Spouse Caregiver Intervention. *American Journal Geriatric Psychiatry*, 15(9): 780-789.
- Ministry of Health Well-being and Sport of the Netherlands (2013). Deltaplan Dementie.

- Morin, D., Saint-Laurent, S., Dallaire, C., Boucher-Dancause, G., Lalancette, S., Leblanc, N. (2007). Living in the community while waiting for an admission in long-term care: Satisfaction with a transitional nursing home project. *Journal of Nursing Care Quality*, 22(1): 66-72.
- Mundt, J., Lusch, R.F., (1997). Informal and Formal care of the Elderly: Decision Determinants and Their Implications. *Health Marketing Quarterly*, 14(3): 53-68.
- Murray, J., Schneider, J., Banerjee, S., Mann, A. (1999). Euro care: A cross-national study of co-resident spouse caregivers for people with Alzheimer's disease: II-a qualitative analysis of the experience of caregiving. *International Journal of Geriatric Psychiatry*, 14: 662-667.
- Nieboer, A.P., Koolman, X., Stolk, E.A. (2010). Preferences for long-term willingness to pay estimates derived from a derived a discrete choice experiment. *Social Science & Medicine*, 70(9): 1317-1325.
- Noël-Miller, C. (2010). Spousal Loss, Children, and the Risk of Nursing Home Admission. *Journal of Gerontology: Social Science* 65B(3): 370-380.
- Norton, M.C., Smith, K.R., Østbye, T., et al. (2010). Greater Risk of Dementia When Spouse Has Dementia? The Cache County Study. *Journal of the American Geriatrics society, Brief Reports*, 58: 895-900.
- Olsen, R.M., Hellzén, O., Enmarker, I. (2013). Nurses' information exchange during older patient transfer: prevalence and association with patient and transfer characteristics. *International Journal of Integrated Care*, 13: March.
- Pangalila, R.F., van den Bos, G.A.M., Stam, H.J., van Exel, N.J.A., Brouwer, W.B.F., Roebroek, M.E. (2012). Subjective caregiver burden in parents of adult men with Duchenne Muscular Dystrophy. *Disability and Rehabilitation*, 34: 988-996.
- Payakachat, N., Tilford, J.M., Brouwer, W.B.F, van Exel, N. J.A., Grosse, S.D. (2011). Measuring health and well-being effects in family caregivers of children with craniofacial malformations. *Quality of Life Research*, 20: 1487-1495.
- Peeters, J., Francke, A., van Beek, S. & Meerveld, J. (2007). Welke groepen mantelzorgers van mensen met dementie ervaren de meeste belasting? Resultaten van de monitor van het Landelijk Dementieprogramma (Factsheet 3). Utrecht, NIVEL.
- Peeters J., van Beek S. & Francke A. (2007). Problemen en wensen van mantelzorgers van mensen met dementie; Resultaten van de monitor van het Landelijk Dementieprogramma (Factsheet 2). Utrecht, NIVEL.
- Peeters, J.M., van Beek, P.A., Meerveld, H.C.M., Spreeuwenberg, M.M., Francke, A.L. (2010). Informal caregivers of person with dementia, their use of and needs for special professional support: a survey of the National Dementia Programme. *BMC-Nursing*, 9: 9.
- Penrod, J., Yu, F., Kolanowski, A., Fick, D.M., Loeb, S.J., Hupcey, J.E. (2007). Reframing Person Centered Nursing Care for Persons With Dementia. *Research Theory Nursing Practise*, 21(1): 57-72.
- Pimouguet, C., Lavaud, T., Dartigues, J.F., Helmer, C. (2010). Dementia case management effectiveness on health care costs and resource utilization : a systematic review of randomized controlled trials. *Journal of Nutrition Health & Aging*, 14(8): 669-676.
- Pinquart, M., Sörensen, S. (2005). Ethnic Differences in Stressors, Resources, and Psychological Outcomes of Family Caregiving: A Meta-Analysis. *The Gerontologist*, 45(1): 90-106.

- Pot, A.M., Deeg, D.J.H., Knipscheer, C.P.M. (2001). Institutionalization of demented elderly: the role of caregiver characteristics. *International Journal of Geriatric Psychiatry*, 16: 273-280.
- Pruchno, R.A., Michaels, J.E., Potashnik, S.L. (1990). Predictors of institutionalization among Alzheimer disease victims with care giving spouses. *The Journal of Gerontology*, 45: 259-266.
- Raina, P., McIntyre, C., McDowell, I., Santaguida, L., Kristjansson, B., Hendricks, A., Massfeller, H., Chambers, L., (2004). Understanding the influence of the complex relationships among informal and formal supporters on the well-being of caregivers of persons with dementia. *Canadian Journal of Aging*, 23: Suppl. 1: S49 - 59
- Razani, J., Kakos, B., Orieta-Barbalace, C., Wong, J.T., Casas, R., Lu, P., Alessi, C., Josephson, K. (2007). Predicting Caregiver Burden from Daily Functional Abilities of Patients with Mild Dementia. *The American Geriatrics Society*, 55: 1415-1420.
- Risdon, A., Eccleston, G., & McCracken, L. (2003). How can we learn to live with pain? A Q-methodological analysis of the diverse understandings of acceptance of chronic pain. *Social Science & Medicine*, 56: 375-386
- Robinson, B.C. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology*, 38(3): 344-8.
- Rosa, E., Lussignoli, G., Sabbatini, F., Chiappa, A., Cesare, S., Lamanna, L., Zanetti, O. (2010). Needs of caregivers of patients with dementia. *Archives of Gerontology and Geriatrics*, 51: 54-58.
- Ross, L., Holliman, D., Dixon, D.R. (2003). Resilience in family caregivers: Implication for social work practice. *Journal of Gerontological Social Work*, 40: 81-96.
- Ryan, A., Scullion, H.F. Nursing home placement: an exploration of the experiences of family carers. (2000). *Journal of Advanced Nursing*, 32(5): 1187-1195.
- Sadiraj, K., Timmermans, J., Ras, J., et al. (2009). De toekomst van de mantelzorg. *Den Haag Sociaal Cultureel Planbureau*.
- Schneider, J., Murray, J., Banerjee, S., Mann, A. (1999). Euro care: A cross-national study of co-resident spouse caregivers for people with Alzheimer's disease: I-factors associated with caregiver burden. *International Journal of Geriatric Psychiatry*, 14: 651-661.
- Schoenmakers, B., Buntinx, F., Devroey, D., van Casteren, V. (2009). The process of definitive institutionalization of community dwelling demented vs non demented elderly: data obtained from a network of sentinel general practitioners. *International Journal of Geriatric Psychiatry*, 24: 523-531.
- Schulz, R., Beach, S.R. (1999). Caregiving as a Risk Factor for Mortality. *American Medical Associations*, 282(23): 2215-2219.
- Smidt, S.R. (2012). Extraordinary memories for exceptional Events. *Psychology Press*.
- Smith, G.E., O'Brein, P.C., Ivnik, R.J., Kokmen, E., Tangalos, E.G. (2001). Prospective analysis of risk factors for nursing home placement of dementia patients. *Neurology*, 57: 1467-1473.
- Smith, N.W. Current systems in psychology. (2001). *History, theory, research and applications*. Wadsworth.

- Smits, C.H.M., de Lange, J., Dröes, R.M., Meiland, F., Vernooij-Dassen, M., Pot, A.M. (2007). Effects of combined intervention programmes for people with dementia living at home and their caregivers: a systematic review. *International Journal of Geriatric Psychiatry*, 22: 1181-1193
- Söderberg, M., Ståhl, A., Emilson, U.M. (2012). Family members' strategies when their elderly relatives consider relocation to a residential home – Adapting, representing and avoiding. *Journal of Aging Studies*, 26: 495-503.
- Spijker, A., Verhey, F., Graff, M. (2009). Systematic care for caregivers of people with dementia in the ambulatory mental health service: designing a multicentre, cluster, randomized, controlled trial. *BMC Geriatrics*, 9: 21.
- Stenner, P.H.D., Dancey, C.P. & Watts, S. (2000). The understanding of their illness amongst people irritable bowel syndrome: A Q-methodological study. *Social Science & Medicine*, 51(3): 439-452.
- Stephenson, W. (1935). Correlating persons instead of tests. *Character and Personality*. 4: 17-24.
- Strang, V.R., Koop, P.M., Dupuis-Blanchard, S., Nordstrom, M., Thompson, B. (2006). Family Caregivers and Transition to Long-term Care. *Clinical Nursing Research*, 15(1): 27-45.
- Strauss, A.L. (1987). Qualitative analyses for social scientists. New York: Cambridge University Press.
- Sullivan, M.T. (2003). Caregiver Strain Index. *Home Health Nurse*, 21(3): 197-198.
- Sury, L., Burns, K., Brodaty, H. (2013). Moving in: adjustment of people living with dementia going into a nursing home and their families. *International Psychogeriatrics*, 25(6): 867-876.
- Tielen, M., Van Staa, A., Jedeloo, S., van Exel, N.J.A., & Weimar, W. (2008). Q-methodology to identify young adult renal transplant recipients at risk for non-adherence. *Transplantation* 85(5): 700-706.
- Timmermans, J. Boer de, A., Iedema, J. (2005). De Mantelval: over dreigende overbelasting van mantelzorgers. *The Netherlands Institute for Social Research*, Work document 120, ISBN 90-377-0245-7.
- Van Exel, N.J.A., Scholte op Reimer, W.J.M., Brouwer, W.B.F., van den Berg, B., Koopmanschap, M.A. & van den Bos, G.A.M. (2004). Instruments for assessing the burden of informal care giving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. *Clinical Rehabilitation*, 18(2): 203-214
- Van Exel, N.J.A., Koopmanschap, M.A., van den Berg, B., Brouwer, W.B.F., van den Bos, G.A.M. (2005). Burden of Informal Caregiving for Stroke Patients. *Cerebrovascular Diseases*, 19: 11-17.
- Van Exel, N.J.A. & de Graaf, G. (2005). Q-methodology: A sneak preview. Available from www.qmethodology.net
- Van Exel, N.J.A., Moree, M., Koopmanschap, M.A., Schreuder-Goedheijt, T., Brouwer, W.B.F. (2006). Respite care: An explorative study of demand and use in Dutch informal caregivers. *Health Policy*, 78: 194-208.
- Van Exel N.J.A., Moree M., Koopmanschap M.A., Schreuder-Goedheijt T., Brouwer W.B.F. (2006). Respite care: An explorative study of demand and use in Dutch informal caregivers. *Health Policy*, 2006;78(2/3): 194-208.

- Van Exel, N.J.A., de Graaf, G. & Brouwer, W.B.F. (2006). Everyone dies, so you might as well have fun! Images of youths about their lifestyle. *Social Science & Medicine*, 63(10): 2628-2639.
- Van Exel, N.J.A., de Graaf G. & Brouwer, W.B.F. (2007). Care for a break? An investigation of informal caregivers' attitudes toward respite care using Q-methodology. *Health Policy*, 83(2/3): 332-342.
- Van Exel, N.J.A., de Ruiter, M., Brouwer, W.B.F. (2008). When time is not on your side... Patient experiences with waiting for home care and admission to a nursing or residential home. *The Patient*, 1(1): 55-71.
- Van der Poel K., van Beek A.P.A. (2006). Ontwikkeling vragenlijst 'Wensen en problemen van mantelzorgers van mensen met dementie'. Utrecht, NIVEL <www.nivel.nl>.
- Verbeek, H., Meyer, G., Leino-Kilpi, H., Zabalegui, A., Hallberg, I.R., Saks, K., Soto, M.E., Challis, D., Sauerland, D., Hamers, J.P.H. (2012). A European study investigating patterns of transition from home care towards institutional dementia care: a protocol of a Right Time Place Care study. *MBC Public Health*, 12: 68.
- Verkade, P.J., Meijel, B., van Brink C., van Os-Medendorp, H., Koekkoek, B., Francke, A.L. (2010). Delphi-research exploring essential components and preconditions for case management in people with dementia. *BMC Geriatrics*, 10: 54.
- Vermaire, J.H., Hoogstraten, J., van Loveren, C., Poorterman, J.H.G., van Exel, N.J.A. (2010). Attitudes toward oral health among parents of six-year-old children at risk of developing caries. *Community Dentistry and Oral Epidemiology*, 38(6): 507-520.
- Vernooij-Dassen, M. (1996). Demeterende patiënten: opname uitstellen? (Demented patients: Delay admission?) *Bijblijven*, 12(2): 31-36.
- Vernooij-Dassen, M., Lamers, G., Bor, J., et al. (2000). Prognostic factors of effectiveness of a support program for caregivers of dementia patients. *International Journal of Aging and Human Development*. 51(4): 259-274.
- Vernooij-Dassen, M., Olde Rikkert, G.M. (2004). Personal disease management in dementia care. *International Journal of Geriatric Psychiatry*, 19: 715-717.
- Vickrey, B.G., Brian, S., Mittman, S., Connor, K.I., Pearson, M.L., Della Penna, R.D., et al. (2006). The effect of a Disease Management Intervention on Quality and Outcomes of Dementia Care. *American College of Physicians*, 145(10): 713-726.
- Victoroff, J., Mack, W.J. & Nielson, K.A. (1998). Psychiatric Complications of Dementia: Impact on Caregivers. *Dementia* 9: 50-55.
- Vreugdenhil, A., Cannel, J., Davies, A., Razay, G. (2011). A community-based exercise programme to improve functional ability in people with Alzheimer's disease: A randomized controlled trial. *Scandinavian Journal Caring Science*, 1471-6712.
- Vugt de, E., Riedijk, R., Aalten, P., Tibben, A., van Swieten, J.C., Verhey, F.R.J. (2006). Impact of Behavioural Problems of Spousal Caregivers: A Comparison between Alzheimer's Disease and Front temporal Dementia. *Dementia and Geriatric Cognitive Disorders*, 22: 35-41.
- Wallenburg, I., van Exel, N.J.A., Stolk, E., Scheele, F., de Bont, A., Meurs, P. (2010). Between trust and Accountability: Different Perspectives on the Modernization of Postgraduate Medical training in the Netherlands. *Academic Medicine*, 85(6): 1082-1090.

- Wancata, J., Musalek, M., Alexandrowicz, R. & Krautgartner, M. (2003). Number of dementia sufferers in Europe between the years 2000 and 2050. *European Psychiatry*, 18(6): 306-13.
- Watts, S. & Stenner, P. (2005). Doing Q methodology: theory, method and interpretation. *Qualitative Research in Psychology*, 2: 67-91.
- Waugh, F. Where does risk feature in community care practice with older people with dementia who live alone. (2009). *Dementia* 8(2): 205-222.
- Wierdsma, A., Schee, M., Mulder, C. Breakdown of continuity in public mental healthcare in the Netherlands: a longitudinal case study. (2011). *International Journal of Integrated Care*, 11: 16 September.
- Wimo, A., Winblad, B., Aguero-Torres, H. & Von Strauss, E. (2003). The magnitude of dementia occurrence in the world. *Alzheimer Disease and Associated Disorders*, 17(2): 63-7.
- Wimo, A., Winblad, B., Jönsson, L. (2009). The worldwide societal costs of dementia: Estimates for 2009. *Alzheimer & Dementia*, 6: 98-103.
- Windle, G., Bennet, K.M. (2012). Caring Relationships: How to Promote Resilience in challenging time. *The social Ecology of Resilience chapter*, 18: 219-231.
- Wolfson, C., Wolfson, D.B., Asgharian, M. et al. (2001). A re-evaluation of the duration of survival after the onset of dementia. *New England Journal of Medicine*, 344: 1111-6.
- World Alzheimer Report 2010. London: *Alzheimer's disease international*.
- World Health Organization (2012): *Dementia: A public health priority*. ISBN: 9789241564458.
- Yee, J.L., Schulz, R. (2000). Gender Difference in Psychiatric Morbidity Among Family Caregivers: A Review and Analyses. *The Gerontological Society of America*, 40(2): 147-164.
- Yilmaz, A., Turan, E., Gundogar, D. (2009). Predictors of burn-out in the family caregivers of Alzheimer's disease: Evidence from Turkey. *Australasian Journal on Ageing*, 28: 16-21.
- Zabalegui, A., Bover, A., Rodriquiz, E., Cabrera, E., Diaz, M., Gallart, A., Conzalez, A., Gaul, P., Izquierdo, M.D., López, L., Pulpón, A.M., Ramírez, A. (2008). Informal Caregiving: Perceived Needs. *Nursing Science Quarterly*, 12(2): 166-172.
- Zwaanstra, Marieke., Peeters, José M., Van Beek, Adriana P.A., Meerveld, Julie H.C.M., Francke, Anneke L. (2013). Informal Caregivers of People with Dementia, Needs and Support in the Initial Stage and in Subsequent Stages if Dementia: A Questionnaire Survey. *The open Nursing Journal*, 7: 6-13.

SUMMARY

Introduction

In this thesis, the perseverance time of informal carers is introduced as a new concept in dementia care. The introduction in Chapter 1 starts with the social and political context of this study, followed by a description of the impact of caring for persons with dementia. The concept of perseverance time is a result of discussions with and among professionals and informal carers, and is defined as the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia; the length of this period of time is influenced by a combination of factors. The assumption was that if informal carers are asked how long they think they can continue current care, this could help to prevent or reduce overburdening and crisis situations by providing timely and appropriate support at home. Therefore, we introduced and evaluated a measure of perseverance time as an indication of the end of the informal caregiving period. The perseverance time measure was developed to be useful in the daily practice of caring for persons with dementia. It was operationalized in a very direct fashion by asking informal carers the following question:

‘If the informal care situation stays as it is now, how long will you be able to cope with the care?’

This is the first study on perseverance time.

The overall question of the studies presented here is to explore the feasibility, validity, and added value of perseverance time, both as a concept and as a measure within the context of decision making in dementia care.

To investigate perseverance time, we addressed the following research questions:

1. What is the feasibility and convergent validity of perseverance time?
2. Which characteristics of the informal carer, the person with dementia, and the care situation are associated with perseverance time? (content validity)
3. To what extent is perseverance time indicative of observed perseverance time? (predictive validity)

4. Can different profiles of caregiving be distinguished, and how do these relate to perseverance time?
5. How do spouses experience the decision to place their partner with dementia in a nursing home?
6. How is the timing of placing persons with dementia in nursing homes related to the perseverance time of their informal carers?

Finally, we described in Chapter 1 the outline of the study and the methods used.

Chapter 2

In this chapter, we tested the convergent and content validity of perseverance time in a sample (n = 223) of informal carers of persons with dementia living at home. During the study, it became apparent that the perseverance time measure was understandable for informal carers (user validity). They were able and willing to indicate how long they expected to be able to continue current care.

We studied the convergent validity of the perseverance time measure by investigating associations with validated measures for subjective burden and happiness. The convergent validity of the perseverance time measure with subjective burden was reasonably strong. Happiness was also significantly associated with the perseverance time measure, but less strongly than with the measures for subjective burden.

The content validity of perseverance time was fair to good for the perseverance time categories of more than six months and more than one year, and declined for a perseverance time of more than two years. Determinants of perseverance time showed a marked resemblance with known determinants of subjective burden such as the health status of the informal carer and the objective burden of the care situation measured by hours of caring per week. Nevertheless, it is important to note that perseverance time is conceptually different from subjective burden. The main variables that were positively associated with perseverance time were the health status of the person with dementia and the care setting (such as the carer living elsewhere). Negative associations were found with the need for supervision, the objective burden, and reductions in working hours and hobbies in order to continue providing the care. Contrary to what one might expect, informal carers who had adjusted their working time downwards still indicated a lower perseverance time than informal carers who had not. Similar

effects were found for reductions in other forms of social participation, such as voluntary work and hobbies. Therefore, such adjustments can be interpreted as a need for support rather than as a prospect for increasing perseverance time. On the other hand, perseverance time may increase if the needed additional support is provided. The interaction between providing informal care and social participation appears to be an important area for further research.

It appeared that the perseverance time measure provides a useful and valid way to investigate how long informal carers can continue to provide informal care. Based on this first study, the usefulness and validity of the concept appear favourable. However, more research is required to confirm these findings.

Chapter 3

In this study, we followed informal carers of persons with dementia for two years to find determinants of perseverance time. Predicting the end of one's perseverance time creates a possibility for timely interventions to prevent the overburdening of informal carers, and makes it more likely that admission of dementia patients will take place at an appropriate time in the carers' point of view. In this Chapter our main research question explored the extent to which perseverance time predicts the end of the caring capacities of the informal carer. After answering this question, it appeared that there was a difference between informal carers who indicated a short or time-limited perseverance time and those who did not. In the group of informal carers with a perseverance time of less than one year, 80% of the persons with dementia they cared for had died or had been admitted to a nursing home within a year. The implication of this finding is that perseverance time has to be taken seriously by health care professionals, and underlines the need for timely support. The results of the predictions of informal carers who reported unlimited perseverance time vary. In such cases, professionals should focus on the changes to informal carers' overestimates of their ability to provide care.

On average, persons with dementia still living at home one year after the baseline measurement were younger and needed constant supervision less often, are less care-dependent, and were more often the partner of the informal carer. The carers of these persons with dementia were less often employed and the intensity of the care task was higher, but they had made fewer adjustments to work or hobbies. On average, the subjective burden of care was lower, and their reported perseverance time was higher.

The concept of perseverance time can be used to investigate the period of time that informal carers expect to be able to continue performing their current care tasks. The perseverance time measure is an instrument that can be used to prevent crisis situations and the overburdening of informal carers.

Chapter 4

In this chapter, we investigated how informal carers experience their personal caregiving situation. Knowledge of their experiences may contribute to the development of more specific, demand-driven interventions to support informal carers of persons with dementia. We used Q-methodology to create caregiving profiles based on how informal carers deal with the dilemmas inherent to dementia care at home. We were able to distinguish the following five profiles: (1) Carers who cope well with providing care, (2) Carers who would like to receive help with providing care, but at the same time want to remain in control of the care process, (3) Carers who find it quite demanding to maintain the level of care needed, but who get a lot of help and support from their family and friends, (4) Carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends, (5) Carers who can barely cope with providing the care required by their relative with dementia.

The profiles were associated with the perseverance times indicated by the informal carers. For an overview of the profiles, see Figure 2 of Chapter 4.

Chapter 5

This study showed that the decision regarding nursing home placement was taken in two distinct steps. The first step entailed the decision to place the person with dementia on a waiting list for a nursing home. The second step related to the decision of actual placement. This decision was normally taken by informal carers when a place in a nursing home became available. The focus of this chapter was on the second, final, decision. Informal carers classified the admission as follows: (1) at the right time, (2) too early, (3) too late, or (4) out of control. This classification generates knowledge about placement practices (within the Dutch context) and its effects on the burdening (and overburdening) of informal carers. Special attention to the categories 'too late' and 'out of control' could help to prevent possible crisis admissions. This study has shown that the nursing home may view the timeliness of a placement differently than the

informal carer. Including the viewpoints of informal carers in decision making on nursing home placement for their relative with dementia could avoid situations in which placement is delayed or takes place too early. This could also reduce the number of crisis situations, or they could at least be noticed at an earlier stage. Informal carers should therefore have a key role in the decision to place their relative in a nursing home.

Chapter 6

In this quantitative study, we confirmed that informal carers could have continued to care for their relative with dementia if the admission to a nursing home had not taken place at that particular time. We defined a 'right-time' placement in cases where informal carers reported a retrospective perseverance time of less than one month (= 47%). This would imply that in 53% of the cases, admission could have been postponed. To optimize the admission process, this result should be taken into account by home care organizations and nursing homes.

We found that there were major differences between informal carers who lived with the person with dementia and those who lived elsewhere. Informal carers who lived elsewhere (usually the children) were frequently employed and had more opportunities for respite, so their subjective burden was relatively more bearable. Caregiving by informal carers who lived together with the person with dementia (mostly partners) could be characterized as a full-time job with a high level of subjective burden. Nevertheless, they generally wanted to continue to care for their relative with dementia for as long as possible to postpone admission to a nursing home.

To persevere in their caring tasks, informal carers had a strong need for additional support and more opportunities for respite. These needs, and especially a reduction in hobbies and working hours, indicated that the end of their perseverance time was approaching. These signals should be taken seriously by professionals so that they can provide timely support or so that the person with dementia can be admitted at an appropriate time. Timely periodic talks about perseverance time could foster a demand-oriented, forward-looking approach to supporting informal carers.

Our study provides some signals for preventing crisis admissions. These include (1) a growing need for continuous supervision by the person with dementia, (2) severe co-morbidity inherent to the dementia process, and (3) the

observation that most of the crisis admissions took place within a perseverance time of less than six months. Monitoring of perseverance time by health care professionals could therefore help to prevent crisis situations. Further research on the nature of crisis admissions could help to identify additional signals for preventing such admissions.

This study demonstrates that practically all informal carers continued to be involved with the care of their relatives with dementia once they were admitted to a nursing home. However, they were not often active as volunteers in the nursing home. We suggest involving informal carers as partners in care at the nursing home, because they are experienced experts in caring for their relative with dementia.

Chapter 7

In this chapter, we reviewed the main results, and highlighted several implications for further research as well as implications for practice and policymaking. During the study, it became apparent that the perseverance time measure is understandable for informal carers. When a professional asks an informal carer for his or her perseverance time, it shifts the focus from the actual situation to the future. This makes it easier to discuss the possibilities for timely support to prevent overburdening. The text below presents an overview of the research questions, answers and the general conclusion.

1. What is the feasibility and convergent validity of perseverance time?

The convergent validity of the perseverance time measure based on its association with subjective burden measured by the Caregiver Strain Index (CSI) and the Self-Rated Burden (SRB) appeared to be good. The association with happiness (CarerQoI-VAS) was also significant, but less strong

2. Which characteristics of the informal carer, the person with dementia, and the care situation are associated with perseverance time? (content validity)

The content validity of perseverance time appeared fair to good for the categories more than six months and more than one year, and declined for a perseverance time of more than two years. The main positive associations with perseverance time were the health status of the person with dementia and the care setting (such as the carer living elsewhere). Negative associations were found with the need for

supervision, the objective burden, and reductions in working hours and hobbies.

3. To what extent is perseverance time indicative of observed perseverance time? (predictive validity)

To answer this research question, it appeared relevant to differentiate between informal carers who indicated a limited perseverance time and those who did not. The first category of informal carers made a reliable prediction of the end of their perseverance time. The predictive value of informal carers who indicated an unlimited perseverance time varied.

4. Can different profiles of caregiving be distinguished, and how do these relate to perseverance time?

Based on the experiences of informal carers, we were able to distinguish the following five profiles: (1) Carers who cope well with providing care, (2) Carers who would like to receive help with providing the care, but at the same time want to remain in control of the care process, (3) Carers who find it quite demanding to maintain the level of care needed, but who get a lot of help and support from their family and friends, (4) Carers who experience their task of caregiving as very demanding and who do not receive much support from family and friends, (5) Carers who can barely cope with providing the care required by their relative with dementia. The profiles differed significantly from each other, and were associated with perseverance time.

5. How do spouses experience the decision to place their partner with dementia in a nursing home?

Informal carers classified the admission as: (1) at the right time, (2) too early, (3) too late, or (4) out of control. This study shows that the decision regarding nursing home placement was taken in two distinct steps. The first decision was to place the person with dementia on a waiting list for a nursing home. The second, final, decision related to the actual placement, and was taken by informal carers when a place in a nursing home became available.

6. How is the timing of placing persons with dementia in nursing homes related to the perseverance time of their informal carers?

Six months after the admission to a nursing home, informal carers reported that they could have continued their care tasks for another six months on average if the admission had not taken place. Partners of a

person with dementia were able to predict the end of their perseverance time better than informal carers who lived elsewhere. Informal carers who lived elsewhere found that they could have continued their care tasks for another ten months.

General conclusion

The overall aim of this thesis was to explore the feasibility, validity, and added value of perseverance time, both as a measure and as a concept within the context of decision making in dementia care. Because of the limitations of the studies presented here and the fact that this thesis has presented only the first explorations of these issues, this thesis cannot provide definitive answers to the related research questions. Still, our results suggest that both feasibility and validity of the perseverance time as a concept and as a measure are favourable within the context of informal care for persons with dementia. The way we chose to operationalize perseverance time provided a direct way of investigating how long informal caregivers can continue their current informal care tasks. In addition to its relevance for research in the field of informal care, the measure may also prove useful in practice in providing timely support to informal carers.

In closing

The basic motivation for this thesis was to develop an instrument that could help predict when informal carers of persons with dementia would no longer be able to provide this care, with the aim of preventing overburdening and crisis situations that lead to emergency admissions of persons with dementia. While many questions remain unanswered, we hope that this thesis and the perseverance time measure will contribute to this ultimate goal. It is encouraging that one insurance company in the Netherlands has added perseverance time to its monitoring toolkit for case managers in dementia care.

SAMENVATTING

Introductie

In dit proefschrift wordt volhoudtijd van mantelzorgers geïntroduceerd als een nieuw concept in de zorg voor mensen met dementie. De introductie in Hoofdstuk 1 wordt gestart met een schets van de sociaal maatschappelijke context van deze studie, gevolgd door een beschrijving van de impact van het geven van mantelzorg aan mensen met dementie. Het concept volhoudtijd is ontstaan op basis van discussies met en tussen professionals en mantelzorgers in het kader van het Landelijk Dementie Programma (2004-2008) en gedefinieerd als de periode dat mantelzorgers verwachten in staat te zijn de zorgtaken voor hun naaste met dementie te kunnen continueren; de lengte van die periode wordt beïnvloed door een combinatie van factoren.

De veronderstelling was dat als mantelzorgers gevraagd wordt hoe lang zij de zorg nog denken te kunnen volhouden dat zou kunnen helpen bij het tijdig signaleren van overbelasting en crisissituaties. In dit proefschrift introduceren en evalueren wij daarom de vraag naar volhoudtijd met als doel te onderzoeken hoelang mantelzorgers verwachten de huidige zorg voor hun naaste met dementie te kunnen continueren. Dit meetinstrument geeft dus ook een indicatie over het einde van de mantelzorgperiode. Het concept volhoudtijd was ook ontworpen om te kunnen gebruiken in de dagelijkse praktijk van het zorgen voor mensen met dementie. Daarom is volhoudtijd geoperationaliseerd door mantelzorgers de volgende vraag voor te leggen: 'Als de mantelzorgsituatie blijft zoals die nu is, hoe lang kunt u de zorg dan nog aan?'

Dit is de eerste studie over volhoudtijd.

De overall doelstelling van de studies die hier worden gepresenteerd is het aantonen van de haalbaarheid, de validiteit en de toegevoegde waarde van volhoudtijd als concept en als instrument in de context van besluitvorming in de dementiezorg.

Om die doelstelling te realiseren werden de volgende onderzoeksvragen opgesteld die in de volgende hoofdstukken worden beantwoord.

1. Wat is de haalbaarheid en convergente validiteit van volhoudtijd?
2. Welke kenmerken van mantelzorgers, personen met dementie en de zorgsituatie zijn geassocieerd met volhoudtijd? (content validiteit)

3. In welke mate is volhoudtijd indicatief voor gerealiseerde volhoudtijd? (voorspellende validiteit)
4. Kunnen verschillende mantelzorgprofielen worden onderscheiden en hoe zijn deze gerelateerd aan volhoudtijd?
5. Hoe ervaren partners van personen met dementie de beslissing tot opname in een verpleeghuis?
6. Hoe is de timing van de plaatsing van personen met dementie in verpleeghuizen gerelateerd aan de volhoudtijd van hun mantelzorgers?

Tenslotte beschreven we in Hoofdstuk 1 de structuur en methoden van de studie.

Hoofdstuk 2

In dit hoofdstuk werden de convergente en content validiteit van volhoudtijd onderzocht in een populatie van 223 mantelzorgers van thuiswonende mensen met dementie (de onderzoeksvragen 1 en 2). Gedurende deze studie bleek dat het instrument volhoudtijd herkenbaar was voor mantelzorgers. Zij waren bereid en in staat in te schatten gedurende welke periode zij de huidige zorg zouden kunnen volhouden.

De convergente validiteit van volhoudtijd werd bestudeerd door de associaties te onderzoeken met gevalideerde meetinstrumenten voor subjectieve belasting en geluk. De convergente validiteit van het instrument volhoudtijd met subjectieve belasting was significant. De associatie met geluk was ook significant doch was minder sterk dan bij de maten voor subjectieve belasting.

De content validiteit (dat wil zeggen de toepasbaarheid van bij de onderzoekspopulatie) van volhoudtijd was redelijk tot goed voor de categorieën volhoudtijd van: meer dan een half jaar en meer dan een jaar en afnemend voor een volhoudtijd van meer dan twee jaar. Determinanten van volhoudtijd vertoonden gelijkenis met bekende determinanten van subjectieve belasting zoals de gezondheid van de mantelzorger en de objectieve belasting gemeten in aantal uren zorg per week. Niettemin is het belangrijk op te merken dat volhoudtijd conceptueel verschilt van subjectieve belasting. De belangrijkste positieve associaties met volhoudtijd waren de gezondheidstoestand van de persoon met dementie en de zorgsetting, zoals het elders wonen van de mantelzorger. Negatieve associaties werden gevonden met de behoefte aan toezicht van de dementerende, de objectieve belasting en de vermindering van

het aantal uren dat men werkt of aan een hobby besteedt. In tegenstelling tot wat men zou verwachten gaven mantelzorgers die minder gingen werken een lagere volhoudtijd op dan mantelzorgers die dat niet deden. Een vergelijkbaar effect deed zich voor bij andere vormen van sociale participatie zoals vrijwilligerswerk en het beoefenen van een hobby. Vermindering van maatschappelijke participatie zou daarom eerder geïnterpreteerd moeten worden als behoefte aan extra ondersteuning dan aan perspectief op een langere volhoudtijd. Aan de andere kant zou de volhoudtijd kunnen toenemen wanneer aan de behoefte van extra ondersteuning wordt voldaan. De interactie tussen het geven van mantelzorg en sociale participatie lijkt een belangrijk onderwerp voor verder onderzoek.

Geconcludeerd werd dat het instrument volhoudtijd een nuttige manier is om te onderzoeken hoe lang mantelzorgers de zorg denken te kunnen continueren. Meer onderzoek is gewenst om de bruikbaarheid en validiteit van volhoudtijd verder te ondersteunen.

Hoofdstuk 3

In dit hoofdstuk volgden we mantelzorgers van thuiswonende mensen met dementie gedurende twee jaar met als doel determinanten van volhoudtijd te onderzoeken. Het voorspellen van volhoudtijd van mantelzorgers schept mogelijkheden voor tijdige ondersteuning ter voorkoming van overbelasting. Voorts wordt daarmee bevorderd dat de opname van de persoon met dementie op een voor de mantelzorger geschikt tijdstip kan plaatsvinden. De belangrijkste onderzoeksvraag was in welke mate het instrument volhoudtijd een voorspellende waarde heeft voor het einde van de zorgmogelijkheden van mantelzorgers. Na beantwoording van die vraag bleek het relevant een onderscheid te maken tussen mantelzorgers die een korte of gelimiteerde volhoudtijd opgaven en mantelzorgers die dat niet deden. Van de groep mantelzorgers met een Volhoudtijd van minder dan een jaar werd 80% van hun naasten met dementie binnen dat jaar overleden of opgenomen in een verpleeghuis. De implicatie van dit resultaat is dat volhoudtijd door zorg professionals serieus genomen moet worden en het onderstreept de noodzaak van tijdige ondersteuning van mantelzorgers. De uitkomsten van de voorspelling van mantelzorgers die ongelimiteerde volhoudtijd rapporteerden was divers. Bij deze groep zouden professionals zich moeten richten op een mogelijke overschatting van de zorgmogelijkheden van die mantelzorgers.

Personen met dementie die na een jaar nog thuis woonden waren jonger en hadden minder behoefte aan constant toezicht. Hun zorgafhankelijkheid was lager dan van de reeds opgenomen patiënten. Zij waren vaker de partner van de persoon met dementie. De mantelzorgers van deze thuiswonende naasten met dementie hadden minder vaak een betaalde baan. Zij besteedden relatief meer uren aan zorgtaken. Het was voor hen minder vaak nodig om de tijdsbesteding aan hun werk of hobby aan te passen. Gemiddeld vonden zij zich minder zwaar belast en registreerden een langere volhoudtijd.

Het concept volhoudtijd kan worden gebruikt om te onderzoeken hoelang mantelzorgers de huidige zorg nog vol kunnen houden. De vraag naar volhoudtijd is een instrument waarmee crisissituaties en overbelasting van mantelzorgers kunnen worden geminimaliseerd.

Hoofdstuk 4

In dit hoofdstuk onderzochten we hoe mantelzorgers hun persoonlijke mantelzorgsituatie ervaren. Kennis van hun ervaringen kan een bijdrage leveren aan de ontwikkeling van vraaggerichte ondersteuning door professionals van mantelzorgers van mensen met dementie. We gebruikten de Q-methodologie om mantelzorgprofielen op te sporen, gebaseerd op hoe mantelzorgers omgaan met dilemma's die inherent zijn aan dementie zorg. Als resultaat van deze studie konden de volgende vijf te onderscheiden mantelzorgprofielen worden beschreven: (1) Mantelzorgers die de zorgsituatie goed aan kunnen; (2) Mantelzorgers die wel hulp zouden willen ontvangen bij de zorg maar zelf de controle willen houden op het zorgproces; (3) Mantelzorgers die moeite hebben de noodzakelijk zorg vol te houden maar die wel veel hulp van hun familie en vrienden krijgen; (4) Mantelzorgers die de zorg zwaar vinden en weinig steun ontvangen van familie of vrienden; (5) Mantelzorgers die de zorg eigenlijk niet meer aankunnen.

De profielen associeerden significant met de door mantelzorgers geïndiceerde volhoudtijd. Een beknopte beschrijving van de profielen staan vermeld in figuur 2 van Hoofdstuk 4.

Hoofdstuk 5

Deze studie toont aan dat mantelzorgers de beslissing voor opname in het verpleeghuis gefaseerd in de tijd nemen. De eerste beslissing het plaatsen

van de persoon met dementie op een wachtlijst voor opname. De tweede en definitieve beslissing wordt door mantelzorgers genomen op het moment dat er een plaats beschikbaar komt in het verpleeghuis. De focus van deze studie was op die tweede beslissing. Mantelzorgers classificeerden de opname in het verpleeghuis als volgt: (1) op het juiste moment; (2) te vroeg; (3) te laat en (4) het niet meer in de hand hebben. Deze classificatie genereert kennis over de opnamepraktijk en de effecten op (over)belasting van mantelzorgers. Speciale aandacht voor de laatste twee categorieën (3 en 4) zou kunnen helpen crisisopnamen te voorkomen. Deze studie maakte duidelijk dat mantelzorgers en verpleeghuizen verschillende verwachtingen en belangen hebben bij de bepaling van het tijdstip van de feitelijke opname in het verpleeghuis. Het betrekken van de mantelzorgers bij het bezetten van een beschikbaar gekomen plaats in het verpleeghuis kan voorkomen dat personen met dementie te vroeg of te laat worden opgenomen. Het aantal crisissituaties zou hierdoor ook kunnen verminderen of tenminste op tijd worden onderkend. Mantelzorgers zouden daarom een sleutelrol moeten vervullen bij het nemen van de beslissing tot opname in een verpleeghuis.

Hoofdstuk 6

In aansluiting op de kwalitatieve studie van het vorige hoofdstuk werd in dit kwantitatieve onderzoek bevestigd dat mantelzorgers het gemiddeld langer hadden kunnen volhouden wanneer de opname van hun dementerende naaste in het verpleeghuis op dat specifieke moment niet had plaatsgevonden. Met dit resultaat zou rekening moeten worden gehouden door thuiszorgorganisaties en verpleeghuizen bij het optimaliseren van het opnameproces.

We constateerden in deze studie vele verschillen tussen mantelzorgers die in huis wonen bij de naaste met dementie en mantelzorgers die elders wonen. De elders wonende mantelzorgers (veelal de kinderen) hadden vaker een betaalde baan en hadden meer mogelijkheden voor respijt met als gevolg dat de door hen ervaren belasting als dragelijker werd ervaren. De zorg door mantelzorgers die in huis wonen bij de naaste met dementie (meestal de partner) kan worden gekarakteriseerd als een fulltime baan met een hoge mate van ervaren belasting. Desalniettemin wilden deze mantelzorgers de zorg zo lang mogelijk volhouden om een opname van hun naaste uit te stellen.

Om de zorg te kunnen volhouden hebben mantelzorgers een sterke behoefte aan extra ondersteuning en meer mogelijkheden voor respijt. Die behoeften en met name de vermindering van de beschikbare tijd voor hobby's en werk zijn signalen voor de nadering van het einde van hun volhoudtijd. Deze signalen zouden serieus genomen moeten worden door professionele zorgverleners met als doel het geven van tijdige ondersteuning of het realiseren van een tijdige opname. Verondersteld kan worden dat een tijdige en periodieke bespreking door professionals met mantelzorgers van hun Volhoudtijd, een vraag- en toekomstgerichte manier van ondersteuning zou kunnen bevorderen.

Deze studie levert een aantal signalen op die kunnen worden gebruikt om crisissituaties te voorkomen: (1) ernstige co-morbiditeit (2) toenemende behoefte aan continue toezicht die inherent zijn aan het dementieproces (3) de meeste crisisopnamen vonden plaats binnen een gerapporteerde volhoudtijd van minder dan zes maanden. Monitoring van volhoudtijd door professionals zou daarom behulpzaam kunnen zijn bij het voorkomen van crisissituaties. Verder onderzoek naar de aard van de crisisopnamen wordt aanbevolen om meer aanknopingspunten te vinden voor preventie.

Uit dit onderzoek is gebleken dat na de opname praktisch alle mantelzorgers betrokken blijven bij de zorg voor hun naaste met dementie. Zij deden echter nauwelijks algemeen vrijwilligerswerk in het verpleeghuis. Wij adviseren daarom mantelzorgers meer te betrekken bij de zorg in het verpleeghuis, zij zijn immers de ervaringsdeskundigen waar het gaat om de zorgverlening aan hun naaste.

Hoofdstuk 7

In dit hoofdstuk wordt een overzicht gegeven van de belangrijkste resultaten en worden suggesties gedaan voor verder onderzoek, implicaties voor praktijk en beleidsvorming. Gedurende de studie werd duidelijk dat het de vraag naar volhoudtijd begrijpelijk is voor mantelzorgers. Wanneer een professional een mantelzorger vraagt naar zijn of haar volhoudtijd wordt daarmee de focus verlegd van de actuele situatie naar de toekomst. Daardoor wordt het beter mogelijk te spreken over vormen van tijdige ondersteuning ter voorkoming van overbelasting. De tekst hieronder geeft een samenvatting van de belangrijkste onderzoeksvragen, antwoorden en algemene conclusie.

1. Wat is de haalbaarheid en convergente validiteit van volhoudtijd?

De convergente validiteit van volhoudtijd met subjectieve belasting, gemeten met de Caregiver Strain Index (CSI) en de Self-Rated Burden (SRB) was significant. De associatie met geluk (CarerQol-VAS) was ook significant maar minder sterk.
2. Welke kenmerken van mantelzorgers, personen met dementie en de zorgsituatie zijn geassocieerd met volhoudtijd? (content validiteit)

De content validiteit van volhoudtijd bleek redelijk tot goed voor de categorieën meer dan een half jaar en meer dan een jaar en was lager voor een volhoudtijd van meer dan twee jaar. De belangrijkste positieve associaties met volhoudtijd bleken de gezondheid van de persoon met dementie en de zorgsetting te zijn zoals mantelzorgers die elders wonen. Negatieve associaties werden gevonden met de behoefte aan toezicht, objectieve belasting en vermindering van de tijdbesteding aan werk en hobby's.
3. In welke mate is volhoudtijd indicatief voor gerealiseerde volhoudtijd? (voorspellende validiteit)

Om deze vraag te beantwoorden was het relevant onderscheid te maken tussen mantelzorgers met een opgegeven gelimiteerde volhoudtijd en zij die dat niet deden. De eerste categorie mantelzorgers was in staat om tijdens de 2-jarige longitudinale studie een betrouwbare voorspelling te doen van hun volhoudtijd. De voorspellende waarde van volhoudtijd bij de andere groep mantelzorgers was minder goed.
4. Kunnen verschillende mantelzorgprofielen worden onderscheiden en hoe zijn deze gerelateerd aan volhoudtijd?

Gebaseerd op de ervaringen van mantelzorgers konden de volgende vijf mantelzorgprofielen worden getraceerd: 1) Mantelzorgers die de zorgsituatie goed aan kunnen; 2) Mantelzorgers die wel hulp willen ontvangen bij de zorg maar zelf de controle willen houden op het zorgproces; 3) Mantelzorgers die moeite hebben de noodzakelijke zorg vol te houden maar die wel veel hulp krijgen van hun familie en vrienden; 4) Mantelzorgers die de zorg zwaar vinden, weinig steun ontvangen van familie of vrienden; 5) Mantelzorgers die de zorg eigenlijk niet meer aan kunnen.

De profielen associeerden significant met de door mantelzorgers geïndiceerde volhoudtijd.

5. Hoe ervaren partners van personen met dementie de beslissing tot opname in een verpleeghuis?

Mantelzorgers classificeerden de opname als: (1) op het juiste moment; (2) te vroeg; (3) te laat en (4) het niet meer in de hand hebben. De resultaten van deze studie ondersteunen het gegeven dat de beslissing tot opname in het verpleeghuis gefaseerd in de tijd wordt genomen. De eerste beslissing door de mantelzorgers betreft het plaatsen van de persoon met dementie op een wachtlijst voor opname. De tweede en definitieve beslissing wordt door mantelzorgers genomen op het moment dat er een plaats beschikbaar komt in het verpleeghuis.

6. Hoe is de timing van de plaatsing van personen met dementie in verpleeghuizen gerelateerd aan de volhoudtijd van hun mantelzorgers?

Een half jaar na de opname in een verpleeghuis rapporteerden de mantelzorgers dat zij de zorg gemiddeld nog wel zes maanden hadden kunnen volhouden wanneer de opname toen niet had plaatsgevonden. Samenwonende partners van dementerenden waren beter in staat het einde van hun volhoudtijd te voorspellen dan mantelzorgers die elders wonen. De elders wonende mantelzorgers vonden dat zij de zorg nog wel tien maanden langer hadden kunnen volhouden.

Algemene conclusie

De overall doelstelling van de studies die hier worden gepresenteerd was het aantonen van de praktische bruikbaarheid, de validiteit en de toegevoegde waarde van volhoudtijd als concept en als instrument in de context van besluitvorming in de zorg voor mensen met dementie.

Dit proefschrift geeft geen definitieve antwoorden op de verschillende onderzoeksvragen vanwege de beperkingen van de gepresenteerde studies. Echter, onze resultaten ondersteunen de bruikbaarheid en validiteit van het concept volhoudtijd in de context van de dementiezorg. De gekozen operationalisering bood een directe manier te onderzoeken hoelang mantelzorgers hun huidige mantelzorgtaken kunnen volhouden. Naast relevantie voor het onderzoek van de informele zorg kan het meetinstrument volhoudtijd nuttig zijn voor het tijdig kunnen voorzien in ondersteuning van mantelzorgers.

Tenslotte

De basismotivatie voor het schrijven van dit proefschrift was het ontwikkelen van een instrument voor het voorspellen van het einde van de zorgmogelijkheden van mantelzorgers van personen met dementie met als doel het minimaliseren van overbelasting en crisisopnamen. Hoewel veel vragen nog onbeantwoord zijn gelet op de beperkingen van het onderzoek hopen wij dat dit proefschrift een begin kan zijn voor verder wetenschappelijk onderzoek en praktische ontwikkeling van het concept en het instrument volhoudtijd in de dementiezorg en bij andere chronische ziekten. Het is bemoedigend dat tijdens de studie een van de Nederlandse zorgverzekeraars het concept volhoudtijd heeft opgenomen in hun tool-kit voor de casemanagers dementie.

DANKWOORD

Een dankwoord kan een precaire onderneming zijn. De kans iemand te vergeten is altijd aanwezig. Maar de medewerking van de 223 mantelzorgers van naasten met dementie uit de Gooi- en Vechtstreek kan ik natuurlijk niet vergeten. Integendeel, hun deelname aan de diverse onderzoeken is van cruciaal belang geweest voor de totstandkoming van mijn dissertatie. Ik ben hen daarvoor dan ook zeer erkentelijk. Ook dank voor de medewerkers van de regionale afdeling CIZ. Zij maakten het mogelijk de mantelzorgers te kunnen aanschrijven.

In de panelgesprekken in het kader van het Landelijk Dementie Programma kwam een aantal schrijnende situaties naar voren. Mijn verontwaardiging over het overheidsbeleid dat onvoldoende rekening hield met de toenemende belasting van deze mantelzorgers werd steeds sterker. Dat heeft mij geïnspireerd me te verdiepen in de vraag: hoelang kunnen deze mensen de zorg nog volhouden, ofwel: wanneer zou het 'elastiekje' knappen? En vooral: wat is er nodig om dat op tijd te onderkennen en te voorkomen? De term *Volhoudtijd* was hiermee geboren.

Het idee om het concept volhoudtijd nader invulling te geven werd door mijn eerste promotor Guus Schrijvers positief ontvangen. Hij was gedurende het hele onderzoeksproces mijn enthousiasmerende mentor. Maar naast enthousiasme, heb je natuurlijk gedegen gereedschap nodig voor het doen van kwantitatief en kwalitatief onderzoek.

Mijn eerste copromotor Job van Exel is hierbij voor mij van onschatbare waarde geweest. Bij hem klopte ik nooit tevergeefs aan als ik weer eens in de knoop dreigde te raken bij het werken met het SPSS-programma, dat voor statistische analyses van belang is. Naast het maken en interpreteren van multivariate analyses reikte Job mij het instrument aan van de Q-methodologie. Dat is een slimme combinatie van kwantitatieve en kwalitatieve technieken. Daarmee heb ik profielen van mantelzorgers zichtbaar kunnen maken.

Gaandeweg sloot Werner Brouwer zich bij ons aan en werd mijn tweede promotor. Zijn feedback zorgde ervoor dat de kwantitatieve resultaten goed werden beschreven en bediscussieerd.

Mijn tweede copromotor Rob de Leeuw leerde mij naast de kwantitatieve analyse de fijne kneepjes van het kwalitatieve onderzoek. Onderzoek met als bron de gesprekken met mantelzorgers was zeer motiverend. Het was een uitdaging om die gesprekken methodisch verantwoord te laten landen in een wetenschappelijk artikel.

Na het gereedkomen van de artikelen moest het proefschrift nog worden afgerond. Het schrijven van de overkoepelende introductie en discussie bleek een vak apart, dat veel fine-tuning vergde. De suggesties van beide promotoren waren daarbij onmisbaar.

Tijdens het hele traject heeft de begeleidingscommissie mij op de voet gevolgd en van adviezen voorzien. Het positieve eindoordeel van de beoordelingscommissie vormde het sluitstuk.

Naast intrinsieke motivatie voor het maken van een proefschrift is het onmisbaar mensen om je heen te hebben, die regelmatig vragen naar jouw volhoudtijd. Thuis heb ik voortdurend de steun van Jannie, mijn levensvriendin, ervaren. Bij de start van mijn studie maakte zij een schilderij over het onderwerp van mijn onderzoek. Dat schilderij staat nu op de voorkant van mijn proefschrift. Als creatieve sparringpartner keek ze niet alleen kritisch naar de tekst maar ook het inhoudelijke had haar aandacht.

Wetenschap en praktijk

Het geeft veel voldoening dat *Volhoudtijd* sinds 2013 als instrument wordt gebruikt door zorgverzekeraar Achmea in het kader van hun meerjarenproject '*Kwaliteit van leven voor mensen met dementie en hun mantelzorgers*'. Ook zal het concept volhoudtijd worden ingepast in het curriculum voor Toegepaste Gerontologie aan de Hogeschool Windesheim.

OVER DE AUTEUR

Henk Kraijo is 25 jaar werkzaam geweest bij verschillende zorgorganisaties in de care sector. Hij werkte achtereenvolgens als directeur bij een Riagg in Twente, een Psychiatrisch Ziekenhuis in Gelderland en bij de Thuiszorg in de Gooi en Vechtstreek. Van 2004 tot 2008 was hij regionaal projectleider Dementie in het kader van het Landelijk Dementie Project.

Daarna begon hij aan zijn promotieonderzoek naar volhoudtijd van mantelzorgers van thuiswonende mensen met dementie. Hij vindt het belangrijk dat het nieuwe concept volhoudtijd zijn weg vindt van wetenschap naar praktijk. Dit, vanuit zijn overtuiging dat het concept volhoudtijd kan bijdragen aan het tijdig ondersteunen van mantelzorgers. Met als voornaamste doel het voorkomen van overbelasting van mantelzorgers en crisisopnamen van mensen met dementie in verpleeghuizen.

Naast het promotieonderzoek is hij als onafhankelijk voorzitter van de Wmo-adviesraad van Deventer betrokken bij drie decentralisaties in het sociale domein (AWBZ, Wet op de Jeugdzorg, WWB). Zijn affiniteit met de eerstelijnszorg kwam ook tot uitdrukking door zijn lidmaatschap van de Raad van Toezicht van de huisartsenposten in Oost-Nederland.

Because of the expected increase of dementia patients in the next decades and the growing demand for informal care, an important question appears: how to predict and influence the caring possibilities of informal carers. This study introduces the concept perseverance time, described as the period of time that informal carers expect to be able to continue performing their care tasks for their relative with dementia; the length of that period of time is influenced by a combination of factors. The overall aim of the studies was to explore the feasibility, validity, and added value of perseverance time within the context of decision making in dementia care.

Perseverance time is operationalized in a very direct fashion by asking informal carers of persons with dementia the following question: 'If the informal care situation stays as it is now, how long will you be able to cope with the care?' Results of the studies suggest that the feasibility and validity of perseverance time is favourable within the context of informal care for persons with dementia. In addition to its relevance for research in the field of informal care, information about perseverance time may also prove useful in practice in providing timely support to informal carers to prevent overburdening and crisis situations.