Care needs in dementia and digital interactive information provisioning

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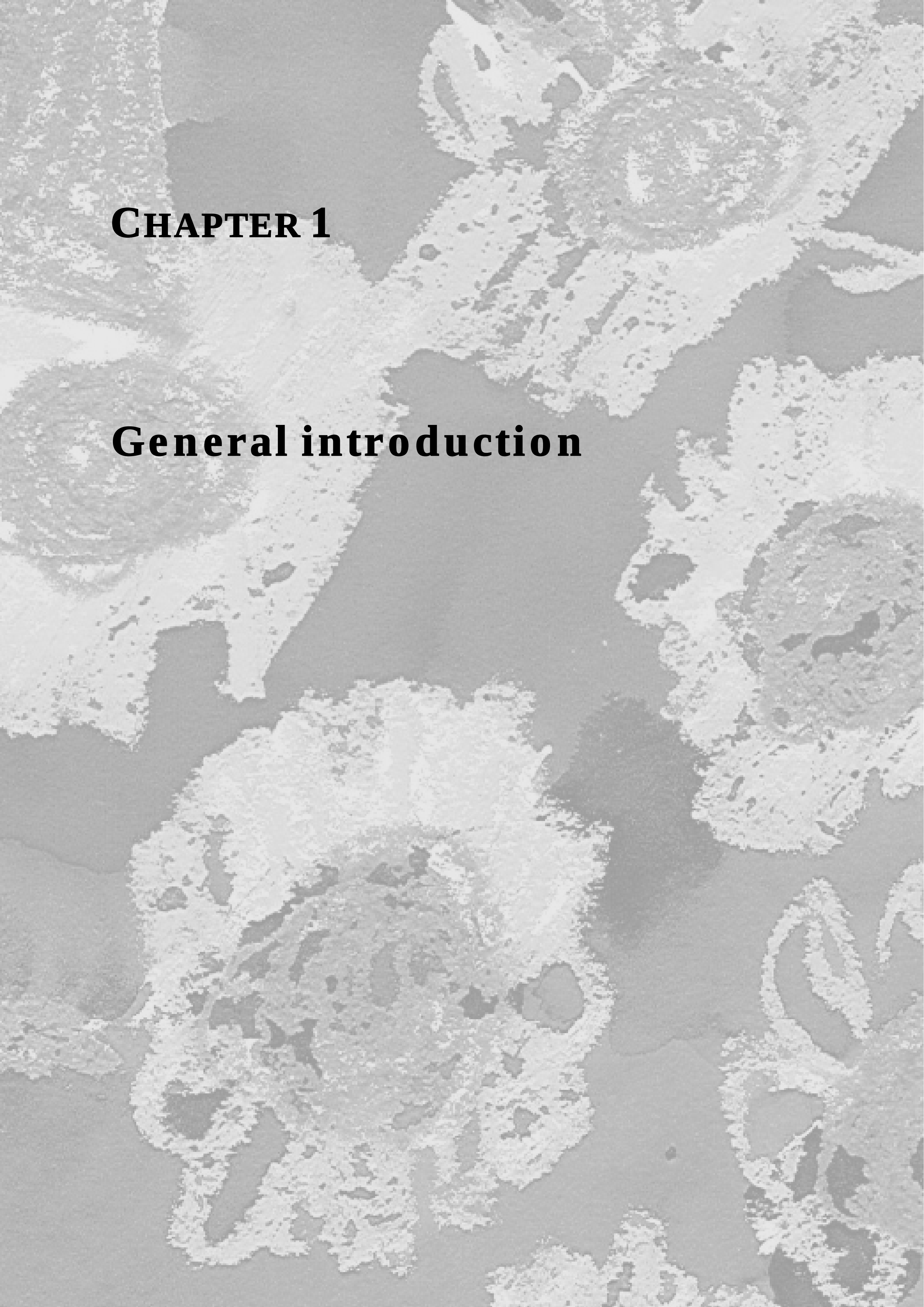
promotoren: prof.dr. R.M. Dröes
prof.dr. C. Jonker
copromotoren: dr. F.J.M. Meiland
prof.dr. P. Scheltens

Try hard and learn…

Voor mijn ouders

Contents



CHAPTER 1

General introduction

This thesis addresses the needs of people with dementia living in the community and describes the development and evaluation of an Information Communication Technology (ICT)-based solution to inform people with dementia and their carers on care and welfare services that could alleviate and meet these needs. The development of this information system, the so-called DEMentia-specific Digital Interactive Social Chart (DEM-DISC) required a multidisciplinary team, including designers, developers, technicians and expert dementia researchers. The study was carried out in the framework of the Dutch FReeband User eXperience (FRUX) project (Buis *et al.*, 2004; Freeband, 2008), which offered such a multidisciplinary team. The aim of the FRUX project was to support groups of people by investigating and developing new innovative ICT services. The project focused on two societal areas, the police and dementia care.

Background of the study

People with dementia

Dementia is mainly a disease of the aged. It is well known that the prevalence of dementia is estimated at 5% for people of 65 years and older, and it increases exponentially with every five years of age (Ferri *et al.*, 2005). With the ageing of the world population, the number of people with dementia will therefore also grow. The incidence rate of dementia is expected to double every 20 years; by 2040 81.1 million people worldwide will be suffering from dementia (Health Council of the Netherlands, 2002; Ferri *et al.*, 2005). Alzheimer's disease is the major cause of dementia: about 54% of the people with dementia are diagnosed with this type of dementia. Approximately 16% of the people with dementia are diagnosed with vascular dementia (Lobo *et al.*, 2000; Van der Flier and Scheltens, 2005). These causes are followed in prevalence by the mixed type of dementia (Alzheimer's disease and vascular) and more rare forms, e.g. Lewy Body dementia, frontotemporal dementia and Parkinson dementia. In each type of dementia the brain is affected in a different manner or in different areas, causing (slightly) different problems in (non) cognitive functions and in daily life.

Due to the progressive nature of the disease, people become more and more dependent on professional and informal care as time goes by. The type of care that is needed varies with the different stages of the disease. For instance, people in the beginning stages will have mild cognitive disabilities, such as memory and orientation problems and word-finding impairments. They are relatively independent and often only need some support with housekeeping and/or daily activities. People with severe dementia, on the other hand, have severe cognitive problems that affect all areas of daily functioning and they therefore need full time care in all areas of daily living.

Besides the functional problems that people experience because of their disease, (the onset of) dementia also has a psychological impact on the persons who suffer from it (Clare, 2003). Awareness and distress in people with dementia have been reported in clinical literature (Haycox, 1983; Reisberg, 1983; Cohen and Eisdorfer, 1986), and also the high prevalence of depression in people with dementia indicate the negative consequences of awareness of the disease (Reifler and Larson, 1989; Lee and Lyketsos, 2003). Dementia may be viewed as a threat to the self, and as people are aware of their memory problems, they use different coping strategies in order to regain control (Clare, 2003; De Boer *et al.*, 2007). Factors such as personal background characteristics, appraisal of the dementia, and the physical and social environment will mediate people's response to the awareness of dementia (Cotrell and Lein, 1993). Since the last decade it is more and more acknowledged that people with dementia are able to express their views, needs and concerns. The importance of research into the subjective experience of dementia is therefore emphasized (Keady *et al.*, 1995; Kitwood, 1997; Dröes *et al.*, 2006).

In the Netherlands, approximately 35% of the people with dementia are living in a care facility, home for the aged or nursing home. The other 65% live independently or with family or friends in the community (Health Council of the Netherlands, 2002). These community-dwelling people with dementia and their informal carers are the subjects under study in this thesis.

Informal carers

The majority of community-dwelling people with dementia are supported by informal carers. Informal care is unpaid care, provided to people who need assistance in daily living due to mental or physical problems, and is generally provided by relatives and/or friends. As the onset of dementia is usually late in life, the most common informal carers for people with dementia are their spouses or adult/middle-aged children (Selmes Van Den Bril, 2005; Georges *et al.*, 2008). As the dementia progresses people with dementia become highly dependent on their informal carers for assistance with household activities, like shopping, meal preparation, yard work, banking and for personal care (Jaglal *et al.*, 2007). The care for a person with dementia gradually develops into 24-hour care, 7 days a week, and many informal carers therefore experience negative physical, psychological and social consequences. Numerous studies report on these negative consequences, such as: high levels of strain, distress, anxiety and depression (Donaldson *et al.*, 1997; Dunkin and Anderson-Hanley, 1998; Pot *et al.*, 2000) and high financial burden (Moore *et al.*, 2001). Informal carers play an important role in delaying the nursing home admission of people with dementia. Studies show that carer variables, such as burden and physical health are strong predictors of institutionalization of the person with dementia, even stronger than patient variables like severity of cognitive impairments and ADL disabilities (Dunkin and Anderson-Hanley, 1998).

Psychiatric symptoms such as depression, anxiety and psychotic symptoms displayed by people with dementia have a high emotional impact on informal carers, especially on those who have a low sense of competence or higher financial expenditure, or if the person with dementia that they are caring for is in the milder stages of the disease and hence does not yet utilize professional care (Meiland *et al.*, 2005). While in former studies unmet care needs were usually only associated with carer burden and stress, Gaugler *et al.* (2004; 2005) found that unmet needs for formal support are not only predictors for carer burden, but unmet needs also directly influence nursing home admission and mortality in dementia. These findings are of great concern. They imply that meeting care and support needs is not only relevant for alleviating unmet needs, but also for improving carer well-being, and delaying institutionalization, i.e. enabling people with dementia to live in their own home for as long as possible. Reducing unmet care needs in dementia may even delay mortality. It is therefore very important to develop strategies to meet the care and support needs of people with dementia and their carers.

Demand-oriented care

In general people with dementia want to remain in their own environment. They report that continuing to live with their partner and receiving sufficient care is important for their quality of life (Dröes *et al.*, 2006). Dutch healthcare policy aims at keeping people with dementia in their own home for as long as possible (Health Council of the Netherlands, 2002). In line with that idea the Dutch Health Council states that interventions should be available for people with dementia in all stages of the disease to optimize functional abilities; compensate disabilities; preserve autonomy, identity and self-esteem; limit the consequences of secondary somatic disorders and behavioural and psychiatric problems; enhance feelings of safety; use the possibilities to enjoy; and provide support in coping with and accepting the disease (Health Council of the Netherlands, 2002).

As a result of the changing healthcare policy the Dutch healthcare and welfare system is also changing. The same changes can be seen in many European countries. The client in the care system is given a (more) central position and care suppliers are encouraged to become more responsive to the needs and wishes of their clients (De Blok *et al.*, 2009). In other words, the approach in health care and welfare shifts from supply-driven care provision towards demand-based care provision. The following definition, derived from De Klaver *et al.* (2003) describes the concept of demand-based healthcare and welfare delivery: "*Demand-driven home care is the joint effort of client and care provider which results in the client receiving the care that meets his wishes, needs and expectations, and which also meets the professional standards; in this effort the client also has the means to actually direct the offer. In demand-driven home care the client determines the demand and he is also in control.*" This concept is also known as 'demand-oriented care', 'demand-driven care', 'consumer-driven health care', 'patient/client-centred care', or 'patient/client-oriented care' (De Blok *et al.*, 2009).

In the 'old' supply-driven system there were long waiting lists for care. These caused problems especially for those who needed nursing or urgent care, and for informal carers who felt heavily burdened (Meiland *et al.*, 2001). In 2002 the Dutch government opened up the healthcare market to commercial organizations besides non-profit suppliers, with the intention of creating a climate that stimulates the empowerment of the client and in which a bigger capacity of care can be achieved. The overall goals were to decrease waiting lists, improve the quality of care and to provide a respectful, patient-centred treatment (Bomhoff, 2002; Raad voor de Volksgezondheid en Zorg, 2002).

Apart from the expected benefits, stimulating market force in health care and welfare can also have negative consequences. As the offer of healthcare and welfare services is comprehensive and very fragmented and changes continuously, there is the risk that clients, carers and referrers can no longer see the wood for the trees and will therefore not utilize the broad spectrum of available services in dementia care optimally (Dröes *et al.*, 2005).

Ways to inform people are needed to help persons with dementia and their carers in the community find the adequate services for their needs. According to the Dutch healthcare policy, clients are free to choose the service provider they prefer. The information service that is needed should therefore inform people with dementia and their carers about all available services that are relevant for them regarding their needs, as well as support these users in making a considered and free decision – to the maximum extent possible – for dementia healthcare and welfare services.

Care needs

In order to provide demand-based care and meet needs in an adequate and efficient way it is essential to first identify the needs of the care recipient. Although extensive research has been executed into the needs of people with dementia to date, they themselves were rarely involved in these studies. Needs were either reported by professional carers or proxies and family carers (Philp *et al.*, 1995; Aggarwal *et al.*, 2003;

Gaugler *et al.*, 2005), or observed by researchers (Ballard *et al.*, 2001). However, the opinions of proxies on needs are not necessarily the same as the needs felt by people with dementia. Also, people with dementia are individuals who experience individual needs (Kitwood, 1997). In other words, the opinion of people with dementia cannot be ignored.

In the course of our study we involved people with dementia in the systematic assessment of their needs. The instrument used to assess needs was the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds *et al.*, 2000). This CANE assesses environmental, physical, social and mental health needs of elderly persons on 24 domains of daily living. It takes four different perspectives into account: that of the elderly person, the informal carer, the professional carer, and an observer. The CANE inventories whether needs are met or unmet, the amount of provided informal and formal care and satisfaction on care. When an individual experiences difficulty in a particular area where appropriate support is being provided in such a way that the person is satisfied with it, it is concluded that the need has been met. An unmet need is defined as an area of difficulty for the individual on which no, or an inappropriate level of support is received, and the need reduces the person's Quality of Life (Orrell and Hancock, 2004). The CANE enables users to compare different perspectives on needed care and creates a comprehensive overview of needs experienced. Based on a CANE assessment an appropriate care intervention can be developed and applied for the person with dementia.

Technology in health care

As the amount of available professional care is not expected to rise in proportion with the growing demand in the ageing society (Health Council of the Netherlands, 2002), the number of unmet needs is expected to increase in the future. ICT is seen as a promising means to support people with dementia and carers in their home environment, thereby improving their quality of life (Nugent, 2007). Various ICT applications are already developed for people with dementia, for example in the categories: providing general and personalized information; providing support with regard to symptoms of dementia; facilitating social contact and company; monitoring health; and perceived safety by the person with dementia (Lauriks *et al.*, 2007). Several ICT applications to provide support for symptoms of dementia, social contact, monitoring health and enhancing (feelings of) safety of people with dementia have been proven effective. However, existing ICT applications that provide information on dementia and services are generally found to be of a generic nature, and have not yet been systematically studied for their usefulness (Lauriks *et al.*, 2007). Within the FRUX project a need-based digital social chart system was developed that provides general and personalized information on dementia healthcare and welfare services. This so-called

DEM-DISC (DEMentia-specific Digital Interactive Social Chart) was evaluated in a controlled trial with informal carers and people with dementia.

Study objectives

The needs of community-dwelling people with dementia and a possible ICT solution to support them and their carers to find the right service(s) for their needs in a demand-oriented manner were the focus of the research reported on in this thesis. The first part of the study focused on gaining insight into the met and unmet needs of people with dementia as experienced by the people with dementia themselves and as perceived by their informal carers. The second part of the study aimed at developing and evaluating an ICT application to meet unmet needs in an efficient and personalized way.

The central questions of the research reported on in this thesis were:

1. *What is the state of the art with respect to knowledge on the needs that community-dwelling people with dementia experience?*
2. *What needs do community-dwelling people with dementia experience and what needs are reported by their informal carers?*
3. *Is the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE) a valid and reliable instrument to assess needs of people with dementia?*
4. *How can a human-centred design be applied in the development of DEM-DISC?*
5. *Is DEM-DISC a user-friendly and useful system to meet the needs of people with dementia and their carers in the community and does DEM-DISC use have a positive impact on the daily life of people with dementia and their carers?*

Contents of this thesis

To answer the first two research questions a literature study and a field survey were conducted. To answer question 3 the Dutch translation of the CANE was subjected to a reliability and validity study. To answer question 4 the development process of DEM-DISC was described in detail and to answer questions 5 a controlled pilot study was executed involving community-dwelling people with dementia and their carers.

Chapter 2 provides an overview of the literature on the subjective needs of community-dwelling people with dementia. Needs were derived from studies that were found in an extensive search of the literature published between 1985 and 2005. Segments of text in which people with dementia were interviewed on their needs and their experiences with the disease were classified as a need (an implicitly communicated felt state of deprivation), a want (an expression of a need) or a demand (a preferred solution to fulfil a need) within specific problem areas (Meerveld *et al.*, 2004) or quality of life domains (Dröes *et al.*, 2006).

Chapter 3 describes the results of an elaborate cross-sectional study among community-dwelling people with dementia (n = 236) and their informal carers (n = 322) in two regions in the Netherlands: Noord-Holland and Nijmegen. This chapter gives insight into the met and unmet needs of people with dementia, into the amount of professional and informal care that was provided to them regarding their needs, and the level of agreement between people with dementia and their informal carers on needs and received support. Furthermore, reasons for unmet needs and relationships between sociodemographic variables and needs were described.

Chapter 4 describes the study that was conducted to assess the construct and criterion validity and the test-retest reliability of the Dutch version of the CANE (Reynolds *et al.*, 2000). Construct and criterion validity and test-retest reliability were based on ratings of informal carers of community-dwelling people with dementia. Construct validity was also studied for ratings of people with dementia. Data were derived from the needs study described in Chapter 3; about one-fifth of the informal carers involved in this study were interviewed twice for reliability and validity purposes.

Chapter 5 reflects upon the human-centred design approach that was applied in the development of DEM-DISC. This iterative development process is described from four different perspectives: A domain-specific content perspective (specifying needs, offerings, information and advice), an ICT perspective (knowledge management and application), a user perspective (people with dementia, informal and professional carers) and an organizational perspective (necessary collaboration, governance and control, business modelling). The outcome of the development process, the first prototype of DEM-DISC, is also described in this chapter.

Chapter 6 describes a pilot study into the usefulness and user friendliness of the first version of DEM-DISC as well as its impact on the daily lives of people with dementia and their carers. The study was carried out according to a pretest-posttest control group design among informal carers (n = 28) of community-dwelling people with dementia.

In *Chapter 7*, General discussion, the results of the studies reported on in this thesis are summarized and conclusions are drawn. Limitations of the studies are considered in the light of the FRUX project and the methodology used. Finally, the scientific and societal implications of this study are discussed.

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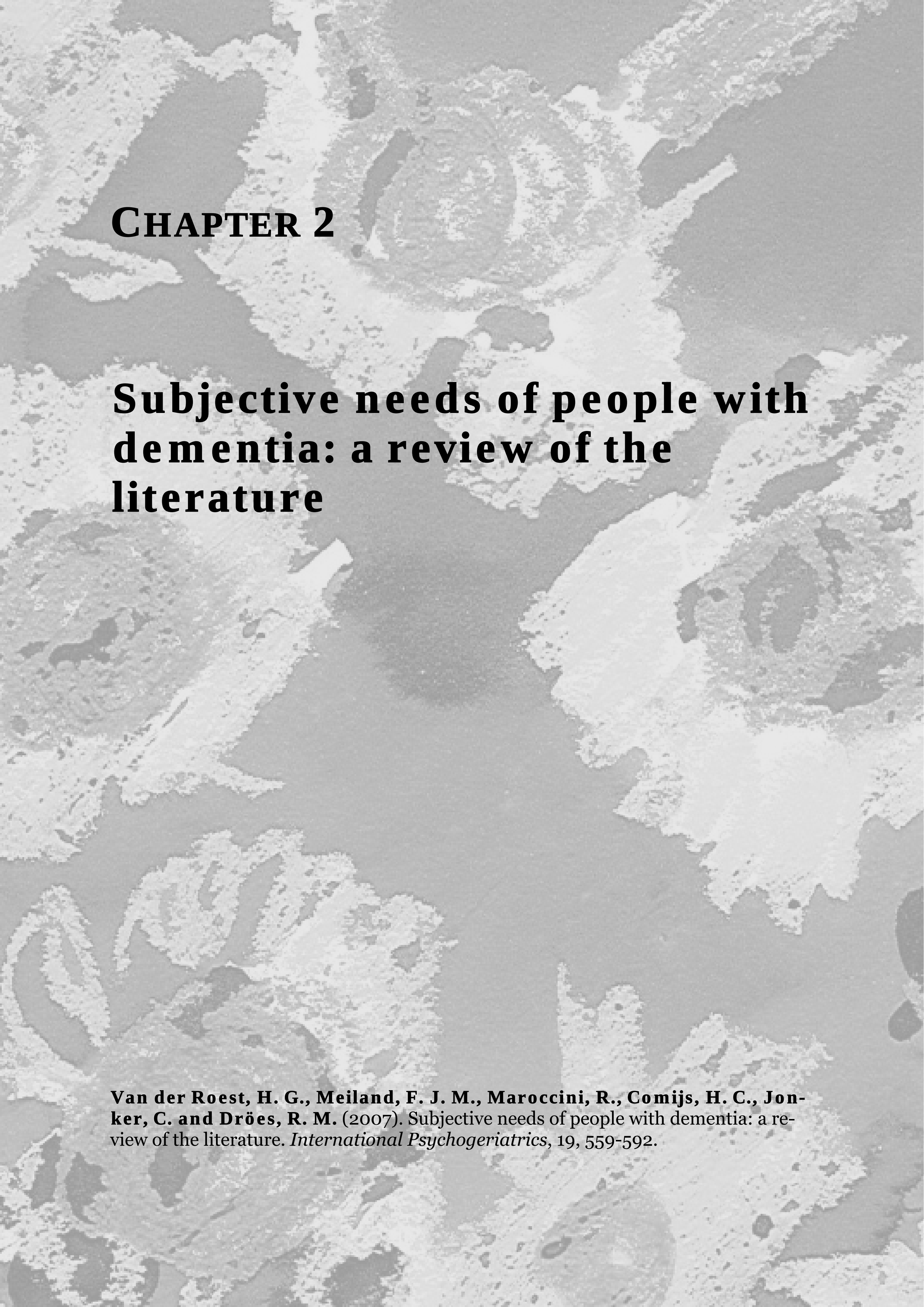

CHAPTER 2

Subjective needs of people with dementia: a review of the literature

Van der Roest, H. G., Meiland, F. J. M., Maroccini, R., Comijs, H. C., Jonker, C. and Dröes, R. M. (2007). Subjective needs of people with dementia: a review of the literature. *International Psychogeriatrics*, 19, 559-592.

Abstract

Objective: Insight into the individual care needs of the growing number of people with dementia is necessary to deliver more customized care. Our study aims to provide an overview of the literature on the subjective needs of people with dementia.

Method: Electronic databases were searched for publications on subjective needs between January 1985 and July 2005, and reference lists were cross-referenced. Extracts of needs were classified within problem areas of the (Dutch) National Dementia Program and quality of life domains, and the extracts were classified as a “need” (an implicitly communicated felt state of deprivation), “want” (expression of a need) or “demand” (suitable solution to fulfil a need).

Results: Subjective needs were found in 34 studies with various research aims, such as awareness and coping. Few studies aimed to measure needs of people with dementia. The most frequently reported needs of people with dementia were the need to be accepted and respected as they are, the need to find adequate strategies to cope with disabilities, and the need to come to terms with their situation. Explicit wants or demands were reported less frequently than needs.

Conclusion: The high number of reported needs and the limited number of wants and demands show that people with dementia do not frequently mention how they want their needs to be met. Most reported needs are not instrumental, but are related to well-being and coping. Further research to inventory these needs could help achieve more demand-directed and better attuned care in the future.

Introduction

The demographic effects of the post-World War II baby boom are that about one-sixth of Europe's population is now aged over 65. By 2025 it is estimated that this figure will have increased to a quarter (International Institute for Applied Systems Analysis, 2002; United Nations, 2005). From 2030 onwards, the population of younger people is expected to decrease while that of people older than 65, and especially older than 85, will increase (European Commission, 2005). One of the consequences of this is an increase in the number of people with dementia. Almost 5% of people over 65 have dementia, rising to 40% for people of 90 years and older (Fratiglioni *et al.*, 2000; Launer and Hofman, 2000). Exact numbers on the prevalence of dementia are not available but estimates can be made. According to Alzheimer Europe, more than 5,700,000 people with dementia are presently living in Europe (Alzheimer Europe, 2006).

Since there still is no cure for dementia, this massive increase in the number of people with dementia requires a drastic adaptation of the healthcare system. Facilities such as nursing homes and homes for the elderly have neither the capacity nor the resources to expand to take care of this growing group (Health Council of the Netherlands, 2002). Future care solutions must therefore enable people to live in their own homes for longer. Gaugler *et al.* (2005) found that as the number of unmet care needs reported by informal caregivers rose, so the likelihood increased that people with dementia would be placed in a nursing home or would die. Better attunement of care to the individual needs of people with dementia and their caregivers (customized care) is therefore required. In general one could say that the healthcare system should be reformed from service-based care into demand-directed care that is attuned to the individual experience and needs of people with dementia (experience-oriented care) and the needs of their caregivers. In that context further needs assessment and detection of unmet needs of people with dementia and their caregivers is considered crucial (Kitwood, 1997; Health Council of the Netherlands, 2002; Clare *et al.*, 2005). The literature makes a distinction between objective and subjective needs. Objective needs are those needs that can be measured by instruments, or the needs of people as perceived and expressed by others. In the case of people with dementia, these "others" are informal carers or professionals. Subjective needs are those that they themselves express.

Though various models have been developed since the late 1980s to explain and understand the subjective experience of people with dementia (Hall and Buckwalter, 1987; Kitwood, 1989; Dröes, 1991; Bakker, 1992; Miesen, 1992; Hagberg, 1997; Harris and Sterin, 1999; Finnema *et al.*, 2000; Clare, 2002a; Pratt and Wilkinson, 2003), little research has been carried out on the subjective needs of people with dementia. Most dementia care research is based on proxy reports, observations and judgments by informal and professional caregivers and therefore reports only objective needs.

Most available instruments for assessing social, physical, psychiatric and health needs in the elderly are constructed for the general population (Brewin *et al.*, 1987; Phelan *et al.*, 1995; Reynolds *et al.*, 2000; Nelson *et al.*, 2004). Only very recently have a few studies specifically reported on measured needs as expressed by people with dementia themselves: Hancock *et al.* (2006) found that needs with respect to sensory and physical disabilities, mental health needs and social needs were often unmet among people with dementia in residential care (*n* = 238) in the United Kingdom. Among Irish community-dwelling people with dementia (*n* = 82), high levels of unmet needs were found in the domains of behavioral problems, mental state and social interaction (Meaney *et al.*, 2005). In the United States Edelman *et al.* (2006) identified needs for services and information about stages and symptoms of Alzheimer's disease and information about approved and experimental drug treatments for memory loss (*n* = 100). Note that in the work published by Meaney *et al.* (2005) the opinions of the persons with dementia and those of informal caregivers were not discussed separately.

To develop customized care for people with dementia (i.e. demand-directed and experience-oriented care), an inventory of what is known about the subjective needs of people with dementia at different stages of the disease appears to be vital.

This paper aims to provide an overview of the literature on subjective needs as expressed by people with dementia living in the community, in various types of research reported between January 1985 and July 2005.

Method

Search procedure and selection criteria

We started by searching the electronic databases of PubMed and PsycINFO. The search was limited to material published in English between January 1985 and July 2005. The inclusion criteria restricted the publications to study reports on subjective needs of people with dementia living in the community, on their experiences with the disease or on what they found to be important in their daily life and for their quality of life. Studies reporting on the needs of persons with dementia as expressed by (in)formal caregivers were excluded. Special attention was paid to determining the sets of keywords for meeting the selection criteria (Table 1). Categories were formed with free text words and "MeSH" and "Thesaurus". An additional search was performed for papers that used the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds *et al.*, 2000). These three searches resulted in a total of 275 articles, of which only six articles met the inclusion criteria. Cross-referencing the reference lists of these articles resulted in another 19 titles. Using this “snowball” method a total of 34 papers were finally identified for further analysis.

Table 1. Domains of keywords for the search of needs of persons with dementia

Dementia	**People with dementia**	**Subjective needs**	**Method**
MeSH[1] *& free text:* dementia	*Free text:* person with dementia, people with dementia, elderly with dementia, elderly person with dementia, elderly persons with dementia, elderly people with dementia, patient with dementia, client with dementia, individual with dementia, elder with dementia	*MeSH*[1]*:* health services needs and demand *MeSH*[1] *& free text:* quality of life, personal satisfaction, patient satisfaction *Free text:* need perception, care need, care expectation, need of care, latent need, manifest need, subjective need, unmet need, care problem, complaint patient, care demand, care want, patient need, support need, help, perceived need, want, demand, preference, well being	*MeSH*[1]*:* Interview [Publication Type], Interviews; Interview, Psychological *Free text:* client interview, patient interview, face-to-face interview, patient report, client report, self report
MeSH[1] *& free text:* dementia			*Free text:* Camberwell assessment, CANE[3]
Thesaurus[2] *& free text:* dementia		*Thesaurus*[2]*:* health service needs, quality of life, client satisfaction, need satisfaction	*Thesaurus*[2]*:* methodology *Free text:* Interview

[1] Used for indexing articles in the PubMed database

[2] Used for indexing articles in the PsycINFO database

[3] Camberwell Assessment of Need for the Elderly

Theoretical framework and analysis

A qualitative data analysis was performed on those papers selected for analysis. The results sections of those papers were screened for extracts that referred to different types of needs or domains of quality of life. In line with Kotler’s marketing theory (1980), we made a distinction between needs, wants and demands.

Needs are defined as an implicitly communicated felt state of deprivation (including basic needs, social needs and individual needs), for example the need for social contact. A *want* is defined as the expression of a need, as shaped by a person's culture and individual development, for example "I need someone to talk to." A *demand* is defined as the suitable solution for a person to fulfil his or her need (depending on the resources a person has), for example "I want a volunteer from the Red Cross to visit me every week." Expressed met as well as unmet needs were inventoried in the literature.

In order to classify the subjective needs of people with dementia, we began by using the 14 problem areas described in the Dutch National Dementia Program (NDP) (Meerveld *et al.*, 2004). The NDP was developed as a working program for professionals seeking to generate more demand-oriented care within the chain of care services in a particular region. The program gives an overview of the most common problems and questions regarding dementia, categorized in 14 problem areas which are based upon literature research, interviews with professional caregivers (experts in dementia care), informal caregivers and people with dementia. Two problem areas, *Cannot cope anymore* (*NDP-10*) and *For better and for worse* (*NDP-12*), are specifically focused on informal caregiver problems, and so we excluded these areas from our classification model.

The way in which people with dementia judge their situation and express their needs may not always be in terms of "problems". Needs can also be associated with aspects of well-being (Clare *et al.*, 2005) and expressed in terms of quality of life or experiences that are important to people. Therefore, we also used Quality of Life (QoL) domains that are considered relevant by people with dementia. From a field study in which people with dementia were asked: "Which aspects of daily life do you feel have an influence on your quality of life?", Dröes *et al.* (2006) were able to distinguish 12 QoL domains (see Table 2). Most of these are also included in the present dementia-specific quality of life instruments (Brod *et al.*, 1999; Logsdon *et al.*, 1999; Rabins *et al.*, 1999; Volicer *et al.*, 1999; Ready *et al.*, 2002).

The classification procedure for the current review was undertaken as follows: the first paper was coded according to the NDP and QoL domains (Table 2) by all researchers (HvdR, FM, RM and RMD) independently, and discussed in detail. This discussion resulted in a sharpening of the description of the domains. All other papers were coded independently by two researchers and compared afterwards. In case of discrepancies between the assigned codes, the extract was looked at in the context of the original text. Relevant context information was considered and the coding was discussed until consensus between the two researchers was reached. Discrepancies were discussed in approximately one- third of the coded extracts. Some extracts could be classified in more than one domain and if the traced needs, wants and demands could not be classified in one of the NDP problem areas or QoL domains, the researchers were permitted to create new domains.

The coded extracts from the text were imported into the QSR NUDIST VIVO program (Qualitative Solutions and Research, 1999), listed for each NDP and QoL domain and independently checked by two assessors for correct classification (HvdR, FM or RMD). Incorrect classifications were discussed as described above and the extracts were re-classified. After this an inventory was made of extracts for each NDP and QoL domain. In some cases contextual information was reread to better understand statements made by individual persons.

Table 2. Domains in the classification of subjective needs of people with dementia

DOMAINS NATIONAL DEMENTIA PROGRAM		DOMAINS QUALITY OF LIFE	
NDP-1:	Feeling that something is wrong, sense of	QoL-1	Affect
	unease	QoL-2:	Self-esteem/self-image
NDP-2:	What is the problem and what can help?	QoL-3:	Attachment
NDP-3:	Frightened, angry and confused	QoL-4:	Social contact
NDP-4:	Having to face everything on your own	QoL-5:	Enjoyment of activities
NDP-5:	Avoiding contacts	QoL-6:	Sense of aesthetics in living environ-
NDP-6:	Physical care	QoL-7:	ment
NDP-7:	Danger	QoL-8:	Physical and mental health
NDP-8:	Medical problems as well	QoL-9:	Financial situation
NDP-9:	Loss	QoL-10:	Security and privacy
NDP-11:	Being patronized by (in)formal carers	QoL-11:	Self-determination and freedom
NDP-13:	Miscommunication with formal carers	QoL-12:	Being useful/giving meaning to life
NDP-14:	Resistance to institutionalization		Spirituality

Results

The literature search resulted in a total of 34 articles (Table 3). Although the literature searched spans a period of 20 years, all of the articles found were published after 1992. In the 1990s people with dementia were still only sporadically involved in research. Most of the publications in which people with dementia were interviewed date from 2000 or later.

Respondents in the majority of the studies are referred from day-care centers and memory or psychogeriatric clinics. In almost one-third of the studies the severity of dementia is not mentioned, and those studies that state the severity do not always declare how the severity was determined. Where the severity is mentioned, the range is between early dementia and moderately severe dementia. Respondents with severe dementia were included in only three studies. Most of the people with dementia in the studies were diagnosed with (probable) Alzheimer's disease.

The articles cover a wide range of research aims, with only a few studies being specifically conducted to measure the care needs of people with dementia (Bamford and

Table 3. Literature review of subjective needs in dementia, 1985-2005

AUTHOR	SETTING AND SAMPLE	AGE (RANGE) AND SEVERITY OF DEMENTIA (RANGE)	AIM OF THE STUDY	METHOD OF DATA COLLECTION AND ANALYSIS	DOMAINS IN WHICH NEEDS ARE MENTIONED IN PAPER
Acton *et al.* (1999)	United States 20 persons with (possible) AD (sample from larger study which recruited subjects from groups associated with the Alzheimer's Disease and Related Disorders Association, local health fairs, churches, physicians and other health care professionals)	Mean age 74.89 (55–84) Mean MMSE (*Mini Mental State Examination*) 18.5 (6-30)	Examining communication episodes from individuals with dementia for content and meaning	Semi-structured interviews Content analysis (based on an inductive process)	Loss; Distress; Being useful; Medical problems; Spirituality; Attachment; Facing everything alone; Avoiding
Aggarwal *et al.* (2003)	United Kingdom 10 persons with dementia in day care 17 persons with dementia in residential care 28 relatives	Various stages of dementia	Eliciting the views and feelings of people with dementia and their relatives, on care services and on experiences of dementia	Semi-structured interviews, examination of care plans, files and diaries, observation and filming Non-participant time sampling observations and qualitative analysis	Loss; Distress; Affect; Activities; Medical problems; Freedom; Social contact
Bamford and Bruce (2000)	United Kingdom 15 persons with dementia using day and respite care 1 male; 14 female	60–69 (*n* = 1) 70–79 (*n* = 2) 80–89 (*n* = 9) > 90 (*n* = 3) Mild and moderate dementia	Identifying the desired outcomes of community care in people with dementia and their carers	Formal and informal group discussions, individual interviews, informal conversations Search and retrieval procedures to explore emerging themes	Freedom; Self-esteem; Socia contact; Activities; Health; Attachment; Loss; What can help?; Facing everything alone; Institutionalization; Affect; Security
Basting (2003)	United States Autobiographies of 3 persons with dementia 2 male; 1 female	Mild dementia	Describing how the three people with dementia worry over and create a sense of selfhood in the midst of their perceived loss	Three autobiographies Text analysis	Loss; Being useful; Self-esteem; Distress; Affect; Something is wrong; Attachment; What can help? Miscommunication; Spirituality; Security

Author	Setting and sample	Age (range) and severity of dementia (range)	Aim of the study	Method of data collection and analysis	Domains in which needs are mentioned in paper
Beattie *et al.* (2004)	United Kingdom 14 younger people with dementia (1 person living in a residential home) referred by day centres for younger people with dementia 9 male; 5 female	Mean age 59.43 (41–66; *SD* = 6.78)	Investigating how younger people with dementia deal with their perceived experiences of memory problems, their care needs and their views on the currently available services	Semi-structured, in-depth interviews Comparative textual analysis based on the Grounded Theory Method	Miscommunication; Activities; Self-esteem; Social contact; Freedom; Attachment; Something is wrong Loss; Distress; Being patronized
Cahill *et al.* (2004)	Norway, Finland, Ireland, Lithuania 92 persons with dementia living in the community included in ENABLE project 34 male; 58 female	Mean age 76 (54-97) Mean MMSE 20.93 (12-29)	Assessing quality of life of people with dementia and exploring whether people with moderate dementia can be good informants of their own quality of life	In-depth interviews and questionnaires Statistical analysis and textual analysis	Loss; Attachment; Social contact; Affect; What can help?; Activities; Health; Being useful; Aesthetics; Distress; Self-esteem; Finance; Security
Clare (2002a)	United Kingdom 12 persons with dementia of a memory clinic and an old age psychiatry service 9 male; 3 female Partners of persons with dementia	Mean age 71 (57–83) Early stage dementia	Exploring the contribution of psychological and social factors to the expression of awareness	In-depth interviews Interpretative Phenomenological Analysis	Loss; Miscommunication; Self-esteem; Something is wrong; What can help?; Distress; Being useful; Freedom
Clare (2002b)	United Kingdom 12 persons with dementia from a memory clinic 9 male; 3 female Partners of persons with dementia	Mean age 71 (57–83) Early stage dementia Mean MMSE 23 (19-29)	Identifying and conceptualizing the coping strategies used by people with early-stage Alzheimer's disease	In-depth interviews Interpretative Phenomenological Analysis	Loss; Being useful; What can help?; Distress; Health; Facing everything alone; Avoiding; Affect; Activities

Author	Setting and sample	Age (range) and severity of dementia (range)	Aim of the study	Method of data collection and analysis	Domains in which needs are mentioned in paper
Clare (2003)	United Kingdom 12 persons with dementia of a memory clinic 9 male; 3 female Partners of persons with dementia	Mean age 71 (57-83) Mild or minimal range of severity Mean MMSE 23 (19-29)	Exploring the way in which awareness is expressed in the accounts of personal experiences given by people with early-stage dementia, in order to develop an understanding of the psychosocial elements of a comprehensive model of awareness	In-depth interviews Interpretative Phenomenological Analysis	Loss; Miscommunication; Self-esteem; Something is wrong; What can help?; Distress; Being useful; Freedom; Institutionalization; Attachment; Security Activities
Clare and Shakespeare (2004)	United Kingdom 10 married couples who recently attended a memory clinic and from whom one partner is assigned a diagnosis of early AD	Age range 53-83 Early stage dementia Mean MMSE 24 (20-29)	Investigating conversational interactions between people with early-stage dementia and their spouses	Conversation tasks between people with early-stage dementia and their partners Voice Relational Method	Loss; Attachment; What can help?; Something is wrong Institutionalization; Being patronized; Freedom; Affect; Social contact
Fukushima *et al.* (2005)	Japan 18 patients at a day care facility 6 male; 12 female 21 family carers 8 staff members of a day-care facility	Male: Mean age 78.2 (66–93; *SD* = 8.9) Female: Mean age 81.2 (70–98; *SD* = 4.5) Moderate to severe dementia	Investigating aspects of quality of life from the point of view of people with dementia and the role of their acceptance of the dementia in presenting these aspects	Questionnaires and interviews Analysis of the responses	Attachment; Social contact; Freedom; Being useful; Affect; Health; Finance
Gillies and Johnston (2004)	United Kingdom Study 1: 16 patients with cancer 14 family carers Study 2: 20 persons with dementia living at home 11 male; 9 female 20 family carers	Age range 64-89	Exploring the similarities of identity loss as experienced by cancer patients and people with dementia	Semi-structured interviews Study 1: Grounded Theory approach Study 2: line-by-line analysis by a process of comparative analysis	Loss; Being useful; Self-esteem

AUTHOR	SETTING AND SAMPLE	AGE (RANGE) AND SEVERITY OF DEMENTIA (RANGE)	AIM OF THE STUDY	METHOD OF DATA COLLECTION AND ANALYSIS	DOMAINS IN WHICH NEEDS ARE MENTIONED IN PAPER
Gillies (2000)	United Kingdom 20 persons with dementia drawn from urban/rural health and social services (1 person living in a local authority residential home) 11 male; 9 female	Age range 64-89	Examining the experience of people living with dementia, their attribution of and coping with the dementia	Semi-structured interviews Line-by-line thematic coding	Loss; Self-esteem; Somethin is wrong; Freedom; What can help?; Avoiding; Distress; Social contact
Gilmour and Huntington (2005)	New Zealand 9 persons living at home 5 male; 4 female	Age range 56-79	Exploring the experiences of living with memory loss in people with dementia	Semi structured interviews Thematic analysis	Loss; What can help?; Self-esteem; Attachment; Health; Miscommunication; Something is wrong; Freedom; Activities
Gwyther (1997)	United States Single case of Tommy Thompson and review of literature 1 male	Age 59	Highlight subjective perceptions of people with early to middle stage AD about meaningful goals and outcomes	Individual interviews and literature review Analysis of the interview and transcripts of people with dementia in literature	Self-esteem; Loss; Being useful; Attachment; Social contact; Health; Security; What can help?; Something is wrong; Activities; Affect; Facing everything alone; Distress; Freedom
Holst and Hallberg (2003)	Sweden 11 attendees of a psychogeriatric clinic, living at home	Moderate level of dementia	Exploring the meaning of everyday life of people with dementia as expressed by themselves	Individual interviews according to the oral history approach Biographical method procedure	Loss; Distress; Self-esteem; Affect; Avoiding; Social contact; Miscommunication; Facing everything alone; Something is wrong Freedom; Being useful; Ac tivities

AUTHOR	SETTING AND SAMPLE	AGE (RANGE) AND SEVERITY OF DEMENTIA (RANGE)	AIM OF THE STUDY	METHOD OF DATA COLLECTION AND ANALYSIS	DOMAINS IN WHICH NEEDS ARE MENTIONED IN PAPER
Howorth and Saper (2003)	United Kingdom 32 attendees of two day-hospitals 13 male; 19 female 32 family carers	Mean age 73.75 (63.17-87.17) Mild to moderate dementia (mean BDS (*Blessed Dementia Screen*) 24.3; 12-31; *SD* = 5.3)	Characterizing the factors determining the retention or loss of insight in dementia	Semi-structured interviews Non-parametric statistics and coding of responses into categories and themes (methods of Robson (1993))	Loss; Medical problems; Health
Katsuno (2003)	United States 23 persons with dementia, attendees of a dementia-specific day-care centre and a residential-care facility 5 male; 18 female	Mean age 79.0 (66–91; *SD* = 8.26) Early stage dementia (mean MMSE 20.8; 18–28; *SD* = 2.8)	Describing the spiritual experiences of people with dementia and exploring the relationship between personal spirituality and perceived quality of life	Structured and semi-structured interviews and quantitative measures on personal spirituality and quality of life Statistical analysis and qualitative analysis with methods of Miles and Huberman (1994) and Knafl and Webster (1988)	Spirituality; Loss; Activities; Attachment; Self-esteem; Distress; Being useful; Affect; Social contact
Katsuno (2005)	United States 23 persons with dementia, attendees of a dementia-specific day-care centre and a residential care facility 5 male; 18 female	Mean age 79.0 (range 66–91; *SD* = 6.2) Early stage dementia (mean MMSE 20.8)	Exploring subjective and objective assessments of quality of life of people with dementia, describing personal experiences of the disease and reactions to the negative public attitudes towards dementia	Semi-structured interview guide and structured questionnaires Methods employed by Miles and Huberman (1994) and Knafl and Webster (1988)	Self-esteem; Loss; Social contact; Attachment
LaBarge and Trtanj (1995)	United Kingdom 10 persons, referred from the St. Louis Chapter helpline, ADRC staff, and from a select group of geriatricians and geriatric clinics 6 male; 4 female	Age range 54-83 Early stage dementia	Describing the process and outcomes of a support group for people with early stage dementia from their perspective	Logging, questionnaire and verbal answers Audit trail	What can help?; Loss; Freedom; Being useful; Affect; Self-esteem; Social contact; Activities; Education

AUTHOR	SETTING AND SAMPLE	AGE (RANGE) AND SEVERITY OF DEMENTIA (RANGE)	AIM OF THE STUDY	METHOD OF DATA COLLECTION AND ANALYSIS	DOMAINS IN WHICH NEEDS ARE MENTIONED IN PAPER
MacQuarrie (2005)	Canada 13 persons with dementia, most attendees of a memory clinic 9 male; 4 female	Mean age 76.5 (60–89; *SD* = 8.26) Mean MMSE 22.4 (17–26; *SD* = 2.99)	Understanding and interpreting experiences of people with Alzheimer dementia	Two semi-structured interviews over a six month period Methodological hermeneutics	Loss; Distress; Being patronized; Freedom; Self esteem; Social contact; Avoiding; Something is wrong; Being useful; Activities; Danger; Health
Marzanski (2000)	United Kingdom 11 inpatients and 19 outpatients of an old age psychiatric service, all diagnosed with dementia 10 male; 20 female	Mean age 81 (range 63–92) Mean MMSE 18 (range 7-29)	Discovering what people with dementia feel is wrong with them, whether and what they have been told and by whom and what they wish to know about their illness	Individual interview with structured questionnaire Descriptive analysis of responses	Needs, wants and demands in: Loss; Something is wrong; Miscommunication; What can help?
Pearce *et al.* (2002)	United Kingdom 20 men with dementia, attendees of 7 memory clinics 20 wives	Mean age 74.8 (63–84; *SD* = 0.43) Mean MMSE 24.15 (*SD* = 0.25)	Exploring the appraisals and coping processes of men with early AD and offering a framework for understanding how they cope with dementia	Semi-structured interviews Interpretative Phenomenological Analysis	Loss; Attachment; What can help?; Being useful; Self-esteem; Something is wrong; Distress
Phinney (1998)	United States 5 community-dwelling persons with a diagnosis of probable Alzheimer's disease 1 male; 4 female 3 spouses	Age range 75-89 Mild to moderate dementia Mean MMSE 19 (17-23); mean GDS (*Global Deterioration Scale*) 4 (3-5)	Seeking to understand the experience, meaning and concerns of living with dementia from the perspective of people who received a diagnosis of Alzheimer's disease	Two semi-structured interviews over a two week period, spouse interviews, observation, quantitative measures Thematic analysis (Van Manen, 1990)	Loss; Something is wrong; Being useful; Self-esteem; Social contact; Freedom
Pratt and Wilkinson (2003)	Scotland 24 people with dementia from memory clinics, dementia support workers, psychiatrists, primary care professionals, day centres and support agencies 11 male; 13 female	Age range 44-78	Presenting a psychosocial model of understanding the experience of people with dementia	Interviews guided by themes (not structured) Analysis by looking for key themes (Denzin and Lincoln, 1998), generating meaning (Miles and Huberman, 1994) and case study analysis (Holloway and Jefferson, 2000)	Loss; Something is wrong; Self-esteem; Social contact; Miscommunication; Being patronized; Affect; What can help?; Distress; Freedom; Activities; Security

Author	Setting and sample	Age (range) and severity of dementia (range)	Aim of the study	Method of data collection and analysis	Domains in which needs are mentioned in paper
Proctor (2001)	United Kingdom 4 women with dementia		Finding out how women viewed the services they received and understanding their world view, and investigating the possibilities of interviewing people with dementia	Semi-structured interviews Voice Relational Method	Miscommunication; Being patronized; Self-esteem; Social contact; Loss; Institutionalization; Affect; Finance
Quayhagen and Quayhagen (1996)	United States of America 10 persons with dementia and their spouses, recruited through the Alzheimer's Disease Research Centre and Alzheimer Association 4 male; 6 female	Male: Mean age 72.5 (*SD* = 3.1) Female: Mean age 66.5 (*SD* = 6.7) Mild to moderate dementia	Investigating the personal experience of caregivers of a cognitive remediation intervention, the impact of the intervention and what changes occurred within the care giving dyad during implementation	Interviews, observation, caregiver log recordings and semi-structured process evaluation forms Coding of data according to methods of Strauss and Corbin (1990)	Loss; Danger; Distress; Self-esteem; Activities
Reid *et al.* (2001)	United Kingdom 19 people with dementia, attendees of three different day-care services		Exploring the question of unmet needs in relation to people with dementia receiving respite services and considering their status as service users	Semi-structured interviews and group discussions Analysis for emerging themes (Glaser and Strauss, 1967)	Activities; Loss; Being useful Security; Social contact; Attachment; Freedom; Health; Institutionalization; Distress; Affect; Self-esteem
Sabat and Harré (1992)	United States 3 people with dementia attending an adult day care facility 1 male; 2 female		Exploring the loss of self by using the constructionist theory of the nature of the self	Conversations, interviews and observations Analyzing discursive events	Loss; Distress; Self-esteem; Attachment
Sabat *et al.* (1999)	United States 4 people with AD attending a day-care facility 1 male, 3 female	Range age 68-70 Moderate to severe dementia	Examining the relations between Alzheimer's disease sufferers and the non-afflicted, focusing on strategies of AD sufferers to maintain their sense of self-worth	Individual interviews and observations Exploring narrative-based beliefs and events	Loss; Being useful; Activities Distress; Affect; Self-esteem; Social contact; Security

AUTHOR	SETTING AND SAMPLE	AGE (RANGE) AND SEVERITY OF DEMENTIA (RANGE)	AIM OF THE STUDY	METHOD OF DATA COLLECTION AND ANALYSIS	DOMAINS IN WHICH NEEDS ARE MENTIONED IN PAPER
Silberfeld *et al.* (2002)	Canada 20 persons with dementia referred by a memory clinic, a hospital or general practitioners in retirement homes or community centres 20 family caregivers 8 male; 12 female	Mean age 79 (range 62–89) Early stage dementia Mean MMSE 22 (*SD* = 2.54; range 18-6)	Exploring which aspects of quality of life were perceived as important and compare these to generic quality of life instruments to evaluate their potential usefulness within the context of AD	Semi-structured interviews Grounded Theory Method (Glaser and Strauss, 1967)	Health; Loss; What can help?; Activities; Aesthetics; Security; Avoiding; Danger; Distress; Freedom; Being useful; Spirituality; Self-esteem; Attachment; Social contact; Finance
Smith *et al.* (2005)	United Kingdom 18 people with dementia living at home, 1 in nursing home 4 male; 15 female 16 main family carers and 4 additional carers	Age range 69-85 Mild to severe dementia	Understanding what determines health-related quality of life for people with dementia, and examine differences between self-reports and family carers' descriptions of the HRQL of the person with dementia	Individual semi-structured interviews Content analysis	Loss; Self-esteem; Social contact; Something is wrong; Distress; Being useful; What can help?; Danger; Attachment; Activities; Health
Struttman *et al.* (1999)	France 27 people with dementia attending the neurology department of a university hospital 10 male; 17 female 30 patients with cancer attending the cancer department of a university hospital	Mean age 79 Moderate senile dementia MMSE > 15	Assessing potentially divergent profiles of quality of life in persons with moderate dementia and in persons with cancer	Self-report questionnaire, administered twice within a two week period Statistical analysis	Attachment; Affect; Social contact
Zarit *et al.* (2004)	United States 24 people with dementia attending a memory club 23 care partners 48.8 % male; 51.2 % female	Mean age 70.1 (*SD* = 8.1) Significant memory problems	Description and evaluation of the Memory Club	Individual interviews and post-treatment questionnaire Statistical analysis, descriptive analysis of responses to open-ended questions	Loss; What can help?; Self-esteem; Something is wrong; Freedom; Being useful; Affect; Miscommunication; Being patronized Social contact; Activities; Health

Bruce, 2000; Proctor, 2001; Reid *et al.*, 2001; Aggarwal *et al.*, 2003; Beattie *et al.*, 2004), or their opinion on their own quality of life (Struttman *et al.*, 1999; Silberfeld *et al.*, 2002; Cahill *et al.*, 2004; Fukushima *et al.*, 2005; Katsuno, 2005; Smith *et al.*,2005). Most studies examined communication (episodes) of people with dementia, and their awareness of, or coping with, dementia. In all these studies, however, different types of subjective needs are also mentioned. Most subjective needs are implicitly expressed by people with dementia as felt states of deprivation. These needs can be distinguished from concrete wants and demands. Wants were described far less frequently than needs, whereas demands rarely occur in the reviewed studies.
In the following we will first give a summary of the inventoried *needs* in the different domains, and then present the found *wants* and *demands*.

Expressions of needs in different domains

The found subjective needs could all be classified within the domains of the National Dementia Program and the domains of Quality of Life. No extra domains were added to the model. Inspection of Table 4 shows that subjective needs within the domain of *Loss* (*NDP-9*) are mentioned in almost all studies, and needs in the domains of *Self-esteem/self image* (*QoL-2*), *Social contact* (*QoL-4*), *Enjoyment of activities* (*QoL-5*) and *Being useful/giving meaning to life* (*QoL-11*) are described in a majority of the studies. No subjective needs were found in the domain of *Physical care* (*NDP-6*) in any of the studies. See Table 4 for examples of found needs for every domain.

Needs in the domains of the National Dementia Program

- *NDP-1: Feeling that something is wrong, sense of unease.* People mention uneasy feelings caused by the first symptoms of dementia. People appear to be aware that there is something wrong with them, notice that their memory is not functioning as it used to and say that they feel insecure. They wonder what causes this, dementia or old age maybe? In these cases there is not yet a diagnosis of dementia, but there seems to be a need for clarity.
- *NDP-2: What is the problem and what can help?* People who are diagnosed with dementia say they wonder what will happen in the future, how their illness will develop, whether they will suffer and what will help them to come to terms with their diagnosis. There is a clear need for information about the process of their own illness and about sources of possible support both now and in the future.
- *NDP-3: Frightened, angry and confused.* People express their confusion and feelings of fear, shame, sadness and anger about various problems and disabilities they experience due to the dementia. The need that seems to be expressed is the need for comfort, safety, acceptance, warmth and support.
- *NDP-4: Having to face everything on your own.* In a few studies people with dementia express the feeling of being left alone with their disease and having to take

care of everything by themselves. Their descriptions show the need for emotional, social and practical support.

Table 4. Extracts of subjective needs out of inventoried studies (*n* = 34)

EXAMPLES WITHIN DOMAINS NATIONAL DEMENTIA PROGRAMME	EXAMPLES WITHIN DOMAINS OF QUALITY OF LIFE
NDP-9: Loss (32 studies) ***Coping with disabilities (25 studies)*** *I’m trying to control it. Trying to improve on things that I forget about, to improve my memory if I can… Appointments… I try to write everything down in my diary and look at it. If I remember to look at it. (Gillies, 2000, p. 370)* ***Acceptance of dementia and support (25 studies)*** *I think coming to terms with the matter is, um, well it has to happen… Still in the middle of that process I think. (Clare, 2002b, p. 145)* ***Grief and frustrations about disabilities (24 studies)*** *“It’s hard because I’ve always liked to do things like that.” “I can’t manage it anymore so it’s okay. It’s a pity though that you lose contact with so many nice people.” (Holst and Hallberg, 2003, p. 362)* ***Worry about disabilities (13 studies)*** *I’m alright now, I worry if I get worse, I’d hate not to be able to look after myself (Cahill et al., 2004, p. 322)* ***Hiding of disabilities (11 studies)*** *‘Well I try to keep up a normal façade, like when I went to work, you know, I sort of more or less go through the same as I did then, as if I’m getting ready to go out, things like that pass the time’ (Smith et al., 2005, p. 893)* ***NPD-3: Frightened, angry and confused (19 studies)*** *And if I think that somebody’s been, that my wife had been gone a while, I get very antsy. And I may be just a short time that she’s been away-it feels like forever. (Basting, 2003, p. 95)* ***NDP-2: What is the problem and what can help? (17 studies)*** *Yes, I am worried about the disease, how it will develop and how it will be. (Cahill et al., 2004, p. 322)* ***NDP-1: Feeling that something is wrong, sense of unease (16 studies)*** *“Do you think there’s something wrong with me? I don’t seem to think well anymore.” (Gwyther, 1997, p. 21)*	***QoL-2: Self-esteem/self-image (26 studies)*** *My status has gone… you’re no longer necessary. (Clare, 2002a, p. 305)* ***QoL-4: Social contact (23 studies)*** *A female participant described her relatives’ responses to her: “[When] they know you have Alzheimer’s, they will just kind of ignore you. You are just there and that’s it. You can go to a family affair and everybody is kind of gabbing, gabbing, and this and that. They leave you alone because they figure you don’t know what you’re talking about, you don’t know what is going on. Oh, I used to hate that. (Katsuno, 2005, p. 206)* ***QoL-5: Enjoyment of activities (20 studies)*** *When you’ve been here [day care] and you go home, you feel good don’t you? (Bamford and Bruce, 2000, p. 555)* ***QoL-11: Being useful/giving meaning to life (20 studies)*** *I hate sitting, doing nothing. (Acton et al., 1999, p. 10)* ***QoL-3: Attachment (19 studies)*** *Our family, a lot of people say to us, ‘Oh, what are you doing in this great house?’ I’ve probably said this to you before, but we love this house. We love this position, and we can cope with it, as long as [husband’s name] can still mow the lawn. (Gilmour and Huntington, 2005, p. 121)* ***QoL-10: Self-determination and freedom (18 studies)*** *When I can’t have my own way about various things. Erm, such as driving the car and where shall we go… I don’t always get my, get my sort of idea to control a situation…it isn’t always a pleasant situation… (Clare, 2003, p. 1024)*

Examples within domains National Dementia Programme	Examples within domains of Quality of life
NDP-13: Miscommunication with formal carers (10 studies) *“The first time I asked for help because of memory problems which affected my job as a teacher, the doctor told that it was normal to forget things. She said that most people have some problems remembering things. I felt that she paid no attention to my problem.” (Holst and Hallberg, 2003, p. 363)*	***QoL-1: Affect (17 studies)*** *“What is very helpful about the program is that we can freely talk about our feelings or express them with each other. We cannot do this in other groups. It is a healthy thing when you can go and express things freely.” (Zarit et al., 2004, p. 267)*
NDP-11: Being patronized by (in)formal carers (7 studies) *So you know how these daughters are. ’Shouldn’t do this Mum. You shouldn’t do that Mum‘. But I don’t take no notice–I just does it. Same if she catches me on ladders... I’d been washing windows and putting curtains up–she went mad! ‘We’ll do that, we’ll do that!’ (Reid et al., 2001, p. 387)*	***QoL-7: Physical and mental health (12 studies)*** *And I’m honored I have good health. (MacQuarrie, 2005, p. 437)*
NDP-5: Avoiding contacts (5 studies) *“I withdraw because I don’t feel involved in what they’re talking about.” (Holst and Hallberg, 2003, p. 362)*	***QoL-9: Security and privacy (9 studies)*** *Some worried that their wives would leave them, and wondered how they would manage if that happened. (Clare, 2003, p. 1024)*
NDP-14: Resistance to institutionalization (5 studies) *When I first started coming [day-care service] I was frightened to death. I thought they were going to keep me here. Do you know what I mean? Well you’re not used to these things are you when you first? And then I got into it and I love to come. That’s what I thought when I first started coming. I thought, ‘oh they’ve put me in a home. They’ve got shot of me’. Do you know what I mean? (Reid et al., 2001, p. 386)*	***QoL-8: Financial situation (4 studies)*** *I am comfortable in my own house, I feel well and I have good economy, that is important too! (Cahill et al., 2004, p. 325)*
NDP-4: Having to face everything on your own (4 studies) *”the worst part is feeling cheated, belittled or alone with it.” (Gwyther, 1997, p. 21)*	***QoL-12: Spirituality (4 studies)*** *You gotta have something you believe in and a faith; if you don’t you will be unhappy. (Katsuno, 2003, p. 324)*
NDP-7: Danger (4 studies) *One care recipient cried as he talked of the frustration he feels in not being able to remember where he is when he is driving his car alone. (Quayhagen and Quayhagen, 1996, p. 128)*	***QoL-6: Sense of aesthetics in living environment (2 studies)*** *Several people talked about getting pleasure from watching the colours of the sky and the clouds and listening to the birds. Two thirds (n=58) claimed they derived pleasure from such sensory awareness and the appreciated beauty (aesthetics) either a lot or quite a bit. (Cahill et al., 2004, p. 324)*
NDP-8: Medical problems as well (3 studies) *When asked about their problems they spontaneously mentioned physical disabilities, which interfered with their everyday life, only secondarily mentioning memory problems when specifically asked about them. (Howorth and Saper, 2003, p. 118)*	

- *NDP-5: Avoiding contacts*. Due to communication problems or because they do not want to be confronted with their disabilities, people with dementia sometimes say they withdraw from situations where they expect to come into contact with others. By withdrawing they demonstrate their need to avoid confrontation over their disabilities and the need to control situations.
- *NDP-7: Danger*. People with dementia occasionally reported feelings of disorientation and getting lost; thus expressing their need for physical guidance.
- *NDP-8: Medical problems as well*. Physical disabilities, arthritis and loss of continence, vision and hearing were mentioned by people with dementia as interfering with their daily life. By mentioning this, they express the need for aids to compensate for their disabilities and the need for treatment.
- *NDP-9: Loss*. People with dementia report experiencing many losses because of their disease, some of which are expressed in terms of how they cope with dementia. Because the domain of *Loss* proved to be very broad, we introduced a number of subcategories. These and their corresponding needs are presented in order of frequency of occurrence.
    - The need to find adequate coping strategies in order to cope with (consequences of) the disease (*Coping with disabilities*).
    - The need to come to terms with the disease and to gain insight into their own situation – shown in expressions of acceptance of the dementia and of support (*Acceptance of dementia and support*).
    - The need to function normally and to be able to do the things one used to do – shown in expressions of grief and frustrations about disabilities (*Grief and frustrations about disabilities*).
    - The need for information on the progress of the dementia and a guarantee they will receive good care when they are no longer able to make their own decisions in a later stage of the disease (*Worries about disabilities*).
    - The need to keep the disease hidden from others and therefore to be seen as a "normal" person (*Hiding of disabilities*).
- *NDP-11: Being patronized by (in)formal carers*. People with dementia reported being bullied into day care by their spouses, not being told the diagnosis by doctors, and in general being treated protectively by (informal) caregivers. There is a clear need to be treated as adults and as accountable persons.
- *NDP-13: Miscommunication with formal carers*. Miscommunications between clients and professionals are described in different situations. Extracts reflect that they can occur when people with dementia perceive a lack of interest in the professional, feel they are not taken seriously by their professional carer, receive ambivalent or no information about their diagnosis, or interpret a lack of follow-up as nothing being wrong with them. With these examples of miscommunication, they express the need for adequate communication with their formal caregivers.

- *NDP-14: Resistance to institutionalization.* In one study a respondent expressed a subjective need on the domain of resistance to institutionalization. The woman in question stated that when she first came to day care, she was afraid she would be put in a home and that her family was getting rid of her, thus expressing the need for staying in her own home.

Needs in Quality of Life domains

- *QoL-1: Affect.* People with dementia express all kinds of emotions like happiness, anger, sadness, loneliness and love towards others. They also report they sometimes react angrily towards others, because of their own frustrations. But thankfulness and happiness with their life were also reported. These examples illustrate the need of people with dementia to be able to communicate their positive and negative feelings towards others, and thereby the need for being understood.
- *QoL-2: Self-esteem/self-image.* When interacting with others, people with dementia feel a certain degree or lack of acceptance. They describe how this felt acceptance affects their identity and self-esteem in a positive or negative manner. People with dementia report how they feel they are treated by others and the effects this treatment has on their self-esteem. They also mention the feeling of having lost their status and being stigmatized, which gives them low self-esteem. These examples illustrate the need of people with dementia to be accepted as they are and respected for who they are, not stigmatized by others.
- *QoL-3: Attachment.* People with dementia express the wish to be able to continue to live in their own home and live with their partner. They also feel attached to their home environment. On the other hand, they also worry about becoming a burden to their relatives. They express a need for adequate professional care that will provide the support they need to stay in their own homes and provide their informal caregivers with support to alleviate their care tasks.
- *QoL-4: Social contact.* Contact with others, especially partners, (grand)children and friends, is expressed as being important by people with dementia. The negative feelings caused by social exclusion demonstrate the need for social contact as a precondition for their well-being.
- *QoL-5: Enjoyment of activities.* People with dementia mention attending daycare, socializing, reading, walking, singing and visiting church as activities they are still involved in and like to do. These are expressions of the need to engage in activities and enjoy them for as long as they are able.
- *QoL-6: Sense of aesthetics in living environment.* People with dementia report appreciating being outdoors in nature, listening to music and seeing art, thereby expressing the need to engage in these activities.
- *QoL-7: Physical and mental health.* People with dementia express being thankful for having good health, while also reporting problems with their health. Their

need for good health is clearly expressed by the interest they take in maintaining their health and staying as active as they can.

- *QoL-8: Financial situation.* People with dementia say that having financial security is important to them.
- *QoL-9: Security and privacy.* People with dementia mention they receive good care, but also express fears that their relatives might leave them, thus expressing their anxiety of being abandoned and the need for guarantees that they will be cared for.
- *QoL-10: Self-determination and freedom.* The need to be in control was frequently mentioned, often by people who reported a lack of control. Freedom to act and to decide was also frequently mentioned and considered very important.
- *QoL-11: Being useful/giving meaning to life.* People with dementia report they need to have a goal in their life and to be useful. For instance, some feel the need to contribute to dementia research by donating their brains to science. They also report the need to be useful to others and explain how they do this, for instance in day care.
- *QoL-12: Spirituality.* Some people with dementia report having faith and trust in God, and appreciate religious activities like praying and going to church, thus expressing their need for this dimension in their lives.

Table 5. Extracts of wants from inventoried studies (n = 34)

EXAMPLES WITHIN DOMAINS NATIONAL DEMENTIA PROGRAMME	EXAMPLES WITHIN DOMAINS QUALITY OF LIFE
NDP-9: Loss (16 studies) ***Loss: Coping with disabilities (12 studies)*** *I couldn't help pick it [newspaper article about Iris Murdoch] up and read it; I needed to do that, so as if to say "I'm not going to be frightened of you." (Clare, 2002a, p. 306)* ***Loss: Acceptance of dementia and support (4 studies)*** *"Everyone I'm close to...the Ramblers and my children...get it and I welcome help. It's a great life... I'm not afraid to die." (Gwyther, 1997, p. 19)* ***Loss: Grief and frustrations about disabilities (4 studies)*** *I'm trying to guard that... the reputation, you know... don't want to be looked down on... like... don't want the feeling of being back in first grade or whatever... of going in the other direction. Going down instead of up. Decreasing instead of improving... and [I have] inward anger. (Katsuno, 2005, p. 206)*	***QoL-4: Social contact (10 studies)*** *"My best hope is to be able to live more to be able to continue with my friendships I guess." (MacQuarrie, 2005, p. 435)* ***QoL-11: Being useful/giving meaning to life (9 studies)*** *"I have to feel like I'm useful to somebody." (Gwyther, 1997, p. 21)* ***QoL-2: Self-esteem/self-image (6 studies)*** *The public is not too kind. They are not trained, there isn't enough publicity [that says] what it is all about. There is a way to let the public know that you are not crazy... and out of your mind. That is one thing that should be publicised a lot. (Katsuno, 2005, p. 207)* ***QoL-5: Enjoyment of activities (6 studies)*** *That's another good thing about the club here, they do a lot of art work an material work... I mean, I was sawing a concrete block this morning... They have different things to do, which makes life a bit*

EXAMPLES WITHIN DOMAINS NATIONAL DEMENTIA PROGRAMME	EXAMPLES WITHIN DOMAINS QUALITY OF LIFE
NDP-2: What is the problem and what can help? (11 studies) *Some tried to find out more from newspapers and TV. (Clare, 2003, p. 1023)*	*more interesting… You get opportunities to do things that you wouldn't normally get to do. (Beattie et al., 2004, p. 364)*
NDP-13: Miscommunication with formal carers (5 studies) *Under pressure of a friend, she goes to see a neurologist the day after her fall at the family picnic. "I loathed his habit of referring to me in the first person plural we…," she writes of her first neurologist, who excuses her symptoms and tells her to "keep her nose clean" (Basting, 2003, p 89)*	***QoL-3: Attachment (5 studies)*** *These responses make it clear that patients with dementia hope to maintain their present, 'ordinary' lifestyles. (Fukushima et al., 2005, p. 36)*
NDP-14: Resistance to institutionalization (4 studies) *Not gonna send us away, are they?… I mean I know what I do all in my house and cooking and that… (Clare, 2003, p. 1024)*	***QoL-10: Self-determination and freedom (5 studies)*** *I told my wife, I want to do everything I can for as long as I can. (LaBarge and Trtanj, 1995, p. 295)*
NDP-1: Feeling that something is wrong, sense of unease (3 studies) *I just about broke my heart when I found out but I've come through it and I'd rather know, yeah. I'd rather know. (Pratt and Wilkinson, 2003, p. 193)*	***QoL-1: Affect (4 studies)*** *'I needed somebody to take me by the hand, to be the optimist.' (Pratt and Wilkinson, 2003, p. 195)*
NDP-5: Avoiding contacts (3 studies) *Yeah, another bad thing is I find now, that I don't want to speak to anybody in here (meaning his housing complex). Because I can't talk to them soon as they talk. (MacQuarrie, 2005, p. 435)*	***QoL-7: Physical and mental health (4 studies)*** *Nothing big comes to mind, I just wish to keep my health. (Cahill et al., 2004, p. 322)*
NDP-11: Being patronized by (in)formal carers (3 studies) *"So I'd like to be asked by the Handi Dart drivers how well I am on my feet (rather than) have this 200 pounder pick me up like a bag of potatoes and help me in! That's not help!" (MacQuarrie, 2005, p. 432)*	***QoL-12: Spirituality (1 study)*** *We were not people that were wealthy, but we had love, we had religion, which I think is a very important thing regardless of what kind it is… Religion is important to me from day to day… and that's the way it's been… yes, in my upbringing. (Katsuno, 2003, p. 324)*
	QoL-8: Financial situation (1 study) *However, she said that she had not seen her bank books since she had moved into her present house near her son; she would like to know more what he was doing with her money. (Proctor, 2001, p. 370)*
	QoL-9: Security and privacy (1 study) *For example, Thompson tends to overestimate the adequacy of his support system to meet his current and future needs. At the same time, he expresses willingness to move to a more protected residential setting should his physician recommend it. (Gwyther, 1997, p. 23)*

Expressions of wants in different domains

As mentioned earlier, specific wants are found less frequently than needs in the selected studies. Wants reflect the specific needs and desires of people. In Table 5 examples of wants that were found in the papers are given in order of frequency of occurrence. Most wants concern the domains *Loss* (*NDP-9*), *What is the problem and* *what can help?* (*NDP-2*) and *Miscommunication with formal carers* (*NDP-13*). No specific wants were mentioned on the following six domains *Frightened, angry and confused* (*NDP-3*); *Having to face everything on your own* (*NDP-4*); *Physical care* (*NDP-6*); *Danger* (*NDP-7*); *Medical problems as well* (*NDP-8*) and *Sense of aesthetics in living environment* (*QoL-6*).

Expressions of demands in different domains

Concrete demands were expressed in only 15 extracts out of ten studies. These demands pertained to seven domains and explicitly state how and why people want to be, or already are, involved in a certain situation or want to use a specific support service. Demands reflect the concrete way people choose to solve their needs and desires. See Table 6 for examples of the inventoried demands in the different studies.

Table 6. Extracts of demands from inventoried studies (n = 34)

Examples within domains National Dementia Programme	Examples within domains Quality of Life
NDP-1: What is the problem and what can help? (2 studies) *Thompson pays a social worker to keep track of his medicine and appointments and to help him with occasional travel logistic. (Gwyther, 1997, p. 19)*	***QoL-5: Enjoyment of activities (3 studies)*** *I enjoy coming here [day care]. I think it's lovely. Breaks up my day. I really like it. No complaints about anything – pick us up, take us home, fed, entertained – what more can I ask? (Aggarwal et al., 2003, p. 191)*
NDP-13: Miscommunication with formal carers (2 studies) *The doctors should tell you when they make decisions about you. (Proctor, 2001, p. 369)*	***QoL-10: Self-determination and freedom (2 studies)*** *Similary, a lack of control over hair styling was reported: "They're always wanting to do my hair. Now I can't help it but I cannot do with my hair taken that way… I know it sounds silly but it annoys me." (Bamford and Bruce, 2000, p. 559)*
NDP-7: Danger (1 study) *Movement Toward strategies also involved reaching out to more formalized services for information and support, including wandering registry bracelets: "I ought to get one." (MacQuarrie, 2005, p. 435)*	***QoL-2: Self-esteem (1 study)*** *Finding a doctor who will treat her with respect and honesty becomes her mission. (Basting, 2003, p. 89)*
	QoL-4: Social contact (1 study) *I'd rather come here than go somewhere with more elderly people… (Beattie et al., 2004, p. 363)*

Discussion

This exploratory review of the literature on the subjective needs of people with dementia living at home produced 34 studies that met our criteria, which were published between January 1985 and July 2005. Over a period of 20 years the number of studies found is relatively small, but from 2003 onwards the number of studies increases considerably. This indicates a growing attention to (the study of) the experience and needs of people with dementia.

Of the studies identified, only five focused on recording the care needs of people with dementia (Bamford and Bruce, 2000; Proctor, 2001; Reid *et al.*, 2001; Aggarwal *et al.*, 2003; Beattie *et al.*, 2004). The other studies mainly examined either how people experience their dementia, or how the dementia affects their quality of life. Although most studies are experience-oriented and did not explicitly aim to inventory needs, the results sections of these (mostly qualitative) studies still discuss many different types of needs. We did not come across many explicitly expressed *wants* or *demands* in these studies (Kotler, 1980). Most of the subjective needs are located in the domain of *Loss* (*NDP-9*), and more specifically the need to find adequate coping strategies (*Loss: coping with disabilities*), the need to come to terms with the disease and to gain insight into their own situation (*Loss: acceptance of dementia and support*), and the need to function normally (*Loss: grief and frustrations about disabilities*). There was also a relatively large number of subjective needs in the domain *Self-esteem/self-image* (*NDP-2*; people with dementia want to be accepted for who they are and not be stigmatized) and within the domain *Social contact* (*QoL-4*), where there is a need for contact with other people.

The majority of wants were related to wanting to be able to cope with the disease (*Loss: coping with disabilities*), the need for information on the course of the disease and possible (professional) care (*NDP-2: What is the problem and what can help?*), and the need for social contact (*QoL-4: Social contact*). Demands were mentioned predominantly in the domain of *Enjoyment of activities* (*QoL-5*) and they indicate the need to participate in activities.

The subjective needs found in these studies are related not so much to instrumental needs, but rather to how persons with dementia as well as the people around them and (informal) carers, cope with the disease, and to well-being. The relatively large number of found needs and the limited number of traced wants and demands show that people with dementia do not often spontaneously and explicitly express what they want or how they want their needs to be met.

The conclusions of this exploratory literature review are preliminary. It is unlikely that the subjective needs found in these studies apply to all people with dementia who live at home, in all stages of the disease. Many of the selected studies looked at relatively young elderly people with mild to moderately severe dementia. Only three studies included people with severe dementia with many not reporting the severity of dementia at all. Therefore no conclusions can be drawn from this review about needs at different stages of the disease. However, it is likely that people in the early stages of dementia report more needs than people with severe dementia, because of the limited awareness of their problems in later stages of the disease. This is supported by research from Zank and Leipold (2001) who found a relation between severity of dementia and subjective well-being. People with mild dementia felt less supported by their environment than people with more advanced dementia. The same applies to the needs of older people compared with those of younger people with dementia. The latter often have a job and younger children, and are at a stage in their lives where dementia does not fit at all. It is also not possible to make definitive statements about the difference in needs in the different types of dementia, as most studies focus on Alzheimer's disease.

As stated earlier, almost all of the studies we found did not explicitly set out to list the subjective needs of people with dementia, but rather described the experience of living through dementia. We therefore did not expect to find other articles that specifically focused on needs in other databases or other articles in which needs would have been described. This was confirmed by Steeman *et al.* (2006) who reviewed the subjective experience of the disease by people with dementia. It is conceivable that the needs described in the results sections of the articles identified in our search are related to the quotations selected by the authors based on the specific objectives of their studies. This would mean that the mentioned needs do not necessarily represent all needs, or the main needs of the studied people with dementia.

During our review we ran into several obstacles. We used the PubMed and PsycINFO databases for our literature search. It proved impossible to develop a search strategy on the basis of keywords and combinations of keywords that would trace only those studies that examined the opinions of people with dementia. Finding appropriate keywords for subjective needs also proved difficult. Out of the 275 articles found through these databases, only six could be used for our review. Careful examination of all references eventually led us to the other articles. However, authors frequently refer to the same, easily traced studies. As a result we may have overlooked studies that are more difficult to find (for example, studies published in books and journals that are not included in these databases).

The theoretical model used to classify the subjective needs of people with dementia who live at home proved to be very suitable for this study. All of the found needs could be placed in the problem areas of the National Dementia Program and the Quality of Life domains. Because of the large number of needs found within the domain *Loss* (*NDP-9*), we defined several subcategories. Some domains of the National Dementia Program and Quality of Life domains, such as *Physical care* (*NDP-6*) and *Physical and mental health* (*QoL-7*), and *Avoiding contacts* (*NDP-5*) and *Social contact* (*QoL-4*) overlapped to some extent. However, because the National Dementia Program domains focus primarily on problems, and the Quality of Life domains focus on well-being, we decided to maintain the distinction for the purposes of this study.

Compared with studies that provide inventories of the needs of people with dementia (Meaney *et al.*, 2005; Edelman *et al.*, 2006; Hancock *et al.*, 2006), this review gives a broader view of the different needs of people with dementia, and covers needs in different problem areas as well as those for improving quality of life. The limited number of concrete wants and demands found in the studies show that people with dementia do not spontaneously express and define their needs. It is therefore necessary to continue to question people with dementia with regard to their subjective needs. Various methods can be used to study these needs, such as standardized instruments, open interviews and focus groups. The provision of care should also be evaluated regularly, to investigate whether the care is attuned to the needs of people with dementia. The theoretical model used in our study may serve as a base for the development of a measuring instrument that can be used to inventory subjective needs.

We recommend that future studies should document the characteristics that may affect various needs in order to increase our understanding – for example, age, gender, severity and type of dementia, as well as the living situation, social contacts, income, and the use of professional care services.

To be able to supply demand-directed care, knowledge of subjective and objective needs of people with dementia who live at home is essential. Most of the subjective needs found in this exploratory literature review are not instrumental, but are related to coping with losses as a result of the dementia, to self-esteem and to social contact. As mentioned earlier, many more young elderly people with mild to moderately severe dementia relative to older ones were involved in the studies we found. For this group it is obviously very important that they receive assistance in coming to terms with and learning to cope with their dementia, in order for them to maintain their self-esteem and to prevent them becoming socially isolated. For these emotional and social needs, emotion-oriented care seems to be required. Following recommendation by the American Psychiatric Association (1997), studies of this type of care have become increasingly more common (Finnema *et al.,* 2000; Livingston *et al.*, 2005). Though several studies found positive effects in emotional and social behaviour, conclusions are limited because of the paucity of high quality research, which is now greatly needed.

Research into the subjective needs of people with dementia living at home is in its infancy. In order to make useful general statements, the study of more varied and larger populations of people with dementia is recommended.

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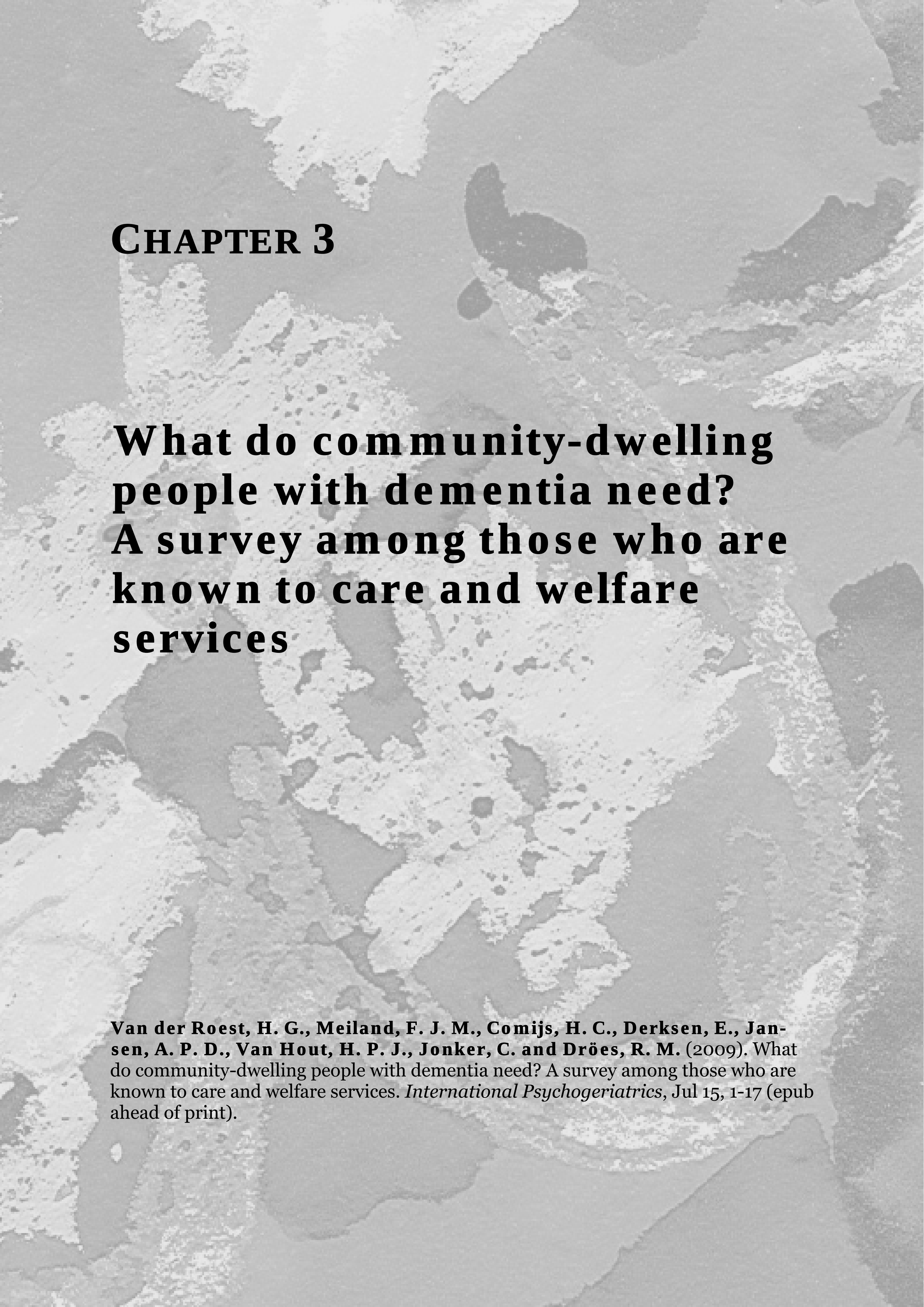

CHAPTER 3

What do community-dwelling people with dementia need? A survey among those who are known to care and welfare services

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Abstract

Objective: The ageing society will bring an increase in the number of people with dementia living in the community. This will mean a greater demand on care and welfare services to deliver efficient and customized care, which requires a thorough understanding of subjective and objective care needs. This study aims to assess the needs of community-dwelling people with dementia as reported by themselves and by their informal carers. Furthermore the study aims to give insight into the service use and gaps between needs and availability of services.

Method: 236 community-dwelling people with dementia and 322 informal carers were interviewed separately. (Un)met needs were assessed with the Camberwell Assessment of Need for the Elderly (CANE).

Results: Most unmet needs were experienced in the domains of memory, information, company, psychological distress and daytime activities. People with dementia reported fewer (unmet) needs than their carers. Type and severity of dementia, living situation and informal carer characteristics were related to the number of reported needs.

Conclusion: This study showed a large number of unmet needs in dementia. Reasons for unmet needs are lack of knowledge about the existing service offer, a threshold to using services and insufficient service offer. These results provide good starting points to improve community care for people with dementia.

Introduction

As our society ages, so the number of people with dementia living in the community will increase enormously, creating an even greater demand on care and welfare services to deliver efficient and customized care. The policy in Northern European countries is increasingly directed at enabling people with dementia to live in their own homes for as long as possible, which is also perceived to be the desire of most people with dementia. To be able to provide the appropriate care needed to realize this aim, it is important to know what the individual social, physical and emotional care needs of community-dwelling people with dementia are (Van der Roest *et al.*, 2007). Unfortunately, their opinions and wishes regarding care are generally neglected in research.

There are different ways to determine the care needs of people with dementia: Through survey of needs among informal carers and professional carers (proxy care needs) or among people with dementia themselves (subjective care needs) (Huijsman, 1990; De Klaver and Scholten, 2002). Until recently studies into the care needs of people with dementia focused mainly on proxy reports (Bjorkhem *et al.*, 1992; Vernooij-Dassen, 1993; Philp *et al.*, 1995; Gordon *et al.*, 1997; Koffman and Taylor, 1997; Dello Buono *et al.*, 1999; Toseland *et al.*, 1999; Aggarwal *et al.*, 2003; Bowes and Wilkinson, 2003; Rodriguez *et al.*, 2003; Gaugler *et al.*, 2005; Buntinx *et al.*, 2006). These studies show that community-dwelling people with dementia have substantial care needs, and a relatively high level of service use, especially regarding mobility, personal care, household tasks, behaviour problems and supervision.
The few studies that investigate subjective needs in dementia are mainly small sample sized and qualitative, and focus on how people with dementia experience their disease and their satisfaction on received care (Van der Roest *et al.*, 2007). So far, the subjective care needs of people with dementia have not been assessed systematically on a large scale.

This study aimed to gain insight into the care needs of community-dwelling people with dementia. For the first time a large sample of community-dwelling people with dementia and their carers were interviewed on their experienced needs, the extent to which these needs are met or unmet, and on the reasons why they experience unmet needs. Furthermore this study investigated service use, agreement on needs between people with dementia and their carer, and the relationship between sociodemographic characteristics and needs.

Method

Design

By means of a cross-sectional design the met and unmet care needs of persons with dementia were inventoried among people with dementia and informal carers. The relationship between these needs and background characteristics of people with dementia and informal carers were examined as well. A between-subjects design was used to investigate the level of agreement between the needs mentioned by patients and carers within patient-carer dyads, and to describe the experienced deficiency in the offered care. To investigate possible regional differences, needs as well as the available care offer were inventoried in two regions in the Netherlands.

This study was approved by the Medical Ethical Committee of the VU University Medical Centre.

Setting and participants

The study was carried out in two regions in the Netherlands, i.e. the North of the Netherlands (Noord-Holland) and the South of the Netherlands (Nijmegen). People with dementia and (if possible) their informal carers were approached via public recruitment in three Alzheimer Cafés and in the Mantelzorgkrant (magazine for informal carers) and through various care providing organizations: the Centrum Indicatiestelling Zorg (CIZ: organization that determines the type and amount of care one needs and is entitled to), two memory clinics, ten meeting centres, that provide a combined support programme for people with dementia and their informal carers (Dröes *et al.*, 2004a), and three psychogeriatric day care centres. Finally, respondents were included from an ongoing study in GP practices in Noord-Holland (PIKOM project) (Jansen *et al.*, 2005).

Inclusion criteria for participation in the study were: having a diagnosis of dementia and living at home. A total of 891 patient-carer dyads were approached with a letter inviting them to participate in the study (Figure 1). 367 (41.2%) dyads were not reached or did not meet the inclusion criteria. Of the remaining 524 dyads, 372 (70.9%) dyads initially agreed to participate. 51 dyads dropped out in the second instance due to, amongst other things, nursing home admission, illness and time constraint on the informal carer. The final response was 61.3%. Data were gathered on 332 persons with dementia that were living in the community and who were known to healthcare or welfare services: 236 persons with dementia and 322 informal carers were interviewed (Figure 1).

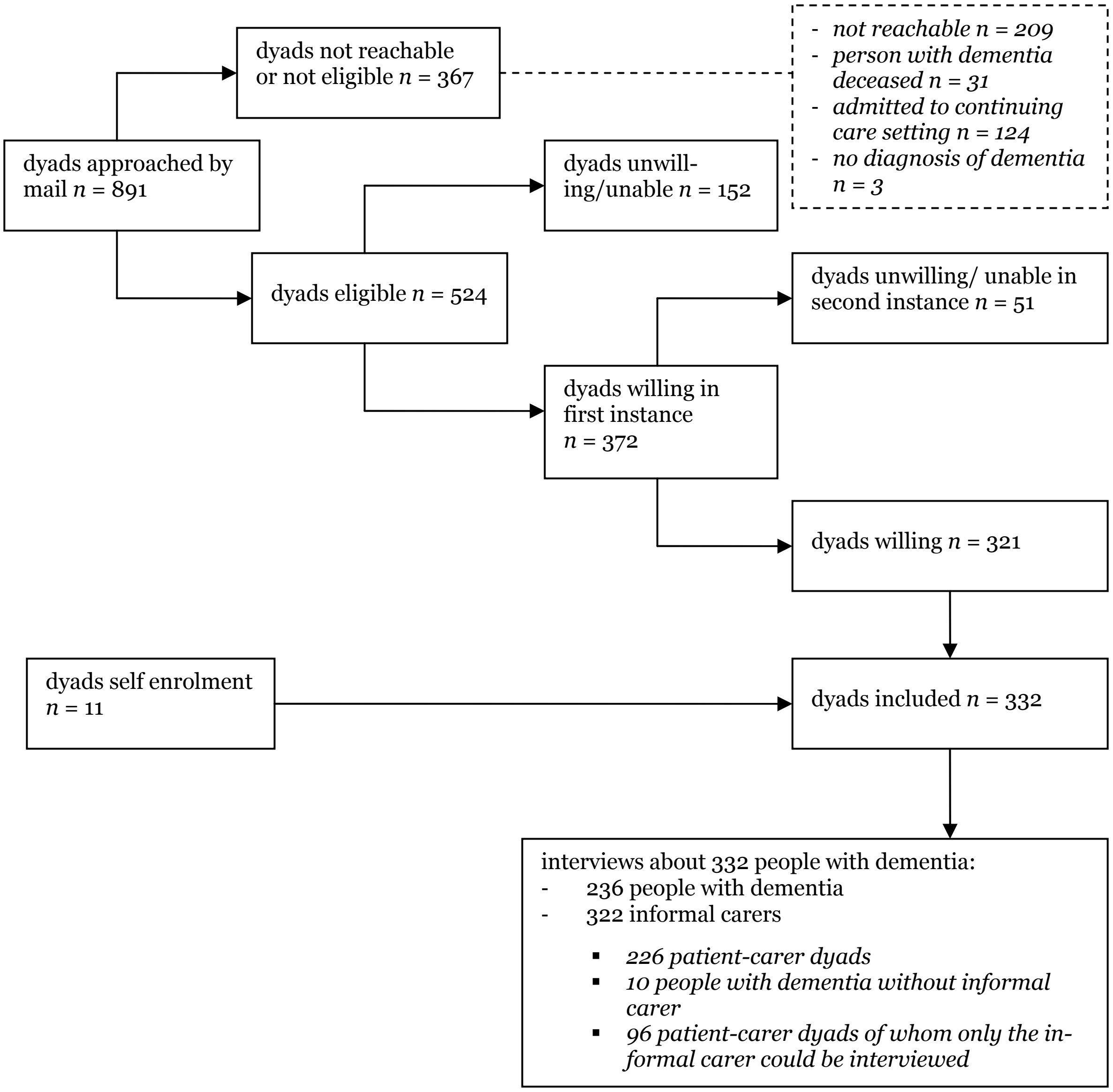


Figure 1. Inclusion of participants in research

Instruments

By means of a background characteristic list, informal carers were interviewed on the sociodemographics of themselves and of the people with dementia. Furthermore personal characteristics, social economic status, objective burden, service use and social support were recorded. Care needs and care use of people with dementia were mapped using the Camberwell Assessment of Need for the Elderly (CANE) (Reynolds *et al.*, 2000; Dröes *et al.*, 2004b; Orrell and Hancock, 2004).

The CANE is a semi-structured interview that assesses met and unmet care needs and care use in 24 areas (social, medical, and psychological needs, and needs regarding (living) environment). Respondents are asked about any difficulties or problems with performing activities in each of the areas. For instance the area of 'Food' includes activities of shopping for food, preparing food, the ability to compose a healthy diet, or being able to eat at all. Needs are met when a difficulty in a particular area is being provided for, in such a way that the person does no longer feels its negative impact on his or her overall Quality of Life. For instance, a person can be assisted by an informal or professional carer on a certain task. Unmet needs are experienced when a person is not supported for a problem that occurs in a particular area, or receives insufficient or inadequate support. In our study we also inventoried reasons for unmet needs.

Besides the care needs within the 24 areas, the CANE assesses the amount of informal and professional support actually received, and the amount of professional support that is desired by the respondents. Because the CANE takes into account four different viewpoints (of the person with dementia, the informal carer, the professional carer and of an independent observer), it is easy to compare the different views on the care needs of an elderly person. In our study only the opinions of people with dementia and informal carers were recorded. Reliability and validity of the Dutch CANE are good (test-retest reliability: $0.66 \geq K \leq 0.84$ (Dröes *et al.*, 2004b; Van der Roest *et al.*, 2008)).

The subjective burden of the informal carer was measured using the Self-Perceived Pressure from Informal Care (SPPIC; reliability $Rho = 0.79$: Pot *et al.*, 1995).

A clinical judgment about the severity of dementia was determined with the Global Deterioration Scale (GDS; $\alpha = 0.90$: Reisberg *et al.*, 1982; Muskens, 1993), and the Mini-Mental State Examination (MMSE; test-retest reliability: Pearson $r = 0.98$: Folstein *et al.*, 1975; Roth *et al.*, 1986) was administered to all people with dementia who were interviewed in person.

The available care offer for the most frequent unmet needs was inventoried in two specific regions (Amsterdam-Zuid and Nijmegen) by using the internet, relevant documentation such as brochures from local authorities and welfare organizations and by consulting professional carers (social worker, elderly worker, care coordinator of the memory clinic, social psychiatric nurse, employee of the carer support organization) in these regions.

Procedure

All community-dwelling persons with dementia and their informal carers who were identified via databases of care providing organizations and open public recruitment and who met the inclusion criteria were informed about the study in writing and verbally respectively. People who were prepared to participate in the study gave their written consent. Face-to-face interviews with persons with dementia and informal carers were separately conducted at home by trained interviewers (graduate students of psychology and medicine). Verification of diagnosis type and severity of dementia was retrieved in writing from the general practitioner or specialist after the interview. As the respondents who joined through the PIKOM project were not yet formally diagnosed, their GDS score was determined on the basis of their MMSE score, using the guideline of Reisberg and Lauter (1993), and Reisberg *et al.* (1982). The different GDS stages were classified as follows: MMSE > 29: GDS 1-2; 29 ≤ MMSE ≥ 24: GDS = 3; 23 ≤ MMSE ≥ 18: GDS = 4; 17 ≤ MMSE ≥ 14: GDS = 5; and 13 ≤ MMSE ≥ 6: GDS = 6, MMSE < 6: GDS = 7.

Analysis

The data were analyzed using SPSS 11.0. Frequency distributions were determined to identify needs on the different areas. Subsequently the level of agreement between the needs reported by people with dementia and their informal carers was assessed by calculating Kappa coefficients. Kappa values between 0.00-0.20 were valued as poor agreement, 0.21-0.40 fair, 0.41-0.60 moderate, 0.61-0.80 good, and 0.81-1.00 very good agreement (Altman, 1991). A Wilcoxon signed rank test was executed to determine significant differences between the amounts of received and desired professional care. Chi-square tests, ANOVA-tests and t-tests were conducted and Pearson correlation coefficients were calculated to check for relationships between sociodemographic characteristics and needs. The service offer and possible reasons for unmet needs were identified.

Table 1a. Sociodemographic data persons with dementia (whole group and interviewed group)

PERSONS WITH DEMENTIA	**Whole group (n = 332)**	**Interviewed group (n = 236)**	**Statistic**
Male Female	150 (45.2%) 182 (54.8%)	110 (46.6%) 126 (53.4%)	$X^2_{(1)} = 0.11$, $p = 0.401$
Age	79.8 (*SD* = 7.6, range 56.7-99.2)	80.0 (*SD* = 7.5, range 56.7-99.2)	$t_{(566)} = -0.37$, $p = 0.710$
Married	192 (57.8%)	134 (56.8%)	$X^2_{(2)} = 0.09$, $p = 0.957$
Widowed	111 (33.4%)	80 (33.9%)	
Other	29 (8.7%)	22 (9.3%)	
Living alone	119 (36.5%)	89 (37.7%)	$X^2_{(2)} = 0.39$, $p = 0.822$
High level of education	42 (12.7%)	30 (12.7%)	$X^2_{(1)} = 0.00$, $p = 0.978$
Missing	8 (2.4%)	6 (2.5%)	
Income < €10.000,-	65 (19.6%)	38 (16.1%)	$X^2_{(3)} = 0.76$, $p = 0.859$
Income €10.000 - €20.000,-	82 (25.9%)	54 (22.9%)	
Income €20.000 - €30.000,-	46 (12.7%)	32 (13.6%)	
Income > €30.000,-	36 (10.8%)	23 (9.7%)	
Income missing	103 (31.0%)	89 (37.7%)	

PERSONS WITH DEMENTIA	**Whole group (n = 332)**	**Interviewed group (n = 236)**	**Statistic**
Number of months since first symptoms (*Median*)	48.0 (*SD* = 51.1, range 2-452)	42.6 (*SD* = 48.4, range 2-452)	$U = 28565.00$, $p = 0.276$
Alzheimer's disease (AD)	125 (37.6%)	91 (38.6%)	$X^2_{(3)} = 0.39$, $p = 0.942$
Vascular dementia (VaD)	43 (13.0%)	33 (14.0%)	
Mixed dementia (MD)	43 (13.0%)	29 (12.3%)	
Other type of dementia	32 (9.6%)	22 (8.5%)	
Type of dementia unknown	89 (26.8%)	63 (26.7%)	
No cognitive decline *(GDS 1)*	3 (0.9%)	3 (1.3%)	$U = 28345.50$, $p = 0.031$
Very mild cognitive decline *(GDS 2)*	31 (9.3%)	27 (11.4%)	
Mild cognitive decline *(GDS 3)*	61 (18.4%)	51 (21.6%)	
Moderate cognitive decline *(GDS 4)*	89 (26.8%)	76 (32.2%)	
Moderately severe cognitive decline *(GDS 5)*	69 (20.8%)	44 (18.6%)	
Severe cognitive decline *(GDS 6)*	36 (10.8%)	16 (6.8%)	
Very severe cognitive decline *(GDS 7)*	4 (1.2%)	-	
Severity of dementia unknown	39 (11.7%)	19 (8.1%)	
MMSE-score		20.6 (*SD* = 5.5, range 3-29)	
Professional help	290 (87.6%)	205 (87.2%)	$X^2_{(1)} = 0.02$, $p = 0.893$
Number of professional care hours per week (*Median*)	14.3 (*SD* = 12.5, range 0.5-100.0)	13.3 (*SD* = 10.5, range 0.5-71.7)	$t_{(434)} = 1.23$, $p = 0.220$
Number of used professional services (*Median*)	2.0 (*SD* = 1.0, range 1.0-5.0)	2.0 (*SD* = 0.9, range 1.0-4.0)	$t_{(493)} = 0.22$, $p = 0.824$
Household services	191 (57.5%)	141 (59.7%)	$X^2_{(1)} = 0.46$, $p = 0.560$
Activating assistance	134 (40.4%)	94 (39.8%)	$X^2_{(1)} = 0.01$, $p = 1.000$
Self-care	115 (34.6%)	77 (32.6%)	$X^2_{(1)} = 0.22$, $p = 0.708$

Results

A total of 332 persons with dementia and/or their informal carers were included in the study, 236 persons with dementia and 322 informal carers agreed to be interviewed. Table 1a describes the sociodemographic characteristics of the people with dementia. More than half of the included people with dementia were female (n = 182, 54.8%) and married (n = 192, 57.8%) and more than one third of them lived alone (n = 119, 36.5%). Their mean age was 79.8 years (*SD* = 7.6). The majority of the respondents were diagnosed with Alzheimer's disease (n = 125, 51.4%), followed by vascular dementia (n = 43, 17.7%) and mixed dementia (n = 43, 17.7%). Of 89 respondents the type of dementia was unknown. The stages of dementia ranged between mild cognitive impairment and very severe cognitive decline (GDS 1-7); most respondents suffered from mild cognitive decline to moderately severe dementia (GDS 3-5). A large proportion of the people with dementia received professional household services (n = 191, 57.5%) or attended a form of day-care (n = 134, 40.4%). More than half of the people with dementia were cared for by their partner (n = 175, 54.3%), most informal carers were female (n = 221, 68.6%). Their mean age was 65.4 (SD = 14.1) (Table 1b). The interviewed group of people with dementia (n = 236) did not differ from the total group of included persons with dementia (n = 332) except for the severity of dementia (U = 28345.50, p = 0.031): the interviewed group of persons with dementia contained few respondents with severe to very severe dementia (Table 1a).

Table 1b. Sociodemographic data informal carers of people with dementia

INFORMAL CARERS (N = 322)	
Male Female	101 (31.4%) 221 (68.6%)
Age	65.4 (*SD* = 14.1, range 23.1-90.3)
Married Widowed Other	266 (82.6%) 9 (2.8%) 47 (14.6%)
Partner Daughter Son Other	175 (54.3%) 77 (23.9%) 33 (10.2%) 37 (11.5%)
Shared household	199 (61.8%)
High level of education	77 (23.9%)
Income < €10.000,- Income €10.000 - €20.000,- Income €20.000 - €30.000,- Income > €30.000,- Income missing	41 (12.7%) 76 (23.6%) 50 (15.5%) 62 (19.3%) 93 (28.9%)
Other activities besides care Paid work	157 (48.8%) 88 (54.0%)
Number of months informal care giving (*Median*)	24.0 (*SD* = 32.0, range 0-283)
Number of hours of informal care per week (*Median*)	37.0 (*SD* = 63.0, range 1-168)
Self-Perceived Pressure from Informal Care (SPPIC) (*mean*)	4.9 (*SD* = 2.6, range 0-9)

Needs

Persons with dementia indicated on average 5.4 (*SD* = 3.1, range 0-15) needs. On average 4.9 of these needs were *met* and 0.5 were *unmet*. More than half of the interviewed persons with dementia indicated they needed or received assistance from professional or informal carers regarding food (for instance shopping for groceries and preparation of food) (90.8%), household activities (69.9%), memory (e.g. support of memory and coping with memory loss) (57.1%) and money (52.7%) (Figure 2). In the areas of food, household activities and money the majority of the respondents felt that they received appropriate care. The highest proportions of *unmet* needs reported by persons with dementia concerned support for memory problems, information about dementia, available care and treatment, company, and psychological distress (see Figure 2 for the percentages of met and unmet needs for each domain).

Informal carers reported an average of 9.6 (*SD* = 3.4, range 0-17) needs, i.e. an average of 7.9 *met* needs and 1.7 *unmet* needs. More than half of the interviewed informal carers indicated that their relative needed, or received assistance (informal and professional) with household activities (92.5%), memory (87.2%), money (86.0%), food (81.3%), self-care (68.2%), daytime activities (65.8%), physical health (60.7%) and mobility (56.4%) (Figure 3). The informal carers, like the persons with dementia, most frequently reported *met* needs on the domains of household activities, money and appropriate food. The highest proportion of *unmet* needs were reported by informal carers regarding memory, daytime activities and company (see Figure 3 for the percentages of met and unmet needs for each domain). Informal carers on average reported 4.2 more needs than people with dementia ($t_{(537)} = -14.61$, $p < 0.001$). Of those 3.0 were *met* needs ($t_{(537)} = -12.25$, $p < 0.001$) and 1.2 were *unmet* needs ($t_{(537)} = -7.27$, $p < 0.001$).

Professional support

The interviewed people with dementia reported that they received professional care largely for self-care, daytime activities, company and household activities (Figure 4). Persons with dementia wanted more professional help in 33.3% of the studied areas, with the areas of company, and memory being mentioned most frequently (Figure 4). Informal carers reported that most of the professional assistance for the people with dementia was received on the domains of company, daytime activities, household activities, physical health and self-care (Figure 4). Informal carers wanted more professional help on seventeen (70.8%) of the investigated domains, with the highest desire for more support for daytime activities and memory problems (Figure 4).

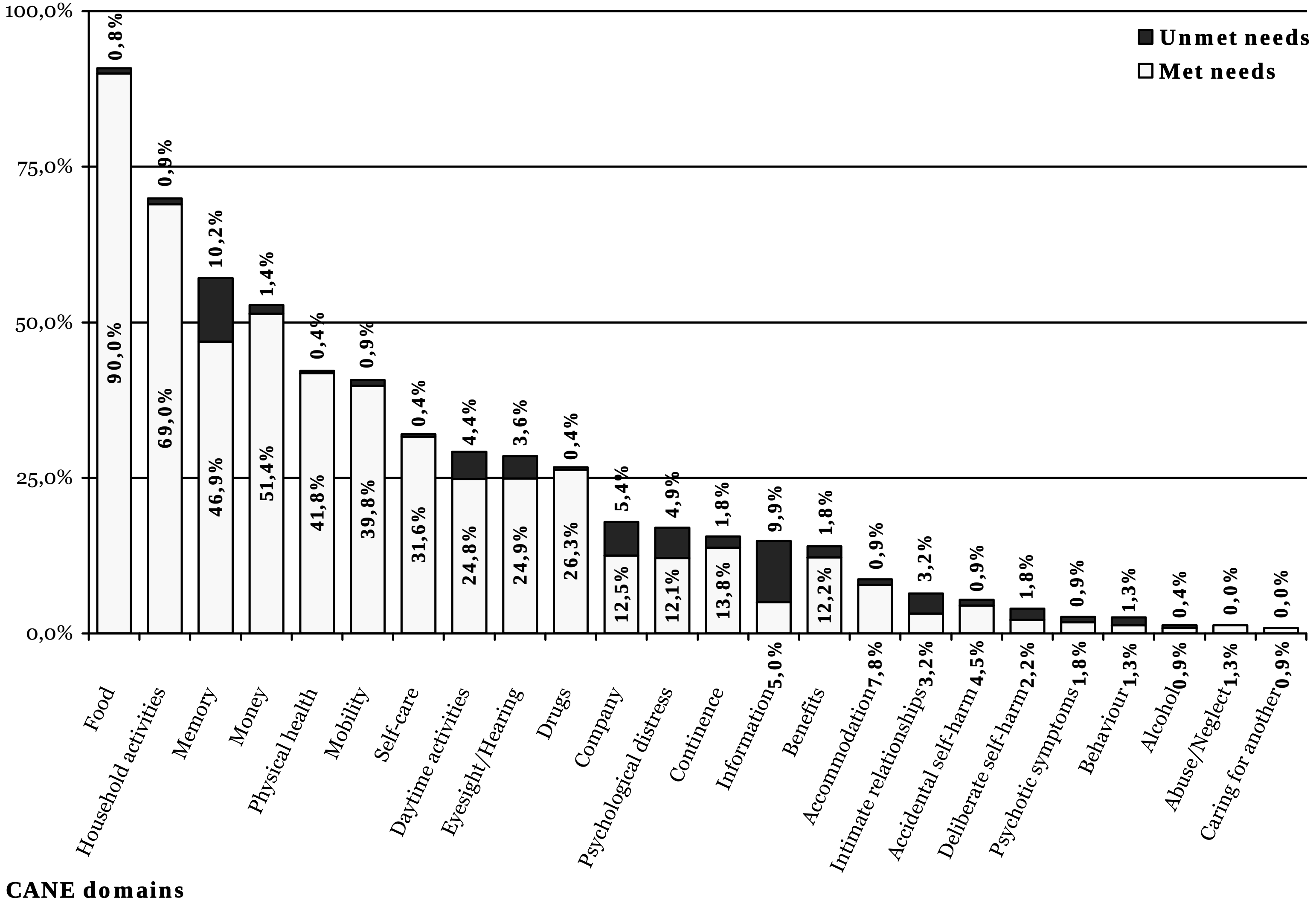


Figure 2. Percentage of (met and unmet) needs as reported by people with dementia

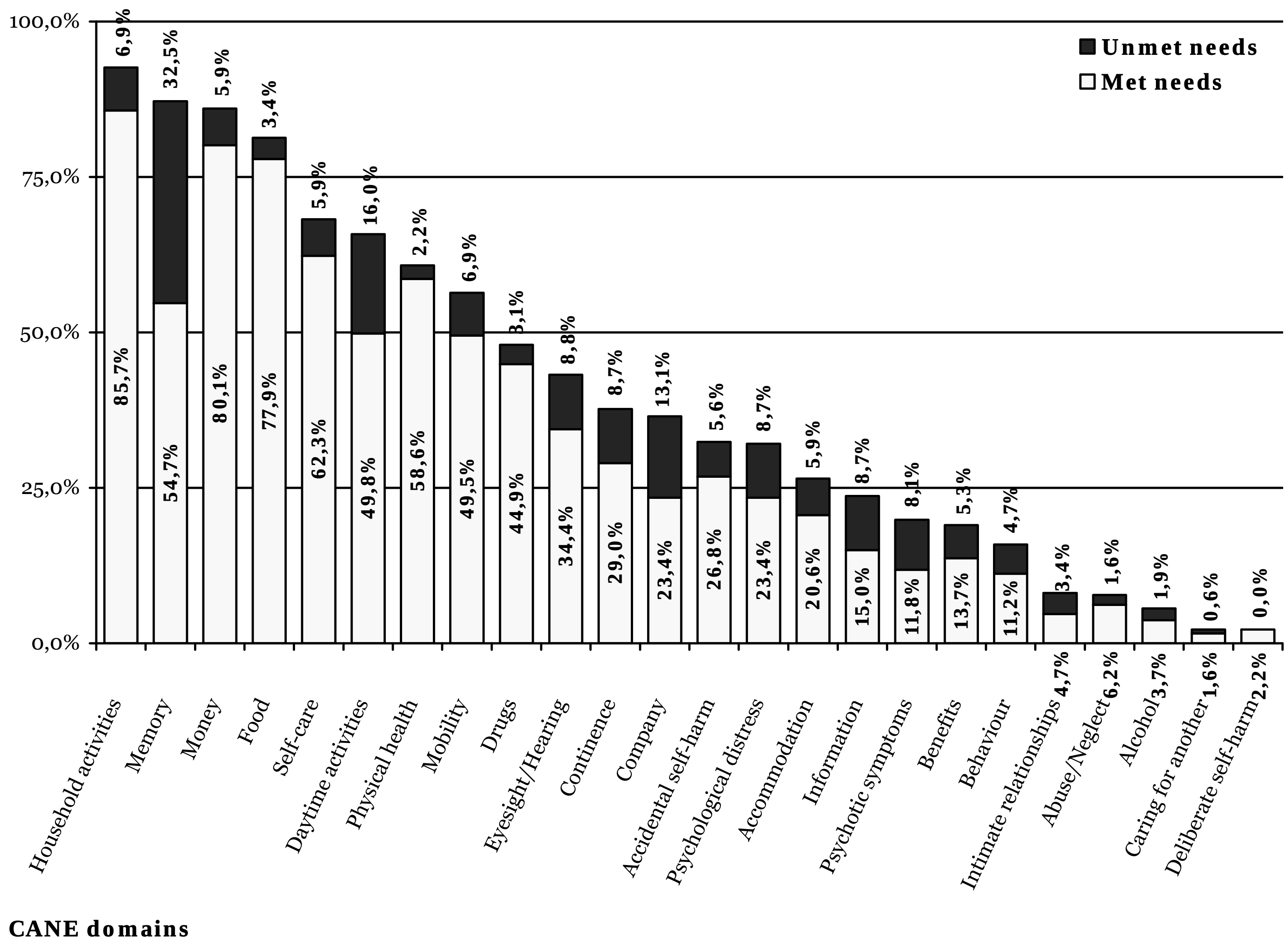


Figure 3. Percentage of (met and unmet) needs as reported by informal carers of people with dementia

Agreement within patient-carer dyads

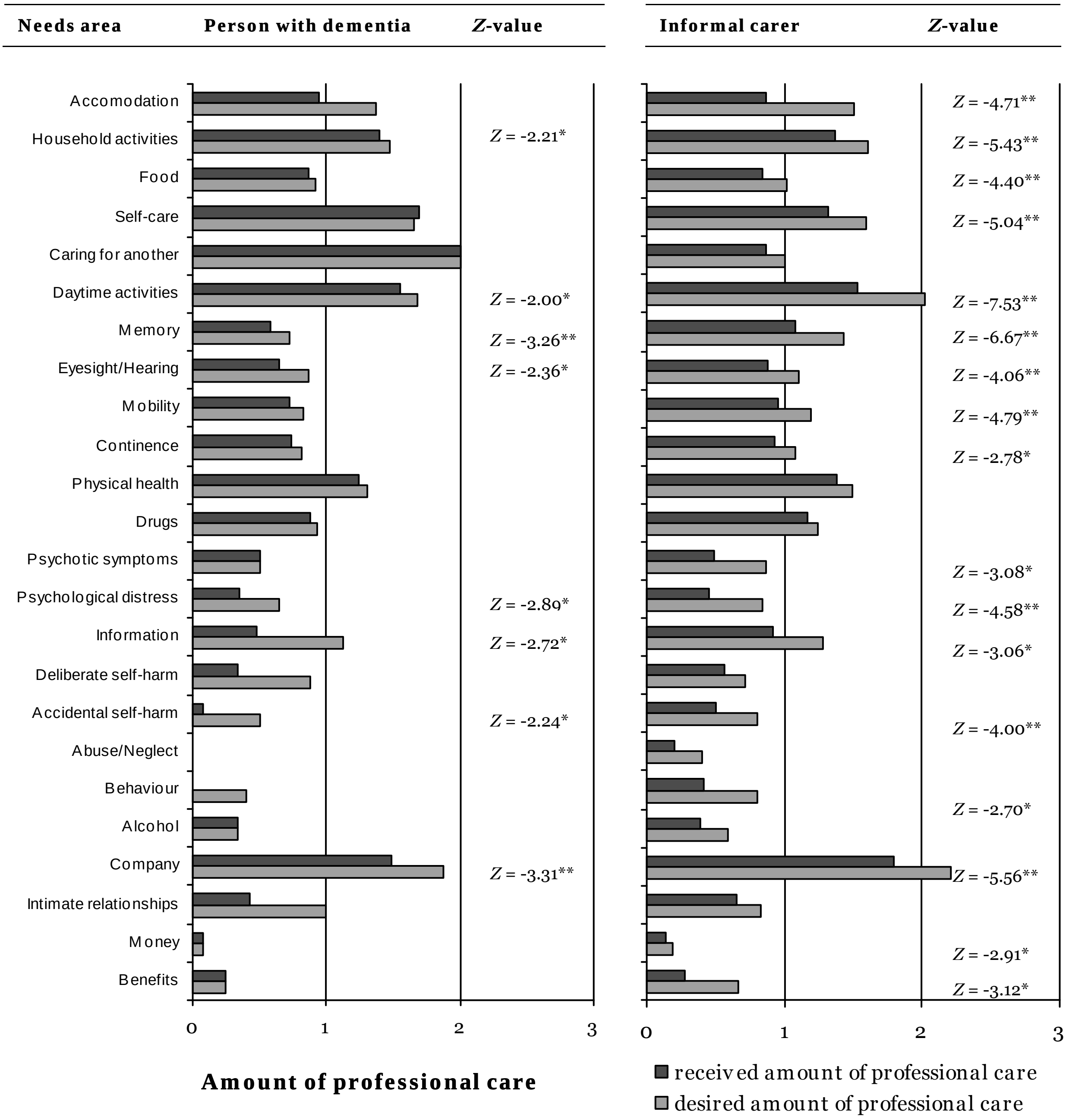
Needs: The degree of agreement (*K*) between the needs of people with dementia and the needs as reported by their informal carers varied between 0.10 and 0.54 (poor to moderate). The highest values were found in areas related to physical functioning, namely: mobility (*K* = 0.54), eyesight/hearing (*K* = 0.49) and physical health (*K* =0.45). Poor agreement was found for more subjective measures like behaviour problems (*K* = 0.13), deliberate (*K* = 0.13) and accidental self-harm (*K* = 0.11) and abuse/neglect (*K* = 0.10) (Table 2).

Professional support: Overall there was fairly good agreement on the actual amount of professional help provided within patient-carer dyads. Most Kappa values varied between 0.90 (very good) and 0.22 (fair). The highest values were calculated for the received amount of professional care on the domains of accommodation (*K* = 0.90), daytime activities (*K* = 0.81) and household activities (*K* = 0.79); the lowest levels of agreement were found for received professional care on psychotic symptoms (*K* = 0.29), information about the disease and care and treatment possibilities (*K* = 0.38), alcohol (*K* = 0.00) and intimate relationships (*K* = 0.00) (Table 2).

Relationships between personal and context variables and number of reported needs

Several sociodemographic characteristics of people with dementia and informal carers proved to be related to the number of reported needs, i.e. type and severity of dementia, living situation, carer type, gender, age, subjective burden and number of informal carer hours. People who had another type of dementia than Alzheimer's disease, who did not live with their carer or had a carer who was not their partner, experienced more needs in total and more *met* needs than people with Alzheimer's disease who shared the household with their carer, or who were cared for by their partner. Furthermore, people with other types of dementia than Alzheimer's disease and people with a carer who experienced high levels of burden, experienced more *unmet* needs as compared to people with Alzheimer's disease or people who were cared for by not highly burdened carers.

Informal carers caring for a person with other types of dementia than Alzheimer's disease, who cared for a person with severe dementia, who did not share the household, or who took care of someone who was not their partner, who were female, or were experiencing high levels of burden, reported more needs (in total and more *unmet*) as compared to carers of a person with Alzheimer's disease, in the beginning stages of dementia, who shared a household, cared for their partner, who were male, or experienced low levels of burden. Carers of people with other types of dementia than Alzheimer's disease or who were experiencing high levels of burdened reported



Amount of professional help: 0 = no help, 1 = low help, 2 = moderate help, 3 = high help
* $p < 0.05$
* $p < 0.001$

Figure 4. Differences between received and desired amount of professional care by people with dementia and informal carers.

Table 2. Agreement within patient-carer dyads on needs and on amount of received professional support

	AGREEMENT ON NEEDS			AGREEMENT ON AMOUNT OF RECEIVED PROFESSIONAL CARE		
	% total agreement	**Kappa-coefficient**	n_{dyads}	**% total agreement**	**Kappa-coefficient**	n_{dyads}
Accommodation	84.9%	0.40	*219*	92.9%	0.90	*14*
Household activities	74.3%	0.32	*218*	86.9%	0.79	*144*
Food	70.8%	0.42	*219*	86.5%	0.78	*104*
Self-care	63.0%	0.34	*216*	75.4%	0.65	*65*
Caring for another	97.3%	0.24	*216*	#	#	*1*
Daytime activities	56.8%	0.28	*213*	89.8%	0.81	*49*
Memory	53.8%	0.27	*212*	61.9%	0.43	*110*
Eyesight/Hearing	75.5%	0.49	*209*	61.9%	0.43	*55*
Mobility	75.6%	0.54	*213*	77.9%	0.66	*76*
Continence	75.1%	0.37	*213*	70.8%	0.53	*24*
Physical health	71.1%	0.45	*211*	77.7%	0.64	*76*
Drugs	72.2%	0.43	*205*	66.7%	0.54	*48*
Psychotic symptoms	87.9%	0.22	*206*	60.0%	0.29	*5*
Psychological distress	78.2%	0.39	*207*	75.0%	0.50	*24*
Information	75.5%	0.22	*184*	58.8%	0.38	*17*
Deliberate self-harm	94.8%	0.13	*211*	#	#	*1*
Accidental self-harm	71.0%	0.11	*204*	71.4%	0.22	*7*
Abuse/Neglect	93.3%	0.10	*209*	#	#	*1*
Behaviour	84.3%	0.13	*210*	100.0%	1.00	*4*
Alcohol	93.4%	0.21	*213*	50.0%	0.00	*2*
Company	73.2%	0.36	*205*	73.1%	0.61	*26*
Intimate relationships	93.0%	0.25	*200*	50.0%	0.00	*4*
Money	69.4%	0.40	*209*	94.4%	0.48	*108*
Benefits	89.8%	0.43	*179*	81.8%	0.51	*22*

relatively many *met* needs as well, while younger carers and carers of people with a low income, reported more *unmet* needs than elderly carers and carers of people with a high income. Furthermore, higher educated carers reported more needs in total and more *met* needs than carers with lower education levels. See Table 3 for mean values and significant test statistics.

The relationship with met or unmet care needs on specific areas was studied for the following characteristics: severity of dementia, gender of the informal carer, type of patient-carer relationship and carer burden.

Severity of dementia: While no relationship was found between the severity of dementia and the amount of (met or unmet) needs people with dementia themselves reported, informal carers of people with severe dementia reported relatively more *met* needs regarding self-care, than carers of people with mild to moderate dementia ($X^2_{(4)}$ = 15.71, p = 0.003). They also reported more *unmet* needs regarding support for memory problems ($X^2_{(4)}$ = 17.70, p = 0.001), psychotic symptoms ($X^2_{(4)}$ = 13.88, p = 0.008), accidental self-harm ($X^2_{(4)}$ = 17.28, p = 0.002) and handling finances ($X^2_{(4)}$ = 13.40, p = 0.004).
Carer gender: No relationships were found between experienced (un)met needs by people with dementia or informal carers on specific need areas and gender of the informal carer.
Type of patient-carer relationship: People with dementia who were cared for by a non-partner carer, relatively more frequently experienced *unmet* needs regarding support for household activities ($X^2_{(2)}$ = 12.93, p = 0.008), company ($X^2_{(2)}$ = 9.28, p = 0.010) and intimate relationships ($X^2_{(2)}$ = 6.84, p = 0.033). Non-partner carers in turn also reported relatively more *unmet* needs regarding household activities ($X^2_{(2)}$ = 7.13, p = 0.028), company ($X^2_{(2)}$ = 14.47, p = 0.001) and intimate relationships ($X^2_{(2)}$ = 11.09, p = 0.004). Additionally they experienced more *unmet* needs in the areas of self-care ($X^2_{(2)}$ = 15.82, p = 0.000) and drugs ($X^2_{(2)}$ = 9.08, p = 0.011).
Carer burden: People with dementia who had highly burdened carers reported experiencing relatively more often insufficient support with communication problems ($X^2_{(2)}$ = 6.29, p = 0.004) and psychological distress ($X^2_{(2)}$ = 6.16, p = 0.046) relatively more often. Highly burdened carers reported more frequently that the person with dementia received adequate support (met needs) for food ($X^2_{(2)}$ = 7.90, p = 0.019), self-care ($X^2_{(2)}$ = 7.30, p = 0.026), daytime activities ($X^2_{(2)}$ = 15.38, p = 0.000), psychological distress ($X^2_{(2)}$ = 6.09, p = 0.004) and money ($X^2_{(2)}$ = 7.44, p = 0.024), but at the same time they reported more frequently that support (met and unmet need) was needed for continence ($X^2_{(2)}$ = 9.33, p = 0.009), company ($X^2_{(2)}$ = 15.71, p = 0.024), memory problems ($X^2_{(2)}$ = 16.86, p = 0.000), psychotic symptoms ($X^2_{(2)}$ = 13.84, p = 0.001) and behaviour problems ($X^2_{(2)}$ = 10.87, p = 0.048). They also reported that the provided (in)formal care was insufficient more often.

Service offer and reasons for unmet needs

Investigation revealed that service offer was available for the main unmet care needs (Table 4). The available service offer in the north of the Netherlands was similar to the offer available in the south. A check for differences in the amount of (un)met

Table 3. Significant relationships between person and context variables and number of (met and unmet) needs as reported by people with dementia and informal carers

	PERSON WITH DEMENTIA (SUBJECTIVE NEEDS)			**INFORMAL CARER (OBJECTIVE NEEDS)**		
	Mean number of total needs *[SD]* Test statistic	Mean number of met needs *[SD]* Test statistic	Mean number of unmet needs *[SD]* Test statistic	Mean number of total needs *[SD]* Test statistic	Mean number of met needs *[SD]* Test statistic	Mean number of unmet needs *[SD]* Test statistic
Alzheimer's Disease vs other types of dementia	4.3 *[2.7]* vs 6.0 *[3.5]* $t_{(159)} = -3.03, p = 0.00$	4.0 *[2.5]* vs 5.2 *[2.8]* $t_{(159)} = -3.57$, p = 0.00	0.3 *[0.8]* vs 0.8 *[1.4]* $U = 2635.00, p = 0.01$	8.8 *[3.2]* vs 10.7 *[3.0]* $t_{(230)]} = -4.64, p = 0.00$	7.6 *[2.9]* vs 8.6 *[2.8]* $t_{(230)} = -2.70, p = 0.01$	1.2 *[1.7]* vs 2.0 *[2.2]* $U = 5017.00, p = 0.00$
Severity dementia: GDS 1-3 vs GDS 4-5 vs GDS 6-7				8.3 *[3.6]* vs 9.9 *[3.1]* vs 10.8 *[2.8]* $F_{(2)} = 8.40, p = 0.00$		1.1 *[1.7]* vs 1.5 *[1.9]* vs 2.3 *[2.2]* $F_{(2)} = 5.64, p = 0.00$
Living with carer vs not living with carer	5.0 *[3.0]* vs 6.1 *[3.1]* $t_{(209)} = -2.57$, $p = 0.01$	4.5 *[2.6]* vs 5.5 *[2.8]* $t_{(209)} = -2.69$, $p = 0.01$		9.2 *[3.4]* vs 10.1 *[3.3]* $t_{(316)} = -2.16, p = 0.03$		1.4 *[1.8]* vs 2.15 *[2.5]* $U = 10231.00, p = 0.03$
Carer is partner vs carer is not partner	4.9 *[3.0]* vs 6.0 *[3.0]* $t_{(209)} = -2.57, p = 0.01$	4.5 *[2.6]* vs 5.5 *[2.8]* $t_{(209)} = -2.67$, $p = 0.01$		9.1 *[3.4]* vs 10.2 *[3.3]* $t_{(316)} = -2.91, p = 0.00$		1.3 *[1.6]* vs 2.14 *[2.6]* $U = 10474.00, p = 0.01$
Male vs female carer				8.9 *[3.3]* vs 9.9 *[3.4]* $t_{(316)} = -2.39, p = 0.02$		1.3 *[1.8]* vs 1.8 *[2.2]* $U = 9284.50$, $p = 0.04$
Younger vs older carer						2.0 *[2.5]* vs 1.3 *[1.6]* $r = -0.13, p = 0.02$
Low vs high subjective burden carer (SPPIC)			0.4 *[0.7]* vs 0.6 *[1.2]* $r = 0.14, p = 0.04$	8.5 *[3.3]* vs 10.3 *[3.2]* $r = 0.37, p = 0.00$	7.4 *[2.9]* vs 8.3 *[2.9]* $r = 0.21, p = 0.00$	1.1 *[1.6]* vs 2.1 *[2.3]* $r = 0.30, p = 0.00$
Less informal care hours per week		5.1 *[2.8]* vs 3.9 *[2.6]* $r = -0.19, p = 0.02$				
Low vs high education level informal carer				9.3 *[3.4]* vs 10.6 *[3.0]* $t_{(316)} = -2.95, p = 0.00$	7.6 *[2.8]* vs 8.7 *[3.0]* $t_{(316)} = -2.81, p = 0.01$	
Income person with dementia (< € 10k vs € 10 - € 20k vs € 20 - € 30k vs > € 30k)						2.63* *[2.48]* vs 1.91 *[2.09]* vs 1.34* *[1.85]* vs 1.83 *[2.36]* $F_{(3)} = 3.04, p = 0.03$

GDS = Global Deterioration Scale; SPPIC = Self-Perceived Pressure from Informal Care.

Table 4. Most frequently mentioned unmet needs by people with dementia and informal carers in relation to service offer in two Dutch regions

PERCEIVED UNMET NEEDS	AVAILABLE SERVICES IN AMSTERDAM-ZUID	AVAILABLE SERVICES IN NIJMEGEN
Memory	Memory clinics (Alzheimer centre VUmc, AMC, Slotervaart Hospital, Mentrum) (drug therapy) Mental health Care (ambulatory, outpatient, admission) (drug therapy) Meeting Centres (memory training) Day-care centres (memory training)	Knowledge centre Geriatry UMC St. Radboud (memory clinic, research project with patients with MCI and carers) (drug therapy) Mental health Care (ambulatory, outpatient, admission) (treatment groups for persons with mild dementia, drug therapy) Meeting Centres (memory training) Day-care centres (memory training)
Daytime activities	Meeting Centres ((re)creational activities, psychomotor therapy) Day-care centres ((re)creational activities) District post for elderly (visits) Humanitas/ Zonnebloem (visits) "Rent a daughter" bureau (visits)	Meeting Centres ((re)creational activities, psychomotor therapy) Day-care centres ((re)creational activities) Elderly Welfare foundation (SWON) Humanitas/ Zonnebloem (visits)
Eye-sight/hearing	General practitioner (diagnostic, referral for aids) Home care (rent aids) Specialist (hospital) (diagnostic, referral for aids)	General practitioner (diagnostic, referral for aids) Home care (rent aids) Specialist (hospital) (diagnostic, referral for aids)
Psychological distress	District post for elderly (support) Mental health Care (ambulatory, support and treatment, support groups) Meeting Centres (psychomotor therapy, social and emotional support, consultation hour, support groups) Day-care centres (social and emotional support)	Elderly Welfare foundation (SWON) (support) Mental health Care (ambulatory, support and treatment, support groups) Meeting Centres (psychomotor therapy, social and emotional support, consultation hour, support groups) Day-care centres (social and emotional support)
Information on health and treatment	General practitioner (diagnosis, information) Memory clinics (Alzheimer centre VUmc, GGZ Buitenamstel, AMC, Slotervaart Hospital, Mentrum) (diagnosis, information) Mental health Care (ambulatory, outpatient, admission) (diagnosis, information)	General practitioner (diagnosis, information) Knowledge centre Geriatry UMC St. Radboud (memory clinic, geriatric diagnostic day centre, care unit) (diagnosis, information) Mental health Care (ambulatory, outpatient, admission) (diagnosis, information)
Company	Meeting Centres (social contact) Day-care centres (social contact) Neighbourhood help (visits) Humanitas/ Zonnebloem (visits) "Rent a daughter" bureau (visits)	Relief service (visits) Day-care centres (social contact) Elderly Welfare foundation (SWON) (visits) Humanitas/ Zonnebloem (visits)

needs reported in the north and south of the Netherlands showed that informal carers in the south of the Netherlands reported more *unmet* needs (m = 2.76, SD = 2.17) than carers in the northern regions ($m = 1.57$, $SD = 2.09$; $t_{(316)} = -2.92$, $p = 0.004$). As compared to carers from the north of the Netherlands, carers that were living in the south reported relatively more often that the support was not adequate and needs were unmet in particular regarding support with memory problems ($X^2_{(2)} = 9.06$, p = 0.011), information for the person with dementia ($X^2_{(2)} = 21.43$, $p = 0.000$) and behavioural problems ($X^2_{(2)} = 6.30$, $p = 0.017$).

When reporting unmet needs, respondents were asked why they were unmet. With regard to unmet needs for memory, daytime activities and psychological distress, both people with dementia and informal carers often said that they were not aware of the available service offer. When they did know about it, informal carers thought that using the offer would not be helpful. With regard to unmet needs for daytime activities, psychological distress and company, professional help was often refused by people with dementia. Furthermore, provided professional care (mostly for memory, daytime activities, company and to a lesser extent also for psychological distress) seemed insufficiently attuned to individual wishes or the offered amount was not enough. One specific reason mentioned for unmet needs on daytime activities was that people were confronted with too much bureaucracy when organizing the care. Regarding unmet needs for information, people with dementia mentioned they had received little to no, or unclear (printed) information about the dementia and possible treatment. Informal carers on the other hand thought the provided information was not understood and indicated that in some cases the dementia was denied.

Discussion

For the first time a large sample of community-dwelling people with mild to severe dementia was interviewed on their met and unmet care needs, and their opinions were compared with the opinions of their informal carers. The needs as reported by people with dementia and informal carers were fairly similar, although the first reported fewer (met and unmet) needs. The areas in which assistance for the person with dementia was most frequently required, according to the person himself and his/her carer were food, household activities, money and memory. The majority of needs in these areas were met, except the need for support with memory problems. Especially informal carers relatively frequently reported unmet needs on other domains as well, such as: daytime activities, company and eyesight/hearing, whereas the persons with dementia, besides memory support, most frequently experienced insufficient or inadequate support for information, company and psychological distress.

Our findings on *subjective* needs in dementia confirm recent research outcomes. As in our study, Edelman *et al.* (2006) found high needs on information. Needs assessed by Meaney *et al.* (2005) on domains of memory, self-care, health, mobility and house care in essence correspond to our findings. Many smaller qualitative studies into the experience of, and coping with dementia, in which people with dementia were interviewed, mentioned problems in the areas of memory, psychological distress, company and information as well (Van der Roest *et al.*, 2007). Extensive research has been done on needs of people with dementia among proxies. Our results correspond to outcomes of earlier studies for example regarding the need for help with household activities, personal care, memory problems, daytime activities, food and company (see e.g. Philp *et al.*, 1995; Nankervis *et al.*, 1997; Dello Buono *et al.*, 1999; Toseland *et al.*, 1999). The surplus value of our study is that earlier small sample research has now been confirmed in a large scale systematic inventory and that more insight is obtained in the frequency of needs in community-dwelling people with dementia as experienced by people with dementia themselves and their carers.

In general, agreement within individual patient-carer dyads on needs was low: the best levels of agreement were found for physical domains, whereas agreement on needs with regard to possible accidental self-harm (e.g. wandering) and abuse/neglect was very poor. Proxy reports generally show that patients asses themselves as less in need of assistance than their informal carer (Lyons *et al.*, 2002). If we compare our Kappa values with other research, they are lower than in studies on patients with other mental disorders (Hancock *et al.*, 2006). It is easy to ascribe this difference to a lack of insight of the person with dementia into the situation. However, agreement within dyads on the amount of received professional care was generally good and recent research by Karel *et al.* (2007) shows that people with mild to moderate dementia are capable of reliable judgment on quality of life and healthcare aspects (see also Dröes *et al.*, 2006). It is also known that proxy opinions on needs of people with dementia appear to be influenced by, for example, the subjective burden of informal carers and the impact behavioural symptoms have on them (Thorgrimsen *et al.*, 2003; Meiland *et al.*, 2005). Coping strategies of persons with dementia such as denial or avoidance, minimization and normalization, and to continue living as before as identified in a literature review by De Boer *et al.* (2007) could perhaps also explain the low agreement on needs found within patient-carer dyads. Trying to maintain feelings of autonomy is important for people with dementia as well (Dröes *et al.*, 2006; Steeman *et al.*, 2007), and this may influence their coping and perception of needs. To remain autonomous people with dementia might scale down their needs, because they are reluctant to allow a home care worker into their house or accept support from relatives. This is illustrated by the percentage of overall agreement between people with dementia and informal carers. The overall agreement on needs for assistance with memory problems (53.8%), daytime activities (56.8%), self-care (63.0%), and money (69.4%) were the lowest: While many informal carers recognized and reported a need for care and assistance on these domains, many people with de-

mentia either did not (want to) report, or did not recognize, their need for support on these specific areas.
Several factors may influence the need for a service and the actual service use (Andersen, 1995; Andersen and Davidson, 1996). For instance, the perception of a need can be influenced by the knowledge people have of healthcare services and the way they value them.

Respondents reported that most professional help was received in the areas of self-care, daytime activities, household activities and physical health, but a desire for extra professional support was expressed on many domains. The agreement on the amount of received help within patient-carer dyads was moderate to good. Following Andersen's Behavioural Model of Health Care Use (Andersen, 1995; Andersen and Davidson, 1996), Toseland *et al.* (2002) found that needs, enabling factors (such as rural/urban location, availability of transportation), and predisposing factors (such as carer-patient relationship or gender), together explained a relative high percentage of variance in use of community-based dementia healthcare and human services. Enabling factors such as knowledge of services, access and other barriers to services and healthcare insurance, explained more variance than the needs itself. When people experience an unmet need and are not aware of an adequate service in their region but only of a service far away, or when they do not have the resources to pay for the service, they are more likely not to use that service. However, this does not mean that there is no desire for the service.

Several sociodemographic characteristics proved to be related to the number of (met and unmet) needs people experience. People with other types of dementia than Alzheimer's disease and being cared for by a highly burdened carer more often experienced insufficient or inadequate support. Carers reported relatively more unmet needs when they cared for a person with non-Alzheimer dementia, the dementia was severe, they did not share a household with, or were not the partner of the person with dementia, when they were young, experienced high subjective burden or when the person with dementia had a low income. Specific background characteristics were also related to different needs: In case of more severe dementia, informal carers were more likely to report unmet needs in the areas of self-care, memory problems, psychotic symptoms, accidental self-harm and money. Non-partner carers were more likely to report unmet needs for household chores, company, intimate relationships, self-care and medication. These are needs that are easily fulfilled by some supervision of a partner or cohabiting carer, but can cause difficulties, or require more effort from a carer who does not cohabit with the person with dementia.

In the regions where this study was carried out services were available for the most frequently mentioned unmet needs. Informal carers living in the southern region of the Netherlands reported relatively more often that support for the problems of their relatives was not sufficient, especially for help with memory problems, information provision and behaviour problems. As the available offer between the north and the south did not differ, a possible explanation for this difference could be that people are less aware of the available services (see also Toseland *et al.*, 2002). Also, the service may not correspond to individual needs, or the amount of support needed. These were also the most common reasons people mentioned for experiencing unmet needs. Reasons known from the literature for non-use of services are (perceived) inadequacy of services, long waiting lists, unavailability and unawareness of services (in an area), high costs and reluctance of the person with dementia to use a service (Brodaty *et al.*, 2005; Forbes *et al.*, 2006). More research on service use is necessary. In particular studies on barriers to use of services, such as costs or individual thresholds, the promotion and thus awareness of a service and its content in a region, will give more insight into the existence of unmet needs and ways to solve them.

The results of this study show that many needs are fulfilled satisfactorily, because the appropriate (in)formal support was provided for the perceived problems. However, for some problems, especially for memory problems, daytime activities, company, information, psychological distress and eyesight/hearing a relatively high percentage of the respondents reported that they received insufficient (in)formal support. It was remarkable that, while most professional support was delivered for company and daytime activities, people still reported unmet needs on these domains. This leads to the conclusion that the offered day care does not meet individual wishes and preferences. In order to solve this problem, more notice should be taken of individual preferences and alternatives can be sought for the available offer. People with dementia received relatively little support for memory problems and information provisioning on dementia and available services. Besides the support from regular care services, utilization of ICT could provide opportunities to solve these needs. At the moment a range of assistive technology devices is available that can provide memory support to people with dementia, for instance devices that give reminders for activities or appointments or can help to locate lost objects (Oriani *et al.*, 2003; Gilliard and Hagen, 2004; Lauriks *et al.*, 2007; Meiland *et al.*, 2007). Regarding information provision on dementia and the available service offer, professionals should be more aware of the need for information and provide clear and up-to-date information to their clients. ICT services may help to provide information, for instance the many websites with information on dementia and the available service offer (Lauriks *et al.*, 2007). A major disadvantage of these websites is that they are generic and static, and sometimes relevant information is difficult to find. Recently, a new web-based DEMentia-specific Digital Interactive Social Chart (DEM-DISC) has been developed and a prototype has been tested (Van der Roest *et al.*, in press). DEM-DISC is a demand-oriented system that aims to provide users with customized advice about available care and welfare services in order to meet and alleviate unmet needs (Van der Roest *et al.*, 2008). The first user field test proved satisfactory. People with dementia as well as their carers had less unmet needs after using DEM-DISC for a two-month period. In general it is likely to be more effective when tailored information is provided that is well attuned to individual needs.

Some caution is required in the interpretation of the results of this study. Since the interviewers were students, they may have had difficulty in recognizing problems and therefore an underreporting may have occurred. Furthermore, the response was not optimal. The non-response was partially caused by overburdening of informal carers. Feeling overburdened was related to more unmet needs in this study, and therefore this non-response may have caused an underrepresentation of unmet needs as experienced by overburdened carers. Another reason for non-response was that people with dementia living alone could not always be reached by telephone and it was frequently not possible to identify their informal carer. Non-inclusion of these people may have led to an underrepresentation of people with dementia living alone in the community. The ethnicity of 76% of the people with dementia was known. Of this group, the majority (92%) were Dutch. No data were collected about the ethnicity of the informal carers. In view of the limited variation in ethnicity no further analysis was conducted into the relationship between ethnicity and care needs. However, since ethnicity is known to be associated with carer burden, the experience of care giving and service needs (Janevic and Connell, 2001; Daker-White *et al.*, 2002), we would recommend including respondents from different ethnic backgrounds in future studies into care needs, in order to get insight into (unmet) care needs of people with different ethnic backgrounds.

The results of this large scale study provide insight into the met and unmet needs of community-dwelling people with dementia as reported by themselves and by their carers, and also into how these needs are related to several sociodemographic characteristics. This insight was lacking until now. In their study on care needs Meaney *et al.* (2005) interviewed both people with dementia and carers, but the researchers reported joint patient-carer responses, and so no insight into individual needs could be gained. This insight was also not provided by the initiative of the National Dementia Programme that inventoried existing needs in different regions of the Netherlands in order to improve dementia care on a regional level (Meerveld *et al.*, 2004). In that study very few people with dementia themselves were involved. The instrument used, the CANE, gave us the opportunity to statistically compare the views of people with dementia and their carers, which gave valuable insight into their needs that may be useful for psychogeriatric care. To be able to provide adequate support care professionals have to bear in mind that the views of people with dementia and their carer are complementary. Care providers should also be aware of the factors that are associated with an increased risk of experiencing unmet needs, such as having non-Alzheimer's dementia or severe dementia, separate households and informal care provided by non-spouses, younger, and female persons or persons who experience high subjective burden.

This study shows that in order to achieve adequate delivery of customized care, care providers should take into consideration the perspectives of both the person with dementia, and the informal carer. To make it easier for people to utilize care services and to increase public awareness of available care services, care providers should at least offer clear and accessible information. The results also offer professionals an indication of what specific groups of people with dementia and informal carers are at risk of experiencing more unmet needs. This will enable professionals to be more alert and efficient in providing the necessary care.

In order to improve the general well-being of people with dementia, all factors that are important for the quality of life of people with dementia should be taken into account. People with dementia value various aspects as important for their own well-being, such as affect, self-esteem, social contact and being useful (Dröes *et al.*, 2006). These quality of life aspects can be strongly influenced by delivering customized care, and they should therefore be included in assessing and fulfilling care needs, in practice and in future research. Insight into the discrepancies between current and desired care offer may help improve care services and increase their efficacy.

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CHAPTER 4

Validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly in community-dwelling people with dementia

Van der Roest, H. G., Meiland, F. J. M., Van Hout, H. P. J., Jonker, C. and Dröes, R. M. (2008). Validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly in community-dwelling people with dementia. *International Psychogeriatrics*, 20, 1273-1290.

Abstract

Objective: Tailor-made care in dementia requires an individual needs assessment. The Camberwell Assessment of Need for the Elderly (CANE) was developed to assess needs of older people with mental disorders. In this study the validity and reliability of the Dutch version of the CANE were studied among community-dwelling persons with dementia and their informal carers.

Method: Interviews were carried out with 236 people with mild to severe dementia and 322 informal carers; 69 informal carers were interviewed twice. Construct and criterion validity and test-retest reliability of the CANE were studied using data for informal carers. Construct validity was also studied for CANE ratings of people with dementia.

Results: The construct validity of the CANE was good among people with dementia and informal carers. Criterion validity could be studied for 76.9% of the CANE items, and all significant correlations were convergent. Test-retest reliability of the CANE varied from poor to very good and was best on domains where needs were explicit and problems well defined.

Conclusions: Use of the Dutch version of the CANE among community-dwelling people with dementia and their carers is supported by the study results, with the study showing acceptable construct and criterion validity and test-retest reliability of the CANE.

Introduction

People with dementia living in the community have specific care and support needs that require particular types of services. An individual needs assessment would help professionals from healthcare and welfare services systematically identify needs experienced by their clients and offer tailor-made (i.e. needs-based) care and support. However, the use of such needs assessment instruments for people with dementia is still uncommon. Also, very few studies have investigated the needs as reported by people with dementia themselves. These were mainly qualitative studies that focused on the experience of dementia and satisfaction with received care (Van der Roest *et al.*, 2007a).

Several instruments to assess care and support needs have been developed for use in mental health care, such as the Camberwell Assessment of Need (CAN; Phelan *et al.*, 1995), the Care Needs Assessment Pack for Dementia (CareNapD; McWalter *et al.*, 1998), the Berliner Bedürfnis Inventar (Hoffmann *et al.*, 1997) and the Need of Support and Service Questionnaire (NSSQ; Jansson *et al.*, 2005). In 2000, the CAN was adapted by Reynolds *et al.* (2000) for use in psychogeriatric populations and became the Camberwell Assessment of Need for the Elderly (CANE). The CANE assesses the needs of elderly people across 24 domains of daily living and measures whether these needs are met or unmet. The instrument also contains two extra items directed specifically at the needs of informal carers. The CANE can record judgments on needs from the viewpoint of the elderly person, of the informal carer, of a professional and of an external assessor, and is therefore very informative if a comprehensive assessment of needs of elderly people from different perspectives is desired.

The validity and reliability of the English version of the CANE were studied in a small heterogeneous psychogeriatric population and were found to be satisfactory (Reynolds *et al.*, 2000). The CANE has now been translated into thirteen languages (Hancock, 2004), including Dutch (Dröes *et al.*, 2004). Even though this version is being used in different psychogeriatric populations and settings in the Netherlands, its validity and reliability have not previously been studied.

In order to assess whether the Dutch version of the CANE is an appropriate instrument to assess the needs of Dutch people with dementia, we studied its validity and reliability. Construct validity was studied among people with dementia who live at home and their informal carers. The criterion validity and test-retest reliability of the CANE were tested among informal carers only.

Method

Design

The construct and criterion validity and the test-retest reliability of the CANE were examined by means of a within-subjects study. Construct validity measures whether item scores are consistent with theoretical expectations. Correlations between the different CANE items were therefore calculated for both the ratings of people with dementia and those of informal carers. Expected positive or negative correlations between items of the instrument were defined as convergent correlations, whereas absent or unexpected correlations were defined as divergent correlations.

Since there is no gold standard for measuring needs in dementia, the criterion validity of the CANE was evaluated by comparison of the CANE with other instruments and single items (see Table 4). The study was approved by the Medical Ethical Committee of the VU University Medical Centre.

Sample

All respondents were participants in a study on needs in dementia. In this cross-sectional study 236 people with dementia and 322 informal carers of people with dementia were interviewed about the care needs of people with dementia (respectively Table 1a and Table 1b; Van der Roest *et al.*, 2007b). The study sought to gain an insight into the met and unmet needs of community-dwelling persons with dementia, the level of agreement on needs as reported by those with dementia and their carers and on the relationship between sociodemographic characteristics of people with dementia and/or carers and their reported needs. The respondents were recruited from various care-providing organizations in the Netherlands. We used the collected data for our study of the reliability and validity of the CANE.

A subsample of 69 informal carers was interviewed twice with a two-week interval for test-retest reliability purposes of the CANE. This subset was representative for the whole study sample (see Table 1a and Table 1b for test statistics).

For construct validity analysis the ratings on the CANE of 322 informal carers and 236 people with dementia were used. Criterion validity of the CANE was studied using data of 322 informal carers. Some criterion instruments were administered only during the second interview, in which case criterion validity was studied with data of the subset (n = 69).

Measuring instruments

As there are no gold standards to assess needs in dementia, we selected scales that approached the content of (groups of) items of the CANE to study criterion validity. First of all, we collected various sociodemographic data on personal characteristics,

Table 1a. Sociodemographic characteristics of people with dementia

PERSONS WITH DEMENTIA	n = 236	n = 69	COMPARISON WHOLE SAMPLE WITH SUBSET	
			TEST STATISTIC	p
Male	110 (46.6%)	28 (40.6%)	X^2 = 0.11	0.76
Female	126 (53.4%)	41 (59.4%)		
Age	80.0 (*SD* = 7.5; *range* 56.7 - 99.2)	78.1 (*SD* = 8.0; *range* 57.1 - 91.9)	t = -1.84	0.07
Married	134 (56.8%)	39 (56.5%)	X^2 = 0.89	0.64
Widowed	80 (33.9%)	25 (36.2%)		
Other	22 (9.3%)	5 (7.3%)		
Living alone	89 (37.7%)	26 (37.7%)	X^2 = 1.56	0.46
Number of months since first symptoms (*Median*)	42.6 (*SD* = 48.4; *range* 2 - 452)	48.0 (*SD* = 36.0; *range* 6 - 180)	t = -1.07	0.29
Alzheimer's disease (AD)	91 (38.5%)	34 (49.3%)	X^2 = 0.75	0.86
Vascular dementia (VaD)	33 (14.0%)	12 (17.4%)		
Mixed dementia (MD)	29 (12.3%)	9 (13.0%)		
Other type of dementia	20 (8.5%)	6 (8.7%)		
Type of dementia unknown	63 (26.7%)	8 (11.6%)		
No cognitive decline *(GDS 1)*	3 (1.3%)	0 (0.0%)	U = 4441.00	0.15
Very mild cognitive decline *(GSD 2)*	27 (11.4%)	7 (10.2%)		
Mild cognitive decline *(GDS 3)*	51 (21.6%)	7 (10.2%)		
Moderate cognitive decline *(GDS 4)*	76 (32.2%)	22 (31.9%)		
Moderately severe cognitive decline *(GDS 5)*	44 (18.6%)	17 (24.6%)		
Severe cognitive decline *(GDS 6)*	16 (6.8%)	9 (13.0%)		
Very severe cognitive decline *(GDS 7)*	0 (0.0%)	1 (1.4%)		
Severity of dementia unknown	19 (8.1%)	6 (8.7%)		
MMSE-score	20.4 (*SD* = 5.5; *range* 3 - 29)	20.0 (*SD* = 5.9; *range* 6 -29)	t = -0.55	0.58

social context and social economical status (SES) of informal carers and people with dementia, on objective burden of informal carers, service use and social support to serve as criterion variables for the CANE items. In addition to these data, the following scales were used as criterion measures for the CANE (all were expected to correlate positively with CANE items): The Interview for Deterioration in Daily living activities in Dementia (IDDD performance scale; Teunisse and Derix, 1991) served as criterion variables for CANE items concerning autonomy-related needs and physical condition; the Neuropsychiatric Inventory (NPI; Cummings *et al.*, 1994; Kat *et al.*,

Table 1b. Sociodemographic characteristics informal carers of people with dementia

INFORMAL CARERS	*n* = 322	*n* = 69	COMPARISON WHOLE SAMPLE WITH SUBSET	
			TEST STATISTIC	*p*
Male Female	101 (31.4%) 221 (68.6%)	25 (36.2%) 44 (63.8%)	X^2 = 0.62	0.43
Age	65.4 (*SD* = 14.1; *range* 23.1 - 90.3)	62.5 (*SD* = 15.0; *range* 6 - 29)	*t* = 1.55	0.12
Married Widowed Other	266 (82.6%) 9 (2.8%) 47 (14.6%)	64 (92.8%) 0 (0.0%) 5 (7.2%)	X^2 = 4.93	0.09
Partner Daughter Son Other	175 (54.3%) 77 (23.9%) 33 (10.3%) 37 (11.5%)	35 (50.7%) 16 (23.2%) 8 (11.6%) 10 (14.5%)	X^2 = .68	0.88
Shared household	199 (61.8%)	38 (55.1%)	X^2 = 1.08	0.30
Other activities besides care Gainfully employed	157 (48.8%) 88 (26.5%)	43 (62.3%) 27 (39.1%)	X^2 = 2.80 X^2 = 1.07	0.09 0.30
Number of months informal care giving (*Median*)	24.0 (*SD* = 32.0; *range* 1 - 283)	24.0 (*SD* = 19.5; *range* 1 -120)	*U* = 7786.00	0.59
Number of hours of informal care per week (*Median*)	37.0 (*SD* = 63.0; *range* 1 - 168)	21.0 (*SD* = 60.0; *range* 2 -168)	*t* = -1.28	0.20

2002) was used as a criterion for CANE items that measure psychologically and emotionally oriented needs; the Self-Perceived Pressure from Informal Care (SPPIC; Pot *et al.*, 1995) and the Short Sense of Competence Questionnaire (SSCQ; Vernooij-Dassen *et al.*, 1999) were used as criterion measures for carer stress- related needs; the Mini-Mental State Examination (MMSE; Folstein *et al.*, 1975) and the Global Deterioration Scale (GDS; Reisberg *et al.*, 1982) were used as criterion variables for the CANE item "memory" (see Table 4).

Procedure

People with dementia living at home (and their informal carers if known) were identified by the various participating care providers. They were approached first by letter and then verbally to see if they would cooperate in this study on needs in dementia. Those who agreed to take part gave their written consent.

The persons with dementia and the informal carers were interviewed face-to-face separately by trained interviewers (graduate students in psychology and medicine). During the interviews with people with dementia, the CANE and MMSE instruments were administered. The average duration time of the CANE for people with dementia was 27.9 minutes (*SD* = 14.3). The informal carers were asked for sociodemographic information about themselves and for the person with dementia; the CANE, the SPPIC and the SSCQ were also conducted during the face-to-face interviews. Duration time of the CANE among informal carers was 31.8 minutes (*SD* = 12.3) on average. After the interview, the informal carers were asked by the interviewer whether they would participate in a second interview to study test-retest reliability. 69 informal carers agreed to take part.

This second interview for test-retest reliability and validity purposes was conducted by telephone by the same interviewer and took place two weeks (on average) after the first interview. The CANE was conducted again (mean duration 21.3 minutes (*SD* = 10.1)), and the IDDD-performance and the NPI were administered.

Verification of the diagnosis of dementia syndrome according to DSM-IV criteria (American Psychiatric Association, 1994) and type and severity of dementia (GDS) were retrieved in writing from the general practitioner or specialist after the first interview.

Analysis

Data were analyzed using the Statistical Package for the Social Sciences, version 13.0 (SPSS, 2004). χ^2 tests, t-tests and Mann-Whitney U tests were performed to compare the characteristics of the 69 informal carers in the subset with the complete group of respondents. Subsequently, summary scores and 95% confidence intervals (CI) were calculated for the ratings on the CANE of people with dementia and informal carers. Frequency distributions of the met and unmet needs were determined to study the needs as reported by people with dementia and by their informal carers.

Correlations (Spearman's ρ) between the various CANE items were calculated for people with dementia and for informal carers, to determine the convergent and divergent construct validity of the CANE. Since the CANE measures problems in various domains of daily living, and as functioning in daily living deteriorates as a consequence of dementia, the CANE items are expected to correlate more positively with each other as the disease progresses. Due to the variation in severity of dementia within the research population, needs will not occur on all domains of daily living. Therefore, not all correlations are expected to reach significant values. As some domains of daily living are expected to be related more to each other than to others, we clustered the CANE items in four categories:

1. *Autonomy* (accommodation, household activities, food, self-care, caring for another, daytime activities, memory, accidental self-harm, money and benefits);
2. *Physical needs* (eyesight/hearing, mobility, continence, physical health, drugs

and alcohol);

3. *Psychological, emotional and social needs* (psychotic symptoms, psychological distress, information, deliberate self-harm, abuse/neglect, behaviour, company and intimate relationships);
4. *Carer needs* (carer's need for information and carer's psychological distress).

Items within a category were expected to correlate more strongly with each other than items in different categories. The calculated correlations were interpreted according to Cohen (1988): correlations of 0.10 are considered small size, 0.30 medium size, and correlations of 0.50 or higher are considered as large.

To evaluate criterion validity, correlations (Spearman's ρ) were calculated between items of the CANE and relevant criterion variables. To adjust for multiple testing, Bonferroni correction was utilized.

For test-retest reliability purposes, the percentage of complete agreement, kappa coefficients and 95% CIs were calculated. κ values between 0 and 0.20 indicate poor agreement, 0.21 and 0.40 fair, 0.41 and 0.60 moderate, 0.61 and 0.80 good, and 0.81 and 1.00 very good agreement (Altman, 1991). Finally, intraclass correlation coefficients (ICC) and 95% CIs were computed between summary scores of the CANE; these values can be interpreted in the same way as κ values (Deyo *et al.*, 1991; Streiner and Norman, 1995).

Results

People with dementia on average reported 5.4 out of 24 needs (95% CI 5.02– 5.83), of which 4.9 (95% CI 4.52–5.23) were met and 0.5 (95% CI 0.40–0.69) were unmet. Informal carers, on the other hand, reported 10.3 out of 26 needs (95% CI 9.88–10.70) on average, of which 8.4 (95% CI 8.03–8.71) were met and 1.9 (95% CI 1.66–2.18) were unmet. The frequency distributions of the reported met and unmet needs by people with dementia and informal carers are shown in Figures 1 and 2 respectively.

Validity

Construct validity

Positive correlations between all CANE items were expected both for people with dementia and for informal carer ratings. For the CANE ratings of people with dementia, convergent correlations were found for 98.8% of the total number of significant correlations (85) (Table 2). Most convergent correlations were found in the areas in which more than 20% of the people with dementia experienced needs. Most significant correlations were found between the items of "psychological distress", "eyesight/hearing", "memory", "daytime activities", "company", "money", "drugs" and the

Table 2. Construct validity for CANE, ratings of people with dementia

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(17)	(23)	(24)	(8)	(9)	(10)	(11)	(12)	(20)	(13)	(14)	(15)	(16)	(18)	(19)	(21)	(22)
(1) Accommodation	1.00	$+^{**}$				$+^{**}$	$+^{**}$											$+^{*}$	$+^{*}$	$+^{**}$			$+^{**}$	
(2) Household activities		1.00	$++^{**}$	$+^{**}$		$+^{*}$			$+^{**}$			$+^{**}$	$+^{*}$		$+^{*}$									
(3) Food			1.00	$+^{**}$		$+^{*}$			$+^{**}$	$+^{**}$		$+^{*}$	$+^{**}$											
(4) Self-care				1.00		$+^{**}$	$-^{**}$		$+^{*}$			$++^{**}$	$+^{**}$		$+^{*}$									
(5) Caring for another					1.00																			
(6) Daytime activities						1.00			$+^{**}$						$+^{**}$			$+^{**}$					$+^{**}$	$+^{**}$
(7) Memory							1.00	$+^{**}$	$+^{*}$		$+^{**}$			$+^{**}$			$+^{*}$	$+^{**}$	$+^{*}$	$+^{**}$		$+^{**}$		
(17) Accidental self-harm								1.00	$+^{**}$		$+^{**}$							$+^{*}$	$+^{*}$		$+^{**}$			
(23) Money									1.00	$+^{**}$	$+^{*}$				$+^{*}$									
(24) Benefits										1.00							$+^{*}$							
(8) Eyesight/Hearing											1.00	$+^{**}$	$+^{*}$	$+^{*}$			$+^{**}$	$+^{**}$	$+^{*}$			$+^{**}$	$+^{*}$	
(9) Mobility												1.00	$+^{**}$	$+^{**}$	$+^{**}$									
(10) Continence													1.00		$+^{*}$									
(11) Physical health														1.00	$+^{*}$		$+^{**}$						$+^{*}$	
(12) Drugs															1.00								$+^{**}$	$+^{*}$
(20) Alcohol																1.00	$+^{*}$	$+^{*}$		$++^{**}$		$++^{**}$		$+^{**}$
(13) Psychotic symptoms																	1.00	$+^{**}$				$+^{**}$		
(14) Psychological distress																		1.00		$++^{**}$		$+^{*}$	$+^{**}$	$+^{**}$
(15) Information																			1.00	$+^{*}$		$+^{*}$	$+^{**}$	$+^{*}$
(16) Deliberate self-harm																				1.00		$++^{**}$	$+^{**}$	$++^{**}$
(18) Abuse/Neglect																					1.00			
(19) Behaviour																						1.00		
(21) Company																							1.00	$++^{**}$
(22) Intimate relationships																								1.00

$+\ 0.10 \le r < 0.30$ / $-\ -0.30 < r \le -0.10$
$++\ 0.30 \le r < 0.50$ / $--\ -0.50 < r \le -0.30$
$+++\ r \ge 0.50$ / $---\ r \le -0.50$
$^{*}\ p < .05$
$^{**}\ p < .01$

Table 3. Construct validity for CANE, ratings of informal carers of people with dementia

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(17)	(23)	(24)	(8)	(9)	(10)	(11)	(12)	(20)	(13)	(14)	(15)	(16)	(18)	(19)	(21)	(22)	(A)	(B)
(1) Accommodation	1.00	$+^{*}$	$+^{*}$	$+^{*}$		$+^{**}$	$+^{**}$	$+^{*}$	$+^{**}$	$+^{*}$	$+^{**}$	$+^{**}$	$+^{*}$	$+^{*}$	$+^{**}$		$+^{**}$					$+^{*}$	$+^{**}$	$+^{**}$	$+^{**}$	$+^{**}$
(2) Household activities		1.00	$++^{**}$	$+^{**}$		$+^{*}$	$+^{*}$		$+^{**}$			$+^{*}$	$+^{**}$				$+^{*}$				$+^{*}$	$+^{**}$				$+^{*}$
(3) Food			1.00	$++^{**}$	$-^{**}$	$+^{**}$	$+^{**}$		$++^{**}$			$+^{*}$	$+^{**}$		$+^{**}$			$+^{*}$	$+^{*}$				$+^{**}$			$+^{*}$
(4) Self-care				1.00		$+^{**}$			$+^{**}$		$+^{**}$	$+^{**}$	$+^{**}$								$+^{*}$		$+^{**}$			$+^{*}$
(5) Caring for another					1.00																					
(6) Daytime activities						1.00	$+^{**}$	$+^{**}$	$+^{**}$			$+^{*}$	$+^{**}$		$+^{**}$	$+^{*}$	$+^{**}$	$+^{*}$	$+^{*}$	$+^{*}$		$+^{**}$	$++^{**}$	$+^{**}$		$+^{*}$
(7) Memory							1.00	$+^{**}$	$+^{**}$				$+^{*}$				$+^{**}$	$+^{**}$	$+^{**}$			$+^{*}$	$+^{**}$	$+^{**}$	$+^{**}$	$+^{**}$
(17) Accidental self-harm								1.00	$+^{**}$						$+^{**}$		$+^{**}$			$+^{*}$		$+^{**}$	$+^{*}$	$+^{*}$	$+^{*}$	$+^{**}$
(23) Money									1.00				$+^{**}$				$+^{**}$					$+^{*}$	$+^{*}$			$+^{*}$
(24) Benefits										1.00		$+^{*}$			$+^{*}$										$+^{*}$	$+^{*}$
(8) Eyesight/Hearing											1.00	$+^{*}$		$+^{*}$											$+^{*}$	
(9) Mobility												1.00	$+^{**}$	$+^{**}$	$+^{**}$								$+^{*}$	$+^{*}$		
(10) Continence													1.00				$+^{*}$				$+^{*}$		$+^{**}$	$+^{*}$		
(11) Physical health														1.00	$+^{**}$									$+^{**}$	$+^{*}$	
(12) Drugs															1.00		$+^{*}$			$+^{**}$			$+^{*}$	$+^{**}$	$+^{**}$	
(20) Alcohol																1.00										$+^{*}$
(13) Psychotic symptoms																	1.00	$+^{**}$				$+^{**}$	$+^{**}$	$+^{**}$		$+^{**}$
(14) Psychological distress																		1.00	$+^{**}$		$+^{**}$	$+^{**}$	$+^{**}$	$+^{*}$		$+^{**}$
(15) Information																			1.00	$+^{**}$					$+^{**}$	
(16) Deliberate self-harm																				1.00	$++^{**}$	$+^{**}$	$+^{*}$	$+^{*}$	$+^{**}$	
(18) Abuse/Neglect																					1.00	$+^{**}$	$+^{*}$			
(19) Behaviour																						1.00	$+^{**}$			$+^{**}$
(21) Company																							1.00	$+^{**}$	$+^{**}$	$+^{**}$
(22) Intimate relationships																								1.00	$+^{**}$	
(A) Carer's need for information																									1.00	$+^{*}$
(B) Carer's psychological distress																										1.00

$+\ 0.10 \leq r < 0.30$ / $-\ -0.30 < r \leq -0.10$
$++\ 0.30 \leq r < 0.50$ / $--\ -0.50 < r \leq -0.30$
$+++\ r \geq 0.50$ / $---\ r \leq -0.50$
$^{*}\ p < .05$
$^{**}\ p < .01$

other CANE items. Only one unexpected significant divergent correlation was found – that between “memory” and “self- care” ($r = -0.21$, $p < 0.01$). Relatively more significant correlations were found between items within the categories than between items in the overall matrix. Relatively speaking, most correlations were found between items within the category of “psychological, emotional and social needs”.

For the CANE ratings of informal carers, 142 significant correlations between the various items were found. Of these correlations, 99.2% were convergent; only one divergent correlation was found – that between “food” and “caring for another” ($r = -0.16$, $p < 0.01$) (see Table 3). Most convergent correlations were found between CANE items that were highly related to symptoms of dementia and other CANE items, i.e. “daytime activities”, “accommodation”, “company”, “memory” and “carer’s psychological distress”. The assumption that stronger correlations exist between items of the same category was partly confirmed. For the CANE ratings of informal carers, relatively more significant correlations were found between items within the categories of “autonomy”, “psychological, emotional and social needs” and “carer needs”. Relatively fewer significant correlations were found between items within the category of “physical needs” than for the number of correlations within the complete matrix.

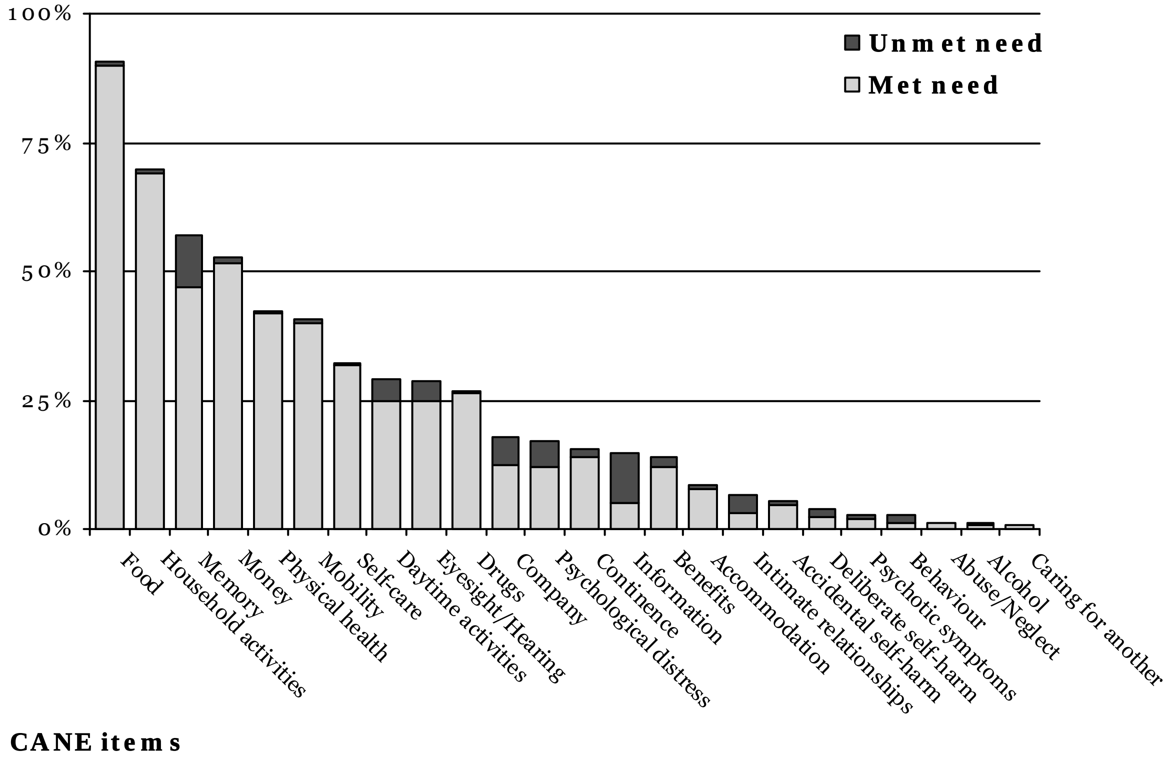

Figure 1. Percentage of met and unmet needs reported by community-dwelling people with dementia (for exact percentages see Chapter 3)

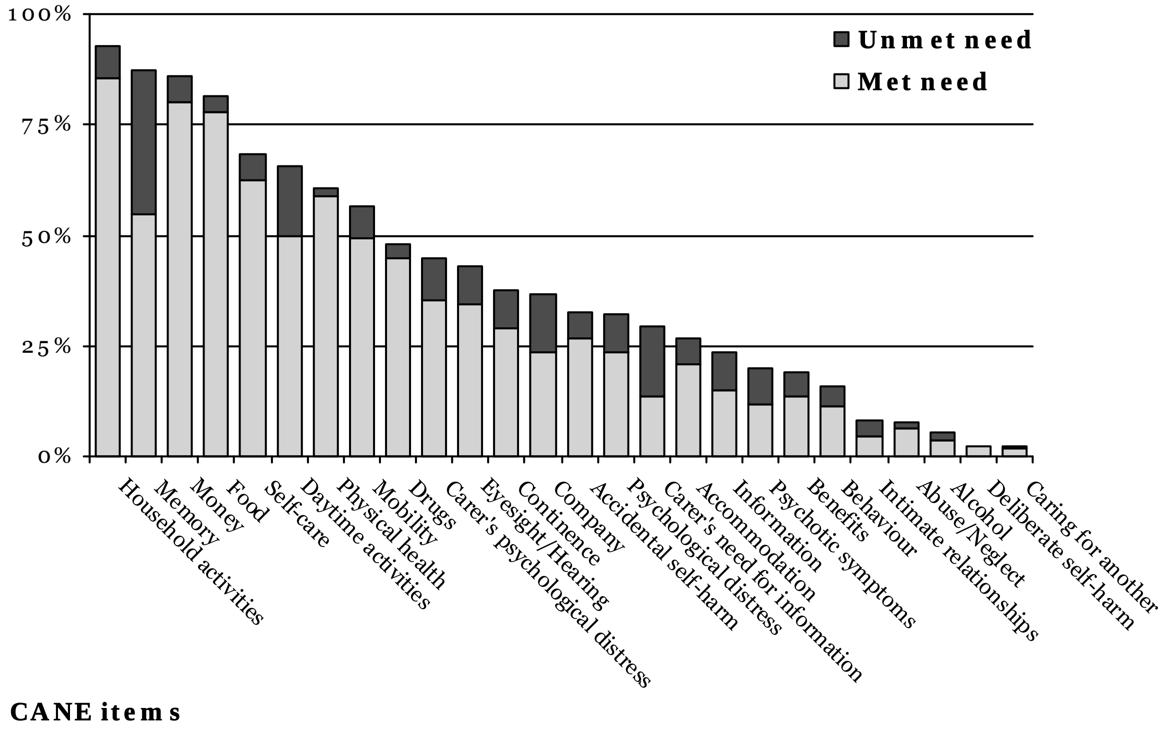

Figure 2. Percentage of met and unmet needs reported by informal carers of community-dwelling people with dementia (for exact percentages see Chapter 3)

Criterion validity

Criterion validity for the items of “eyesight/hearing”, “alcohol” and “benefits” could not be established, since no criterion instruments were included for these items. Using the Bonferroni correction, no significant correlations were found between the criterion variables and the CANE items of “drugs”, “deliberate self-harm” and “abuse/neglect”. This means that criterion validity could be assessed for only 76.9% of the CANE items. Previous relevant criterion variables were selected. In Table 4 all significant correlations between these variables and CANE items are reported. High correlations were found between “self-care” and items of the IDDD-performance scale, between “psychotic symptoms” and the NPI item of depression and for several background characteristics items in relation to the items “mobility” and “physical health” (see Table 4). All significant correlations were convergent, but most were of small size.

Table 4. Criterion validity CANE for informal carer use

CANE ITEM	CRITERION ITEM/SCALE	SPEARMAN'S RHO
Daytime activities	Receives professional activating assistance[1]	$r = 0.23^{**}$
Memory	MMSE score	$r = -0.34^{**}$
	GDS score	$r = 0.22^{**}$
Accidental self-harm	Supervision by informal carer[1]	$r = 0.16^{**}$
	Informal carer wishes (professional) help with supervision[1]	$r = 0.22^{**}$
Accommodation	On waiting list for residential care[1]	$r = 0.20^{*}$
Household activities	Received help with household activities *(10)*[2]	$r = 0.38^{**}$
Food	Informal carer helps with coffee/tea, groceries or cooking meals[1]	$r = 0.27^{**}$
	How often does the person with dementia get groceries him/herself[1]	$r = 0.30^{**}$
Self-care	Person with dementia receives professional self-care[1]	$r = 0.40^{**}$
	Received help with washing *(1)*[2]	$r = 0.54^{**}$
	Received help with dressing *(3)*[2]	$r = 0.53^{**}$
	Received help with combing hair and brushing teeth *(4)*[2]	$r = 0.45^{**}$
Caring for another	Background CANE: is person with dementia an informal carer him/herself[1]	$r = 0.30^{**}$
Money	Received help with finances *(11)*[2]	$r = 0.37^{**}$
Benefits	*No criterion item/scale available*	
Eyesight/hearing	*No criterion item/scale available*	
Mobility	Informal carer gives help by walking or transport[1]	$r = 0.22^{**}$
	Aids needed for transport[1]	$r = 0.50^{**}$
Continence	Informal carer helps with toileting[1]	$r = 0.38^{**}$
	Extra costs for incontinence materials[1]	$r = 0.25^{**}$
	Receives professional self-care[1]	$r = 0.29^{**}$
Physical health	Person with dementia has physical complaints and receives treatment[1]	$r = 0.58^{**}$
Drugs		*n.s.*
Alcohol	*No criterion item/scale available*	
Psychotic symptoms	Delusions *(1)*[3]	$r = 0.52^{**}$
	Hallucinations *(2)*[3]	$r = 0.48^{**}$
Psychological distress	Depression *(14)*[3]	$r = 0.40^{**}$
Information	*No criterion item/scale available*	
Deliberate self-harm		*n.s.*
Abuse/Neglect		*n.s.*
Behaviour	Agitation/aggression *(13)*[3]	$r = 0.39^{**}$
Company	Person with dementia and informal carer share household[1]	$r = 0.28^{**}$
	How often is person with dementia alone? [1]	$r = -0.20^{**}$
	How often does person with dementia go out to meet friends? [1]	$r = 0.30^{**}$
Intimate relationships	Relation informal carer with person with dementia[1]	$r = 0.20^{**}$
	Civil status person with dementia[1]	$r = 0.18^{**}$
	Number of days of informal care per week[1]	$r = -0.23^{**}$
Carer's need for information	Informal carer has received sufficient information from professionals[1]	$r = -0.24^{**}$
Carer's psychological distress	Burden[4]	$r = 0.45^{**}$
	Competence[5]	$r = -0.33^{**}$

* $p < .05$
** $p < .01$
[1] sociodemographic background list item
[2] Interview for Deterioration in Daily living activities in Dementia-performance scale item
[3] Neuropsychiatric Inventory item
[4] Self-Perceived Pressure from Informal Care
[5] Short Sense of Competence Questionnaire

Table 5. Test-retest reliability CANE for informal carers (n = 69-62)

CANE ITEM	% COMPLETE AGREEMENT	KAPPA VALUE	95% CI KAPPA VALUE	
			LOWER BOUND	UPPER BOUND
Accommodation	85.5%	0.56	0.32	0.80
Household activities	91.1%	0.54	0.20	0.87
Food	89.3%	0.42	0.06	0.77
Self-care	86.6%	0.74	0.58	0.90
Caring for another	98.5%	0.66	0.02	10.00
Daytime activities	70.6%	0.52	0.34	0.71
Memory	76.5%	0.43	0.20	0.66
Eyesight/Hearing	81.3%	0.58	0.37	0.79
Mobility	80.9%	0.58	0.38	0.77
Continence	84.7%	0.68	0.50	0.86
Physical health	79.5%	0.61	0.43	0.79
Drugs	86.3%	0.73	0.57	0.89
Psychotic symptoms	83.3%	0.61	0.42	0.80
Psychological distress	76.1%	0.50	0.30	0.70
Information	74.2%	0.38	0.15	0.62
Deliberate self-harm	100.0%	1.00	1.00	1.00
Accidental self-harm	74.6%	0.42	0.20	0.63
Abuse/Neglect	92.6%	0.61	0.31	0.91
Behaviour	85.3%	0.38	0.07	0.70
Alcohol	95.5%	0.55	0.10	10.00
Company	74.2%	0.51	0.31	0.72
Intimate relationships	90.7%	0.22	0.00	0.62
Money	95.6%	0.65	0.27	10.00
Benefits	91.9%	0.14	0.00	0.39
Carers need for information	77.9%	0.40	0.16	0.65
Carers psychological distress	83.8%	0.70	0.54	0.86

Agreement levels K value: < 0.20 poor; 0.21-0.40 fair; 0.41-0.60 moderate; 0.61-0.80 good; 0.81-1.00 very good (Altman, 1991)

Test-retest reliability

The calculated κ values showed moderate to good levels of agreement for the majority of the CANE items (Table 5). Test-retest reliability was good for domains of daily living on which possible problems and needs are explicit and clear, such as "deliberate

self-harm” (κ = 1.00), “self-care” (κ = 0.74), “drugs” (κ = 0.73) and “continence” (κ = 0.68) and only fair for less explicit and less well-defined problems in the areas of “information” (κ = 0.38) and “intimate relationships” (κ = 0.38). The CI’s of the κ values fell within an acceptable range (0–0.49) for 69% of the CANE items. In particular, CANE items with a small range of ratings had large CIs, such as “caring for another” and “alcohol” on which few needs were reported, and on the items “money”, “food”, and “household activities” on which most people reported met needs (see Figure 2).
Finally, ICC for test-retest reliability on the summary scores of the CANE ratings of the carers showed good to very good agreement: 0.78 (95% CI 0.66–0.86) for the total number of reported needs, 0.66 (95%, CI 0.50–0.78) for the number of *met* needs and 0.84 (95%, CI 0.75–0.90) for the number of *unmet* needs reported by informal carers.

Discussion

The aim of the study was to assess the validity and reliability of the Dutch version of the CANE in community-dwelling people with dementia and their informal carers.
Construct validity of the CANE in people with mild to severe dementia was very good. As expected not all correlations were significant due to the variation in reported needs. All correlations except one were convergent. The correlation between self-care and memory appeared to be divergent for people with dementia. A possible explanation for this is that as the disease progresses, insight into one’s situation decreases. Also, the assumption that correlations between items within a category were stronger than correlations between items of different categories was confirmed. Relatively, most correlations were found between items of the category “psychological, emotional and social needs”.
Construct validity of the CANE in informal carers was also very good. In comparison to the ratings of people with dementia, more significant inter-item correlations were found within the ratings of the informal carers. Only one divergent correlation was found. Relatively more inter-item correlations were found between items within the different categories.
The criterion validity of the CANE was also good. The correlations varied from small to large size, most correlations being small (< 0.30). The highest correlations (> 0.50) were found between criterion instruments/variables and the CANE items “self-care”, “psychotic symptoms”, “psychological distress”, “mobility” and “physical health”.
The study results further showed moderate to good test-retest reliability for the majority of the CANE items. The summary scores indicated good to very good test-retest reliability of the CANE as a whole. Use of the CANE among Dutch community-dwelling people with dementia and their carers is therefore supported by the results of this study. Overall, the study results showed acceptable construct and criterion validity and test-retest reliability of the CANE among Dutch informal carers of commu-

nity-dwelling people with dementia. The construct validity of the CANE was also acceptable among Dutch people with mild to severe dementia.

The CANE has been used to assess needs within different populations: people living in institutional settings (Martin *et al.*, 2002), people with mental health problems (Hancock *et al.*, 2003) and people with dementia in residential care (Hancock *et al.*, 2006).

The validity and reliability of the English and Spanish versions of the CANE have been studied previously among psychogeriatric populations by Reynolds *et al.* (2000) and Mateos *et al.* (2004) respectively, by interviewing service users, carers and care professionals. Both studies found highly acceptable psychometric properties of the instrument. Because Reynolds *et al.* (2000) and Mateos *et al.* (2004) found high test-retest reliability, we expected to find similar results. The κ values that were calculated in our study, however, were lower. This may be the result of a different study design. In our study a homogeneous group of informal carers of community-dwelling people with dementia was included, whereas Reynolds *et al.* (2000) and Mateos *et al.* (2004) studied general psychogeriatric groups and their carers. Because of its homogeneity, our study population had less variation in needs ratings. This low dispersal in scores leads to lower κ values and larger CIs for κ values. Another reason for the difference in κ values could be that the average period between the two interviews was two weeks, instead of the one-week interval in the study of Reynolds *et al.* (2000) and the seven to fifteen-day interval in the Spanish study (Mateos *et al.*, 2004). Finally, the different interview methods, face-to-face contact during the first interview and telephone contact during the second interview may also have caused a lower test-retest reliability.

The results of this study should be treated with some caution. Proportionally fewer people with severe dementia could be interviewed in comparison with the number of people with mild to moderate dementia included in the study. People at different stages of the disease will experience different needs. Some needs may therefore be underrepresented in our study while others will be overrepresented. Secondly, the interviews were conducted by trained graduate students, who were perhaps not experienced enough to recognize problems and therefore did not probe deeply enough or they misinterpreted answers. This could not be verified since inter-rater reliability was not determined. Care professionals from primary practice may be better able to administer the CANE owing to their experience.

Overall, based on this large study among community-dwelling people with dementia and their informal carers, the Dutch version of the CANE can be considered a valuable instrument to measure needs of people with dementia from different perspectives. The CANE covers a broad perspective of the domains of daily life and its ratings can be recorded in a systematic manner. This gives more insight into the experiences and needs of people with dementia and their carers. The systematic recording of data also provides the opportunity to discriminate met and unmet needs between, for example, different types and severity of dementia or different psychogeriatric populations. Besides that, the CANE is a very useful instrument for comparing different opinions, i.e. those of people with dementia, informal carers and professional carers.

It is very important to be aware of the different perspectives when planning suitable care. Since the number of people with dementia will double in the coming decades and with the prospect of paucity in care provision, care delivery should be optimized in terms of effectiveness and efficiency. It is therefore of great social relevance to identify needs accurately so that care can be attuned to individual demands. The CANE can contribute to this by enabling professionals to identify met and unmet needs in people with dementia and by assessing whether the offered care is adequate. In this sense, the CANE could contribute to the well-being of people with dementia and their carers.

Future epidemiological research with the CANE is recommended to gain insight into needs and service use on a national and international level and within different subgroups of people with dementia and their informal carers.

Future studies on the psychometric properties of the CANE should also focus on its responsiveness. Only two intervention studies have used the CANE as an outcome measure (Ashaye *et al.*, 2003; Orrell *et al.*, 2007). Both studies showed that the number of unmet needs was reduced after the intervention period, but no significant differences were found between the number of unmet needs in the experimental or control group. Orrell *et al.* (2007) found a tendency for a reduction in the number of unmet needs in their intervention group, particularly in the areas of eyesight/hearing, mobility, drugs and psychological distress. Further study into the responsiveness of the CANE is necessary to determine whether the CANE is a useful instrument to investigate the effectiveness of interventions on needs of people with dementia.

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CHAPTER 5

Finding the service you need: human centered design of a Digital Interactive Social Chart in DEMentia care (DEM-DISC)

Van der Roest, H. G., Meiland, F. J. M., Haaker, T., Reitsma, E., Wils, H., Jonker, C. and Dröes, R. M. (2008). Finding the service you need: human centered design of a Digital Interactive Social Chart in DEMentia care (DEM-DISC). *Studies in Health Technology and Informatics*, 137, 210-224.

Abstract

Community-dwelling people with dementia and their informal carers experience a lot of problems. In the course of the disease process people with dementia become more dependent on others and professional help is often necessary. Many informal carers and people with dementia experience unmet needs with regard to information on the disease and on the available care and welfare offer, therefore they tend not to utilize the broad spectrum of available care and welfare services. This can have very negative consequences like unsafe situations, social isolation of the person with dementia and overburden of informal carers with consequent increased risk of illness for them.

The development of a DEMentia-specific Digital Interactive Social Chart (DEM-DISC) may counteract these problems. DEM-DISC is a demand-oriented website for people with dementia and their carers, which is easy, accessible and provides users with customized information on healthcare and welfare services.

DEM-DISC is developed according to the human entered design principles, this means that people with dementia, informal carers and healthcare professionals were involved throughout the development process.

This paper describes the development of DEM-DISC from four perspectives, a domain-specific content perspective, an ICT perspective, a user perspective and an organizational perspective. The aims and most important results from each perspective will be discussed. It is concluded that the human-centred design was a valuable method for the development of the DEM-DISC.

Introduction

The FReeband User eXperience (FRUX) project is part of the Freeband Communication program, which aims to generate public knowledge in advanced telecommunication (technology and applications). The focus of the FRUX project is to design ICT services and service bundles, in particular in the healthcare and safety domain. The objective is to improve our understanding of how to design ICT bundles that a) really matter to end users and b) are profitable for service providers and their partners and suppliers. The aim of the Health Care pilot within the FRUX project is to investigate and develop new innovative services to support elderly people with dementia who live in the community, their informal carers (family and friends that care for the patient) and professional carers.

People with dementia and their carers are experiencing a lot of problems as a consequence of the illness. The needs of people with dementia change and often increase in number during the process of the disease. Whereas in the early stages of the dementia it can be sufficient to support memory, in severe stages of the dementia full support on daily functioning is often needed. People with dementia are often assisted by caring family members and to a lesser extent by professional carers.

Innovative technology may play an important role in the field of care and support for persons with dementia and their carers as the field of dementia care faces a number of problems now and in the near future. These problems include, in the first place, the variation, fragmentation and continuous changing of care and welfare services in a region. Clients and referrers experience difficulties finding the services they need and therefore tend not to utilize the broad spectrum of available services. Possible consequences are: not receiving the specific care and support one needs, unsafe situations, social isolation of patients and frustration, overburden and illness of carers. Thus, the need for a more transparent, easily accessible and integrated offer of healthcare and welfare services is growing.

Another problem (or challenge) is the generally recognized need to create a continuum of flexible care and welfare bundles in every region in the Netherlands that dynamically meets the care needs and wishes of individual persons with dementia and their informal carers in the different stages of the disease. Understanding the gaps in the present offer, requires insight into the care needs and wishes of this client group and their informal carers, as well as an up-to-date overview of regional (and national) services. Recently, a first step was taken to collect this type of information in the

Netherlands: a National Dementia Program (NDP) was developed which describes needs of the target group and examples of potential care offerings (Meerveld *et al.*, 2004). The aim of the NDP is to bring relevant care and welfare providers together, to signal problems in dementia care on a regional level and to make up solutions for these problems.

The addressed problems in the field of dementia care may be counteracted by a Digital Interactive Social Chart for DEMentia care (DEM-DISC). The DEM-DISC will be a demand-oriented site for people with dementia and their carers, that is easy to use, easy accessible, and that contains customized information on national and regional healthcare and welfare services. From a recent state of the art review of ICT services, we know that there is no such proven effective ICT service in this field (Lauriks *et al.*, 2007). The existing social charts are typically quite static, generic, and often provide incomplete lists of addresses. The DEM-DISC operates at three levels:

- At a *micro level* to support with information advice in a user-friendly and context-sensitive manner, by providing bundles of services (if relevant), thus counteracting the negative consequences of the fragmentation of services and to help people stay in their own home for a longer period of time with adequate services.
- At a *meso level* by stimulating the collaboration between care and welfare services and by detecting gaps in the continuum of services in a region.
- And at a *macro level* by helping people with dementia to stay in their homes for a longer time, DEM-DISC will contribute to a delay of nursing home admission and consequently to a reduction in healthcare expenditure (Dröes *et al.,* 2005).

DEM-DISC is developed from four different perspectives: a domain-specific content perspective (needs, offerings, information and advice), an ICT perspective (knowledge management and application), a user perspective (people with dementia, informal and professional carers) and an organizational perspective (necessary collaboration, governance and control, business modelling) (Dröes *et al.,* 2005). The aims and most important questions from each perspective will be discussed.

Domain-specific content perspective: DEM-DISC aims to recognize specific needs of patients with dementia and informal carers and therefore will contain an elaborated set of needs, formulated in the words of potential users (patients, informal carers and professional referrers). To be able to compile this dataset and to inform users about available services tailored to their needs and personal situation, the following questions have to be answered:

1. What are the needs of community-dwelling people with dementia and their informal carers and how do they formulate their needs?
2. Which care and welfare services are available to fulfil those needs?
3. Which characteristics of the patient, carer or care situation are related to preferences for using specific services?

ICT perspective: DEM-DISC aims to be accessible, anytime and everywhere and to provide the answers to needs by offering customized information on the available care and welfare services. This means that DEM-DISC should be available by the internet and should be able to connect specific service bundle(s) to specific (complex) needs that are expressed by users. The most important questions with respect to the ICT perspective are:

1. How can DEM-DISC be designed as a web application (requirements, technology) and what requirements are needed for the user interface when used by people with dementia and/or carers?
2. How can relevant context information be gathered in DEM-DISC?
3. How can user needs, context information and available services be matched in the system?

User perspective: From the perspective of the person with dementia and the informal carer, it is important that DEM-DISC provides them with information in a user-friendly manner, that it supports carers in their task and that it gives users insight into the available care and welfare offer according to their needs. The main questions here are:

1. Do users find and use the information they search for in DEM-DISC and is this information perceived as understandable, useful, up-to-date and sufficiently customized?
2. Does DEM-DISC have an impact in the daily lives of the people with dementia and their informal carers? Does it contribute to their quality of life, does it reduce the number of experienced unmet needs and does it alleviate the care giving task and burden?

Organizational perspective: A viable exploitation of DEM-DISC in the future requires extensive collaboration and coordination between care and welfare organizations that participate in DEM-DISC. A business model needs to be developed that describes how organizations can cooperate and how legal boundaries and financial arrangements can be taken into account in DEM-DISC. The most important questions for the organizational perspective of DEM-DISC are:

1. What is the impact of health specific legislation and current organizational and financial arrangements on the options for business models and service bundling?
2. Is it possible to link DEM-DISC with actual service delivery in the future (digital shop for care and welfare services)?
3. What viable business models exist for DEM-DISC?

Method

A human-centred design was used to develop DEM-DISC. Common practice when using this method is to involve potential users or domain experts in the developmental process for obtaining user requirements and to evaluate and adapt the technology in small-scale tests or a pilot study with potential users. Different methods were used to collect information for the development of a user-friendly and useful DEM-DISC. A similar approach was used by Sixsmith *et al.* (2007) to develop a technology wish list to enhance the quality of life of people with dementia.

The FRUX Health Care Pilot has been approved by the medical ethical committee of the VU University medical centre.

Domain-specific content perspective

In order to gain more knowledge about the needs of people with dementia a systematic literature review was accomplished (Van der Roest *et al.,* 2007a) and a large scale survey on (unmet) needs in dementia among 236 community-dwelling people with dementia and 322 informal carers (Van der Roest *et al.,* 2007b; Van der Roest *et al.,* in press). Background characteristics were inventoried and met and unmet needs of the people with dementia as expressed by themselves and by their informal carers. Descriptive analyses were performed and correlations between needs and background characteristics of people with dementia and informal carers were investigated.

For the formulation of the needs, wants and demands in DEM-DISC, the National Dementia Program (NDP) was utilized. The NDP describes fourteen problem areas in dementia as formulated by informal carers (Meerveld *et al.,* 2004). For our project we focused on five NDP areas. The needs that were inventoried in the large scale survey (Van der Roest *et al.,* 2007b; Van der Roest *et al.,* 2009) were transformed according to the wordings of the NDP problem areas in order to make them recognizable for the users (informal carers). In DEM-DISC users can access a question tree that leads from needs to wants to concrete demands, in order to arrive at the specific demand description that expressed their felt need best (see Figure 1). Three healthcare professionals were asked to criticize the used terminology during interviews in which the descriptions of needs were presented.

To build up a comprehensive, up-to-date dataset on offerings for DEM-DISC, the available care and welfare offer for people with dementia and carers in two districts in Amsterdam (Amsterdam Zuid and Amsterdam Zuideramstel) was inventoried. Data were restricted to the five need areas that were selected from the NDP. This information was collected by consulting paper guides, brochures, information on the internet and by interviewing three healthcare and welfare professionals working in the region. To enable DEM-DISC to provide customized information, service features with regard to product, personnel, price, place and promotion, according to the marketing model of Kotler (1980) were inventoried.
To relate user characteristics to care needs, data from the large scale survey were analyzed.

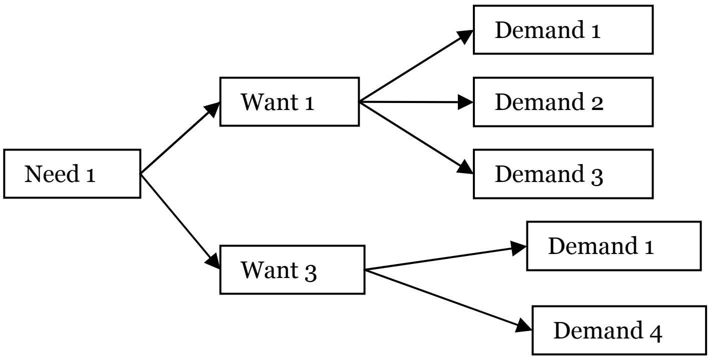

Figure 1. Question structure in DEM-DISC: Needs, wants and demands

ICT perspective

To be able to produce service bundles in DEM-DISC that provide customized answers to expressed needs, a service ontology was developed based on earlier research on service bundling. The ontology selects services based on their outcomes (demand-driven), which is rather new in this field (Baida, 2006). A main advantage of ontologies is that they can be represented in a machine-interpretable form, so that software can use them to reason about a domain, in this case: about customer needs and available services. The validation of the ontology was an iterative process. Service bundles were generated with an algorithm that uses the underlying service ontology as basis and were evaluated by domain experts on two points, 1) whether the service bundle offers a good solution to the demand and 2) whether all suitable solutions (service bundles) were generated.

User perspective

Potential users and domain experts participated in different phases of the development process.

Phase 1: In a workshop with potential stakeholders, professional and informal carers and researchers, three groups discussed the user requirements of DEM-DISC (Hulstijn *et al.,* 2005). The informal carer perspective, person with dementia perspective and domain expert perspective were discussed in separate groups. Discussion points in these groups were: how people would pose the system questions? Does DEM-DISC have to give insight into earlier and/or future needs? How should care advice be presented in DEM-DISC and how will DEM-DISC remain appealing to users? Based on the requirements that were agreed upon, a first prototype of DEM-DISC was developed.

Phase 2: In a workshop with three healthcare professionals preliminary designs of the user interface and the expert interface were presented and discussed. The professionals were asked to evaluate the terminology used in DEM-DISC user interface and to give their opinion on the design of the expert interface.

Phase 3: A demonstrator of DEM-DISC was tested among five informal carers of people with dementia in a small-scale test (Meiland *et al.,* 2007). The informal carers were recruited from Meeting centres for people with dementia and informal carers and from the large survey on needs in dementia (Van der Roest *et al.,* 2007b; Van der Roest *et al.,* 2009). The duration of the tests was at maximum three hours, all tests took place at the Valerius clinic and during these tests an interviewer, an observer and a technician were present. All tests started with an inventory of background characteristics of the informal carer and the person with dementia he or she cared for. Subsequently participants received a short introduction on DEM-DISC and were invited to explore the DEM-DISC website. Then participants were asked to perform a maximum of five tasks (this number depended on the computer skills of the individual participant and the time it took to fulfil the tasks) (see Figure 2). A task consisted of trying to find a satisfactory solution for a specific need by using DEM-DISC. After each task questions were asked (how did they accomplish the task, opinion on usefulness of the provided solution and user friendliness of the system) and observations were reported on. To record system reactions and to log all actions of participants a specific logging tool was used (TUMCAT: Vermeeren and Kort,

Figure 2. Setting small-scale test

2006). The tests ended with a questionnaire conducted by the researcher on usefulness and user friendliness of DEM-DISC and questions regarding the input and acceptability of entering personal information into the system. To evaluate the first demonstrator of DEM-DISC descriptive and qualitative analyses were performed. Based on the results of the small-scale tests, DEM-DISC was further improved.

Phase 4: The improved DEM-DISC demonstrator was evaluated by three healthcare professionals. During separate sessions the professionals were introduced to DEM-DISC and were invited to explore the site (user interface). During the sessions the professionals were asked to think out loud and to give their comments on the user interface (user friendliness and usefulness) and the content. During all sessions two researchers and a technician were present. Some of the problems mentioned by the professionals during the sessions were solved immediately by the technician. All comments were written down and discussed afterwards with the technical developer and the researchers.

Phase 5: During the further development the researchers, domain experts, performed several tests on DEM-DISC themselves. During these tests problems regarding the user friendliness or usefulness of both the user interface and expert interface, the content and the ontology were identified and discussed with the technical developers in order to improve DEM-DISC from an end-user point of view. The researchers were also responsible for the content of DEM-DISC. Issues with regard to updating information and modifying DEM-DISC were discussed with the developers throughout the whole process.

Organizational perspective

There are numerous potential stakeholders for DEM-DISC. To study what business model is preferred to exploit DEM-DISC, 14 stakeholder representatives with different backgrounds were interviewed (Moen, 2006; De Vos *et al.,* 2007; De Vos *et al.,* 2008). The organizations involved were care providing organizations (n = 6), governmental organizations (n = 3), an insurance company (n = 1) and interest groups (n = 2). Five alternative business models were developed and presented to the representatives (see Table 1). In two series of interviews and workshops they were asked amongst other things for their opinion on these models, on the perceived added value of DEM-DISC for users and on potential benefits for their organization.

Table 1. Alternative business models for DEM-DISC (De Vos *et al.*, 2008)

BUSINESS MODEL	PROVIDER	USER	DESCRIPTION
Commercial model	Commercial party	General public	All providers are allowed to provide information on their services, a quality standard should be applied. Exploitation cost could be covered by revenues from sponsors and advertisers.
Community model	Patient or informal carer community	General public	The community will be an important provider of information on dementia and specific care and support alternatives, as well as care providers that meet specific quality standards. The quality of information is important.
Government model	Governmental institution	General public	The aim is to create transparency and enhance competition between service providers. The quality of provided information can not be guaranteed.
Provider model	Group of care providers	General public	Services of network partners and complementary ones will be provided.
Insurer model	Insurance company	Own customers	Services provided are likely to be biased or limited, for the preference of the insurance company.

Results

Domain-specific content perspective

In the study on needs, most experienced unmet needs by people with dementia and their informal carers were in the domains of memory, information, social company, psychological distress and daytime activities (Van der Roest *et al.,* 2007b; Van der Roest *et al.,* 2009). The five problem areas of the NDP that match with these needs were specified in seven general questions in DEM-DISC (the problem area 'What is the problem and what can help' was specified in three sub questions, see Table 2). By choosing one of the questions at the start, users are helped to specify the need. The architecture of the question tree in DEM-DISC is build in such a way that users are guided from general needs to more specific wants or concrete demands (see Figure 1). The relevant information on available care and welfare services for the two districts in Amsterdam (Amsterdam Zuid and Zuideramstel) was added into the database of DEM-DISC and finally services were matched to the relevant demands, according to the ontology.

Table 2. Selected need domains and terminology for DEM-DISC

NDP DOMAIN	**TERMINOLOGY IN DEM-DISC**
Feeling that something is wrong, sense of unease	– I want to get rid of the feeling that something is off
What is the problem and what can help	– I would like to know what is going on – I would like to know what can help for the person with dementia – I would like to know what can help for the informal carer
Having to face everything on your own	– I would like to know what can help, so that I am not on my own
Avoiding contacts	– I want help with maintaining social contacts
Can not cope anymore	– I want help, because I can not cope anymore

54 Services were filed in the demonstrator of DEM-DISC. All services were characterized by the following features: product, personnel, price, place and promotion (the 5 P's by Kotler (1980)).

To enable DEM-DISC to generate customized and tailored advices several background and context characteristics of people with dementia and informal carers were related to the (number of) experienced needs by people with dementia and their informal carers, i.e. type and severity of dementia, living situation, carer-patient relationship, gender and age of informal carer and the subjective burden experienced by the informal carer (Van der Roest *et al.,* 2007b; Van der Roest *et al.,* 2009).

ICT perspective

The validation of the ontology with domain experts was an iterative process. The generated service bundles were presented to domain experts. If a proposed service bundle was judged negatively or if domain experts missed suitable service bundles, it was analyzed why this occurred. In all these cases the shortcomings were due to wrong modelling, inaccurate production rules (considering demands/resources while neglecting to consider their properties) or wrong modelled service dependencies. These defects were corrected and new service bundles were generated. After the third iteration all generated service bundles were seen as suitable solutions and all desired service bundles were generated (Baida, 2006).

User perspective

Workshops

During the workshop with possible stakeholders, professional and informal carers and researchers, several user requirements were advised. The main requirements and the implemented solutions were:

R1. The content should be general as well as personalized. Solution: A menu option to insert personal information was designed. With information on age, zip code, day or evening availability and whether transport is available, personalized information within DEM-DISC is generated.

R2. Keep the threshold for use as low as possible. Solution: DEM-DISC is designed as a web based application, with a simple interface and clear structure in which information can be found by a free search function or by a question tree.

R3. DEM-DISC should use existing databases. Solution: DEM-DISC refers to/links to information in existing systems, e.g. available websites of care and welfare organizations.

R4. Do not design just an information system, but support (online) contact between users (fellow sufferers, professional carers, support system). Currently this possibility is not developed for DEM-DISC.

The three healthcare professionals in the workshop on the user and expert interface brought up some questions/bottlenecks with regard to the expert interface in the future.

- Who will be the domain expert(s) that manages DEM-DISC? One person or several parties?
- Is every supplier allowed to store data in DEM-DISC? And what are the consequences for quality and uniformity of stored information?
- Who will guarantee the quality of the information? Does DEM-DISC require an independent person or organization that conducts this quality control?
- How exhaustive should information in DEM-DISC be? How will the information be described?

Small-scale test

During the small-scale test respondents' attitudes were not explicitly positive or negative toward the usefulness, user friendliness and satisfaction of DEM-DISC (Meiland *et al.,* 2007). Data from the small-scale test resulted in judgments and advice on adaptations of the interface. These were categorized in five aspects: system, functions, content, interaction and behaviour and design (see Table 3 for main results).

Table 3. Main conclusions of the small-scale test (Meiland *et al.*, 2007)

ASPECT	RECOMMENDATIONS
System	– develop a caching strategy
Functions	– improve the search function – improve given advices – add a personal page – add new functions
Content	– adapt terminology and present it to other readers – improve the introduction text on DEM-DISC as an information system – change the order of standard questions – provide complementary information on services by making links to the websites of these organizations available
Interaction and behaviour	– make the questioning process tangible – present services orderly
Design	– advices on font types – use more colours to make DEM-DISC appealing and user friendly – consider an introduction on each page – consider adding organization logos by the links to these organizations – improve the design of several pages

DEM-DISC was adapted according to the recommendations made in the small-scale test and the database was extended with more services. The adapted version was tested among professional carers. They mainly commented on the lay out (font size, colours, representation of service bundles). A starting page with an explanation on DEM-DISC was added to improve its user friendliness. DEM-DISC was also extended with a new function, i.e. regularly updated news items on dementia. This was positively judged by the professionals. As a consequence of the evaluation erroneous content was changed and unclear terminology was adapted.

In the course of the process the researchers tested the user interface and various adaptations were made on content, layout, interaction and functions. The researchers also acted as domain experts and tested the expert interface. Due to bugs in the system and to insufficient caching, the expert interface was unstable and parts of the database were lost. In the course of the development process the decision was made to use a basal and more reliable database to fill DEM-DISC, based on Excel. A user-friendly interface that could be used by domain experts in the future still has to be developed.

Organizational perspective

The consulted stakeholder representatives did not have a unanimous preference for one business model (Moen, 2006; De Vos *et al.,* 2007; De Vos *et al.,* 2008). During the interviews and workshops the community model and the governmental model were considered to be the most viable options to exploit DEM-DISC, the insurer model and the provider model were less preferred, whereas the commercial model was assessed as not viable at all. Commercial parties may have interests that conflict with that of DEM-DISC. The community model was favoured because patient or informal carer communities represent the interest of the patient and are independent, but the professionalism of these communities was doubted by the interviewed representatives. Because governments have a general interest in the well being of elderly people, this model was also favoured. However the expected focus on short term politics weakened the positive attitude.

The quality of provided information is seen as an important success factor for a business model by the interviewed stakeholders, but an acceptable distribution of roles is considered of less importance. The parties are more ambiguous in their opinions about acceptable distribution of profits and clear network strategies.

Description of the first prototype of DEM-DISC

The first prototype of DEM-DISC is available on the internet with Mozilla Firefox (FRUX, 2007). The user interface is kept simple with even colours and consists of three parts: On the left side the menu is situated, the main content of DEM-DISC is displayed in the middle of the page and on the right side a map of the Netherlands is presented and several dementia-related websites (see Figure 3). On the top of the page a search field is provided in which keywords can be entered. The DEM-DISC contains information on 229 care and welfare services in two districts in Amsterdam.

Hoe werkt de DementieWijzer?

De DementieWijzer helpt u gericht te zoeken naar antwoorden op uw vragen over de zorg voor mensen met dementie. Daarnaast biedt de DementieWijzer actueel nieuws rondom dementie en de mogelijkheid om door te linken naar interessante landelijke en regionale websites. U kunt zelf een regio kiezen door deze op het landkaartje rechts op het scherm aan te klikken.

Veel gestelde vragen

De DementieWijzer gaat uit van veel gestelde vragen. Wilt u bijvoorbeeld weten waar u terecht kunt voor hulp of hoe u in contact kan komen met anderen die in een vergelijkbare situatie zitten? Dan kan de DementieWijzer u helpen. Klik de voor u relevante vraag aan. DementieWijzer helpt uw vraag nader te specificeren.

Informatie op maat

Naast algemene informatie over uw regio kunt u ook informatie op maat krijgen, die aansluit bij uw persoonlijke situatie. Wilt u dit, klik dan in het menu op

Nationaal

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
Alzheimer Café
Een Alzheimer Café is een maandelijkse informele bijeenk...
Alzheimer Nederland
Alzheimer Nederland zet zich al ruim 20 jaar in voor mens...
Benjamin en de anderen
Een film over leven met dementie. Deze film rekent af met...
Breed Platform Verzekerden & Werk
Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 3. DEM-DISC homepage

Menu options

The menu contains six buttons: '*How does it work?*' (homepage), '*Frequently asked questions*', '*News*', '*Tailored information*', '*Helpdesk*', and '*Colophon*'.
'How does it work?'. This gives information on DEM-DISC, on how to search in DEM-DISC and how 'Tailored information' works.
'Frequently asked questions'. Seven general questions are presented to the user. In three steps users can specify their question or problem by going from a general need to a specific demand. For the selected demands relevant information on services is shown, including information on required resources (f.i. an care indication), required services, optional services and conflicting services. If relevant for a demand, it is possible to select preferences with regard to the service provision (internet, phone, group, individual conversation), information type (general, specialistic), location (own home, outside) and place (care facility, community centre, elsewhere).
'News'. This option provides regular updates on news with regard to dementia.
'Tailored information'. By logging into the system, users can enter their personal page. On this page information can be entered about both informal carer and the person with dementia on age, zip code, day or evening availability and whether transport is available. This input personalizes the information on the care and welfare offer that DEM-DISC provides to users.
'Helpdesk'. Contact information of the helpdesk is provided in this section in case users experience problems.

Map and websites

On the map the separate provinces of the Netherlands are displayed. By selecting a specific province, a list of websites that provide information on dementia, care, legislation and financial issues in that particular province is shown. National websites on these issues can also be selected. Links to the websites are opened by clicking on the titles.

Discussion

Using a human-centred design during the development process of DEM-DISC has proved its merit. The involvement of people with dementia, informal carers and healthcare professionals by means of interviews, workshops and test sessions provided a substantial amount of high quality information and input for DEM-DISC. Many research questions from the different perspectives could be satisfactorily answered.

Domain-specific content perspective

Interviewing a large group of community-dwelling people with dementia and informal carers provided insight into their needs and the way in which they express their needs. It also gave insight into which needs are related to personal characteristics. While people with dementia and their carers informed us on their needs, professional carers gave useful feedback on the proposed formulation of these needs in DEM-DISC and provided additional information on relevant care and welfare services. Altogether, this information enabled us to compose a comprehensive and realistic dataset of needs in dementia and available care and welfare services that enables DEM-DISC to provide users with customized information on the available services.

ICT perspective

Modelling user demands and services in the field of dementia care according to an algorithm based on a service ontology proved to be feasible for DEM-DISC (Baida, 2006). Using this ontology in DEM-DISC and making DEM-DISC available online, enables informal carers to judge if the presented customized service bundles actually meet their demands. The opinion of informal carers on the proposed service bundles and interface will be further evaluated within a pilot study in which, among other things, the user friendliness of the first prototype of the DEM-DISC will be evaluated. This pilot study is conducted in the period of December 2007 until March 2008.

User perspective

During the small-scale tests with informal carers and test sessions with professionals, a lot of information on user friendliness and usefulness of DEM-DISC was gathered. Although the informal carers that took part in the small-scale tests did not have an explicit positive or negative attitude towards the usefulness and user friendliness of the application, they gave many tips and comments on how to improve DEM-DISC. This resulted in the first prototype of DEM-DISC: A system that has a user-friendly interface and that contains a broad offer of services and is able to advise personalized bundle(s) of services for specific demands.

As mentioned before, this first prototype will be tested in the final stage of the FRUX project. DEM-DISC will be installed in the homes of informal carers and they will have the opportunity to use DEM-DISC for two months in their own environment. Besides the user friendliness and the usefulness, the impact on daily life will be investigated. Results of this study will be used for further development and valorisation of DEM-DISC.

Organizational perspective

The workshops and interviews with stakeholder representatives did not result in a unanimous preferred business model (Moen, 2006; De Vos *et al.,* 2007; De Vos *et al.,* 2008). Although most stakeholders preferred the community model, the governmental model was also evaluated positively. Whereas quality of information was highly valued by the stakeholders, it was considered most feasible to combine business models for DEM-DISC, like the government model and the provider model. A business model for DEM-DISC should be chosen very accurately, since for the well-being of the users it is highly important that all relevant parties cooperate and coordinate their services intensively, and no parties are excluded. The choice for a business model will also determine the requirements of the expert interface. For example, decisions on single or multiple entry points for information entry, authorizations and methods to obtain uniform and up-to-date information will partly depend on the selected business model.

Though the human-centred design offered DEM-DISC many benefits, we also experienced some disadvantages using this design strategy.
Using the human-centred design in developing ICT solutions for this target group of users proved very time consuming, because of the iterative process required and the involvement of users in different phases of the developmental process. For instance, the need survey took a year and the user and expert workshops as well as the recruitment of users for the small-scale tests also demanded quite a lot of organization time of the researchers. Unfortunately, due to time constraints of this three year project and delay in the technical development of DEM-DISC, we were therefore only able to do one small-scale test on the first demonstrator of DEM-DISC and were unable to test the more advanced version with users before the start of the final pilot study. The first prototype of DEM-DISC is designed to serve informal carers of people with dementia. The majority of them is aged above 55 years. Especially most of the elderly informal carers are currently not very experienced in computer use. From this point of view it was felt important to include many informal carers in the design process, in order to obtain a better understanding of the user friendliness and usefulness of DEM-DISC for this group. However, this proved difficult due to the nature of the target group: Although the majority of the approached informal carers supported the idea of DEM-DISC, only a few volunteered to participate in the project. The main reason was that many informal carers experienced high levels of burden, and had limited or no computer skills. Since the next generation of elderly will be more familiar with computers, this offers great potential for web based information systems, such as DEM-DISC, in the future and will make the application of human-centred design approaches easier.

The FRUX Health Care pilot ends in March 2008. The final results of the DEM-DISC pilot study will be published on the project website, http://www.freeband.nl, in international publications and on (inter)national congresses.

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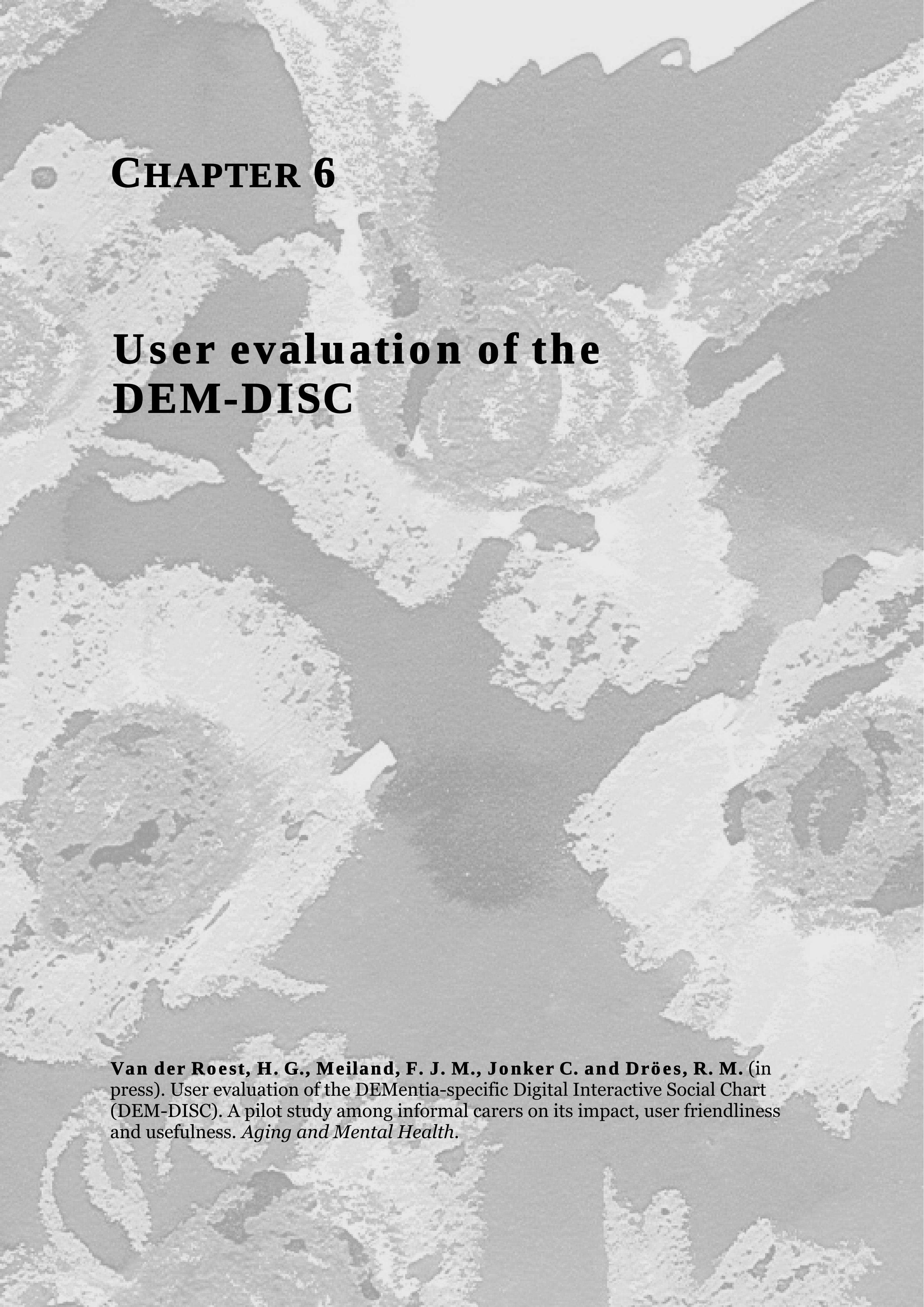

CHAPTER 6

User evaluation of the DEM-DISC

Van der Roest, H. G., Meiland, F. J. M., Jonker C. and Dröes, R. M. (in press). User evaluation of the DEMentia-specific Digital Interactive Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and usefulness. *Aging and Mental Health.*

Abstract

Objective: The need for information about the disease and coping with the consequences as well as on available care and welfare services, is frequently unmet in people with dementia and their carers. To provide carers of community-dwelling people with dementia with tailored information, the DEMentia-specific Dynamic Interactive Social Chart (DEM-DISC) was developed. User friendliness, usefulness and impact of a first prototype of DEM-DISC on the daily life of people with dementia and their carers were evaluated.

Method: DEM-DISC was tested among informal carers in a pretest-posttest control group design. Fourteen informal carers were provided with access to DEM-DISC in their own home during a two-month period. Fourteen controls did not have access to DEM-DISC. Data were collected by separate interviews with people with dementia and carers at pretest and posttest, by digital logging, by short telephone interviews and a bottleneck checklist during the intervention period.

Results: Though carers were not explicitly satisfied with this first prototype of DEM-DISC, they found DEM-DISC easy to learn and relatively user friendly and already after two months reported higher levels of competence than controls. People with dementia and informal carers in the DEM-DISC group also reported more *met* and less *unmet* needs.

Conclusion: The positive effects might be caused by the systematic and tailored individual way of information provisioning by DEM-DISC. Further development of DEM-DISC and randomized trials into the impact on patients and carers as well as the impact on nursing home admission and healthcare expenditure are worthwhile to investigate.

Introduction

The last decade research into the needs of people with dementia is receiving more and more attention. Research and practice prove that care and support needs that are a consequence of the disease are not always (being) met, despite the availability of care and welfare services that could meet those needs (Raivio *et al.*, 2007). Recent research shows that community-dwelling people with dementia as well as their informal carers especially report unmet needs (lack of support) on the domains of memory problems, information about care and welfare services, information about dementia symptoms, company, psychological distress, daytime activities, accidental self harm and eyesight and hearing (Edelman *et al.*, 2006; Miranda and Orrell, 2006; Van der Roest *et al.*, 2009). Informal carers also report unmet needs with regard to financial support, physiotherapy, transport and respite care for the person with dementia (Raivio *et al.*, 2007), and wish more information, coordination of care and emotional support (Peeters *et al.*, 2007). Due to the variation, fragmentation and continuous change of regional care and welfare services, clients and referrers have difficulty finding the appropriate service. They therefore tend to utilize only familiar and established services and do not utilize, or refer the client to the broader spectrum of available services. As a consequence needs will often remain unmet. Research also shows that informal carers are often dissatisfied with the professional services they receive. Poor perceived control over services and difficulty getting information about services are predictors of dissatisfaction (Raivio *et al.*, 2007). Another cause for unmet needs is that people simply are not willing to use particular services, because they consider them not attuned to their personal wishes.

As the number of people with dementia will double in the coming decades (Health Council of the Netherlands, 2002; Ferri et al., 2005) and as the amount of professional care is not expected to rise proportionally, the number of unmet needs will only increase in the future. To solve this problem, alternative solutions are needed besides the existing support of regular care and welfare services. Information communication technology (ICT) based devices, that assist and support people with dementia and their carers, could play an important role in the future. Various ICT services to support this target group in activities of daily living (Lauriks *et al.*, 2007; Wherton and Monk, 2008) and information provision (Finkel *et al.*, 2007; Lauriks *et al.*, 2007; Thompson *et al.*, 2007) have already been developed and have proven to be effective to a variable degree.

One of the solutions that may counteract the reported unmet need for information is a DEMentia-specific Digital Interactive Social Chart (DEM-DISC) (Dröes *et al.*, 2005). DEM-DISC is a demand-oriented web-based social chart for dementia care, which is easy accessible, anywhere and anytime. The system guides users in clarifying their experienced needs to specific demands, in a user-friendly way. Its final goal is to provide users with customized answers about potentially relevant care and support services in their region that may fulfil their needs. People with dementia, informal carers and professionals were involved in different stages of the development of DEM-DISC (Van der Roest *et al.*, 2008a).

In this article we report on the results of a study in which this first prototype of DEM-DISC was tested among informal carers of people with dementia. The study focused on the following questions:

1. Do informal carers experience DEM-DISC as user friendly?
2. Do informal carers judge DEM-DISC as useful?
3. Does using DEM-DISC have an impact on the daily life of people with dementia and their informal carers, more specifically on the care needs and care use of people with dementia and on the feelings of competence and self-efficacy of their carers?

Methods

Design

A controlled trial was conducted to study the effects of the use of DEM-DISC on the daily life of people with dementia and their carers. We used a pretest-posttest control group design with two groups. Measurements were carried out among people with dementia and carers: at baseline, before the introduction of DEM-DISC, and at posttest, approximately two months after baseline.

During the intervention period actions and opinions of carers from the experimental group on DEM-DISC were digitally logged and inventoried.

The study was approved by the Medical Ethical Committee of the VU University Medical Centre.

Intervention

Informal carers in the experimental group were able to use DEM-DISC via the internet on their personal computer in their own home for two months (Figure 1). Whenever they had questions about dementia or related needs or care and welfare services they could consult the system. The version of DEM-DISC under study could inform carers on a limited set of needs and demands that are especially relevant in the early stages of dementia: “Sensing that something is wrong”, “Seeking support for a specific problem”, “Having difficulties with coping”, “Having the feeling of facing everything alone”, and “Having difficulties finding company (for the person with dementia or themselves)” (Meerveld *et al.*, 2004). The information offered by DEM-DISC was further restricted to the available care and welfare offer in two specific districts of Amsterdam (Amsterdam Zuid and Amsterdam Zuideramstel). Besides specific information, DEM-DISC provided links to regional and national dementia-related websites and services and it offered news items on dementia-related topics (FRUX, 2008; Van der Roest et al., 2008a).

The control group had no access to the DEM-DISC website but had to find information about available care and welfare services as usual: Via the normal public channels such as printed guides, regional newspapers, internet, care consultants, etc.

During the experimental period, the carers from both the experimental and the control group were contacted by the researchers by telephone (twice and once respectively). The carers of the experimental group were asked whether they had used DEM-DISC and whether they had experienced any bottle-necks, while both the carers of the experimental and control group were asked whether they had experienced any problems finding the information they needed.

Hoe werkt de DementieWijzer?

De DementieWijzer helpt u gericht te zoeken naar antwoorden op uw vragen over de zorg voor mensen met dementie. Daarnaast biedt de DementieWijzer actueel nieuws rondom dementie en de mogelijkheid om door te linken naar interessante landelijke en regionale websites. U kunt zelf een regio kiezen door deze op het landkaartje rechts op het scherm aan te klikken.

Veel gestelde vragen

De DementieWijzer gaat uit van veel gestelde vragen. Wilt u bijvoorbeeld weten waar u terecht kunt voor hulp of hoe u in contact kan komen met anderen die in een vergelijkbare situatie zitten? Dan kan de DementieWijzer u helpen. Klik de voor u relevante vraag aan. DementieWijzer helpt uw vraag nader te specificeren.

Informatie op maat

Naast algemene informatie over uw regio kunt u ook informatie op maat krijgen, die aansluit bij uw persoonlijke situatie. Wilt u dit, klik dan in het menu op 'Informatie op maat'. Hier kunt u uw gebruikersnaam en inlogcode intypen.

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
Alzheimer Café
Een Alzheimer Café is een maandelijkse informele bijeenk...
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Alzheimer Nederland zet zich al ruim 20 jaar in voor mens...
Benjamin en de anderen
Een film over leven met dementie. Deze film rekent af met...
Breed Platform Verzekerden & Werk
Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 1. Screenshot homepage of DEM-DISC

Sample

The study was carried out among informal carers of people with dementia who live in Amsterdam. Carers were recruited through various care providing organizations: Via six Meeting Centres for people with dementia and their informal carers (Dröes *et al.*, 2004), three day care facilities, two memory clinics, a day clinic for frail, elderly people, a support organization for informal carers, two welfare organizations, 79 general practitioners in Amsterdam Zuid and Zuideramstel; visitors of one Alzheimer Café (Miesen, 2002) and the project Family Meetings (FaMe) (Van Hout and Joling, 2008). Finally, a public call for participation in the study was made via an article in a weekly door-to-door newspaper in Amsterdam.

Inclusion criteria for the carers were: Taking care of a person with dementia who lives in his or her own home at least four hours per week. Carers also had to (have) experience(d) problems in at least one of the selected problem areas on which this first prototype of DEM-DISC provided information (see Intervention). Additional inclusion criteria for informal carers in the experimental group were that they had to be familiar with computers and the internet and that they took care of a person with dementia who lived in the districts of Amsterdam selected for the study (Zuid or Zuideramstel). Fourteen informal carers agreed to participate in the experimental group and fifteen informal carers in the control group. Due to hospital admission, one carer of the control group dropped out. Finally, fourteen carers in the experimental group and fourteen carers in the control group were included in the effect analyses.

Instruments

Background characteristics

To inventory the personal and contextual characteristics of informal carers and people with dementia a background characteristics list was used. The Caregiver Management Style questionnaire (CMS) determined the caring style of the carer (De Vugt *et al.*, 2004). Carer well-being was measured with the Dutch version of the General Health Questionnaire 28 (GHQ-28: $\alpha = 0.93$: Goldberg and Hillier, 1979; Krol *et al.*, 1994) and the Centre for Epidemiologic Studies Depression scale (CES-D: $\alpha = 0.90$: Radloff, 1977; Beekman et al., 1994).

The occurrence of neuropsychiatric symptoms was measured by the Neuropsychiatric Inventory (NPI: $\alpha = 0.88$: Cummings *et al.*, 1994; Kat *et al.*, 2002). The Mini-Mental State Examination (MMSE; test-retest reliability: *Pearson r* = 0.98: Folstein *et al.*, 1975; Roth *et al.*, 1986) and the Global Deterioration Scale (GDS: $\alpha = 0.90$: Reisberg *et al.*, 1982; Muskens, 1993) were used to assess cognitive functioning. Type and severity of the dementia and MMSE score were retrieved in writing from a specialist or general practitioner. During the intervention period life events of the carer were registered.

Primary outcome measures

To study the impact of DEM-DISC use on daily life of people with dementia and their carers a needs assessment was carried out with the Camberwell Assessment of Need for the Elderly (CANE; test-retest reliability: *ICC* varies between 0.84 and 0.66: Reynolds *et al.*, 2000; Van der Roest *et al.*, 2008b). Actual care and welfare use was measured with the Use of services list (Dröes *et al.*, 2003). The Short Sense of Competence Questionnaire (SSCQ: $\alpha = 0.76$: Vernooij-Dassen *et al.*, 1999) was conducted to measure the burden experienced by informal carers. The Pearlin Mastery Scale (PMS: $\alpha = 0.69$: Pearlin and Schooler, 1978) was administered to detect changes in carers' perceived self-efficacy.

Secondary outcome measures

Some measures were included for exploration, since the intervention period was expected to be too short to result in significant effects. Quality of life was measured with the Quality of Life Alzheimer's Disease scale (QoL-AD: $\alpha = 0.82$: Thorgrimsen *et al.*, 2003). A questionnaire on knowledge about care and welfare services was administered as well as a questionnaire on methods used by informal carers to collect information about the available care and welfare services.

Use and user experience of DEM-DISC

The user friendliness and the usefulness of, and the satisfaction with DEM-DISC were measured by the USE Questionnaire (USE: Lund, 2001) at posttest. This questionnaire is specifically developed to assess subjective reactions to the usability of a product or application in the ICT-field. The questionnaire contains four components, 'usefulness', 'ease of use', 'ease of learning', and 'satisfaction'. Questions are scored on a five-point scale (1 to 5). Low scores express positive reactions, whereas high scores indicate negative reactions towards the application. In situ measurements were performed with a Testbed for User experience for Mobile Context-Aware applicaTions (TUMCAT) (Vermeeren and Kort, 2006; TNO, 2007). TUMCAT logged the actions of users during the experimental period and prompted preconfigured fixed experience samples, f.i. on satisfaction on advice given by DEM-DISC). Informal carers were also asked to keep a problems checklist in case they experienced specific difficulties using DEM-DISC. During the intervention period all respondents were asked by telephone whether they had met any problems with the care of their relative. Respondents in the experimental group were also asked whether they had used DEM-DISC and had experienced any problems with it.

Procedure

Informal carers that were known to the participating care and welfare organizations and met the general inclusion criteria were identified and informed about the study in writing and verbally. Brochures about the study were also distributed by the participating organizations. Interested informal carers contacted the researchers and received verbal information about the study. Written consent was obtained from all people included in the study.

Informal carers were assigned to the experimental or control group depending on their computer and internet skills and on the living area of the person with dementia they cared for.

In the period from November 2007 until April 2008, carers and people with dementia were interviewed separately in their own homes by trained interviewers (graduate students psychology, health sciences and medicine) at baseline and two months after baseline. After the baseline interview, DEM-DISC and TUMCAT were installed on the personal computers of carers in the experimental group. They received a short explanation of DEM-DISC and a simple manual. If carers experienced any problems with DEM-DISC they could contact the researchers by phone or email and they were asked to complete the problems checklist. During the intervention period all informal carers in the study were contacted by telephone by the researchers to inventory bottlenecks in using DEM-DISC and/or in the process of information collection.

Analysis

SPSS 14.0 (2006) was used to analyze the data. Descriptive statistics were used to analyze respondents' characteristics and DEM-DISC use (frequency, duration, strategies and experiences). To test for differences between the experimental and control group, two-sided Chi-square tests, Mann-Whitney U tests and t-tests were conducted on the baseline data ($p < 0.05$). To study the effects of DEM-DISC use on the outcome measures, univariate covariance analyses (ANCOVAs) were conducted on the posttest data, while baseline data were included as covariates. This strategy of analysis is advised in small samples (Cole, 1988). Spearman rank correlation coefficients, one way analysis of variance (ANOVA), Mann-Whitney U tests and Kruskal-Wallis H tests between respondents background characteristics and the outcome measures at baseline were conducted to decide which variables should be included in the ANCOVAs as potential confounders. We used one-tailed tests with $\alpha \leq 0.05$. Levene's tests of equality of error variances were performed to test for homogeneity. Furthermore, effect sizes were calculated for the effect variables, according to Cohen (1988): Small effect $d = 0.2$, moderate effect $d = 0.5$, large effect $d \geq 0.8$.

Wilcoxon signed ranks tests and Mann-Whitney U tests were used to analyze results on the methods respondents used for collecting information about available care and welfare services. Descriptive statistics were used to analyze data on the use, usefulness and user friendliness of DEM-DISC.

Qualitative data about experienced problems with DEM-DISC and bottlenecks, collected via the problems checklist, additional remarks on experience samples and opinions on DEM-DISC, were summarized and described.

Results

Sample characteristics and potential confounders

The experimental group consisted of fourteen informal carers. Twelve people with dementia whom they cared for participated in the baseline interview and nine people with dementia participated in the posttest interview. In the control group fourteen informal carers and eleven persons with dementia were interviewed at pretest and posttest.

The sociodemographic characteristics of the respondents are described in Table 1. No differences were found between the age, level of education, carer strategy and well-being of the informal cares in the DEM-DISC and the control group. Also no differences were found for the age, type and severity of dementia, cognitive impairment and psychiatric symptoms of people with dementia in the DEM-DISC and control group. Chi-square tests show that as compared to the control group more people with dementia in the experimental group were female (78.6%; $X^2_{(1)} = 7.04$, $p = 0.01$) and fewer informal carers were spouses of the person with dementia (14.3%; $X^2_{(2)} = 7.66$, $p = 0.02$). Informal carers in the experimental group reported spending less care hours per week ($m = 18.86$, $SD = 27.97$) than carers in the control group ($m = 80.29$, $SD = 70.53$; $U = 39.00$, $p = 0.01$). To prevent these differences between the groups from confounding the outcomes, we included the gender of the person with dementia and the relationship between the carer and the person with dementia as potential confounding variables in all ANCOVAs. Since a strong relationship was found between the number of informal care hours and the type of relationship carers have with the person with dementia ($X^2_{(2)} = 14.22$, $p = 0.00$), we decided to include only the type of relationship as a potential confounder in the analyses.

Additionally we assumed that the amount of professional care and support people received at baseline could influence (some of) the outcome measures. Significant correlations between the number of used services and total number of needs ($r = 0.47$, $p = 0.02$) and number of met needs as reported by people with dementia ($r = 0.52$, $p = 0.01$), quality of life as reported by the carer ($r = -0.41$, $p = 0.04$) and knowledge about care and welfare services ($r = 0.43$, $p = 0.02$) confirmed an interrelationship between these variables. The number of services people used was therefore also included as a potential confounding variable in all ANCOVAs.

Finally, type of dementia was included as a potential confounder in the analyses of the reported needs by people with dementia, because type of dementia was significantly related to the total number of needs ($F_{(3)} = 9.84$, $p = 0.00$); the number of unmet needs ($F_{(3)} = 5.38$, $p = 0.01$); and the number of met needs ($F_{(3)} = 7.88$, $p = 0.00$).

Table 1. Sociodemographic characteristics of respondents

Informal carer characteristics	Experimental group (n = 14)	Control group (n = 14)	Test statistic
Male	5 (35.7%)	1 (7.1%)	$X^2_{(1)} = 3.39, p = 0.06$
Female	9 (64.3%)	13 (92.9%)	
Age	60.2 (*SD* = 14.3)	69.9 (*SD* = 13.2)	$t_{(26)} = 1.87, p = 0.07$
Spouse	2 (14.3%)	9 (64.3%)	**$X^2_{(2)} = 7.66, p = 0.02$**
Child	9 (64.3%)	3 (21.4%)	
Others	3 (21.4%)	2 (14.3%)	
High level of education	11 (78.6%)	8 (57.1%)	$X^2_{(1)} = 1.47, p = 0.22$
Low level of education	3 (21.4%)	6 (42.9%)	
Caring strategy	7 (50.0%)	6 (42.9%)	$X^2_{(2)} = 0.37, p = 0.83$
Supporting strategy	5 (35.8%)	7 (50.0%)	
Confronting strategy	1 (7.1%)	1 (7.1%)	
Missing	1 (7.1%)	-	
Number of care hours per week	18.9 (*SD* = 28.0)	80.3 (*SD* = 70.5)	**$U = 39.00, p = 0.01$**
GHQ-28	6.3 (*SD* = 8.1)	5.6 (*SD* = 4.7)	$U = 89.50, p = 0.69$
CES-D	8.5 (*SD* = 10.1)	8.6 (*SD* = 6.3)	$t_{(26)} = 0.04, p = 0.96$
Person with dementia characteristics			
Male	3 (21.4%)	10 (71.4%)	**$X^2_{(1)} = 7.04, p = 0.01$**
Female	11 (78.6%)	4 (28.6%)	
Age	83.3 (*SD* = 6.2)	80.6 (*SD* = 4.4)	$t_{(1)} = -1.34, p = 0.19$
Alzheimer's Disease (AD)	7 (50.0%)	8 (57.1%)	$X^2_{(3)} = 3.37, p = 0.34$
Vascular dementia (VD)	1 (7.2%)	2 (14.3%)	
Mixed dementia (MD)	3 (21.4%)	3 (21.4%)	
Other type of dementia	3 (21.4%)	0 (0.0%)	
Missing	-	1 (7.2%)	
GDS 0 - 2	3 (21.4%)	2 (14.3%)	$X^2_{(2)} = 0.42, p = 0.81$
GDS 3 - 4	9 (64.3%)	8 (57.1%)	
GDS 5 - 6	2 (14.3%)	3 (21.4%)	
Missing	-	1 (7.2%)	
MMSE score	19.4 (*SD* = 6.2)	20.0 (*SD* = 7.7)	$t_{(24)} = 0.22, p = 0.82$
NPI	21.9 (*SD* = 18.2)	17.4 (*SD* = 18.6)	$t_{(1)} = -0.66, p = 0.52$

Significant differences in bold.
Abbreviations: GHQ-28: General Health Questionnaire 28 (Goldberg and Hillier, 1979); CES-D: Centre for Epidemiologic Studies Depression scale (Beekman *et al.*, 1994); GDS: Global Deterioration Scale (Reisberg *et al.*, 1982); MMSE: Mini-Mental State Examination (Folstein *et al.*, 1975); NPI: Neuropsychiatric Inventory (Cummings *et al.*, 1994).

Primary outcome measures

Table 2 contains all mean scores and standard deviations of the outcome measures at pretest and posttest. Levene's tests showed no homogeneity for the total number of needs as reported by people with dementia and for the consumed amount of professional care per week. Therefore these values were log-transformed before conducting the ANCOVAs.

The results show significant large effects on the following primary outcome measures between the two groups at posttest: The number of *met* needs as reported by people with dementia ($F_{(1)} = 3.26$, $p = 0.05$) and the carers ($F_{(1)} = 9.93$, $p = 0.00$), the number of *unmet* needs as reported by people with dementia ($F_{(1)} = 3.93$, $p = 0.03$) and by carers ($F_{(1)} = 2.97$, $p = 0.05$) and the feeling of competence of carers ($F_{(1)} = 4.11$, $p = 0.03$). Taking differences at pretest into account, people with dementia and informal carers in the experimental group reported more *met* needs at posttest than respondents in the control group ($d = 1.20$ and $d = 1.44$). Additionally, people with dementia and carers in the experimental group reported fewer *unmet* needs at posttest than respondents in the control group ($d = -1.31$ and $d = -0.80$ respectively). Besides these positive effects on needs, carers in the experimental group reported a higher feeling of competence than carers in the control group after the intervention ($d = 0.93$). No effects were found on the other outcome measures, i.e. total number of needs as reported by carers and by people with dementia, self-efficacy of carers, number of services used and amount of received professional care per week (see Table 2).

Since three people with dementia in the experimental group were admitted to a nursing home in the course of the study, a final check was made for nursing home admission. When the variable nursing home admission at posttest was included in the ANCOVAs, this did not change the positive effects found for DEM-DISC use in the experimental group on met needs reported by people with dementia ($F_{(1)} = 3.26$, $p = 0.05$), unmet needs reported by people with dementia ($F_{(2)} = 3.92$, $p = 0.04$), met needs reported by informal carers ($F_{(1)} = 9.93$, $p = 0.02$), unmet needs reported by informal carers ($F_{(1)} = 2.97$, $p = 0.05$), and feeling of competence of informal carers ($F_{(1)} = 4.11$, $p = 0.03$). As potential confounding variables (gender and type of relationship with person with dementia, number of professional services, and type of dementia) were included as covariates in the analyses and no differences between the groups were found in life events of the carers during the intervention period ($X^2_{(1)} = 0.57$, $p = 0.45$), it can be assumed that these effects are indeed caused by DEM-DISC.

Secondary outcome measures

No effects were found on the secondary outcome measures: Quality of life and carer knowledge about care and welfare services (see Table 2).

Table 2. Results of ANCOVAs that were conducted on adjusted posttest scores (see text). Effect sizes (*d*) are reported for each outcome measure (significant effects in bold).

OUTCOME VARIABLES *(RANGE)*	***n***	**BASELINE**		**POSTTEST**		**ADJUSTED MEANS**		***F***	***p***	***d***
		***m*E (*SD*)**	***m*C (*SD*)**	***m*E (*SD*)**	***m*C (*SD*)**	***m*Eadj (se)**	***m*Cadj (se)**			
Total number of reported needs by people with dementia *(0 – 24)*[1]	18	7.92 (4.14)	5.18 (2.18)	7.13 (3.40)	5.27 (3.04)	0.74 (0.10)	0.76 (0.09)	$F_{1;18} = 0.02$	0.45	0.11
Number of reported met needs by people with dementia *(0 – 24)*	19	7.00 (3.33)	4.27 (1.42)*	7.13 (3.40)	4.91 (2.74)	7.61 (1.13)	4.56 (0.91)	$F_{1;18} = 3.26$	**0.05**	**1.20**
Number of reported unmet needs by people with dementia *(0 – 24)*	19	0.92 (1.65)	0.91 (1.22)	0.00 (0.00)	0.36 (0.67)	-0.11 (0.19)	0.45 (0.15)	$F_{1;18} = 3.93$	**0.04**	**1.31**
Total number of reported needs by carers *(0 – 24)*	28	12.64 (3.36)	10.07 (3.32)	11.29 (2.59)	10.00 (3.23)	11.31 (0.82)	9.97 (0.82)	$F_{1;27} = 1.09$	0.15	0.49
Number of reported met needs by carers *(0 – 24)*	28	8.79 (2.94)	8.43 (3.59)	10.29 (2.56)	8.00 (2.60)	10.67 (0.63)	7.62 (0.63)	$F_{1;27} = 9.93$	**0.00**	**1.44**
Number of reported unmet needs by carers *(0 – 24)*	28	3.86 (3.92)	1.64 (1.01)	1.00 (1.30)	2.00 (2.83)	0.63 (0.65)	2.37 (0.65)	$F_{1;27} = 2.97$	**0.05**	**0.80**
Feeling of competence carer *(0 – 7)*	28	4.79 (2.01)	4.64 (1.39)	5.86 (1.41)	4.36 (1.34)	5.69 (0.38)	4.52 (0.38)	$F_{1;27} = 4.11$	**0.03**	**0.93**
Self-efficacy of carer *(14 – 70)*	28	52.93 (8.10)	50.71 (9.08)	53.79 (6.75)	50.79 (9.85)	51.80 (1.54)	52.77 (1.54)	$F_{1;27} = 0.16$	0.34	0.19
Number of used care and welfare services *(0 – 36)*	28	4.79 (1.53)	3.79 (1.97)	3.64 (1.65)	3.50 (1.99)	3.49 (0.53)	3.65 (0.53)	$F_{1;27} = 0.04$	0.42	0.09
Amount of consumed professional care per week *(hours)*	24	23.08 (14.40)	12.15 (9.70)*	66.22 (67.99)	47.69 (64.93)	1.47 (0.14)	1.44 (0.18)	$F_{1;23} = 0.02$	0.45	0.06
Quality of life (reported by person with dementia) *(13 – 52)*	20	35.46 (7.08)	35.36 (5.54)	36.78 (5.40)	37.45 (5.15)	36.54 (1.56)	37.65 (1.35)	$F_{1;19} = 0.21$	0.33	0.31
Quality of life (reported by carer) *(13 – 52)*	27	29.00 (7.11)	30.43 (5.15)	29.85 (8.58)	32.57 (5.93)	30.16 (2.23)	32.28 (2.13)	$F_{1;26} = 0.40$	0.27	0.30
Knowledge about care and welfare *(0 – 10)*	28	5.36 (2.44)	3.64 (2.02)	6.29 (2.13)	4.14 (2.60)	5.70 (0.55)	4.73 (0.55)	$F_{1;27} = 1.28$	0.14	0.53

* $p < .05$

[1] Due to the log-transformation of the total number of needs as reported by people with dementia, one respondent was excluded from the ANCOVA. However, the outcomes did not differ from the ANCOVA performed with the original dataset and unequal error variance.

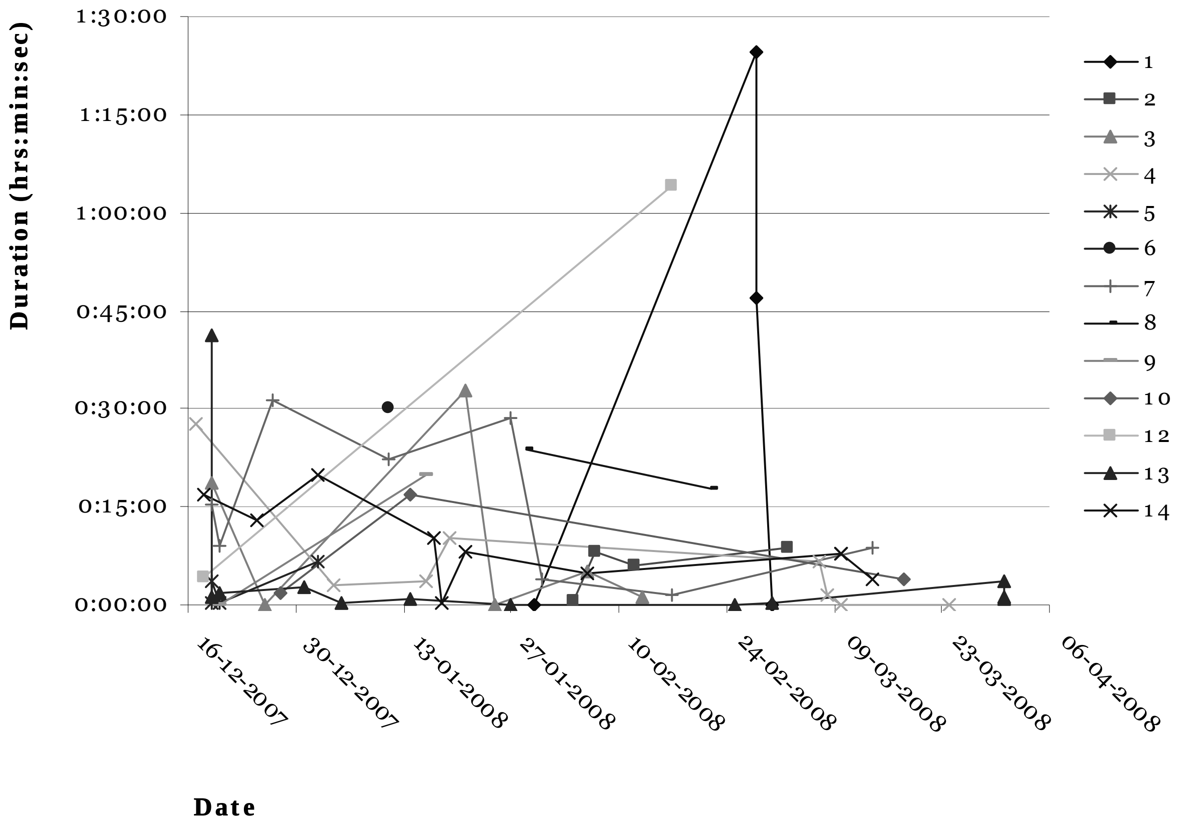


Figure 2. Frequency and duration of DEM-DISC use during the experimental period for each carer user

After the intervention, carers in the experimental group reported having obtained information more frequently from their general practitioner (*Z* = -2.16, *p* = 0.02) and their pharmacist (*Z* = -1.90, *p* = 0.03) than at pretest. At posttest informal carers in the experimental group also went to their general practitioner for information more frequently than carers in the control group (*U* = 51.50, p = 0.03), but they did not go more frequently to their pharmacist for information (*U* = 56.00, p = 0.06). At posttest carers who used DEM-DISC were more satisfied with the information they received from the hospital (*Z* = -2.06, *p* = 0.01) and the Centrum Indicatiestelling Zorg (CIZ: central organ that indicates the amount of care people are entitled to) (*Z* = -2.32, *p* = 0.00), but this did not differ from the satisfaction in the control group (hospital: *U* = 97.50, *p* = 0.98; CIZ: *U* = 73.50, *p* = 0.26).

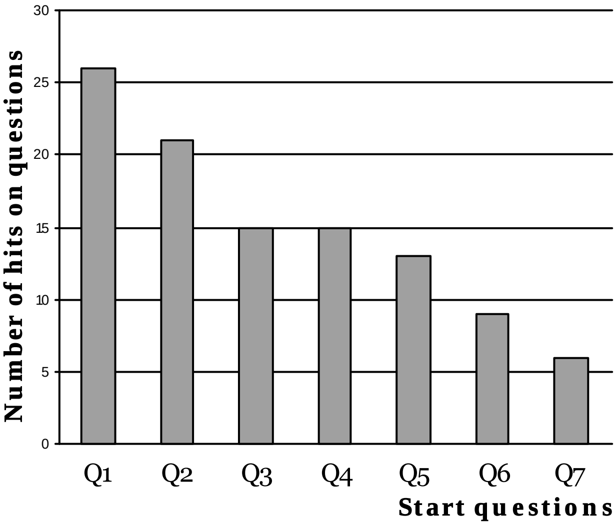
Use and user experience of DEM-DISC

Use of DEM-DISC

During the intervention period, the informal carers used DEM-DISC on average 5.14 times (*SD* = 3.32 times), the most active user consulted DEM-DISC fourteen times.

The mean duration of a session was 14:36 minutes (SD = 10:46 minutes), the shortest session ended immediately after opening the DEM-DISC page and the longest session lasted 1:24:35 hour. Figure 2 shows the frequency and the duration of DEM-DISC use over time for every single user. Women tend to use DEM-DISC less frequently, but in longer sessions than men. However, these differences were not statistically significant ($t_{(12)} = 1.89$, $p = 0.08$; $U = 9.00$, $p = 0.07$).

When consulting DEM-DISC for available care services, users were supported in specifying their questions in three steps. 105 times users started a search path, on 82 occasions (78.1%) users finished their search path and reached an answer to their question. The questions that were most frequently selected as a starting point in DEM-DISC were “Know more about the consequences of dementia” (26 times) and “Support for practical problems” (21 times). The least selected question was “Because of dementia your world gets smaller. How can you maintain social contact?” (six times). See Figure 3 for the frequency of selection of start questions.



Start questions

Q1:	Know more about the consequences of dementia?
Q2:	Support for practical problems?
Q3:	Know more about what can help with dementia?
Q4:	The suspicion exists that something is wrong. How can you get clarity?
Q5:	Support for overburden of the carer.
Q6:	Who is in control when decisions have to be made?
Q7:	Because of dementia your world gets smaller. How can you maintain social contacts?

Figure 3. Number of hits on the start questions

User experience of DEM-DISC

On the USE Questionnaire (Lund, 2001) informal carers judged DEM-DISC as easy to learn ($m = 1.75$, $SD = 0.69$) and relatively user friendly ($m = 2.52$, $SD = 1.19$). The carers’ mean opinion on the usefulness of DEM-DISC was neutral ($m = 3.33$, $SD = 1.09$): on a group level DEM-DISC did not explicitly support them to be more efficient and did not simplify their search for better services noteworthy. On a group level carers also gave neutral responses on questions about their satisfaction with DEM-DISC ($m = 2.99$, $SD = 0.91$), like “DEM-DISC is wonderful”, “I am satisfied with DEM-

DISC", and "DEM-DISC is fun to use". Female carers judged DEM-DISC as more useful (m = 2.99, SD = 1.02) than the male carers in the sample (m = 4.38, SD = 0.45) ($t_{(10)}$ = 2.23, p = 0.05).

During the telephone interviews, through the bottleneck list and with the experience samples carers in the control group expressed their opinion on the user friendliness of DEM-DISC. Most carers felt that DEM-DISC had a clear structure and was easy to use. Two of the fourteen carers reported difficulties navigating through DEM-DISC and experienced problems finding the relevant question that reflected their demand. Comments were also made on the amount of text people had to read, preferences were expressed to limit the amount of text. One carer sometimes unintentionally ended her DEM-DISC sessions, because she was not used to working with the Mozilla Firefox browser.

Despite their own experience with DEM-DISC, carers generally said that others probably would benefit from DEM-DISC. A general comment was that the content of DEM-DISC was not detailed enough: Users missed information on specific types of dementia, like Lewy Body dementia, one user even thought DEM-DISC was only aimed at Alzheimer's Disease. Carers said that this first prototype of DEM-DISC was only relevant for the beginning and mild stages of dementia. They also wanted to be informed more specifically about available care. The informal carers also asked for detailed, concrete procedural information on service provision, like an overview of contacts and procedures in case of crises, specific information about procedures and waiting lists for nursing home admission and how to contact a care organization effectively. Adding a direct link in DEM-DISC to case managers and information about finances was strongly recommended. One user commented she would prefer to find the complete service information in DEM-DISC, instead of being linked to the service page of the relevant organization.

Only one carer made a comment with regard to configuring personal information: After filling in the form the user did not notice that he was logged in and that his personal data were filed, for the system returned immediately to the home page after he pressed the 'adapt' button. This made him insecure about the successfulness of logging in, especially because he did not see any difference between general and personalized information. He therefore finally gave up his search action.

Although the carers were instructed that DEM-DISC was not complete, they searched for information outside the scope of DEM-DISC and obtained no answers to their questions. Therefore some carers reported that DEM-DISC was not particularly useful to them and that it contained little information. Some felt they received useful answers, one carer remarked that the information was useful, but too fragmented.

Log data on the experience samples show that, during the whole user period, carers were asked eighteen times whether they found an adequate answer to their question in DEM-DISC. 56% of these questions were answered by the carers. Ten times (70%) carers reported they had found a (partial) answer to their questions, for the remaining 30% of the questions carers reported they had not received a suitable answer. During the user period carers were asked 29 times about their satisfaction with DEM-DISC. For 46% of the answered questions carers said they were somewhat (31%) to very (15%) satisfied with DEM-DISC. 55% of the experience samples on satisfaction were not answered by the carers.

Discussion

In daily life, carers and people with dementia seemed to benefit from DEM-DISC: Even though DEM-DISC was not consulted very often by the informal carers, after the user period both carers and people with dementia in the experimental group reported more *met* needs and fewer *unmet* needs as compared to people with dementia and their carers in the control group who had no access to DEM-DISC. Carers in the DEM-DISC group also showed higher feelings of competence at posttest, and more often obtained information from their general practitioner and pharmacist after using DEM-DISC, as compared to the carers in the control group. These effects could not be explained by possible differences in gender of the people with dementia, relationship between the people with dementia and the carer, amount of professional care or outcome measures at base-line or nursing home admission, as these all were included in the ANCOVAs as covariates. No effects of using DEM-DISC were found on self-efficacy, quality of life and knowledge of the disease and care and support services.

Carers who used DEM-DISC for two months in their own home, evaluated DEM-DISC as relatively user friendly and easy to learn, few bottle-necks were reported. After the user period, on a group level carers were not explicitly positive nor negative about the usefulness of this version of DEM-DISC for their present situation, but they generally felt it could be useful for others caring for people with dementia.

The results of this study are promising. After only two months, the users of this first prototype of DEM-DISC fulfilled their care needs more effectively and as a consequence the number of unmet needs decreased. The results also indicate that DEM-DISC can reduce carer strain: after DEM-DISC use carers felt more competent than those who did not have access to DEM-DISC. Despite the large effect sizes, the results should be treated with some caution because of the research design (no randomization of groups) and the small sample size.

Although many information-providing social charts are available on the internet, their effects have not yet been studied (Lauriks *et al.*, 2007). The impact of technology used in carer intervention programs is studied more often since ICT is increasingly used in interventions nowadays. However only a few studies have been conducted on the impact of technology-based information and support interventions aimed exclusively at informal carers of people with dementia (Thompson *et al.*, 2007). Problems with quality of care in internet applications were found to be caused by insufficient tailoring of information to patients' needs and by efficiency problems, and thus do not reach their full potential (Kerr *et al.*, 2006; Nijland *et al.*, 2008). Evidence is found that technology can be effective in enhancing knowledge and can promote emotional well-being, but due to methodological limitations of many studies, these conclusions cannot be generalized to date (Schulz *et al.*, 2002).

The customized Computer-Telephone Integration System (CTIS) intervention is quite similar to our study on DEM-DISC (Finkel *et al.*, 2007). It also studied the effect of customized information provision on community services and dementia by computer technology. During a period of six months carers of people with dementia received information, partly through a digital information dataset, about dementia and community resources and received strategies to cope with issues like safety and social support (Finkel *et al.*, 2007). All carers in the experimental group benefited from the intervention and improvements were found for burden, depression and received social support. The outcomes of our study partly confirm the study results of Finkel *et al.* (2007).

DEM-DISC was evaluated by the users as user friendly and easy to learn and few bottle-necks were reported on, probably because of the simple interface. Carers' opinions on the usefulness of DEM-DISC were neither explicitly positive nor negative. Several reasons might explain this outcome: The carers could imagine the benefits for other carers, but they judged information in this first prototype of DEM-DISIC not detailed enough; the merit of tailored information was therefore not evident to them and some carers searched for information about problems and districts outside the scope of DEM-DISC. In other words, the restricted usefulness can be explained by the limited information in this first prototype of DEM-DISC. A second explanation can be found in the recruitment of the sample of informal carers. They were all quite experienced in caring for people with dementia, as the people they cared for had moderate to severe dementia. Carers in the experimental group therefore were already more aware of the available service offer. This first prototype of DEM-DISC focused more on the beginning and mild stages of dementia and the system therefore had no substantial added value for them. Furthermore, only services in two Amsterdam regions were included in DEM-DISC. Though all people with dementia in the experimental group lived in this area, some of their carers lived outside it and searched for services that could support them as a carer in their own neighbourhood.

These explanations of the judged restricted usefulness of the first prototype of DEM-DISC can be seen as limitations of this pilot study. Other important limitations of the study are the study design (quasi experimental and no randomized groups), its small sample size and the rather short user period, which prevented us from investigating the long-term impact of DEM-DISC use.

Because the results of DEM-DISC use are promising, it is worthwhile to develop the system further and study the effects in a randomized clinical trial on a larger scale and among carers of people in various stages of the disease. In future studies DEM-DISC use can be evaluated against two control conditions. In the experimental group participants can access DEM-DISC, the internet and other non-interactive sources of information. In the control conditions participants use non-interactive sources of information only (control group 1) or non-digital and internet-based information sources (control group 2). Since the average process of dementia is seven to ten years (Van der Flier and Scheltens, 2005), DEM-DISC should preferably be tested by carers for a longer period, with a minimum duration of six months. The delivery of tailored, customized information and adding extra functions, like a forum for carers, deserve more attention (Van der Roest *et al.*, 2008a). DEM-DISC should also be tested in different regions.

The focus of future studies should not only be on the merit of DEM-DISC for informal carers and people with dementia, but also on the benefits for professional carers, and on the reduction of healthcare expenditure as a consequence of more customized information. As a result of customized advice on coping with the disease and on healthcare and welfare services, tailored to specific individual needs and demands, it is expected that carers will be able to provide (or arrange) better and more timely care for their relative, healthcare expenses might be reduced and carer burden will be alleviated. As a consequence people with dementia could stay in their own home for a longer period of time, postponing nursing home admission. This will be accompanied by a decrease in healthcare expenditure.

It is expected that professionals will also experience benefits when using DEM-DISC: The system will keep them updated on the available care and welfare services for their clients, and referral of clients will therefore be easier and more efficient. When all information on available services in a region is integrated in a demand-driven system, gaps in the service offer are more easily detected and this in turn could guide policy makers to initiate regional care improvement projects.

To conclude, DEM-DISC is a potentially effective ICT means to support community-dwelling people with dementia and their carers in arranging services to fulfil their care needs and to improve the competence of carers. Further development of the system and studies into the effect of DEM-DISC are needed before implementing this type of digital information provisioning in the public digital information services, such as the internet and general care practice.

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CHAPTER 7

General discussion

Introduction

The focus of this thesis is twofold: a) the needs of community-dwelling people with dementia and b) the development and evaluation of a demand-oriented ICT solution, the DEMentia-specific Digital Interactive Social Cart (DEM-DISC), to inform people with dementia and their carers on services that can provide support for their needs. During the course of this thesis we discussed the state of the art on general needs that people with dementia experience (Chapter 2); this was followed by a large-scale field study we executed into care needs experienced by community-dwelling people with dementia as well as care needs that their carers reported (Chapter 3); a study into the validity and reliability of the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE; Chapter 4); and the development and evaluation of the first prototype of DEM-DISC (Chapters 5 and 6 respectively).

In this final chapter the main findings and conclusions are summarized, and limitations and methodological issues of the studies reported on in this thesis are reflected upon. The relevance of the findings for scientific research and society is discussed and some recommendations are made for delivering demand-oriented information on care and welfare services to people with dementia in the community and their carers are made.

Main findings and conclusions

The key findings and conclusions of this thesis will be summarized according to the main research questions that were outlined in the General introduction.

What is the state of the art with respect to knowledge on the needs that community-dwelling people with dementia experience? (Chapter 2)

To answer this question a review of the literature published from 1985 to 2005 was conducted. Studies recorded in the databases of PubMed and PsycINFO in which people with dementia were questioned about their needs and quality of life were considered for inclusion, and further relevant studies were traced by means of cross-referencing. A total of 34 studies were included in the review. Extracts of text in which needs were reported were coded by two independent researchers on needs domains and whether needs were implicitly or explicitly formulated. Consensus on the coding was sought afterwards.

In the past two decades community-dwelling people with dementia were rarely directly involved in studies on their needs and quality of life. However, from 2003 this has started to change. Few of the papers actually aimed at assessing experienced needs of people with dementia or their quality of life. Most of them addressed the way people with dementia cope with their illness and/or are aware of it, or the way people with dementia communicate. Nevertheless, all these studies reported on needs on different domains. The most frequently expressed needs were related to the acceptance of, and coping with the consequences of dementia in daily life, finding adequate coping strategies, and gaining insight into one's own situation. Other frequently reported needs were to function normally, to be accepted and to be respected as one is, and the need for company. People with dementia often expressed their needs as a state of felt deprivation and less often as an explicit want (a desire) or a demand (a wish for a particular service). The reported needs were all related to the problem areas of the Dutch National Dementia Programme (Meerveld *et al.*, 2004) and quality of life domains that are judged as relevant by people with dementia (Dröes *et al.*, 2006).

What needs do community-dwelling people with dementia experience and what needs are reported by their informal carers? (Chapter 3)

To provide an answer to this research question a large cross-sectional study was conducted in two areas of the Netherlands to assess care needs and care use of community-dwelling people with dementia and their carers. In this study 236 people with dementia and 322 informal carers were interviewed separately using, among other things, the CANE. The results showed that the interviewed people with dementia most frequently experienced needs with regard to food preparation, household chores, memory problems and finances. This confirms the results regarding difficulties with coping with disabilities as a consequence of the disease in daily functioning as found in the literature study. The responses of the interviewed carers confirmed those needs. The most frequently experienced needs that were currently unmet concerned the need for information about dementia, about one's own condition and on supportive care, the need to receive support for memory problems and psychological distress and the need for company. Informal carers most frequent reported unmet needs in the areas of memory support, daytime activities and company. Other less frequently mentioned unmet needs concerned support with psychological distress and information on dementia and available care and support services. Overall, people with dementia reported fewer met as well as unmet needs than their carers, and within patient-carer dyads the reports on (un)met needs differed. In general the agreement on needs within patient-carer dyads was poor to moderate. However, with regard to the amount of received professional support for experienced needs agreement was much better and varied from fair to very good, confirming the reliability of the study results.

Is the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE) a valid and reliable instrument to assess needs of people with dementia? (Chapter 4)

Construct validity of the CANE administered to people with mild to severe dementia proved very good. As dementia progresses the dependency of people with dementia will increase, and accordingly the number of experienced needs is expected to increase too. Therefore all CANE items were expected to correlate positively with each other. Almost all significant correlations proved to be convergent. The construct validity of the CANE administered to informal carers also appeared very good. The assumption that relatively more inter-item correlations would be found between items within the four categories (Autonomy, Physical needs, Psychological, emotional and social needs, and Carer needs) because of the nature of these items, was indeed confirmed for administration of the CANE to both people with dementia and carers. Criterion validity could be tested for the majority of the CANE items and was good, with correlations varying from low (most correlations) to very high.
For practical reasons, test-retest reliability of the CANE was not studied among people with dementia. The interview for retest purposes was conducted by telephone and this interview could therefore not been administered with people with dementia. Among carers summary scores of the CANE as a whole showed good to very good test-retest reliability, the individual CANE items showed moderate to good test-retest reliability. The results of this study support the use of the CANE as a means to assess the needs of community-dwelling people with dementia in the Netherlands.

How can a human-centred design be applied in the development of DEM-DISC? (Chapter 5)

DEM-DISC, a digital interactive social chart for dementia care, was developed according to human-centred design principles. Potential users of the system under development were involved during different phases of the development process. DEM-DISC was intended to be designed as a social chart that could give personalized advice on specific questions regarding dementia care and welfare services. Within the development of ICT applications various perspectives need to be taken into account. In the development of DEM-DISC four different perspectives were elaborated: the domain-specific content perspective, the ICT perspective, the user perspective and the organisational perspective.
Domain-specific content perspective: The domain-specific content perspective focused on identifying specific needs of people with dementia and carers and on service

offerings for these needs. First of all a literature review and a field study on needs of community-dwelling people and their carers were conducted (described in Chapters 2 and 3 respectively). The results showed that there was a need for specific information on dementia and available care and welfare services, thus confirming the need for a demand-oriented information system like DEM-DISC. The content of the first (restricted) prototype of DEM-DISC was based on the most prevalent unmet needs found in the studies. The five relevant problem areas that were included in the first prototype of DEM-DISC were based on five problem areas of the NDP (Meerveld *et al.*, 2004), namely: 'detecting and diagnosing dementia' (sensing that something is wrong); 'identifying specific problems involving the disease and finding solutions for them'; 'finding support for the carer'; 'finding social contact for the person with dementia'; and on 'what to do when the carer is not able to cope anymore'. Information on dementia care and welfare services and their specific features was also collected in the field study, in order to create an extensive dataset of available services, enabling the DEM-DISC system to provide users with advices on (combinations of) services that may provide support for their needs, taking into account their personal situation.

ICT perspective: The ICT perspective deals, among other things, with issues such as how DEM-DISC can be accessible anytime, anywhere and how the offered information on care and welfare services can be customized for each individual user. Designing DEM-DISC as a web-based system gives users access to it anytime and anywhere. To enable the system to provide suitable advices to specific questions the service ontology of DEM-DISC was validated with domain experts (dementia care researchers and care professionals). Service bundles were generated for specific needs according to the ontology. After three iterations of testing the outcomes were adequate and the ontology was considered serviceable.

User perspective: The user perspective addressed issues involved in making the design of DEM-DISC as user friendly and as useful as possible. Several methods were used to achieve maximum user-friendliness and usefulness. At the start of the development process some main requirements for DEM-DISC were formulated during a workshop with professionals and informal carers. Potential users agreed that its contents needed to be general as well as personalized, that DEM-DISC would preferably be low threshold and should enable online contact between users. Professionals emphasized issues regarding management of DEM-DISC and uniformity and (guaranteeing the) quality of the content. A first demonstrator of DEM-DISC was tested with five informal carers. Comments were made on the system, its functions, the content, the transparency of the question selection process and on its lay-out. An improved version of DEM-DISC was subsequently tested with three healthcare professionals. Their main comments were on the lay-out and representation of service bundles in DEM-DISC. Any erroneous content that the healthcare professionals came across was altered immediately during these tests.

Organisational perspective: Regarding the organisational perspective, research was done on viable exploitation models for DEM-DISC. During a series of workshops and interviews potential stakeholders were asked to advise on a viable business model for DEM-DISC. There was no unanimous preference for a particular model, although a community model and a governmental model were expected to be more viable for exploiting DEM-DISC than a commercial, insurer or provider model. Stakeholders emphasized that DEM-DISC had to utilize information from existing databases.

The methods used for research from the different perspectives were regarded as suitable and beneficial for the development process. The process resulted in a first prototype of DEM-DISC that included five problem areas in which users could specify their needs and receive personalized or general (bundles) of information on available healthcare and welfare services. Furthermore this prototype contained links to national and regional websites that offer information on dementia-related subjects and a service with news items on dementia.

Is DEM-DISC a user-friendly and useful system to meet the needs of people with dementia and their carers in the community and does DEM-DISC use have a positive impact on the daily life of people with dementia and their carers? (Chapter 6)

Chapter 6 describes the outcomes of a controlled trial on the first prototype of DEM-DISC among informal carers of community-dwelling people with dementia. Fourteen carers (the experimental group) had access to DEM-DISC in their own house during a two-month intervention period, while carers in the control group had access only to their usual channels of information about care. During this period carers in the experimental group accessed the system five times on average. Afterwards they reported that DEM-DISC was easy to learn and relatively user friendly. Although they felt that this first restricted version of DEM-DISC was not explicitly useful to their present situation, in general they reported that using DEM-DISC would be useful for carers of people with dementia. The carers liked the clear structure of DEM-DISC, but they felt that the information provided by the system could be more detailed, amongst other things with regard to specific services for different types of dementia and different levels of severity of the disease.

The use of DEM-DISC appeared to have had large positive effects on several aspects of the daily life of people with dementia and their carers: Informal carers as well as people with dementia in the DEM-DISC group reported experiencing fewer unmet and more met care needs after the intervention period as compared to carers and people with dementia in the control group. Carers in the experimental group also proved to have a higher sense of competence at posttest, as compared to informal carers in the control group. No effects were found on the other outcome measures, i.e. the total number of needs as reported by the patient-carer dyads, the self-efficacy of carers, the number of used services and the amount of received professional care. DEM-DISC use had no effect on the secondary outcome measures either: quality of life of the person with dementia and knowledge about care and welfare services.

We checked whether nursing home admittance might have caused the positive effects on needs and sense of competence found in the experimental group after the intervention period by including the variable nursing home admission (posttest values) as a covariate in the ANCOVAs. However, this correction did not change the positive effects in the intervention group. Also, when all data of the person with dementia-carer dyads of which the person with dementia was admitted to a nursing home were excluded from the analyses, we still found the same results: Nursing home admission did therefore not explain the positive outcomes.

Because of the positive effects found after a relatively short intervention period, it was concluded that DEM-DISC is a potentially effective ICT means to support community-dwelling people with dementia and carers.

Methodological issues and limitations

All studies described in this thesis have their own methodological issues and limitations. The main points regarding methodological issues such as the external validity, time restrictions, the DEM-DISC intervention, and measuring instruments will be discussed in the following section.

External validity/generisability

Review: Although the literature review on subjective needs of people with dementia (Chapter 2) was performed comprehensively by searching for studies published in a twenty year time span in two large databases, and cross-referencing relevant articles, the results of this study must be interpreted with some caution. As it is not clear if the needs inventoried in the traced studies among mostly mild to moderately demented persons correspond with those of older people in general and in other stages of the disease, one should be cautious when generalizing their needs to people with dementia living in the community.

Cross-sectional field study: The response rate for the performed field study on needs of people with dementia and their carers in the community was high (61.3%) and a large sample of respondents was included in the study (see Chapter 3). Although the participants represented the general population of community-dwelling people with dementia and their carers (Yaffe *et al.*, 2002; Peeters *et al.*, 2007), generalization of the results requires some caution. The non-response to the study proved to be partially caused by overburden of the carer. This may have caused an underreporting of experienced unmet needs that actually do exist in the community. It must be emphasized though that the study sample also contained burdened carers. Another point of concern was that many people with dementia who probably lived alone could not be included in the study because follow-up phone calls from the researchers, after the initial invitation letter was sent, were not answered by the person with dementia, and informal carers' contact details lacked. Therefore, the people with dementia who live alone in the community may be underrepresented in the included sample of people with dementia. Our results show that this group of people with dementia who live alone had more, and different care needs as compared to those who share a household. Since subjects for the study were recruited mainly via care organisations, the number of people with dementia who do not receive any care may also have been underrepresented in this study.

Development of DEM-DISC: During the initial development process of DEM-DISC all possible users were consulted: people with dementia, informal carers, care professionals and possible stakeholders (see Chapter 5). However, in the development of the first prototype of DEM-DISC the focus was on informal carers. They were consulted during the small-scale tests and participated in a two-month pilot study to evaluate the impact of the prototype of DEM-DISC in daily life. Therefore the current prototype of DEM-DISC, as well as the results of the evaluation, principally apply to informal carers. Although DEM-DISC is intended to be used by people with dementia as well as informal carers and care professionals, no statements can be made yet on the user-friendliness and usefulness of the system for people with dementia and care professionals.

Evaluation of DEM-DISC: The external validity of the results of the controlled trial to evaluate the first prototype of DEM-DISC among informal carers of people with dementia is limited. We could not perform a randomized controlled trial (RCT) for several reasons: The DEM-DISC prototype contained information on available healthcare and welfare services in the specific regions Zuid and Zuideramstel of the city of Amsterdam, therefore only carers of people with dementia living in these regions could be included in the experimental group. Another inclusion criterion was that carers were computer skilled. Though this percentage is increasing in elderly people, this is still generally not the case in the largest group of carers. Therefore this criterion complicated the recruitment of participants for the study. For reasons of scarcity, we thus had to include respondents that were computer skilled in the experimental group, while carers who were not computer skilled were assigned to the control group. The same counted for carers of people with dementia who lived outside the selected regions in Amsterdam. They were automatically assigned to the control group. Because of the limited recruiting time, the group of participants was smaller than originally intended. Instead of an RCT we performed a small-scale controlled trial. This led to several limitations in the generalization of the results. Because of the recruitment procedure, characteristics of the experimental group differed from the control group on the following points: as compared to the control group more children providing less hours of care to the person with dementia were included in the

DEM-DISC group. To control for confounding effects caused by group differences several variables were included in the ANCOVAs as covariates. On the whole the background characteristics of the carers and the persons with dementia they cared for, differed from the total population of patients and carers in the Netherlands: the carers in our study were a bit younger, more often the child of a person with dementia, and they provided less care, while the people with dementia in our study were slightly older than the people with dementia in the general population (Peeters *et al.*, 2007; Van der Roest *et al.*, 2009). The results of the evaluation study on DEM-DISC also have to be treated with caution because the version under evaluation was still a prototype. This version only contained a limited set of need areas and the offered care and welfare services were restricted to two city areas. We must therefore conclude that even though the prototype of DEM-DISC was evaluated as user friendly and relatively useful, and its use appeared to have a positive impact on some aspects of the daily lives of the patient-carer dyads, we do not know if these results apply to all carers with all types of needs and living in all parts of the city or elsewhere, including those carers who are older, who are providing a lot of care and who are partners of people with dementia.

Time restrictions

DEM-DISC had to be developed in a three-year period. The research and development work on DEM-DISC that has been done was performed according to human-centred design (HCD) principles. The involvement of potential users in the process and the actual development of DEM-DISC was time consuming. The data collection for the field study on needs in dementia alone took over a year of research time. The two years that were left turned out to be too short to technically develop a final version of DEM-DISC and extensively evaluate its effects among informal carers, people with dementia and professionals. As a consequence we chose to develop the interface primarily for informal carers and to evaluate the DEM-DISC with informal carers only. A user-friendly interface for professional carers and a user interface for people with dementia still need to be developed.

Intervention

The user-friendliness, the usefulness and the impact of DEM-DISC use was evaluated during a two-month intervention period. During these two months informal carers who had access to DEM-DISC reported no problems regarding the stability of the system: DEM-DISC was accessible at all times. The fact that the system under evaluation was a prototype may have influenced the results. Prior to the intervention informal carers in the experimental group were informed that DEM-DISC was not a complete system: that it did not contain solutions to all the problems they might experience and that only services available in Amsterdam Zuid and Zuideramstel were included.

Nevertheless carers made negative comments regarding these points after the intervention. Informal carers who were not living in the selected areas searched DEM-DISC for services in their own residential area and thus could not find satisfactory advice for their questions. Carers were also looking for advice on problems that were not yet included in DEM-DISC: they either could not find the right question or were not satisfied with the advice given. This may have negatively influenced their judgements on the user-friendliness and usefulness of the DEM-DISC prototype, as well as on the impact of DEM-DISC on their daily lives (e.g. on actual care and welfare use and perceived self-efficacy).

Instruments

The needs described in the field study and the DEM-DISC evaluation, were assessed using the Dutch version of the Camberwell Assessment of Need for the Elderly (CANE). The psychometric properties of the English and Spanish versions of the CANE were known to be highly acceptable (Reynolds *et al.*, 2000; Mateos *et al.*, 2004), but the validity and reliability of the Dutch version of the CANE among people with dementia and carers was not known. We therefore included this in our study (Chapter 4). The validity and reliability of the Dutch version of the CANE was established by using data from the field study on needs in dementia (Chapter 3). Although good validity and reliability were found, there were some limitations regarding the establishment of the criterion validity of the Dutch version of the CANE. The study did not include suitable criterion instruments for all CANE items. Sometimes single items from validated instruments were selected, and if no validated instrument was available, non-validated items were included in the study. Criterion validity for the items 'Benefits', 'Eyesight/hearing', 'Alcohol', and 'Information' could not be established, since no criterion items were included in the field study.

Relevance

Scientific relevance

The studies described in this thesis have various scientific implications. First of all, after we indicated the lack of large scale studies on subjective needs of people with dementia in Chapter 2, our field study described in Chapter 3 contributes to filling the knowledge gap of needs that community-dwelling people with dementia and their carers experience with respect to care and support. Many studies on needs in dementia care in the community have been conducted among proxies (see for example Philp *et al.*, 1995; Nankervis *et al.,* 1997; Dello Buono *et al.,* 1999; Toseland *et al.,* 1999). These studies show among other things, the need for support with household activities, self-care, memory problems and day-time activities. Our results confirm the outcomes of these earlier studies. However, our study also shows to what extent needs are being met, and to what extend the views of people with dementia and of their carers are in agreement. For the major part of the needs adequate support was provided, but some needs appeared to be unmet for a substantial number of respondents, such as the needs for memory support, information provision, company, psychological distress and day-time activities. Few studies that focus on care needs report on the views of people with dementia. Most are qualitative and small sample studies (Bamford and Bruce, 2000; Proctor, 2001; Reid *et al.*, 2001; Aggarwal *et al.*, 2003; Beattie *et al.*, 2004).

Recently Meaney *et al.* (2005) assessed the needs of a relatively large sample of people with dementia and their carers with the CareNap-D (McWalter *et al.*, 1998). However, the researchers failed to report the views of patients and carers separately; therefore no insight is provided in possible differences in views of people with dementia and their carers. The cross-sectional study on needs in dementia as described in Chapter 3 provides these insights. It is the first large scale study that systematically reports on the (unmet) care needs as experienced by people with dementia themselves and by their carers. The capability of people with dementia to give a reliable judgment of their quality of life and healthcare was demonstrated earlier by Karel *et al.* (2007). Our study results as described in Chapter 3 again confirm that people with dementia are capable of giving a clear judgment of their experiences. The fact that they report fewer (unmet) needs than their carers may be explained by their decreasing cognitive functioning. However, the assumption that patients feel less need to be assisted than their carers feel they ought to, might be another explanation for this phenomenon (Lyons *et al.*, 2002). Our study results seem to make the latter explanation even more plausible (see Chapter 4).

The development and the evaluation of DEM-DISC as described in Chapters 5 and 6 respectively contribute to the growing body of literature on assistive technology for people with dementia and their carers. The development of DEM-DISC is unique. The aim of the system is that it is to be utilized by people with dementia themselves, as well as by their informal carers and healthcare professionals, whereas most other ICT devices are developed for one type of user only. During the development process of DEM-DISC we used a similar approach to Sixsmith *et al.* (2007), who developed a technology wish-list together with people with dementia, and Freeman *et al.* (2005) who developed a website and made recommendations for enhancing website design for people with dementia: Right from the start we involved potential users as much as possible in the development process using different research methods.

Many assistive devices have been developed to support people with dementia directly in their daily lives. For the development of these devices user requirements were formulated, for instance by Bjørneby *et al.* (2003), Freeman *et al.* (2005), and Meiland *et al.* (2007). Although DEM-DISC does not yet directly assist people with dementia (e.g. by means of a simplified user interface), it already provides customized information and takes into account the in the literature mentioned functional requirements for this target group, such as supporting people in making choices, giving a feeling of independence to the person, and having a positive impact on the life of the person with dementia. These principles were also taken to heart in the development of DEM-DISC. Although various digital social charts are available on the internet, they have not been evaluated among its users on usefulness, user-friendliness and impact on daily life (Lauriks *et al.*, 2007). DEM-DISC is the first digital interactive social chart that has been evaluated with at least one group of its potential users as a start. DEM-DISC distinguishes itself from the existing social charts that are generic and static. The ontology of DEM-DISC is designed to give personalized advice on specific questions, which makes DEM-DISC a demand-driven system. Earlier research showed that provision of customized information by telephone resulted in positive effects on carer burden, depression and social support for informal carers of people with dementia (Finkel *et al.*, 2007).

Psychogeriatric relevance

The results of the cross-sectional study on needs in dementia (Chapter 3) show that in general the needs as reported by people with dementia on a group level were the same as the needs reported by the informal carers as a group; however, agreement on specific needs within patient-carer dyads was low. This means that healthcare professionals need to bear in mind that the views of the person with dementia and the informal carer do not always coincide and should be treated as complementary to each other. When planning or providing care, healthcare professionals need to pay extra attention to the problem areas where agreement within dyads is (very) low, i.e.: safety, abuse or neglect, the behaviour of the person with dementia and deliberate self-harm by the person with dementia. Care providers also need to take into account and anticipate to risk factors for the likelihood of experiencing unmet needs, such as having another type of dementia than Alzheimer's disease, severe dementia, separate households, and informal care provided by non-spouses, younger, female or burdened persons.

Implementation of DEM-DISC will offer major advantages for its users when healthcare and welfare providers are willing to offer information on their services jointly via the system. Because the advice on services will be provided in conveniently arranged service bundles, DEM-DISC users will easily find the available offer for their needs and can choose services that match their personal preferences. On the other hand DEM-DISC can also contribute to the improvement of the dementia healthcare and welfare offer in a region by providing insight into gaps in the service offer for specific care needs. In 2005 the National Dementia Program (NDP) (Meerveld *et al.*, 2004; Landelijk Dementie Programma, 2008) was initiated to solve lacks in dementia care and to promote cooperation between care and welfare providers within regions. This project ended in 2008. Since DEM-DISC uses the same methodology as the NDP, DEM-DISC could be a means to continue this process of improving dementia care and welfare offerings on a regional level relatively easily by tracking lacunas in the service offer. Using the methodology of the NDP in DEM-DISC requires demand-oriented thinking of the care and welfare providers. Instead of providing information about their services based on availability, they need to specify information in DEM-DISC based on the needs and preferences of their potential clients, and make the shift from a supply-driven to a demand-oriented healthcare and welfare culture.

Societal relevance

Providing demand-oriented care to people with dementia has become increasingly important in the last decade. In order to provide effective and efficient care, knowledge on the variety of needs people experience is necessary. The obtained insight into (unmet) needs of community-dwelling people with dementia and their carers provides policy makers and professional carers with the information needed to change the existing care system into a more demand-oriented healthcare system in which attention is also given to presently unmet needs.

People with dementia and their carers will be able to find appropriate services quicker and more easily with DEM-DISC, as DEM-DISC helps to specify the needs of users on the one hand and gives customized advice on available care on the other. DEM-DISC clarifies needs using the methodology of the NDP that describes several problem or need areas based on the formulations of people with dementia and carers themselves (Meerveld *et al.*, 2004). These problem areas are also the basis for the start questions in DEM-DISC and are therefore expected to be readily recognizable for people with dementia and their carers. The same principles were used in the recently launched web-based social chart for dementia ‘Zorgprogramma Dementie’ (Vilans, 2009). DEM-DISC distinguishes itself from this social chart in that it also gives customized and bundled advice on more specific questions and preferences people can have. The advice and information given on services is not only based on the personal preferences of the users, but also on the following marketing principles: product, personnel, price, person, place and promotion (Kotler, 1980). Due to the fragmentation and the continuously changing healthcare and welfare offer nowadays, it is very difficult, if not impossible, for people with dementia or their carers to find the care they need (Dröes *et al.*, 2005). DEM-DISC gives users an easy tool to make informed choices on the type of care that is most suitable for their needs and to use care more effectively. Though several services like case management, informal carer support organisations and governmental regulated societal support organisations (e.g. the *WMO loket*) do exist in the Netherlands that have similar goals, many of those services are only accessible during office hours or by means of personal contact or visits. Though personal contact with an informal carer support service can be very helpful for a lot of people, one can imagine situations in which people are reluctant to personally approach care or welfare organisations actively for information or support, e.g. when they doubt if their problems are severe enough to ask for help, when they feel insecure about their precise needs, when they have little time during the day because of concurrent obligations or when they experience a threshold for asking help from professional organisations or carers. In these cases digital information provisioning, in the anonymity of the own home, might help to clarify needs and demands, to speed up the search process, and to lower the threshold to utilize professional care and welfare organisations. Another possible use of DEM-DISC is offering more detailed information on services to people after they have visited a professional organisation. In case people have forgotten to discuss topics during these appointments and feel reluctant to visit the organisation again, they can easily consult DEM-DISC in their own home. It is well known that it is difficult for professional services and carers to keep up to date with the existing, and changing, care offer. DEM-DISC could solve this problem. Finally, DEM-DISC can provide users with independent information on the broad range of available offerings, whilst professionals often draw information from their familiar networks. The merit of DEM-DISC as compared to the already existing information provisioning services is that the available offerings for dementia care and support can be found via an easy accessible, integrated, digital system and that one can trust that the information is regularly updated, provided that DEM-DISC will be exploited according to a suitable business model.

Reducing or alleviating unmet needs is very important: the more unmet needs people with dementia experience, the higher the risk of being admitted to a nursing home or even death (Gaugler *et al.*, 2005). By targeting unmet needs in time and providing demand-oriented care, nursing home admission can be postponed, the costs of healthcare reduced, and people with dementia will be enabled to live in their own home for a longer period of time.

Recommendations

Recommendations for future research

The research on subjective needs of people with dementia has only just started; hence more research is needed, preferably in population-based samples. The participants in our study on needs in dementia care were all recruited via care providers. To investigate what needs people who do not use any form of care or support experience, it is recommended to recruit people also via e.g. general practitioners and welfare organizations in future research. It is quite conceivable that a reasonable proportion of the non-response in our study consisted of people with dementia who lived alone and who had difficulty responding to our request for participation in our study. In order to be able to study possible differences in care needs between people with dementia who live alone and those who live with their informal carers, the recruitment of people with dementia living alone in the community needs more attention in future research.

The results described in Chapter 4 support the use of the Dutch version of the CANE among community-dwelling people with dementia and their carers. The Dutch CANE was also recently used among a large sample of vulnerable elderly people living in the community and proved feasible to assess their care needs as well (Van der Ploeg, 2009). Nevertheless, for the Dutch version we recommend the further study of the psychometric properties as well as the responsiveness of the CANE. In particular, the establishment of its criterion validity, preferably by using standardized instruments, and the establishment of the inter-rater reliability of the CANE need to be studied in more depth. The English and Portuguese versions are known to have good inter-rater reliability among a psychogeriatric population (Reynolds *et al.*, 2000; Fernandes *et al.*, 2009).

DEM-DISC in its current form is a prototype and needs to be developed further using human-centred design principles. This will increase the chances that the device is accepted and appreciated positively by users, will increase the chances for the market and increase the likelihood of implementation in care services at a later stage.

First of all, the remaining nine problem or need areas of the NDP need to be added to the DEM-DISC system, and additional available services in the region have to be included. To add new services a user-friendly domain expert interface needs to be developed, preferably with a standardized interface so that users (healthcare and welfare providers) are guided in storing the required information in the system such as pricing, location, whether the service is offered in a group or on an individual basis. This detailed input is necessary to provide customized advice.

The user interface also requires further research and development. The current interface was developed specifically for informal carers; although it could also be used by professionals, this user interface is to be expected to be too difficult and confusing for people with dementia.

To be able to generalize effects of DEM-DISC use, the final version of DEM-DISC needs to be tested in a randomized clinical trial among a larger sample of informal carers for a longer period of time. Ideally the intervention period should be at least six months and taking into account an effect size of 0.5, an α of 0.05, a power of 0.8 and a drop-out percentage of 10% during the intervention, power analyses shows that cohorts of at least 70 persons are necessary (Cohen, 1988). Effects of DEM-DISC when used by people with (mild) dementia should also be studied. In the future more people with dementia will be experienced in working with computers, and they might therefore experience few limitations on DEM-DISC use because of a lack of computer skills. And, finally the effects of DEM-DISC use among care professionals also need to be studied. It is likely that DEM-DISC use in healthcare practice will influence the efficacy of referral regarding support for people with dementia and informal carers. In future studies on the efficacy of DEM-DISC use outcomes like unmet care needs, quality of life, care utilization and carer burden definitely need to be examined.

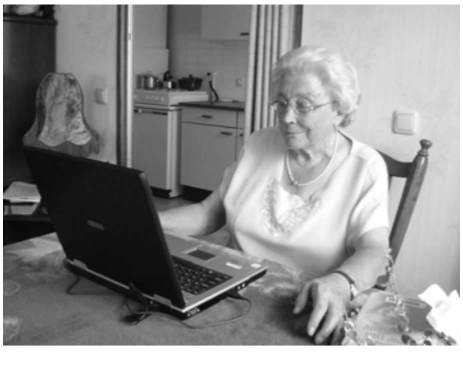
Recommendations for psychogeriatric care

The results that were reported in this thesis can be used by healthcare professionals and welfare workers to obtain a better insight into the needs of the people with dementia and informal carers to which they are offering services. Especially the knowledge about existing relationships between several background characteristics and experienced unmet needs on specific domains can be very helpful for professionals to better tailor their care to the needs of their clients. Knowing for instance that people with severe dementia are more at risk of experiencing unmet needs regarding self-care, that people with dementia who are being cared for by a non-partner are more at risk of having unmet needs regarding household activities or company, gives professionals the opportunity to prioritize and undertake precautionary measures.

To support people with dementia and their carers with tailored care, that is adequately adapted to the needs of their clients, it would be advisable that professionals systematically use the CANE in their daily practice in order to get insight into the (unmet) needs of their clients. Care plans can be designed and adjusted according to the inventoried (unmet) needs, while problems regarding the provisioning and the amount of care can be monitored systematically by using the CANE and care plans can be adjusted accordingly to solve unmet needs.

The involvement of people with dementia in research shows that this group does have a clear opinion about their needs. It is therefore recommended to involve people with dementia in individual care planning to increase the likelihood of successful care practice. Engaging people with dementia in care innovations projects by means of elderly networks, or in sounding board groups might also improve the success ratio of the innovative care once it is put into practice.

DEM-DISC serves both dementia care providers and care users. DEM-DISC procures dementia care providers with a tool to create and maintain a care chain in dementia practice, because it helps to identify needs and lacunas in the service offer in a region. By solving the unmet needs and filling the lacunas, a balanced continuum of dementia care in a region can be created that focuses on people with dementia in different stages of the disease. On the other hand, DEM-DISC provides user groups with rele-



vant information on supportive services, it discloses the care offer in a region and makes the service offer easily accessible for potential users. It is therefore expected that DEM-DISC will ultimately contribute to a better quality of care, to more effective care use and, as a consequence, to a better quality of life for people with dementia.

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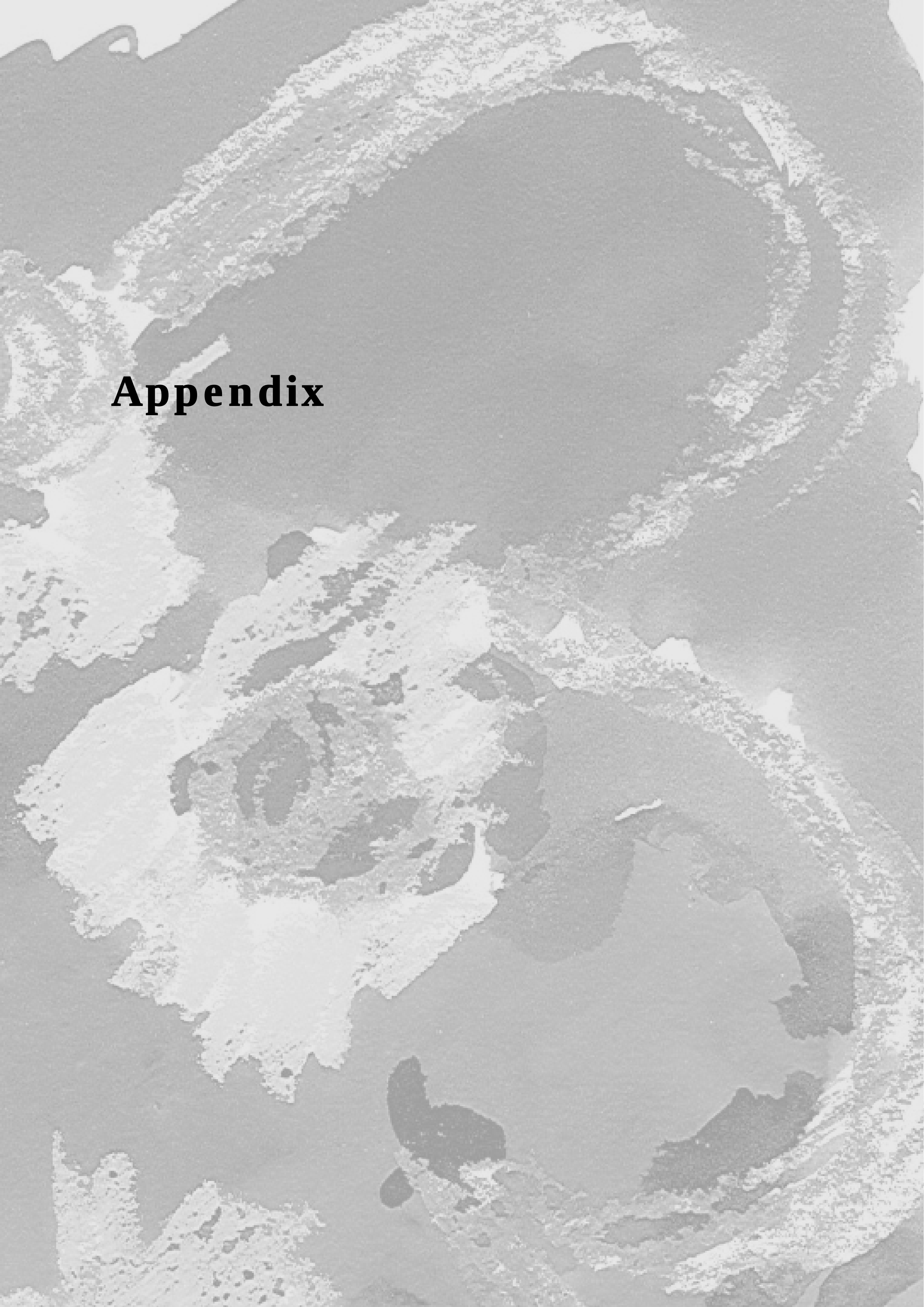
Appendix



Dutch version of the Camberwell Assessment of Need for the Elderly (CANE)

Dröes, R. M., Van Hout, H. P. J. and Van der Ploeg, E. S. (2004). *The Dutch version of the Camberwell Assessment of Need for the Elderly (CANE). Revised Version (IV)*. Available at: http://www.ouderenpsychiatrie.nl/sjablonen/1/infotype/news/newsitem/view.asp?objectID=1190.

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CAMBERWELL ASSESSMENT OF NEED FOR THE ELDERLY

(CANE)

Revised Version (IV)

Nederlandse vertaling: R.M Dröes[1], H.P.J. van Hout[1] en E.S. van der Ploeg[2]
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CODE	

Ondervraagde	Datum	Interview Tijd
Oudere		
Mantelzorger		
Hulpverlener		
Beoordelaar		

Demografische Gegevens

(Vul in of omcirkel voor zover van toepassing)

CODE NUMMER: ________________

INTERVIEWER: ________________

LEEFTIJD: ________________(jaar)

GESLACHT: man / vrouw

LAATSTE BEROEP: ________________________

OPLEIDING: ________________(jaar)

ETNICITEIT: Nederlands/Surinaams /Turks/Marokkaans/Aziatisch/ Afrikaans/
anders……………………….

BURGELIJKE STAAT: alleenstaand / getrouwd / gescheiden/ apart wonend/
weduwe/ weduwnaar

WOONSITUATIE: alleen / met partner / met andere verwanten / met anderen

WOONSITUATIE: flat / huis / beschermd wonen / verzorgingshuis / verpleeghuis

WOONGEBIED: platteland / dorp / stad

GEBRUIK VAN
VOORZIENING(EN): ________________(jaren)

EERDERE OPNAMEN (aantal) ________(excl. huidige opname indien wonend in instelling)

HUIDIGE STATUS: opgenomen bewoner / thuiswonend / bezoeker dagfaciliteit /
(Psychiatrisch / Geriatrisch)

HOOFDDIAGNOSE:

(DSM-IV) delirium
dementie
schizofrenie/ parafrenie
depressieve stoornis/ episode
bipolaire stoornis
manische episode
angststoornis
anders

HEEFT DE PERSOON EEN MANTELZORGER? ja / nee

IS DE PERSOON ZELF MANTELZORGER? ja / nee

Instructies voor de CANE

De CANE is een uitgebreid persoonsgericht behoeftebeoordelingsinstrument, dat speciaal voor ouderen is ontwikkeld. Het is toepasbaar in een scala van klinische en onderzoekssettingen. Omdat de CANE persoonsgericht is, is het mogelijk om de opvattingen van de professionele hulpverlener, de oudere en de mantelzorger, vast te leggen en te vergelijken. Het instrument gaat uit van het principe dat het identificeren van een behoefte bestaat uit het identificeren van een probleem én een passende interventie die de behoefte verhelpt of verlicht. De CANE richt zich dus op de klinische praktijk en is gebaseerd op professionele expertise voor een accurate beoordeling. Hulpverleners die de CANE gebruiken moeten hierin getraind zijn en ervaring hebben met het werken met ouderen. Tevens moeten ze adequate kennis hebben van het houden van klinische interviews en besluitvorming. Ze moeten voldoende bekend zijn met de begrippen behoefte, tegemoet gekomen behoefte en bestaande behoefte. Deze kennis kunnen zij opdoen door volledige CANE beoordelingen te maken en door de handleiding te lezen. Een Nederlandstalige handleiding met voorbeelden en uitleg over de scoring is beschikbaar (H. van Hout, Huisartsgeneeskunde, VUmc).
Er zijn 24 thema's voor de oudere en twee (A & B) voor de mantelzorger. Er zijn vier kolommen om beoordelingen te noteren, zodat zowel de oudere als de mantelzorger, de hulpverlener en een andere beoordelaar (arts/onderzoeker) hun mening kunnen geven. Noteer in het hokje bovenaan de kolom (bij Assessments) welke persoon is geïnterviewd.

SECTIE 1
Het doel van deze sectie is om te beoordelen of er momenteel een behoefte bestaat op een bepaald gebied. Een behoefte wordt gedefinieerd als een probleem met een mogelijke oplossing of interventie. Gebruik de *schuingedrukte* vragen onder iedere hoofdvraag op het formulier om de huidige status van de oudere ten aanzien van de betreffende behoefte vast te stellen. Als er een behoefte is, beoordeel dan of er op passende wijze aan tegemoet gekomen is. Scoor elke geïnterviewde persoon apart, ook al kan de behoefte zoals zij die ervaren op elk gebied verschillen. De interviewer moet aanvullende vragen stellen om het thema zo ver uit te diepen dat hij/zij kan vaststellen of de oudere een belangrijke behoefte heeft die hulp vereist en of de oudere voldoende hulp en de juiste hulp krijgt. Als deze informatie is verzameld kan een behoeftebeoordeling gemaakt worden. De beoordeling in deze sectie moet gebaseerd worden op de gebruikelijke klinische praktijk. De CANE is bedoeld als een kader voor beoordeling, gebaseerd op goed professioneel handelen en professionele kennis. Hoewel sectie 1 voor ieder probleemgebied het belangrijkste onderdeel is voor mensen die met de CANE werken, kan deze sectie vaak niet beoordeeld worden totdat adequate informatie over het probleemgebied is verzameld. Sommige interviewers vinden het zelfs gemakkelijker om sectie 1 pas te beoordelen nadat de informatie over secties 2 t/m 5 is verzameld. Als adequate informatie is verzameld, moet de beoordelaar zonder problemen tot een klinisch oordeel kunnen komen of op dit gebied sprake is van een tegemoet gekomen behoefte, een bestaande behoefte of geen behoefte. Verwarring over oordelen kan worden voorkomen door niet direct een gesloten vraag over een bepaald probleemgebied te stellen (bijvoorbeeld “Heeft u problemen met het eten hier?”), omdat de geïnterviewde dan “nee” kan antwoorden. Dit antwoord kan ten onrechte worden opgevat als “geen behoefte,” terwijl het in feite een “tegemoet gekomen behoefte” is, omdat de oudere van iemand anders hulp krijgt.

- *Geen behoefte*: Scoor een 0 als er geen behoefte is en ga door naar het volgende thema. In dit geval is de oudere zelfstandig en is er geen verdere begeleiding nodig. Bijvoorbeeld, de oudere vertelt dat hij zijn eigen medicatie op succesvolle wijze beheert en geen last heeft van problematische bijwerkingen. Of de hulpverlener meldt dat de oudere zich prettig lijkt te voelen in zijn thuisomgeving en dat er geen veranderingen aan de woning nodig of gepland zijn.

- *Tegemoet gekomen behoefte*: Scoor een 1 als aan een behoefte tegemoetgekomen is of als het een minder grote behoefte betreft, die geen belangrijke interventie behoeft. Aan een behoefte is tegemoetgekomen als er sprake is van een licht, matig of serieus probleem, waarvoor een passende en mogelijk heilzame interventie ingezet is. Deze categorie wordt ook gebruikt voor problemen die normaal gesproken klinisch niet van belang zijn en waarop geen specifieke interventie ingezet wordt. Bijvoorbeeld, de oudere krijgt een beoordeling van haar slechte gezichtsvermogen of een verpleegkundige houdt iedere dag toezicht op het toedienen van medicatie.

- *Bestaande behoefte*: Scoor een 2 als een behoefte momenteel nog aanwezig is. Een bestaande behoefte is een serieus probleem dat interventie of beoordeling behoeft, waarvoor de oudere momenteel geen hulp ontvangt of het *verkeerde* soort of de verkeerde hoeveelheid hulp krijgt. Bijvoorbeeld, als een hulpverlener meldt dat de oudere incontinent is en iedere nacht grote hoeveelheden urine verliest, ondanks dat zij twee keer naar het toilet gaat en incontinentiemateriaal gebruikt. Dan wordt verdere beoordeling of een interventie noodzakelijk. Of een mantelzorger vertelt dat de oudere erg hardhorend is geworden en daar nog geen onderzoek naar is gedaan of geen passende hulpmiddelen heeft ontvangen.

Onbekend: Scoor een 9 als de geïnterviewde niet weet wat de aard van de problemen of de ontvangen ondersteuning is en ga door met het volgende thema. Een dergelijke score kan betekenen dat nadere informatie nodig is om tot een beoordeling te komen.

Voor ieder thema: als er bij sectie 1 een 1 of 2 gescoord is, vul dan sectie 2-4 in.

Als sectie 1 van het thema met een 0 of 9 beoordeeld wordt, vul dan niet sectie 2-4 in, maar ga door naar het volgende thema.

SECTIE 2

Deze sectie vraagt naar hulp door informele bronnen in de afgelopen maand. Onder informele bronnen worden verstaan familie, vrienden en buren. Gebruik de voorbeelden op het beoordelingsformulier om de geïnterviewde te helpen. Scoor een 1 als de hulp slechts zeer incidenteel of onregelmatig gegeven wordt. Scoor een 2 als de hulp regelmatiger is of meer tijd en moeite vergt. Scoor een 3 wanneer de hulp dagelijks wordt gegeven of intensief is (bijv. lange periodes van informele respijtzorg). Scoor een 4 als de hulp zeer intensief is en/of dagelijks wordt gegeven (bijv. de familie woont bij de oudere en helpt deze met de meeste taken). Scoor een 9 als de geïnterviewde niet zeker weet hoeveel hulp gegeven wordt.

SECTIE 3

i). In deze sectie wordt nagegaan of de oudere van de plaatselijke voorzieningen hulp ontvangt voor het probleem. Onder plaatselijke voorzieningen vallen betaalde verzorgenden, verzorgingshuis, verpleeghuis, formele respijtzorg, dagopvang, ziekenhuizen, sociaal psychiatrisch verpleegkundigen of andere hulpverleners. Gebruik de voorbeelden op het beoordelingsformulier om de geïnterviewde te helpen. Scoor een 1 bij minimale, incidentele of lichte hulp. Scoor een 2 voor regelmatiger hulp, bijvoorbeeld 1 keer per week, of voor incidentele zwaardere hulp. Scoor een 3 voor specialistische hulp, als een oudere momenteel wordt onderzocht, of regelmatige ondersteuning ontvangt. . Scoor een 9 als de geïnterviewde niet zeker weet hoeveel hulp gegeven wordt.
ii). In het tweede deel van sectie 3 wordt gevraagd welke typen formele hulp de interviewer vindt dat de oudere *nodig heeft*, waarbij dezelfde schaal als bij deel i). van sectie 3 wordt gebruikt. Dit tweede deel wijst op een onvoldoende tegemoetgekomen behoefte als de oudere minder hulp krijgt (deel i) dan hij nodig heeft (deel ii), of op een ruimschoots tegemoet gekomen behoefte als de oudere meer hulp krijgt (deel i) dan hij nodig heeft (deel ii).

SECTIE 4

i). In deze sectie wordt gevraagd of de geïnterviewde het idee heeft dat de oudere de juiste soort hulp krijgt voor het probleem. Het antwoord op deze vraag is misschien al duidelijk door de antwoorden bij de eerdere secties, met name sectie 1. Bij twijfel: stel specifiekere vragen. Deze sectie kan zowel bestaande behoeftes aan het licht brengen, alsook een *teveel* aan hulp, waarbij de geïnterviewde meldt dat de oudere meer hulp ontvangt dan hij nodig heeft.
ii). De tweede vraag van sectie 4 betreft de tevredenheid van de oudere met de hulp die hij ontvangt. Ook dit kan al duidelijk zijn door eerdere antwoorden, maar vraag het toch specifiek na.

SECTIE 5

In deze sectie kunnen individuele details van de beoordeling en de details van de hulp die de oudere ontvangt en nodig heeft (met name de aard van de geïdentificeerde bestaande behoeftes) genoteerd worden, zodat een actieplan geformuleerd kan worden. Problemen met huidige interventies of zorgplannen en voorziene veranderingen in zorgplannen moeten ook in deze sectie gedocumenteerd worden. Gebruik een code om aan te geven wie de informatie verstrekt heeft (bijv. O=oudere, M=mantelzorger, H=hulpverlener of B=beoordelaar). Het gezichtspunt van de ouderen met betrekking tot hun verwachtingen, persoonlijk(e) potentieel en middelen/hulpbronnen worden hier genoteerd, evenals persoonlijke spirituele en culturele informatie. Deze informatie is onmisbaar voor het opstellen van een individueel zorgplan.

SCORING

Hier moet opgemerkt worden dat het scoren een secundair aspect is van de CANE, omdat het primaire doel het identificeren en beoordelen van iemands bestaande behoeftes is. De CANE totaalscore is gebaseerd op de score in sectie 1 op elk van de 24 probleemgebieden. De twee probleemgebieden (A & B) die samenhangen met behoeften van de mantelzorger worden hier niet bij opgeteld. Tel van de maximaal 24 behoeftes het aantal tegemoetgekomen behoeftes bij elkaar op (gescoord als 1 in sectie 1). Tel het aantal bestaande behoeftes op (gescoord als 2 in sectie 1). Tel het totaal aantal geïdentificeerde behoeftes op (gescoord als 1 of 2 in sectie 1). De beoordelaars (artsen of onderzoekers) baseren hun oordeel op alle informatie die in de loop van de hele beoordeling (tijdens de verschillende interviews) is verzameld. De beoordelaarscore van sectie 1 vormt de basis voor de CANE totaalscore.

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- Actueel nieuws van Britse CANE onderzoekers vindt u op http://www.ucl.ac.uk/~rejugah/

01. WONEN	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON EEN GESCHIKTE PLAATS OM TE WONEN?				

Hoe is uw woonsituatie? Heeft u problemen met uw woonsituatie?

0 = GEEN BEHOEFTE	bijv.	Heeft een gepaste en geschikte woonsituatie (ook indien momenteel in ziekenhuis). Heeft geen behoefte aan hulp bij wonen.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	De woning wordt aangepast/ opgeknapt. Heeft hulp nodig en krijgt deze ook, bijvoorbeeld in een verzorgingshuis, beschermd wonen.
2 = BESTAANDE BEHOEFTE	bijv.	Dakloos, geen geschikt onderkomen, er ontbreken basisvoorzieningen zoals water, elektriciteit, verwarming of essentiële aanpassingen.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 2

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ HET WONEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Doen bij gelegenheid bijzondere klusjes of herstelwerkzaamheden.
2 = MATIGE HULP	bijv.	Aanzienlijke hulp bij het verbeteren van de woning, zoals het organiseren van opknapbeurt of bepaalde aanpassingen.
3 = VEEL HULP	bijv.	Woont bij een familielid, omdat de eigen woning niet voldoet.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ HET WONEN?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ HET WONEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Kleine herstelwerkzaamheden; verwijzing naar woningbouwvereniging, makelaar/ steunpunt wonen.
2 = MATIGE HULP	bijv.	Grote verbeteringen; actief organiseren van veranderingen in woonomstandigheden.
3 = VEEL HULP	bijv.	Moet naar een andere woonsituatie; woont in een verzorgingshuis, verpleeghuis.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ HET WONEN? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ BIJ HET WONEN ONTVANGT? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)				

OPMERKINGEN

	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
02. HUISHOUDEN				
HEEFT DE PERSOON PROBLEMEN MET HET HUISHOUDEN?	☐	☐	☐	☐

Kunt u zelf het huishouden doen? Helpt iemand u?

0 = GEEN BEHOEFTE	bijv.	Doet het huishouden zelfstandig. Het huis is misschien niet opgeruimd, maar wel schoon.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Kan maar beperkt voor het huis zorgen en heeft regelmatig huishoudelijke hulp.
2 = BESTAANDE BEHOEFTE	bijv.	Krijgt geen gepaste hulp bij het huishouden. De woning is een potentieel gevaar voor de gezondheid, brandveiligheid of vluchtmogelijkheid.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 3

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ HET HUISHOUDEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Spoort aan tot of helpt nu en dan opruimen of schoonmaken.
2 = MATIGE HULP	bijv.	Spoort aan tot of helpt schoonmaken, minstens één keer per week.
3 = VEEL HULP	bijv.	Doet bijna alle, of alle, huishoudelijke taken.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ HET HUISHOUDEN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ HET HUISHOUDEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Aansporing/ toezicht door professionals.
2 = MATIGE HULP	bijv.	Enige hulp bij huishoudelijke taken.
3 = VEEL HULP	bijv.	Huishouden wordt grotendeels door professionals gedaan.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ HET HUISHOUDEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HUISHOUDELIJKE HULP DIE HIJ ONTVANGT? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

03. VOEDING	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON PROBLEMEN MET HET KRIJGEN VAN VOLDOENDE VOEDING?				

Kunt u zelf uw maaltijden bereiden en uw eigen boodschappen doen? Krijgt u de juiste voeding?

0 = GEEN BEHOEFTE	bijv.	In staat om gepaste maaltijden te kopen en/ of te bereiden.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Niet in staat eten te bereiden, maar krijgt maaltijden of hulp om de behoefte te ondervangen.
2 = BESTAANDE BEHOEFTE	bijv.	Zeer beperkt dieet; eten past niet bij cultuur; kan niet het juiste voedsel verkrijgen; heeft moeite normaal voedsel door te slikken.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 4

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ HET KRIJGEN VAN VOLDOENDE VOEDING?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Wordt soms voorzien van een maaltijd en/of hulp bij boodschappen doen.
2 = MATIGE HULP	bijv.	Krijgt hulp bij wekelijkse boodschappen en/ of ontvangt meer dan één maal per week een maaltijd, maar niet dagelijks.
3 = VEEL HULP	bijv.	Wordt elke dag voorzien van een maaltijd.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ HET KRIJGEN VAN VOLDOENDE VOEDING?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN VOORZIENINGEN OM VOLDOENDE VOEDING TE KRIJGEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Ontvangt 1-4 maaltijden per week of hulp bij één maaltijd per week.
2 = MATIGE HULP	bijv.	Wordt meer dan 4 keer per week van een maaltijd voorzien of krijgt bij alle maaltijden hulp. Er worden wekelijks boodschappen gedaan
3 = VEEL HULP	bijv.	Wordt van alle maaltijden voorzien.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ HET KRIJGEN VAN VOLDOENDE VOEDING? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN OVER DE HOEVEELHEID HULP DIE HIJ ONTVANGT BIJ HET KRIJGEN VAN VOLDOENDE VOEDING? (0=NEE 1=JA 9=ONBEKEND)				

OPMERKINGEN

	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
04. ZELFZORG				
HEEFT DE PERSOON PROBLEMEN MET ZELFZORG?	☐	☐	☐	☐

Heeft u problemen met de persoonlijke verzorging, zoals wassen, nagels knippen of aankleden? Heeft u wel eens hulp nodig?

0 = GEEN BEHOEFTE	bijv.	Zorgt zelf voor een goed gekleed en verzorgd uiterlijk.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Heeft passende hulp nodig bij zelfzorg en krijgt deze.
2 = BESTAANDE BEHOEFTE	bijv.	Slechte persoonlijke hygiëne, kan zich niet wassen en aankleden en krijgt hierbij geen passende hulp.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 5

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ DE ZELFZORG?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Spoort aan (bijv. om kleren te verschonen) of helpt zo nu en dan.
2 = MATIGE HULP	bijv.	Regelmatige hulp, bijv. wekelijks of vaker.
3 = VEEL HULP	bijv.	Dagelijkse hulp bij zelfzorg bijv. bij aankleden, baden, wekelijkse was.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ DE ZELFZORG?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ DE ZELFZORG?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Zo nu en dan aansporing van een professional.
2 = MATIGE HULP	bijv.	Wekelijks toezicht op wassen en enkele andere onderdelen van de zelfzorg.
3 = VEEL HULP	bijv.	Toezicht op de meeste onderdelen van zelfzorg, bijna alle dagen begeleiding.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ DE ZELFZORG? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT BIJ DE ZELFZORG? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

05. VOOR IEMAND ANDERS ZORGEN	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
HEEFT DE PERSOON PROBLEMEN MET HET ZORGEN VOOR EEN ANDER?				

Zorgt u voor iemand? Heeft u problemen met het zorgen voor die persoon?

0 = GEEN BEHOEFTE	bijv.	Heeft niemand om voor te zorgen, of heeft geen problemen met zorgen.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Problemen met zorgen, maar krijgt hulp.
2 = BESTAANDE BEHOEFTE	bijv.	Grote problemen met het zorgen voor en verzorgen van de persoon.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 6

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ HET ZORGEN VOOR EEN ANDER				

0 = GEEN		
1 = WEINIG HULP	bijv.	Zo nu en dan hulp, minder dan eenmaal per week.
2 = MATIGE HULP	bijv.	Krijgt de meeste dagen hulp.
3 = VEEL HULP	bijv.	De persoon waarvoor wordt gezorgd verblijft bij vrienden of verwanten en heeft alle dagen begeleiding nodig.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ HET ZORGEN VOOR EEN ANDER?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ HET ZORGEN VOOR EEN ANDER?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Dagelijkse zorg; wekelijkse hulp thuis.
2 = MATIGE HULP	bijv.	Bijna dagelijks hulp thuis: doorlopende mantelzorg ondersteuning/ trainingsprogramma
3 = VEEL HULP	bijv.	Respijt zorg, 24-uurszorg of plannen voor opname in verzorgings-/ verpleegtehuis.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ HET ZORGEN VOOR EEN ANDER? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT BIJ HET ZORGEN VOOR EEN ANDER? (0 = NEE 1 = JA 9 = ONBEKEND)				

OPMERKINGEN

06. DAGBESTEDING	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.

HEEFT DE PERSOON PROBLEMEN MET REGELMATIGE, PASSENDE DAGBESTEDING?	☐	☐	☐	☐

Hoe brengt u de dag door? Heeft u genoeg te doen?

0 = GEEN BEHOEFTE	bijv.	Gepaste sociale-, werk- of vrijetijdsactiviteiten, kan eigen activiteiten organiseren.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Enigszins beperkt in zichzelf bezighouden, maar laat anderen passende activiteiten organiseren.
2 = BESTAANDE BEHOEFTE	bijv.	Geen gepaste sociale, werk- of vrijetijdsactiviteiten
9 = ONBEKEND		

INDIEN SCORE 0 OR 9 GA NAAR VRAAG 7

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ HET VINDEN EN BEHOUDEN VAN EEN GEPASTE DAGBESTEDING?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Zo nu en dan hulp bij het regelen van activiteiten.
2 = MATIGE HULP	bijv.	Minstens één maal per week hulp.
3 = VEEL HULP	bijv.	Dagelijkse hulp bij het regelen van activiteiten.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ HET VINDEN EN BEHOUDEN VAN REGELMATIGE EN GEPASTE DAGBESTEDING?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ HET VINDEN EN BEHOUDEN VAN REGELMATIGE EN GEPASTE DAGBESTEDING?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Volwasseneneducatie. Wekelijkse activiteiten.
2 = MATIGE HULP	bijv.	2-4 dagen per week dagbehandeling, dagverzorging- of ontmoetingscentrum.
3 = VEEL HULP	bijv.	5 of meer dagen per week aanbod van gepaste dagbesteding, bv. een dagbehandeling, dagverzorging- of ontmoetingscentrum.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP BIJ DAGBESTEDING? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT BIJ DAGBESTEDING? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

07. GEHEUGEN	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON PROBLEMEN MET ZIJN GEHEUGEN?				

Heeft u vaak moeite om u zich zaken die onlangs zijn voorgevallen te herinneren?
Vergeet u vaak waar u dingen heeft opgeborgen?

0 = GEEN BEHOEFTE	bijv.	Vergeet wel af en toe, maar herinnert het zich naderhand. Geen problemen met het geheugen.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Enige problemen, maar wordt onderzocht/ heeft hulp.
2 = BESTAANDE BEHOEFTE	bijv.	Duidelijk beperkt in het zich herinneren van nieuwe informatie: raakt dingen kwijt, is gedesoriënteerd in tijd en/of plaats. Krijgt geen passende begeleiding.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 8

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN IN VERBAND MET GEHEUGENPROBLEMEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Aansporing, af en toe briefjes, geheugensteuntjes.
2 = MATIGE HULP	bijv.	Meeste dagen hulp/ toezicht.
3 = VEEL HULP	bijv.	Woont bij een familielid. Voortdurend toezicht.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN LOKALE VOORZIENINGEN IN VERBAND MET GEHEUGENPROBLEMEN?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE VOORZIENINGEN IN VERBAND MET GEHEUGENPROBLEMEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Enig advies of hulp bij geheugen. Staat onder controle van de huisarts.
2 = MATIGE HULP	bijv.	Wordt onderzocht. Komt regelmatig bij hulpverlener in de gezondheidszorg, bijv. geheugenpolikliniek, dagbehandeling, specialist. Aangepaste omgeving.
3 = VEEL HULP	bijv.	Speciaal aangepaste zorg als gevolg van geheugenproblemen. Intensieve begeleiding.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
ONTVANGT DE PERSOON DE JUISTE HULP IN VERBAND MET GEHEUGENPROBLEMEN (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN OVER DE HOEVEELHEID ONTVANGEN HULP IN VERBAND MET GEHEUGENPROBLEMEN? (0 = NEE 1 = JA 9 = ONBEKEND)				

OPMERKINGEN

08. GEZICHTSVERMOGEN, GEHOOR & COMMUNICATIE	BEOORDELING Oudere Mantel. Prof. Beoord.

	Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON PROBLEMEN MET ZIEN OF HOREN?	☐	☐	☐	☐

Heeft u, in een stille kamer, moeite met het verstaan van wat iemand tegen u zegt?
Heeft u moeite met de krant lezen of televisie kijken? Kunt u duidelijk maken wat u bedoelt?

0 = GEEN BEHOEFTE	bijv.	Geen problemen (draagt misschien bril/ lenzen of gehoorapparaat, is zelfstandig).
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Enige problemen, maar de hulpmiddelen helpen enigszins. Ontvangt de juiste onderzoeken en/ of hulp bij het onderhouden van de hulpmiddelen.
2 = BESTAANDE BEHOEFTE	bijv.	Veel problemen met zien of horen, ontvangt geen gepaste begeleiding.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 9

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN VOOR PROBLEMEN MET ZIEN OF HOREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Hulp bij maken van afspraken voor problemen met zien of horen. Af en toe hulp.
2 = MATIGE HULP	bijv.	Regelmatige hulp bij moeilijke taken bijv. voorlezen van correspondentie.
3 = VEEL HULP	bijv.	Hulp bij de meeste taken die moeilijk zijn vanwege problemen met zien of horen.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET PROBLEMEN MET ZIEN OF HOREN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE PLAATSELIJKE VOORZIENINGEN IN VERBAND MET PROBLEMEN MET ZIEN OF HOREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Advies over stoornis; hulpmiddelen worden verstrekt en gecontroleerd.
2 = MATIGE HULP	bijv.	Onderzoek/ behandeling. Hulpmiddelen worden regelmatig gecontroleerd. Regelmatige hulp bij taken.
3 = VEEL HULP	bijv.	Meerdere keren per week hulp. Ziekenhuis afspraken/ specialistische hulp of gespecialiseerde dagbehandeling of dagkliniek.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
ONTVANGT DE PERSOON DE JUISTE HULP BIJ PROBLEMEN DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET PROBLEMEN MET ZIEN OF HOREN? (0=NEE 1=JA 9=ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET PROBLEMEN MET ZIEN OF HOREN? (0=NEE 1=JA 9=ONBEKEND)	☐			

OPMERKINGEN

09. MOBILITEIT/ VALLEN	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON BEWEGINGSBEPERKINGEN, VALNEIGINGEN OF PROBLEMEN BIJ GEBRUIK VAN OPENBAAR VERVOER?	☐	☐	☐	☐

Heeft u moeite u binnenshuis te verplaatsen? Valt u wel eens?
Heeft u problemen met transport?

0 = GEEN BEHOEFTE	bijv.	Gezond en mobiel.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Enige moeite met lopen, traplopen of gebruik van openbaar vervoer, maar functioneert met hulp (bijv. stok, looprek, rollator). Valt af en toe. Veiligheidsplan aanwezig.
2 = BESTAANDE BEHOEFTE	bijv.	Zeer bewegingsbeperkt, zelfs met hulpmiddel. Valt meerdere keren per maand. Passende hulp ontbreekt.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 10

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN IN VERBAND MET MOBILITEITSBEHOEFTE?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Zo nu en dan hulp bij bijv. vervoer.
2 = MATIGE HULP	bijv.	Regelmatige hulp bij verplaatsen/ openbaar vervoer. Hulp bij organiseren van woningaanpassingen.
3 = VEEL HULP	bijv.	Dagelijkse hulp en toezicht bij verplaatsen/ vervoer.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET MOBILITEITSBEHOEFTE?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET MOBILITEITSBEHOEFTE?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Advies: een of meer hulpmiddelen.
2 = MATIGE HULP	bijv.	Ondergaat momenteel onderzoek en/ of ergotherapeutische / fysiotherapeutische beoordeling. Regelmatig vervoer bijv. naar dagcentrum.
3 = VEEL HULP	bijv.	Volledig aangepast huis en hulpmiddelen. Meeste dagen hulp. Opname in verzorgingshuis wegens mobiliteitsbehoefte.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP VOOR ZIJN MOBILITEITSBEHOEFTE? (0=NEE 1=JA 9=ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN OVER DE HOEVEELHEID HULP DIE HIJ ONTVANGT VANWEGE MOBILITEITSBEHOEFTE? (0=NEE 1=JA 9=ONBEKEND)	☐			

OPMERKINGEN

10. CONTINENTIE	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
IS DE PERSOON INCONTINENT?				

Heeft u wel eens een ongelukje/ dat u nat bent als u niet snel genoeg bij de toilet bent? (Hoe groot is het probleem? Ook wel ontlasting? Krijgt u enige hulp?)

0 = GEEN BEHOEFTE	bijv.	Geen incontinentie. Zelfstandig in het omgaan met incontinentie.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Enige incontinentie. Ontvangt gepaste hulp/ onderzoek.
2 = BESTAANDE BEHOEFTE	bijv.	Regelmatig nat of bevuild. Verslechterende continentie, wat beoordeling behoeft.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 11

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN IN VERBAND MET INCONTINENTIE?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Aansporingen om continent te blijven.
2 = MATIGE HULP	bijv.	Ontvangt regelmatig hulp met de was, hygiëne en gebruik van incontinentiemateriaal/ hulpmiddelen.
3 = VEEL HULP	bijv.	Volledige hulp bij continentie (was, hygiëne, hulpmiddelen).
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN LOKALE VOORZIENINGEN IN VERBAND MET INCONTINENTIE?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE VOORZIENINGEN IN VERBAND MET INCONTINENTIE?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Aansporingen om continent te blijven en voorzien van incontinentiemateriaal.
2 = MATIGE HULP	bijv.	Onderzoek/ behandeling. Regelmatige hulp bij de was, hygiëne en hulpmiddelen.
3 = VEEL HULP	bijv.	Geplande medische ingreep (bijv. operatie). Voortdurende zorg en begeleiding als gevolg van incontinentie (b.v. verzorgingshuis). Gedegen continentieplan aanwezig.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP VOOR INCONTINENTIE? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN OVER DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET INCONTINENTIE? (0 = NEE 1 = JA 9 = ONBEKEND)				

OPMERKINGEN

11. LICHAMELIJKE GEZONDHEID	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
LIJDT DE PERSOON AAN EEN LICHAMELIJKE ZIEKTE?	☐	☐	☐	☐

Hoe voelt u zich lichamelijk?
Wordt u door uw dokter behandeld voor lichamelijke problemen?

0 = GEEN BEHOEFTE	bijv.	Lichamelijk gezond. Ontvangt geen medische interventies.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Lichamelijke kwaal, zoals hoge bloeddruk, is onder controle, ontvangt gepaste behandeling. Beoordelingen van de fysieke toestand.
2 = BESTAANDE BEHOEFTE	bijv.	Onbehandelde ernstige lichamelijke kwaal. Veel pijn. Wacht op grote medische ingreep.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 12

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ LICHAMELIJKE GEZONDHEIDSPROBLEMEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Maakt afspraken voor doktersbezoek.
2 = MATIGE HULP	bijv.	Regelmatig begeleid naar dokter/ ziekenhuis.
3 = VEEL HULP	bijv.	Dagelijkse hulp in situatie die is ontstaan door lichamelijke gezondheidsproblemen, bijv. bij een familielid wonen tijdens herstel of ziekte.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET LICHAMELIJKE GEZONDHEIDSPROBLEMEN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET LICHAMELIJKE GEZONDHEIDSPROBLEMEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Dieet of gezondheidsadvies. Nu en dan bezoek aan huisarts voor medicatie.
2 = MATIGE HULP	bijv.	Voorgeschreven medicatie. Wordt regelmatig gezien door professional uit gezondheidszorg (huisarts, verpleegkundige, personeel dagbehandeling, polikliniek)
3 = VEEL HULP	bijv.	Opname, 24-uurs verpleeghuiszorg. Zeer regelmatige of intensieve behandeling.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE ZORG VOOR LICHAMELIJKE GEZONDHEIDSPROBLEMEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR LICHAMELIJKE GEZONDHEIDSPROBLEMEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

NB Let op mondhygiëne, huidverzorging en voetverzorging, met name bij mensen die erg kwetsbaar zijn of chronische medische aandoeningen hebben.

12. MEDICATIE

BEOORDELING
Oudere Mantel. Prof. Beoord.

HEEFT DE PERSOON PROBLEMEN MET MEDICIJNEN? ☐ ☐ ☐ ☐

Heeft u problemen (bijv. bijwerkingen) met medicatie? Hoeveel verschillende medicijnen gebruikt u? Is uw medicatie onlangs nog beoordeeld door uw dokter? Gebruikt u medicijnen die niet zijn voorgeschreven?

0 = GEEN BEHOEFTE	bijv.	Geen probleem met medicijninname, bijwerkingen, medicatiemisbruik of afhankelijkheid.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Regelmatige beoordeling medicatie, advies, wijkverpleegkundige, huisarts, doseringsdoos/ hulpmiddelen
2 = BESTAANDE BEHOEFTE	bijv.	Slechte inname medicijnen, neemt te veel of te weinig. Afhankelijk of misbruik van voorgeschreven of niet-voorgeschreven middelen.
9 = ONBEKEND		

INDIEN SCORE 0 OF 9 GA NAAR VRAAG 13

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF VERWANTEN BIJ DE MEDICATIE? ☐ ☐ ☐ ☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Zo nu en dan aansporing. Advies over verkeerd medicatiegebruik.
2 = MATIGE HULP	bijv.	Ophalen, regelmatige herinnering en checken van medicatie. Advies over hulpvoorzieningen.
3 = VEEL HULP	bijv.	Medicatie wordt toegediend en beheerd. Ondersteuning tijdens afbouwprogramma.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN BIJ ZIJN MEDICATIE? ☐ ☐ ☐ ☐

HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ ZIJN MEDICATIE? ☐ ☐ ☐ ☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Advies van huisarts. Aanmoediging om medicatie te nemen.
2 = MATIGE HULP	bijv.	Toezicht door wijkverpleegkundige/ dagbehandeling.
3 = VEEL HULP	bijv.	Dagelijkse toediening van medicatie. Afbouwprogramma onder toezicht.
9 = ONBEKEND		

ONTVANGT DE PERSOON DE JUISTE HULP IN VERBAND MET ZIJN MEDICATIE? (0 = NEE 1 = JA 9 = ONBEKEND) ☐ ☐ ☐ ☐

IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET ZIJN MEDICATIE? (0 = NEE 1 = JA 9 = ONBEKEND) ☐

OPMERKINGEN

13. PSYCHOTISCHE SYMPTOMEN	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON SYMPTOMEN ZOALS WANEN, HALLUCINATIES, FORMELE DENKSTOORNISSEN OF PASSIVITEIT?	☐	☐	☐	☐

Heeft u ooit stemmen gehoord, vreemde dingen gezien, of problemen met uw denken?
Gebruikt u hiervoor medicatie?

0 = GEEN BEHOEFTE	bijv.	Geen vaststelbare symptomen. Geen risico voor of in nood door symptomen en geen medicatie voor psychotische symptomen
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Symptomen verlicht door medicatie of andere hulp, bijvoorbeeld omgangsstrategieën, veiligheidsplan.
2 = BESTAANDE BEHOEFTE	bijv.	Heeft momenteel symptomen of risico daarop.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 14

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR DEZE PSYCHOTISCHE SYMPTOMEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Enige ondersteuning.
2 = MATIGE HULP	bijv.	Mantelzorgers helpen met copingstrategieën of trouwe inname van medicatie.
3 = VEEL HULP	bijv.	Voortdurend toezicht op medicatie en hulp bij coping strategieën.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN LOKALE VOORZIENINGEN VOOR DEZE PSYCHOTISCHE SYMPTOMEN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE VOORZIENINGEN VOOR DEZE PSYCHOTISCHE SYMPTOMEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Psychische status en medicatie worden elke 3 maanden, of minder, bekeken. Ondersteuningsgroep.
2 = MATIGE HULP	bijv.	Psychische status en medicatie vaker dan om de 3 maanden bekeken. Frequente toegespitste therapie bijv. dagbehandeling/ zorg, veel inzet sociaal psychiatrisch verpleegkundige.
3 = VEEL HULP	bijv.	Actieve behandeling/ 24 uurs ziekenhuiszorg, dagelijkse dagbehandeling of crisiszorg thuis.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP VOOR DEZE SYMPTOMEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR DEZE SYMPTOMEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

14. PSYCHISCHE NOOD	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
IS DE PERSOON MOMENTEEL IN PSYCHISCHE NOOD?	☐	☐	☐	☐

Heeft u zich onlangs somber gevoeld of dat u het zat was? Heeft u zich heel angstig, bang of bezorgd gevoeld?

0 = GEEN BEHOEFTE	bijv.	Incidentele of milde spanning. Kan hier zelfstandig mee omgaan.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Heeft doorlopend hulp nodig en krijgt deze.
2 = BESTAANDE BEHOEFTE	bijv.	Spanning tast leven wezenlijk aan, bijv. verhindert persoon om buiten te komen
9 = ONBEKEND		

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HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR DEZE NOOD?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Enig medeleven en steun.
2 = MATIGE HULP	bijv.	Heeft tenminste de mogelijkheid wekelijks om over nood te praten en hulp te krijgen bij copingstrategieën.
3 = VEEL HULP	bijv.	Voortdurende hulp en supervisie.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN VOOR DEZE NOOD?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN VOOR DEZE NOOD?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Beoordeling van psychische status of incidentele hulp.
2 = MATIGE HULP	bijv.	Specifieke psychologische of sociale interventie voor angst. Counseling door hulpverlener tenminste eens per week bijv. op een polikliniek.
3 = VEEL HULP	bijv.	24 uurs ziekenhuiszorg, of crisiszorg thuis
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP VOOR DEZE NOOD? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR DEZE NOOD? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

15. INFORMATIE (OVER GEZONDHEIDSTOESTAND & BEHANDELING)	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON DUIDELIJKE VERBALE OF GESCHREVEN INFORMATIE OVER ZIJN GEZONDHEIDSTOESTAND EN BEHANDELING GEKREGEN?	☐	☐	☐	☐

Heeft u duidelijke informatie over uw toestand, medicatie of andere behandeling gekregen? Wenst u dergelijke informatie? Hoe nuttig is de informatie geweest?

0 = GEEN BEHOEFTE	bijv.	Heeft adequate informatie, ontvangen en begrepen. Heeft geen informatie ontvangen maar wil deze ook niet.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Krijgt hulp om de informatie te begrijpen. De gegeven informatie sluit aan op het communicatie/ begripsniveau van dat van de oudere.
2 = BESTAANDE BEHOEFTE	bijv.	Heeft inadequate of geen informatie ontvangen.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 16

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE IN HET VERKRIJGEN VAN INFORMATIE?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Een beetje advies.
2 = MATIGE HULP	bijv.	Folders ontvangen of in contact gebracht met een zelfhulpgroep.
3 = VEEL HULP	bijv.	Regelmatig contact met GGZ werker of vrijwilligersgroep (bijv. Alzheimer stichting) door vrienden en familieleden.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN OM DEZE INFORMATIE TE VERKRIJGEN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE VOORZIENINGEN OM DEZE INFORMATIE TE VERKRIJGEN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Beknopte verbale of geschreven informatie over ziekte/ probleem/ behandeling.
2 = MATIGE HULP	bijv.	Informatie over zelfhulpgroep. Uitgebreide mondelinge informatie sessies bijv. gedurende poliklinisch bezoek.
3 = VEEL HULP	bijv.	Heeft specifieke persoonlijke educatie gekregen met of zonder gedetailleerde schriftelijke informatie.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP OM INFORMATIE TE VERKRIJGEN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR HET VERKRIJGEN VAN INFORMATIE? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

16. OPZETTELIJK GEVAAR VOOR ZICHZELF	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
IS DE PERSOON EEN GEVAAR VOOR ZICHZELF?	☐	☐	☐	☐

Denkt u er ooit over om uzelf kwaad te doen of doet u zich daadwerkelijk kwaad?

0 = GEEN BEHOEFTE	bijv.	Geen gedachten over gevaarlijk gedrag of zelfmoord/ suïcide.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Suïciderisico wordt in de gaten gehouden door hulpverlener, krijgt gesprekken.
2 = BESTAANDE BEHOEFTE	bijv.	Uit zelfmoordneigingen, verwaarloost zichzelf opzettelijk of heeft zich de laatste maand aan groot gevaar blootgesteld.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 17

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE OM RISICO OP OPZETTELIJK GEVAARLIJK GEDRAG TE VERMINDEREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Kan contact opnemen met vrienden of familie indien hij zich onveilig voelt.
2 = MATIGE HULP	bijv.	Vrienden of familie houden gewoonlijk contact en weten vermoedelijk wanneer hij zich onveilig voelt.
3 = VEEL HULP	bijv.	Vrienden of familie houden regelmatig contact, weten vermoedelijk wanneer hij zich onveilig voelt en bieden hulp.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN OM RISICO OP OPZETTELIJK GEVAARLIJK GEDRAG TE VERMINDEREN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN OM RISICO OP OPZETTELIJK GEVAARLIJK GEDRAG TE VERMINDEREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Iemand te contacteren bij onveilig gevoel.
2 = MATIGE HULP	bijv.	Hulpverlener checkt tenminste eens per week: regelmatige ondersteunende counseling.
3 = VEEL HULP	bijv.	Dagelijks toezicht: opgenomen.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP OM HET RISICO OP GEVAAR VOOR ZICHZELF TE VERMINDEREN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT OM HET RISICO OP GEVAAR VOOR ZICHZELF TE VERMINDEREN? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

17. ONOPZETTELIJK GEVAAR VOOR ZICHZELF	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
IS DE PERSOON ONBEDOELD EEN GEVAAR VOOR ZICHZELF?				

Doet u ooit iets dat uzelf onbedoeld in gevaar brengt? (bijv. gas aanlaten, vuur onbewaakt laten of verdwalen)?

0 = GEEN BEHOEFTE	bijv.	Geen onopzettelijk gevaar voor zichzelf.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Specifiek toezicht of hulp om gevaar te voorkomen: bijv. geheugensteuntjes, aansporingen, veilige omgeving en/ of observatie.
2 = BESTAANDE BEHOEFTE	bijv.	Frequent gevaarlijk gedrag, bijv. verdwalen, gas/ brandrisico.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 18

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE OM HET RISICO VAN ONBEDOELD GEVAARLIJK GEDRAG TE VERMINDEREN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Periodiek toezicht: wekelijks of minder.
2 = MATIGE HULP	bijv.	3-5 dagen per week toezicht.
3 = VEEL HULP	bijv.	Vrijwel voortdurend toezicht / 24 uurs-zorg.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN OM HET RISICO OP ONBEDOELD GEVAARLIJK GEDRAG TE VERMINDEREN?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN OM HET RISICO OP ONBEDOELD GEVAARLIJK GEDRAG TE VERMINDEREN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Het gedrag wordt wekelijks of minder vaak gecheckt.
2 = MATIGE HULP	bijv.	Dagelijks toezicht.
3 = VEEL HULP	bijv.	Voortdurend toezicht bijv. in verzorgingshuis.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP OM HET RISICO OP ONBEDOELD GEVAARLIJK GEDRAG TE VERMINDEREN? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN, TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT OM HET RISICO OP ONBEDOELD GEVAARLIJK GEDRAG TE VERMINDEREN? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)				

OPMERKINGEN

18. MISBRUIK EN VERWAARLOZING	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
LOOPT DE PERSOON EEN RISICO DOOR ANDEREN?				

Heeft iemand iets gedaan om u bang te maken, u kwaad te doen of van u te profiteren?

0 = GEEN BEHOEFTE	bijv.	Geen misbruik of verwaarlozing in de laatste maand.
1 = TEGEMOET GEKOMEN BEHOEFTE	bijv.	Behoeft en krijgt voortdurend steun of bescherming.
2 = BESTAANDE BEHOEFTE	bijv.	Regelmatig schreeuwen, duwen of verwaarlozing. Onrechtmatig toe-eigenen van geld, fysiek geweld/ bedreiging.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 19

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE OM HET RISICO OP MISBRUIK/ MISHANDELING TE VERMINDEREN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Incidenteel advies.
2 = MATIGE HULP	bijv.	Regelmatige steun en bescherming.
3 = VEEL HULP	bijv.	Voortdurend toezicht: veel bescherming: onderhandeling.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE DIENSTEN OM HET RISICO OP MISBRUIK/ MISHANDELING TE VERMINDEREN?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE DIENSTEN OM HET RISICO OP MISBRUIK/ MISHANDELING TE VERMINDEREN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Wekelijks of minder vaak hulp/ toezicht.
2 = MATIGE HULP	bijv.	Meer dan wekelijks hulp/ toezicht.
3 = VEEL HULP	bijv.	Vrijwel doorlopend hulp/ toezicht als gevolg van aanhoudend storend gedrag.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP OM HET RISICO VAN MISBRUIK/ MISHANDELING TE VERMINDEREN? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT OM HET RISICO VAN MISBRUIK / MISHANDELING TE VERMINDEREN? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)				

OPMERKINGEN

19. GEDRAG	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
IS HET GEDRAG VAN DE PERSOON GEVAARLIJK, BEDREIGEND, BEMOEIZUCHTIG OF STOREND VOOR ANDEREN?	☐	☐	☐	☐

Komt u in conflict met anderen b.v. door bemoeienis met hun zaken, ze regelmatig te ergeren, te bedreigen of te storen? Wat gebeurt er dan?

0 = GEEN BEHOEFTE	bijv	Heeft geen geschiedenis van storend gedrag.
1 = TEGEMOET GEKOMEN BEHOEFTE	bijv.	Onder toezicht of behandeling vanwege mogelijk risico.
2 = BESTAANDE BEHOEFTE	bijv.	Recent geweld, dreigementen of zeer bemoeizuchtig gedrag.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 20

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE OM HET RISICO VAN ERGERLIJK OF STOREND GEDRAG TE VERMINDEREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Wekelijks of minder vaak hulp/ toezicht.
2 = MATIGE HULP	bijv.	Meer dan eenmaal per week hulp/ toezicht.
3 = VEEL HULP	bijv.	Vrijwel doorlopend hulp/ toezicht als gevolg van aanhoudend storend gedrag.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN OM HET RISICO VAN ERGERLIJK OF STOREND GEDRAG TE VERMINDEREN?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN OM HET RISICO VAN ERGERLIJK OF STOREND GEDRAG TE VERMINDEREN?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Wekelijks of minder vaak controleren van gedrag.
2 = MATIGE HULP	bijv.	Toezicht overdag of oppas ’s nachts.
3 = VEEL HULP	bijv.	Voortdurend toezicht: gedragsbeïnvloedingprogramma.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP OM HET RISICO OP ERGERLIJK OF STOREND GEDRAG TE VERMINDEREN? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT OM HET RISICO OP ERGERLIJK OF STOREND GEDRAG TE VERMINDEREN? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

20. ALCOHOL	BEOORDELING				
	Oudere	Mantel.	Prof.	Beoord.	

DRINKT DE PERSOON BUITENSPORIG VEEL OF HEEFT HIJ EEN PROBLEEM MET HET ONDER CONTROLE HOUDEN VAN DRANKGEBRUIK?	☐	☐	☐	☐

Drinkt u alcohol? Hoeveel? Heeft u problemen met drinken? Voelt u zich daar ooit schuldig over? Wenst u wel eens dat u uw drankgebruik kon minderen?

0 = GEEN BEHOEFTE	bijv.	Drinkt niet of gecontroleerd.
1 = TEGEMOET GEKOMEN BEHOEFTE	bijv.	Loopt risico op alcoholmisbruik en ontvangt hulp.
2 = BESTAANDE BEHOEFTE	bijv.	Huidig drinkgedrag schadelijk of oncontroleerbaar. Krijgt geen passende hulp.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 21

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR HET DRANKGEBRUIK?	☐	☐	☐	☐

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Geadviseerd om te stoppen
2 = MATIGE HULP	bijv.	Geadviseerd over hulpinstanties, bijv. Anonieme Alcoholisten.
3 = VEEL HULP	bijv.	Voortdurende steun en/ of controle van alcoholinname.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN LOKALE VOORZIENINGEN IN VERBAND MET DRANKGEBRUIK?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN LOKALE VOORZIENINGEN IN VERBAND MET DRANKGEBRUIK?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Informatie gegeven en verteld over de risico's
2 = MATIGE HULP	bijv.	Hulp gegeven en details van hulpinstanties. Er is toezicht op het verkrijgen van drank.
3 = VEEL HULP	bijv.	Bezoekt de verslavingskliniek, afkickprogramma onder toezicht
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP IN VERBAND MET DRANKGEBRUIK? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET DRANKGEBRUIK? (0 = NEE 1 = JA 9 = ONBEKEND)	☐			

OPMERKINGEN

21. GEZELSCHAP	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
HEEFT DE PERSOON HULP NODIG BIJ SOCIAAL CONTACT				

Bent u gelukkig met uw sociale leven? Zou u willen dat u meer sociaal contact had?

0 = GEEN BEHOEFTE	bijv.	In staat om voldoende sociaal contact te arrangeren, heeft voldoende contact met vrienden.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Het gebrek aan contact wordt als probleem gezien. Krijgt ondersteuning vanwege behoefte aan gezelschap, b.v. is ’s avonds eenzaam, maar bezoekt inloop- of dagcentra etc. Inmenging van maatschappelijk werk.
2 = BESTAANDE BEHOEFTE	bijv.	Voelt zich vaker eenzaam en geïsoleerd. Heel weinig sociale contacten
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 22

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR SOCIALE CONTACTEN?				

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Vrienden helpen met sociaal contact of komen minder dan 1 keer in de week langs om iemand gezelschap te houden.
2 = MATIGE HULP	bijv.	Wekelijks of vaker sociaal contact.
3 = VEEL HULP	bijv.	Tenminste 4 keer per week sociaal contact.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN VOOR SOCIALE CONTACTEN?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN VOOR SOCIALE CONTACTEN?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Incidenteel bezoek van een vrijwilliger. Verwijzing naar dagcentrum.
2 = MATIGE HULP	bijv.	Regelmatig bezoek dagcentrum: regelmatige lunch club, georganiseerde sociale activiteit.
3 = VEEL HULP	bijv.	Bezoekt dagcentrum of sociaal huisbezoek 3 keer of vaker per week. Sociale vaardigheidstraining, contact met een maatschappelijk werker.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP VOOR SOCIALE CONTACTEN? (0 = NEE 1 = JA 9 = ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR SOCIALE CONTACTEN? (0 = NEE 1 = JA 9 = ONBEKEND)				

OPMERKINGEN

22. INTIEME RELATIES	BEOORDELING Oudere	Mantel.	Prof.	Beoord.
HEEFT DE PERSOON EEN PARTNER, VERWANTE OF VRIEND MET WIE HIJ EEN INTIEME/ HECHTE EMOTIONELE/ FYSIEKE RELATIE HEEFT?				

Heeft u een partner, verwante of vriend met wie u zich verbonden voelt? Kunt u goed met ze opschieten? Kunt u spreken over uw zorgen en problemen? Ontbreekt het u aan fysiek contact/ intimiteit?

0 = GEEN BEHOEFTE	bijv.	Gelukkig met huidige relaties of wil geen intieme relatie.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Counseling/ advies, dat behulpzaam is.
2 = BESTAANDE BEHOEFTE	bijv.	Wanhopig eenzaam. Gebrek aan vertrouweling.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 23

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR INTIEME RELATIES OF EENZAAMHEID?				

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Incidentele emotionele steun.
2 = MATIGE HULP	bijv.	Regelmatige steun.
3 = VEEL HULP	bijv.	Hulp bij contact leggen met adviesbureau (bijv. voor relatietherapie en rouwverwerking en mogelijk het vergezellen van de persoon daar naartoe.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET INTIEME RELATIES OF EENZAAMHEID?				
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN IN VERBAND MET INTIEME RELATIES OF EENZAAMHEID?				

0 = GEEN		
1 = WEINIG HULP	bijv.	Enige steun/ advies.
2 = MATIGE HULP	bijv.	Regelmatige steun/ advies.
3 = VEEL HULP	bijv.	Intensieve steun. Specifieke therapie. bijv. relatietherapie/ rouwverwerking.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
ONTVANGT DE PERSOON HET JUISTE TYPE HULP IN VERBAND MET INTIEME RELATIES OF EENZAAMHEID? (0=NEE 1=JA 9=ONBEKEND)				
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT IN VERBAND MET INTIEME RELATIES OF EENZAAMHEID? (0=NEE 1=JA 9=ONBEKEND)				

OPMERKINGEN

23. GELD	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
HEEFT DE PERSOON PROBLEMEN OM ZIJN GELD TE BEHEREN OF TE BUDGETTEREN?	☐	☐	☐	☐

Heeft u problemen om uw geld te beheren? Kunt u uw rekeningen betalen?

0 = GEEN BEHOEFTE	bijv.	In staat om noodzakelijke goederen te kopen en rekeningen te betalen.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Profiteert van hulp bij het beheren en budgetteren van geld.
2 = BESTAANDE BEHOEFTE	bijv.	Heeft geen geld voor noodzakelijke goederen of rekeningen. Niet in staat om financiële zaken te regelen.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG 24

HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR HET BEHEREN VAN ZIJN GELD?	☐	☐	☐	☐

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Incidentele hulp bij het uitzoeken huishoudelijke rekeningen.
2 = MATIGE HULP	bijv.	Berekenen van weekbudget. Opnemen van pensioen/ gelden.
3 = VEEL HULP	bijv.	Volledig financiële curatele. Volmacht.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN VOOR HET BEHEREN VAN ZIJN GELD?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN VOOR HET BEHEREN VAN ZIJN GELD?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Incidentele hulp bij budget opstellen.
2 = MATIGE HULP	bijv.	Krijgt toezicht bij betalen van de huur, krijgt een weekbudget.
3 = VEEL HULP	bijv.	Nagenoeg volledig financieel beheer: rechterlijke curatele: permanente volmacht.
9 = ONBEKEND		

ONTVANGT DE PERSOON HET JUISTE TYPE HULP VOOR HET BEHEREN VAN ZIJN GELD? (0 = NEE 1 = JA 9= ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR HET BEHEREN VAN ZIJN GELD? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

24. TOELAGEN / UITKERINGEN	BEOORDELING Oudere Mantel. Prof. Beoord.

	Oudere	Mantel.	Prof.	Beoord.
ONTVANGT DE PERSOON ECHT ALLE TOELAGEN/ UITKERINGEN WAAR HIJ RECHT OP HEEFT?	☐	☐	☐	☐

Weet u zeker dat u al het geld krijgt waar u recht op heeft?

0 = GEEN BEHOEFTE	bijv.	Heeft geen behoefte aan uitkeringen of ontvangt alles waarop men recht heeft.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Krijgt adequate hulp bij het vorderen van aanvraag uitkeringen.
2 = BESTAANDE BEHOEFTE	bijv.	Onzeker/ ontvangt niet alle gelden waarop men recht heeft.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR SECTIE MANTELZORGER

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN VRIENDEN OF FAMILIE VOOR HET VERKRIJGEN VAN ALLE TOELAGEN/ UITKERINGEN WAAROP MEN RECHT HEEFT?	☐	☐	☐	☐

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Er wordt incidenteel gevraagd of de persoon gelden ontvangt.
2 = MATIGE HULP	bijv.	Informeren naar rechten en helpen bij het invullen van formulieren
3 = VEEL HULP	bijv.	Er is voor gezorgd dat alle toelagen/ uitkeringen worden ontvangen.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
HOEVEEL HULP ONTVANGT DE PERSOON VAN PLAATSELIJKE VOORZIENINGEN VOOR HET VERKRIJGEN VAN ALLE TOELAGEN/ UITKERINGEN WAAROP MEN RECHT HEEFT?	☐	☐	☐	☐
HOEVEEL HULP HEEFT DE PERSOON NODIG VAN PLAATSELIJKE VOORZIENINGEN VOOR HET VERKRIJGEN VAN ALLE TOELAGEN/ UITKERINGEN WAAROP MEN RECHT HEEFT?	☐	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Incidenteel advies over rechten.
2 = MATIGE HULP	bijv.	Hulp bij het aanvragen van extra uitkeringen.
3 = VEEL HULP	bijv.	Inzichtelijk overzicht van het huidige rechten.
9 = ONBEKEND		

	Oudere	Mantel.	Prof.	Beoord.
ONTVANGT DE PERSOON HET JUISTE TYPE HULP VOOR HET VERKRIJGEN VAN ALLE TOELAGEN/ UITKERINGEN WAAROP MEN RECHT HEEFT? (0 = NEE 1 = JA 9 = ONBEKEND)	☐	☐	☐	☐
IS DE PERSOON OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR HET VERKRIJGEN VAN ALLE TOELAGEN/ UITKERINGEN WAAROP MEN RECHT HEEFT? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☐			

OPMERKINGEN

A. INFORMATIEBEHOEFTE MANTELZORGER	BEOORDELING Oudere	 Mantel.	 Prof.	 Beoord.
HEEFT DE MANTELZORGER HELDERE INFORMATIE ONTVANGEN OVER DE GEZONDHEID VAN DE PERSOON EN BESCHIKBARE BEHANDELINGEN?	☒	☐	☐	☐

Heeft u duidelijke informatie gekregen over de gezondheid van X en de beschikbare behandelingen en voorzieningen? Hoe nuttig is deze informatie geweest?

0 = GEEN BEHOEFTE	bijv.	Ontvangen en begrepen.
1 = TEGEMOETGEKOMEN BEHOEFTE	bijv.	Heeft niet alle informatie gekregen of begrepen. Krijgt hulp met informatie.
2 = BESTAANDE BEHOEFTE	bijv.	Heeft weinig of geen informatie gekregen. Heeft de informatie niet begrepen.
9 = ONBEKEND		

INDIEN 0 OF 9 GA NAAR VRAAG B

HOEVEEL HULP ONTVANGT DE MANTELZORGER VAN VRIENDEN OF FAMILIE BIJ HET VERKRIJGEN VAN ZULKE INFORMATIE?	☒	☐	☐	☐

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Heeft wat advies gekregen.
2 = MATIGE HULP	bijv.	Heeft folders gekregen of is in contact gebracht met zelfhulpgroepen.
3 = VEEL HULP	bijv.	Regelmatig contact met dokters, andere professionals, zelfhulpgroep of hulp van vrienden en familie.
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE MANTELZORGER VAN PLAATSELIJKE VOORZIENINGEN BIJ HET VERKRIJGEN VAN ZULKE INFORMATIE?	☒	☐	☐	☐
HOEVEEL HULP HEEFT DE MANTELZORGER NODIG VAN PLAATSELIJKE VOORZIENINGEN BIJ HET VERKRIJGEN VAN ZULKE INFORMATIE?	☒	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Korte mondelinge of schriftelijke informatie over de gezondheidstoestand/ probleem/ behandeling.
2 = MATIGE HULP	bijv.	Informatie gegeven over zelfhulpgroepen. Persoonlijke uitleg over medicatie, alternatieve behandelingen/ instanties en te verwachten beloop van de gezondheidstoestand.
3 = VEEL HULP	bijv.	Gedetailleerde schriftelijke informatie gegeven of heeft specifieke individuele educatie ontvangen: b.v. van een centrale hulpverlener.
9 = ONBEKEND		

ONTVANGT DE MANTELZORGER HET JUISTE TYPE HULP BIJ HET VERKRIJGEN VAN ZULKE INFORMATIE? (0 = NEE 1 = JA 9 = ONBEKEND)	☒	☐	☐	☐
IS DE MANTELZORGER OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT BIJ HET VERKRIJGEN VAN ZULKE INFORMATIE? (0 = NIET TEVREDEN 1 = TEVREDEN 9 = ONBEKEND)	☒			

OPMERKINGEN

B. PSYCHISCHE NOOD MANTELZORGER	BEOORDELING			
	Oudere	Mantel.	Prof.	Beoord.
HEEFT DE MANTELZORGER MOMENTEEL PSYCHISCHE NOOD?	☒	☐	☐	☐

Vindt u het moeilijk of belastend om voor X te zorgen? Heeft u behoefte aan een rustperiode of aan veel meer steun voor uzelf?

0 = GEEN BEHOEFTE	bijv.	Gaat er goed mee om.
1 = TEGEMOET GEKOMEN BEHOEFTE	bijv.	Enige belasting: ontvangt hulp/ contact/ steun die ook daadwerkelijk helpt.
2 = BESTAANDE BEHOEFTE	bijv.	Beschouwt zichzelf zeer belast of gedeprimeerd. Wil ondersteund worden in de zorg.
9 = ONBEKEND		

INDIEN 0 OF 9 EINDIG

HOEVEEL HULP ONTVANGT DE MANTELZORGER VAN VRIENDEN OF FAMILIE VOOR DEZE PSYCHISCHE NOOD?	☒	☐	☐	☐

0 = GEEN HULP		
1 = WEINIG HULP	bijv.	Incidenteel advies/ hulp.
2 = MATIGE HULP	bijv.	Wekelijkse praktische en/ of emotionele steun en/ of ondersteuning in de zorg.
3 = VEEL HULP	bijv.	Regelmatig adempauze en hulp bij taken (b.v. 3-4 keer per week).
9 = ONBEKEND		

HOEVEEL HULP ONTVANGT DE MANTELZORGER VAN LOKALE VOORZIENINGEN VOOR DEZE PSYCHISCHE NOOD?	☒	☐	☐	☐
HOEVEEL HULP HEEFT DE MANTELZORGER NODIG VAN LOKALE VOORZIENINGEN VOOR DEZE PSYCHISCHE NOOD?	☒	☐	☐	☐

0 = GEEN		
1 = WEINIG HULP	bijv.	Advies, bijvoorbeeld over andere mogelijkheden zoals verzorgingshuis.
2 = MATIGE HULP	bijv.	Wekelijkse dagopvang: incidentele adempauze: bezoek Soc. Psych. verpleegk: mantelzorger ondersteuningsgroepen.
3 = VEEL HULP	bijv.	Regelmatig tijdelijke opname, behandeling en/ of consultatie voor stress/ depressie.
9 = ONBEKEND		

ONTVANGT DE MANTELZORGER HET JUISTE TYPE HULP VOOR DEZE PSYCHISCHE NOOD? (0 = NEE 1 = JA 9 = ONBEKEND)	☒	☐	☐	☐
IS DE MANTELZORGER OVER HET GEHEEL GENOMEN TEVREDEN MET DE HOEVEELHEID HULP DIE HIJ ONTVANGT VOOR DEZE PSYCHISCHE NOOD? (0 = NEE 1 = JA 9 = ONBEKEND)	☒			

OPMERKINGEN

CANE Beoordelingsrapport

Oudere naam:___________________ Afnemer: ________________Datum:________

Waarderingscijfers:

0 = geen behoefte
1 = tegemoet gekomen behoefte
2 = bestaande behoefte
9 = onbekend

Interview	*Oudere*	*Mantelzorger*	*Hulpverlener*	*Beoordelaar*
1. Wonen				
2. Huishouden				
3. Voeding				
4. Zelfzorg				
5. Voor iemand anders zorgen				
6. Dagbesteding				
7. Geheugen				
8. Gezichtsvermogen, gehoor & communicatie				
9. Mobiliteit/ vallen				
10. Continentie				
11. Lichamelijke gezondheid				
12. Medicatie				
13. Psychotische symptomen				
14. Psychische nood				
15. Informatie				
16. Opzettelijk gevaar voor zichzelf				
17. Onopzettelijk gevaar voor zichzelf				
18. Misbruik en verwaarlozing				
19. Gedrag				
20. Alcohol				
21. Gezelschap				
22. Intieme relaties				
23. Geld				
24. Toelagen / uitkeringen				
Verholpen behoeftes: Tel het aantal keren dat u 1 heeft toegekend.				
Bestaande behoeftes: Tel het aantal keren dat u 2 heeft toegekend				
Totaal aantal behoeftes: Tel het aantal keren dat u 1 of 2 heeft toegekend bij elkaar op				

Kwaliteit van Leven AD (QoL-AD)

Logsdon, R. G., Gibbons, L. E., McCurry, S. M. and Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 2 1–31.

Translated into Dutch by: **Bosboom, P. R.** (1999).

Kwaliteit van leven AD
(QoL-AD)
Instructies voor interviewers

De Qol-AD wordt afgenomen in interviewvorm bij mensen met dementie, waarbij de volgende instructies dienen te worden opgevolgd.

Overhandig de deelnemer het formulier, zodat hij/zij ernaar kan kijken terwijl jij de instructies geeft (instructies dienen nauwkeurig de volgende bewoording te volgen, aangegeven in cursief lettertype).

Ik wil u een aantal vragen stellen over uw kwaliteit van leven en uw waardering laten geven over verschillende aspecten van uw leven door gebruikmaking van vier woorden: slecht, redelijk, goed, of uitstekend.

Wijs naar elk woord (slecht, redelijk, goed of uitstekend) op het formulier terwijl je ze opnoemt.

Wanneer u nadenkt over uw leven, dan zijn er verschillende aspecten, zoals uw lichamelijke gezondheid, vitaliteit, familie, geld en dergelijke. Ik ga vragen om elk van deze aspecten een waardering te geven. We willen nagaan hoe u uw huidige situatie ervaart op elk gebied.
Als u niet zeker bent over wat de vraag betekent, kunt u mij daarover vragen stellen. Als u problemen heeft met het geven van een waardering op een onderdeel, geef dan gewoon uw beste gok.

Het is over het algemeen duidelijk of een persoon de vragen begrijpt, en de meeste personen die in staat zijn om te communiceren en te antwoorden op simpele vragen kunnen de vragenlijst begrijpen. Als de deelnemer alle vragen hetzelfde beantwoordt, of iets zegt dat een gebrek aan begrip indiceert, wordt de interviewer aangemoedigd om de vraag te verhelderen. Hoe dan ook, de interviewer mag onder geen beding een specifiek antwoord suggereren. Elk van de vier mogelijke antwoorden moet worden aangeboden en de deelnemer moet een van de vier kiezen.

Als een deelnemer niet in staat is een antwoord te kiezen op een bepaald onderdeel of onderdelen, moet dit genoteerd worden in het commentaar. Als de deelnemer niet in staat is twee of meer onderdelen te begrijpen of te beantwoorden, zal het onderzoek afgebroken kunnen worden en dit moet genoteerd worden in het commentaar.

Wanneer je de onderaan opgestelde vragen voorleest, vraag de deelnemer zijn/haar antwoorden te omcirkelen. Als de deelnemer moeite heeft met het omcirkelen van het woord, mag je hem/haar vragen het antwoord aan te wijzen of het antwoord te benoemen en je mag voor hem/haar omcirkelen. Je dient de deelnemer zijn/haar eigen formulier vast te laten houden en je te volgen terwijl je de onderdelen voorleest.

1. *Ten eerste, wat vindt u van uw lichamelijke gezondheid? Zou u zeggen dat die slecht, redelijk, goed of uitstekend is? Omcirkel nu welk woord u denkt dat het beste uw lichamelijke gezondheid omschrijft.*

2. *Wat is uw mening over uw vitaliteit? Vindt u dat deze slecht, redelijk, goed of uitstekend is?* **Als de deelnemer zegt dat sommige dagen beter zijn dan andere, vraag hem/haar te bepalen hoe hij/zij zich meestal voelde de laatste tijd.**

3. *Hoe was uw stemming de laatste tijd? Voelde u zich prettig, of heeft u zich somber gevoeld? Zou u uw stemming als slecht, redelijk, goed of uitstekend beoordelen?*

4. *Wat vindt u van uw woonomstandigheden? Wat vindt u van de plek waar u nu woont? Zou u zeggen dat deze slecht, redelijk, goed of uitstekend is?*

5. *Wat vindt u van uw geheugen? Vindt u dat dit slecht, redelijk, goed of uitstekend is?*

6. *Wat vindt u van uw familie en uw relatie met uw familieleden? Zou u die omschrijven als slecht, redelijk, goed of uitstekend?* **Als de deelnemer zegt geen familie (meer) te hebben, vraag dan naar broers, zussen, kinderen, neven.**

7. *Wat vindt u van uw huwelijk? Hoe is uw relatie met (naam partner)? Vindt u dat die slecht, redelijk, goed of uitstekend is?* **Sommige deelnemers zullen alleenstaand, weduwnaar/weduwe of gescheiden zijn. Wanneer dat het geval is, vraag wat zij vinden van de persoon met wie zij de meest intieme relatie hebben, of dat nu een familielid is of niet. Als er een familie 'caregiver' is, vraag naar hun relatie met deze persoon. Als er niemand in aanmerking komt, of de deelnemer is onzeker, scoor dit onderdeel dan als 'missing'.**

8. *Hoe zou u uw relatie met uw vrienden omschrijven? Vindt u die slecht, redelijk goed of uitstekend?* **Als de deelnemer antwoordt dat ze geen vrienden hebben, of al hun vrienden overleden zijn, probeer verder.** *Heeft u iemand wiens gezelschap u op prijs stelt, naast uw familie? Zou u die persoon een vriend noemen?* **Als de deelnemer nog steeds zegt dat ze geen vrienden hebben, vraag dan:** *Hoe voelt dat om geen vrienden te hebben: slecht, redelijk, goed of uitstekend?*

9. *Wat vindt u van uzelf? Wanneer u denkt aan uw gehele persoon, en al de verschillende aspecten over uzelf, zou u zeggen dat u dat slecht, redelijk, goed of uitstekend vindt?*

10. *Wat vindt u van uw vermogen om dingen als karweitjes rond het huis te doen of andere dingen die u moet doen? Zou u zeggen dat, dat slecht, redelijk, goed of uitstekend gaat?*

11. *Wat vindt u van uw vermogen om leuke dingen te doen, waar u plezier aan beleeft? Vindt u dat slecht, redelijk, goed of uitstekend?*

12. *Wat vindt u van uw huidige situatie wat betreft geld, uw financiële situatie? Vindt u deze slecht, redelijk, goed of uitstekend?* **Als de deelnemer aarzelt, leg dan uit dat je niet wilt weten wat hun situatie is (wat betreft hoeveelheid geld), maar dat je alleen wilt weten wat zij vinden van hun situatie.**

13. *Hoe zou u uw leven over het geheel omschrijven? Wanneer u nadenkt over uw leven als geheel, alles bij elkaar genomen, hoe denkt u dan over uw leven? Vindt u dat slecht, redelijk, goed of uitstekend?*

Scoringsinstructie voor de QoL-AD:
Aan elk onderdeel worden punten gegeven als volg: slecht=1, redelijk=2, goed=3, uitstekend=4.
De totaalscore is de som van allen 13 onderdelen

Oorspronkelijke titel: Quality of life – AD (QoL-AD), Rebecca Logsdon, 1999
Nederlandse vertaling 1999
Versie 1, P.R. Bosboom, 16-06-1999.

Quality of Life: AD

(Deelnemer Versie)

Deelnemer Nummer ☐☐☐☐☐☐

Beoordelaar Nummer ☐☐

Datum interview ☐☐ ☐☐ ☐☐
Maand Dag Jaar

Afname interview volgens de standaard instructies.
Omcirkel de antwoorden.

1. Lichamelijke gezondheid.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
2. Vitaliteit.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
3. Stemming.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
4. Woonomstandigheden.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
5. Geheugen.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
6. Familie.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
7. Huwelijk.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
8. Vrienden.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
9. Persoon als geheel.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
10. Vermogen om karweitjes te verrichten.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
11. Vermogen om leuke dingen te doen.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
12. Geld.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
13. Leven als geheel.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**

Quality of Life: AD

(Familie Versie)

Deelnemer Nummer ☐☐☐☐☐☐ **Beoordelaar Nummer** ☐☐ **Datum interview** ☐☐ ☐☐ ☐☐
Maand Dag Jaar

De volgende vragen gaan over de kwaliteit van leven van uw naaste.
Als u denkt over het leven van uw naaste, dan zijn er verschillende gebieden, waarvan sommige hieronder staan weergegeven. Wilt u over elke vraag nadenken en aangeven hoe de huidige kwaliteit van leven van uw naaste is voor elk gebied. Maak daarbij gebruik van één van de vier antwoordmogelijkheden: slecht, redelijk, goed, of uitstekend**. Wilt u deze vragen beantwoorden voor de kwaliteit van leven van uw naaste** op dit moment **(in de afgelopen paar weken). Als er onduidelijkheden zijn over een vraag, kunt u degene die u de lijst gegeven heeft om uitleg vragen.**

Omcirkel uw antwoorden.

1. Lichamelijke gezondheid.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
2. Vitaliteit.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
3. Stemming.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
4. Woonomstandigheden.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
5. Geheugen.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
6. Familie.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
7. Huwelijk.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
8. Vrienden.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
9. Persoon als geheel.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
10. Vermogen om karweitjes te verrichten.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
11. Vermogen om leuke dingen te doen.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
12. Geld.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**
13. Leven als geheel.	**Slecht**	**Redelijk**	**Goed**	**Uitstekend**

Instellingenlijst

Based on: **Dröes, R. M., *et al.*** (2003). *Implementatie Model Ontmoetingscentra: voor mensen met dementie en hun verzorgers. Eindrapport 2003.* Amsterdam: Afdeling Psychiatrie, VU medisch centrum.

Gebruik van instellingen

Wilt u in het onderstaande schema invullen van welke instellingen u op *dit moment* gebruik maakt. Eerst vragen wij u de frequentie en de duur in te vullen, dan de tevredenheid over de geboden steun door de instelling en dan het soort steun dat u van deze instelling ontvangt. Als u geen gebruik maakt van de aangegeven instelling hoeft u voor de instelling niets in te vullen.

Bij **frequentie** vult u het aantal malen *per week* in. Indien u minder dan één maal per week met de instelling contact heeft, vul dan in hoeveel maal *per jaar* dit is.
Bij **duur** vult u het aantal uur per week in dat er zorg geboden wordt. Ook vult u het aantal maanden hoelang er al gebruik wordt gemaakt van deze zorg (tip: de CIZ indicatie vermeldt hoeveel recht men heeft op zorg)

In de kolom **tevredenheid** over de geboden steun door de instelling kunt u invullen:
0 = ontevreden
1 = matig tevreden
2 = tevreden
Kies het antwoord van uw keuze.

Bij **frequentie** vult u het aantal malen *per week* in. Indien u minder dan één maal per week met de instelling contact heeft, vul dan in hoeveel maal *per jaar* dit is.
Bij **duur** vult u het aantal uur per week in dat er zorg geboden wordt. Ook vult u het aantal maanden hoelang er al gebruik wordt gemaakt van deze zorg (tip: de CIZ indicatie vermeldt hoeveel recht men heeft op zorg)

In de kolom **tevredenheid** over de geboden steun door de instelling kunt u invullen:
0 = ontevreden
1 = matig tevreden
2 = tevreden
Kies het antwoord van uw keuze.

Bij **soort steun** zijn de antwoordmogelijkheden:
1 = praktisch
2 = emotioneel
3 = informatief
4 = zowel praktisch als emotioneel
5 = zowel praktisch als informatief
6 = zowel emotioneel als informatief
7 = zowel praktisch, emotioneel als informatief
Kies het antwoord van uw keuze.

Instelling	**Frequentie**	**Duur**	**Tevredenheid**			**Soort steun**						
GGZ (voorheen RIAGG) *(ondersteunende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
GGZ (voorheen RIAGG) *(activerende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
GGZ (voorheen RIAGG) *(verblijf)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
GGZ (voorheen RIAGG) *(behandeling)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Ziekenhuis / Geheugenpolikliniek *(verblijf)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Ziekenhuis / Geheugenpolikliniek *(behandeling)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Thuiszorg *(persoonlijke verzorging)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Thuiszorg *(ondersteunende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Thuiszorg *(activerende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verpleeghuis *(persoonlijke verzorging)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verpleeghuis *(verpleging)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7

Instelling	**Frequentie**	**Duur**	**Tevredenheid**			**Soort steun**						
Verpleeghuis *(ondersteunende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verpleeghuis *(activerende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verpleeghuis *(verblijf, permanent of tijdelijk[*])*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verpleeghuis *(behandeling)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(persoonlijke verzorging)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(verpleging)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(ondersteunende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(activerende begeleiding)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(verblijf, permanent of tijdelijk[*])*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Verzorgingshuis *(behandeling)*	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Ontmoetingscentrum	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Apotheek	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Maatschappelijk werk (algemeen of verbonden aan een instelling)	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Wijkpost voor ouderen (De Voordeur, Wijkpost voor ouderen Buitenveldert etc.)	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Alzheimer Nederland	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Mantelzorgorganisatie (Markant, MEE etc.)	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Gespreksgroepen (anders dan Ontmoetingscentrum)	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Kerk	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Burenhulporganisaties	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Klussendienst	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Formulierenbrigade	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Oppasdienst	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Particuliere hulp/werkster	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Sociaal Raadslieden	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7
Anders, nl. …………………………………	.. per …..	…. uur p/w …. mnd	0	1	2	1	2	3	4	5	6	7

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[*] doorhalen wat niet van toepassing is

Voor welke zorg staat uw …… op de wachtlijst?

○ Niets

○ persoonlijke verzorging
Denkt u aan hulp bij het douchen, het aankleden of de toiletgang

○ verpleging
Voorbeelden zijn wondverzorging, toedienen van injecties en medicijnen

○ ondersteunende begeleiding
Zoals hulp bij het leren zorgen voor het eigen huishouden.

○ activerende begeleiding
Bijvoorbeeld gesprekken om gedrag te veranderen of gedrag te leren hanteren bij gedragsproblemen of een psychische stoornis.

○ behandeling
Zorg bij een aandoening, zoals revalideren na een beroerte en aan geestelijke gezondheidszorg.

○ verblijf
Bijvoorbeeld verblijf in een verpleeg- of verzorgingshuis, tijdelijk of permanent

○ anders, nl.: ……………….

USE Questionnaire

Based on: **Lund, A.** (2001). *Measuring Usability with the USE Questionnaire. Usablity Interface 2001*. Available at: http://www.stcsig.org/usability/newsletter/0110_measuring_with_use.html.

Ik heb nu nog een standaardvragenlijst over de DementieWijzer.

Hieronder volgen een aantal uitspraken over de DementieWijzer. Kunt u aangeven in hoeverre u het met deze uitspraken over uw ervaringen met de DementieWijzer eens bent?

1. De DementieWijzer helpt mij effectiever te zijn	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
2. De DementieWijzer helpt me productiever te zijn	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
3. De DementieWijzer is nuttig	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
4. De DementieWijzer geeft me meer controle over de activiteiten in mijn leven	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
5. De DementieWijzer maakt de dingen die ik wil bereiken gemakkelijker om te doen doen	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
6. Het bespaart me tijd als ik de DementieWijzer gebruik	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
7. De DementieWijzer doet alles wat ik ervan zou verwachten	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens

8. De DementieWijzer helpt met te vinden waar ik naar op zoek ben	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
9. De DementieWijzer is makkelijk te gebruiken	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
10. De DementieWijzer is eenvoudig te gebruiken	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
11. De DementieWijzer is gebruikersvriendelijk	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
12. Met de DementieWijzer kan ik met het minimale aantal stappen bereiken wat ik ermee wil doen	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
13. Ik denk dat ik hulp van een technisch persoon nodig heb om het systeem te kunnen gebruiken	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens
14. Ik heb snel geleerd ermee te werken	○ helemaal mee eens ○ enigszins mee eens ○ mee eens/mee oneens ○ enigszins mee oneens ○ helemaal mee oneens

15. Ik kan makkelijk onthouden hoe ik de DementieWijzer moet gebruiken	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
16. Het is eenvoudig te leren hoe je het moet gebruiken	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
17. Het is moeilijk de weg te vinden in dit systeem	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
18. Ik ben tevreden over de DementieWijzer	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
19. Ik zou de DementieWijzer aanbevelen aan een kennis	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
20. De DementieWijzer is leuk om te gebruiken	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
21. De DementieWijzer werkt zoals ik wil dat het werkt	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens

22. De DementieWijzer is geweldig	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
23. Ik heb het idee dat ik de DementieWijzer moet hebben	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens
24. De DementieWijzer is prettig om te gebruiken	O helemaal mee eens O enigszins mee eens O mee eens/mee oneens O enigszins mee oneens O helemaal mee oneens

User manual DEM-DISC

DementieWijzer
vraagbaak voor zorg- en welzijnsdiensten

Informatie
&
Knelpuntenlijst

GGZ buitenamstel

VU medisch centrum

Academische afdeling Psychiatrie
Alzheimercentrum VUmc

Tel: 020-7885 665

Inhoudsopgave

Introductie

Allereerst danken wij u hartelijk voor uw deelname aan het onderzoek naar de *DementieWijzer, vraagbaak voor zorg- en welzijnsdiensten*!
Tijdens dit onderzoek bekijken we wat mensen van de DementieWijzer vinden.

U gaat nu twee maanden gebruik maken van de DementieWijzer. Tijdens deze periode kunt u het systeem raadplegen wanneer u een vraag heeft over de zorg voor *<<naam persoon met dementie>>*.
Omdat de DementieWijzer nog in ontwikkeling is, is het mogelijk dat u niet op al uw vragen een antwoord vindt. We hebben ervoor gekozen om de meest voorkomende problemen van mantelzorgers op te nemen in de DementieWijzer. Op basis van deze problemen geeft de DementieWijzer u een advies over het beschikbare zorgaanbod. Dit advies kan algemeen zijn, maar indien u dit wilt, kunt u ook een op uw situatie aangepast advies ontvangen.
Verder is het goed om te weten dat de adviezen zijn gericht op de Amsterdamse stadsdelen Zuid en Zuideramstel.
Naast adviezen over de beschikbare zorg vindt u op de DementieWijzer dagelijks nieuwtjes over dementie en een groot aantal interessante links over zaken die met dementie te maken hebben.

In het kader van het onderzoek zijn u en *<<naam persoon met dementie>>*. geïnterviewd over allerlei aspecten van de zorg rond dementie. Tijdens de twee maanden dat u de DementieWijzer gebruikt, zullen wij u ook enkele vragen stellen, zowel telefonisch, als ook via korte vragen op de computer. Ook vragen wij u om een **knelpuntenlijst** bij te houden (zie pag. 13), waarbij u kunt aangeven welke problemen u tegenkomt bij het gebruik van de DementieWijzer. Deze problemen kunt u schriftelijk of op de computer bijhouden.
Aan het einde van de gebruikersperiode zal bij u thuis een afsluitend interview worden gehouden.

Op de volgende pagina's vindt u informatie die van belang is voor het gebruik van de DementieWijzer.

Wij wensen u veel succes bij het gebruik van de DementieWijzer!

De DementieWijzer. Vraagbaak voor zorg- en welzijnsdiensten

Een onderzoeker heeft de DementieWijzer bij u op de computer geïnstalleerd met een zogenaamde installer. Via deze installer wordt de software bij u op de computer geplaatst die nodig is voor het onderzoek. Deze software bestaat uit Firefox (een browser; een programma om webpagina's te kunnen bekijken), Greasemonkey (een aanvulling op Firefox) en TUMCAT (programma waarmee uw handelingen op de website van de DementieWijzer worden bijgehouden en waarmee vragen gesteld kunnen worden). Deze software is niet schadelijk voor uw computer en wordt na afloop van het onderzoek weer verwijderd.

Beginnen

De DementieWijzer is alleen toegankelijk vanaf uw computer en is dus nog niet voor iedereen bruikbaar.

U heeft een inlognaam en wachtwoord nodig om het systeem te kunnen gebruiken en om uw persoonlijke informatie te kunnen wijzigen via 'Informatie op maat'. Uw inlognaam en wachtwoord staan hieronder.

Inlognaam: ***<<inlognaam>>***

Wachtwoord: ***<<wachtwoord>>***

Om naar de DementieWijzer te kunnen gaan start u Firefox op en gaat u naar www.dementiewijzer.nl. Vervolgens voert u uw inlognaam en wachtwoord in.

Op www.dementiewijzer.nl

De DementieWijzer is te bekijken in Firefox. Firefox werkt iets anders dan Internet Explorer, het programma wat de meeste mensen gewend zijn om te gebruiken om internet op te gaan.

Tekstgrootte: Om de tekst in de DementieWijzer te vergroten of te verkleinen, houdt u de Ctrl-knop op uw toetsenbord (meestal linksonder) ingedrukt en drukt u op + of -.

Een andere pagina openen met de DementieWijzer: Wanneer u in de Dementiewijzer op een link naar een andere organisatie klikt, opent Firefox automatisch een nieuw tabblad (zie de pijltjes in figuur 1). De DementieWijzer sluit niet.
In het nieuwe tabblad kunt u de door u opgevraagde website bekijken. Het tabblad sluit u weer door op het rode vakje met het kruisje te klikken. Dit vindt u rechts boven op elke tab (zie figuur 1). Wanneer u terug wilt naar de DementieWijzer klikt u weer op de tab ‘DementieWijzer.nl’ (deze tab is omcirkeld in figuur 1).

Let op. Uw handelingen op deze website worden (anoniem) vastgelegd in verband met het onderzoek.

Niet aangemeld.

Hoe werkt de DementieWijzer?

De DementieWijzer helpt u gericht te zoeken naar antwoorden op uw vragen over de zorg voor mensen met dementie. Daarnaast biedt de DementieWijzer actueel nieuws rondom dementie en de mogelijkheid om door te linken naar interessante landelijke en regionale websites. U kunt zelf een regio kiezen door deze op het landkaartje rechts op het scherm aan te klikken.

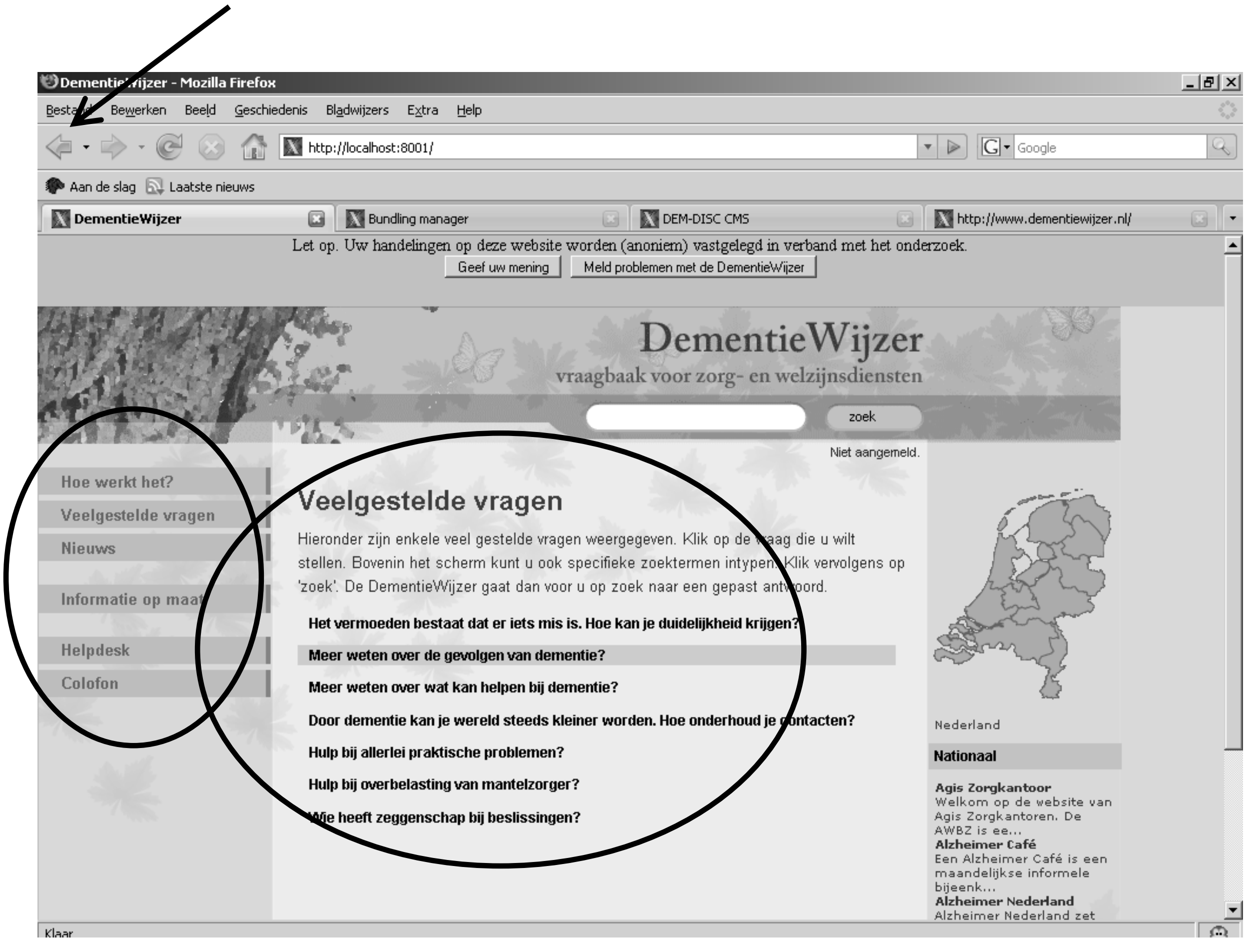
Veel gestelde vragen

Nationaal

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
Alzheimer Café
Een Alzheimer Café is een maandelijkse informele bijeenk...
Alzheimer Nederland
Alzheimer Nederland zet

Figuur 1 ***Tabbladen in Firefox***

Een stap terug gaan in de DementieWijzer: Wanneer u op de DementieWijzer bezig bent en een stap terug wilt, kunt u niet op de pijl rechtsboven drukken om een pagina terug te gaan (zie figuur 2). Dan verlaat u namelijk de DementieWijzer. U kunt gebruik maken van het menu aan de linkerkant van de pagina of van de vraagboom.



Let op. Uw handelingen op deze website worden (anoniem) vastgelegd in verband met het onderzoek.

Veelgestelde vragen

Hieronder zijn enkele veel gestelde vragen weergegeven. Klik op de vraag die u wilt stellen. Bovenin het scherm kunt u ook specifieke zoektermen intypen. Klik vervolgens op 'zoek'. De DementieWijzer gaat dan voor u op zoek naar een gepast antwoord.

Het vermoeden bestaat dat er iets mis is. Hoe kan je duidelijkheid krijgen?

Meer weten over de gevolgen van dementie?

Meer weten over wat kan helpen bij dementie?

Door dementie kan je wereld steeds kleiner worden. Hoe onderhoud je contacten?

Hulp bij allerlei praktische problemen?

Hulp bij overbelasting van mantelzorger?

Wie heeft zeggenschap bij beslissingen?

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
Alzheimer Café
Een Alzheimer Café is een maandelijkse informele bijeenk...
Alzheimer Nederland
Alzheimer Nederland zet

Figuur 1 ***Navigeren in de DementieWijzer***

Helpdesk van de DementieWijzer

Mochten er onverwacht problemen optreden bij het gebruik van de DementieWijzer, dan kunt u contact opnemen met de helpdesk.

De helpdesk is iedere werkdag telefonisch bereikbaar van 9.30 uur tot 17.15 uur.
Telefoon: 020 - 7885 665, eventueel 020 - 7885 623

U kunt ook mailen naar *dementie@ggzba.nl*.

De medewerkers zullen u helpen uw probleem op te lossen.

U kunt de helpdesk behalve voor technische vragen ook benaderen als u bijvoorbeeld een vraag heeft over de zorg waar de DementieWijzer u geen advies op kan geven.

Onderzoek tijdens het gebruik van de DementieWijzer

In de twee maanden dat u de DementieWijzer raadpleegt, onderzoeken wij op verschillende manieren de bruikbaarheid en het ervaren nut van de DementieWijzer. Deze manieren worden hieronder kort toegelicht.

Loggen

Zoals eerder is aangegeven, worden uw handelingen op de DementieWijzer bijgehouden, dit heet het ‘loggen’ van gegevens. Bovenaan elke pagina van de DementieWijzer staat dit ook vermeld met de tekst ‘*Let op. Uw handelingen op deze website worden (anoniem) vastgelegd in verband met het onderzoek*.’ (zie figuur 3). Alleen uw handelingen op www.dementiewijzer.nl worden bijgehouden, wanneer u naar een andere pagina gaat, stopt het loggen automatisch.
Omdat u uw naam niet hoeft in te vullen op de DementieWijzer kunnen deze gegevens niet op u worden teruggevoerd. Alleen de onderzoekers van het VUmc kennen de sleutel van uw naam en code.
Alle gegevens die u in het kader van het onderzoek aan ons verstrekt, verwerken wij anoniem.

Pop-up vragen

Tijdens bepaalde handelingen op de Dementiewijzer stelt de computer u af en toe een vraag. Deze vraag zal zomaar in beeld verschijnen, dit noemen we een ‘pop-up vraag’. Deze vragen kunt u beantwoorden door op een vakje te klikken en soms door een antwoord in te typen. Wanneer u op de knop ‘Verzenden’ drukt, geeft u uw antwoord aan ons door. Hierna kunt u het tabblad sluiten.

Knelpuntenlijst en commentaar

We vragen u de problemen die u tegenkomt tijdens het gebruik van de DementieWijzer bij te houden. Dat is voor ons zeer nuttige informatie. U kunt dit op twee manieren doen:

- Schriftelijk met de knelpuntenlijst die achterin deze handleiding is opgenomen. Deze knelpuntenlijst kunt u na het tweede interview aan de interviewer meegeven.
- U kunt ook op de computer uw knelpunten aangeven. Bovenaan de webpagina ziet u een groene balk met twee knoppen (zie figuur 3). Via de knop ‘Meld problemen met de DementieWijzer’ komt u in de digitale versie van de knelpuntenlijst. Problemen die u bent tegengekomen geeft u aan door het vakje (de vakjes) aan te vinken en de vraag (vragen) te beantwoorden in de tekstbox. Via de knop ‘Verzenden’ onderaan de pagina, geeft u uw bevindingen door.

Als u daar behoefte aan heeft, kunt u via de knop ‘Geef uw mening’ op de groene balk, al uw positieve en negatieve opmerkingen over de DementieWijzer kwijt.

Let op. Uw handelingen op deze website worden (anoniem) vastgelegd in verband met het onderzoek.

Hoe werkt de DementieWijzer?

De DementieWijzer helpt u gericht te zoeken naar antwoorden op uw vragen over de zorg voor mensen met dementie. Daarnaast biedt de DementieWijzer actueel nieuws rondom dementie en de mogelijkheid om door te linken naar interessante landelijke en regionale websites. U kunt zelf een regio kiezen door deze op het landkaartje rechts op het scherm aan te klikken.

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Figuur 1 ***Knoppen voor knelpunten en commentaar***

Telefonisch contact
Tijdens de twee maanden dat u de DementieWijzer gebruikt zullen we af en toe kort telefonisch contact met u opnemen. Mochten er grote problemen bij het gebruik van de DementieWijzer naar voren komen, dan kunnen er in tussentijd aanpassingen worden gemaakt. Als dat gebeurt, stellen we u daarvan op de hoogte.

Knelpuntenlijst voor het gebruik van de DementieWijzer

Naam: ***<<naam mantelzorger>>***

Startdatum gebruikersperiode:	☐☐	☐☐	20 ☐☐
	dag	*maand*	*jaar*
Einddatum gebruikersperiode:	☐☐	☐☐	20 ☐☐
	dag	*maand*	*jaar*

Waarom?

In deze lijst kunt u elk knelpunt of probleem dat u bent tegengekomen tijdens het gebruik van de DementieWijzer noteren. Uw opmerkingen zijn erg nuttig voor ons, hiermee helpt u ons om de DementieWijzer te verbeteren.

Wat?

Er zijn steeds zes mogelijke knelpunten aangegeven. Wilt u het alternatief dat op u van toepassing is aanvinken en de bijhorende vragen beantwoorden? Het is mogelijk dat u tijdens een sessie meerdere knelpunten tegenkomt.
Het kan natuurlijk zijn dat u een ander probleem tegenkomt dan staat aangegeven, dit kunt u dan bij de laatste vraag beschrijven. Er is ook ruimte voor algemene opmerkingen.

Wanneer u knelpunten noteert, vergeet u hierbij alstublieft niet bovenaan de pagina de datum en tijd te vermelden.

Hoe?

Naast dat u knelpunten schriftelijk kunt vermelden, heeft u ook de mogelijkheid om de problemen die u tegenkomt online aan te geven in de DementieWijzer. U hoeft de knelpunten die u per sessie tegenkomt slechts één maal te vermelden, schriftelijk of online.

Welke knelpunt(en) bent u tegengekomen tijdens het gebruik van de DementieWijzer?

○ De vraag die ik wilde stellen, kon ik niet vinden in het menu.
   a. Welke vraag wilde u stellen?

○ Het antwoord dat ik kreeg was niet goed, onduidelijk of onvolledig.
   a. Welke vraag heeft u gesteld?

----

   b. Welk antwoord kreeg u?

----

   c. Welk antwoord of wat voor soort antwoord verwachtte u?

○ Het antwoord dat ik kreeg is niet het meest logische antwoord voor mijn situatie.
   a. Welke vraag heeft u gesteld?

----

   b. Welk antwoord kreeg u?

----

   c. Waarom is dit antwoord niet geschikt voor uw situatie?

○ De combinatie van oplossingen die ik als antwoord kreeg was niet goed, onduidelijk of onvolledig.
   a. Welke vraag heeft u gesteld?

....

   b. Welke combinatie van oplossingen werd u geadviseerd?

----

   c. Waarom is deze combinatie van oplossingen niet goed, onduidelijk of onvolledig?

○ Ik kreeg advies over diensten die niet door mijn naaste of mij gebruikt kunnen worden.
a. Welke vraag heeft u gesteld?

----

b. Welk advies heeft u gekregen?

----

c. Waarom kunt u of uw naaste geen gebruik maken van de geadviseerde dienst?

○ Er worden onduidelijke termen gebruikt.
a. Welke termen bedoelt u?

----

b. Hoe zou u deze termen liever omschreven zien?

○ Het systeem is te traag.
Kunt u dit toelichten?

○ Een ander knelpunt, dat hierboven niet is genoemd.
a. Wilt u het probleem omschrijven?

----

b. Wat is volgens u hiervoor de beste oplossing?

Opmerkingen:

-- Einde van deze lijst --

DementieWijzer
Vraagbaak voor zorg- en welzijnsdiensten

FRUX (2007). *DementieWijzer. Vraagbaak voor zorg- en welzijnsdiensten*. Restricted access in test environment.

Hoe werkt de DementieWijzer?

De DementieWijzer helpt u gericht te zoeken naar antwoorden op uw vragen over de zorg voor mensen met dementie. Daarnaast biedt de DementieWijzer actueel nieuws rondom dementie en de mogelijkheid om door te linken naar interessante landelijke en regionale websites. U kunt zelf een regio kiezen door deze op het landkaartje rechts op het scherm aan te klikken.

Veel gestelde vragen

De DementieWijzer gaat uit van veel gestelde vragen. Wilt u bijvoorbeeld weten waar u terecht kunt voor hulp of hoe u in contact kan komen met anderen die in een vergelijkbare situatie zitten? Dan kan de DementieWijzer u helpen. Klik de voor u relevante vraag aan. DementieWijzer helpt uw vraag nader te specificeren.

Informatie op maat

Naast algemene informatie over uw regio kunt u ook informatie op maat krijgen, die aansluit bij uw persoonlijke situatie. Wilt u dit, klik dan in het menu op

Nationaal

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Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
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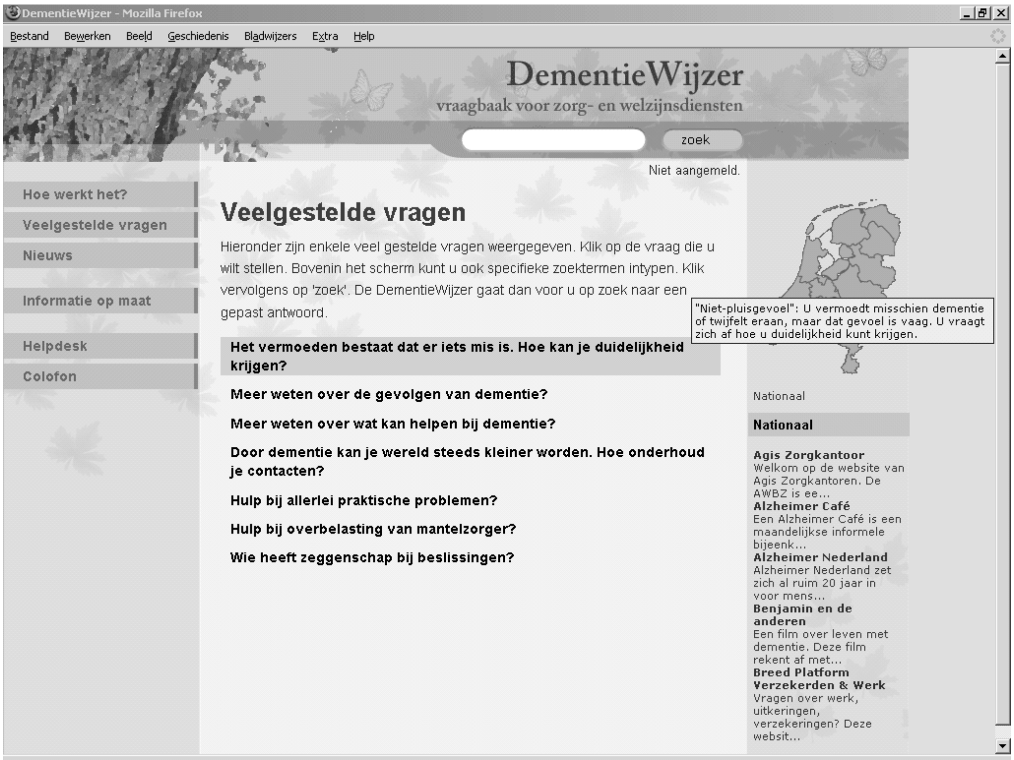
Een Alzheimer Café is een maandelijkse informele bijeenk...
Alzheimer Nederland
Alzheimer Nederland zet zich al ruim 20 jaar in voor mens...
Benjamin en de anderen
Een film over leven met dementie. Deze film rekent af met...
Breed Platform Verzekerden & Werk
Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 1. DEM-DISC home page



Veelgestelde vragen

Hieronder zijn enkele veel gestelde vragen weergegeven. Klik op de vraag die u wilt stellen. Bovenin het scherm kunt u ook specifieke zoektermen intypen. Klik vervolgens op 'zoek'. De DementieWijzer gaat dan voor u op zoek naar een gepast antwoord.

Het vermoeden bestaat dat er iets mis is. Hoe kan je duidelijkheid krijgen?

Meer weten over de gevolgen van dementie?

Meer weten over wat kan helpen bij dementie?

Door dementie kan je wereld steeds kleiner worden. Hoe onderhoud je contacten?

Hulp bij allerlei praktische problemen?

Hulp bij overbelasting van mantelzorger?

Wie heeft zeggenschap bij beslissingen?

"Niet-pluisgevoel": U vermoedt misschien dementie of twijfelt eraan, maar dat gevoel is vaag. U vraagt zich af hoe u duidelijkheid kunt krijgen.

Nationaal

Agis Zorgkantoor
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Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 2. Frequent asked questions

Aangemeld als vumc

Veelgestelde vragen

Hieronder zijn enkele veel gestelde vragen weergegeven. Klik op de vraag die u wilt stellen. Bovenin het scherm kunt u ook specifieke zoektermen intypen. Klik vervolgens op 'zoek'. De DementieWijzer gaat dan voor u op zoek naar een gepast antwoord.

Terug naar alle vragen
↳ **Hulp bij allerlei praktische problemen?**
↳ **Ik wil praktische hulp voor de persoon met dementie.**

SPECIFICEER UW ZOEKVRAAG

Waar wordt voorlichting gegeven over praktische hulp?
Hoe? geen voorkeur
Soort informatie?

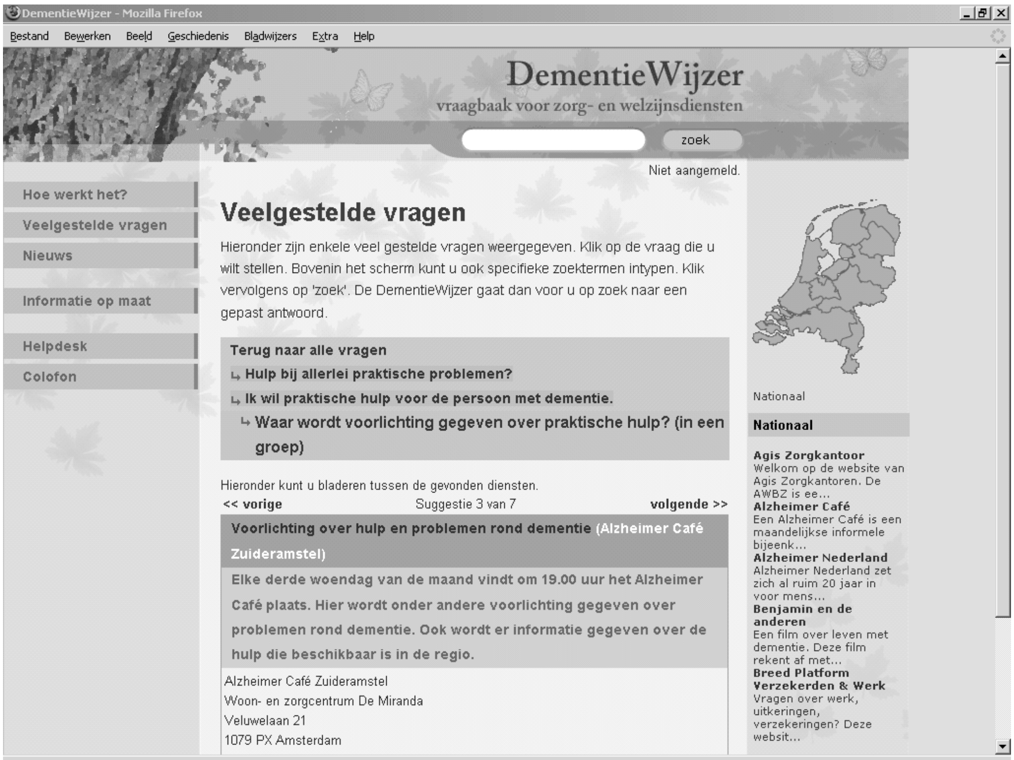
- geen voorkeur
- via internet
- via de telefoon
- in een groep
- in een individueel gesprek

Wie kan helpen i
Wie kan helpen bij de persoonlijke verzorging?
Wie kan de persoon met dementie thuis verplegen?
Waar zijn hulpmiddelen, zoals rolstoelen, te leen?
Waar zijn verpleegartikelen, zoals incontinentiematerialen, te verkrijgen?
Kan ik een warme maaltijd krijgen?

Noord-Holland

Alzheimer Café
Een Alzheimer Café is een maandelijkse informele bijeenk...
Centrum Indicatiestelling Zorg (CIZ)
Het CIZ beoordeelt of u recht heeft op zorg via de AWBZ (...
Boeken- en filmtips over dementie
Bijna iedereen kent wel (verhalen over) demente vaders, m...
Alzheimercentrum VUmc
Het Alzheimercentrum binnen het VU medisch centrum is opg...
Amsterdams Patiënten/Consumenten Platform
Het Amsterdams

Figure 3. Three-step question tree



Niet aangemeld.

Veelgestelde vragen

Hieronder zijn enkele veel gestelde vragen weergegeven. Klik op de vraag die u wilt stellen. Bovenin het scherm kunt u ook specifieke zoektermen intypen. Klik vervolgens op 'zoek'. De DementieWijzer gaat dan voor u op zoek naar een gepast antwoord.

Terug naar alle vragen
↳ **Hulp bij allerlei praktische problemen?**
↳ **Ik wil praktische hulp voor de persoon met dementie.**
↳ **Waar wordt voorlichting gegeven over praktische hulp? (in een groep)**

Hieronder kunt u bladeren tussen de gevonden diensten.

<< vorige Suggestie 3 van 7 **volgende >>**

Voorlichting over hulp en problemen rond dementie (Alzheimer Café Zuideramstel)

Elke derde woendag van de maand vindt om 19.00 uur het Alzheimer Café plaats. Hier wordt onder andere voorlichting gegeven over problemen rond dementie. Ook wordt er informatie gegeven over de hulp die beschikbaar is in de regio.

Alzheimer Café Zuideramstel
Woon- en zorgcentrum De Miranda
Veluwelaan 21
1079 PX Amsterdam

Nationaal

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
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Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 4. DEM-DISC advice

Niet aangemeld.

Langer zelfstandig en bij familie in de buurt - Nieuws.nl

Nieuws

De provincie vindt het belangrijk dat mensen met **dementie** in hun eigen dorp of wijk kunnen blijven wonen en daardoor makkelijker contact kunnen houden met ...<

Vaker dement met korte armen - De Telegraaf

Nieuws

AMSTERDAM - Pak het meetlint maar, want mensen met korte armen of benen hebben een grotere kans op **dementie**. Elke 2.54 centimeter dat een vrouwenbeen langer ...<

Alzheimer onder de 65 jaar agressiever - Algemeen Dagblad

Nieuws

Algemeen Dagblad - 15 uur geleden

Ziekte van Alzheimer op jongere leeftijd agressiever - Blik op Nieuws

Nieuws

Blik op Nieuws - 5 mei 2008

Lezing over dementie in centrum De Wieken - Provinciale Zeeuwse Courant

Nieuws

ZIERIKZEE - Psychologische instelling Indigo/Zeeland en de bibliotheek in

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
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Breed Platform Verzekerden & Werk
Vragen over werk, uitkeringen, verzekeringen? Deze websit...

Figure 5. News items in DEM-DISC

Aangemeld als vumc

Persoonlijk

Gegevens aanpassen

Mantelzorger

Postcode: 1075 BG
Geboortedatum: 26-8-1977
Vervoer beschikbaar: ☑
Beschikbaar tijdens kantooruren: ☐
Beschikbaar tijdens avonduren: ☑

Persoon met dementie

Postcode: 1075 BG
Geboortedatum: 27-8-1941
Vervoer beschikbaar: ☐
Beschikbaar tijdens kantooruren: ☑
Beschikbaar tijdens avonduren: ☑

Agis Zorgkantoor
Welkom op de website van Agis Zorgkantoren. De AWBZ is ee...
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Figure 6. Tailored information – personal page

Alzheimer Café
Noord-Holland | Nationaal

Een Alzheimer Café is een maandelijkse informele bijeenkomst voor mensen met dementie, partners, familieleden, hulpverleners en andere belangstellenden. Na een inleiding door een deskundige kunnen de bezoekers ideeën, informatie en ervaringen uitwisselen.

Centrum Indicatiestelling Zorg (CIZ)
Noord-Holland | Nationaal

Het CIZ beoordeelt of u recht heeft op zorg via de AWBZ (Algemene Wet Bijzondere Ziektekosten) en geeft hiervoor indicaties af. Hoe dat in z'n werk gaat, leest u bij Informatie voor cliënten. Hulp bij het huishouden gaat via de Wmo (Wet maatschappelijke ondersteuning). Het CIZ voert de Wmo niet uit, dat doet de gemeente.

Boeken- en filmtips over dementie
Drente | Noord-Holland

Bijna iedereen kent wel (verhalen over) demente vaders, moeder, opa's, oma's, vrienden of bekenden. Maar hoe bekend dementie ook is, ermee geconfronteerd worden is nooit gemakkelijk. Het is een ziekte die mensen ingrijpend en onherroepelijk verandert. Voor mensen die met dementie te maken krijgen, kunnen de verhalen en ervaringen van anderen tot steun zijn. Maar ook films en boeken over het onderwerp kunnen helpen om beter te begrijpen wat dementie is en hoe je er mee om kunt gaan.

Alzheimercentrum VUmc
Noord-Holland

Het Alzheimercentrum binnen het VU medisch centrum is opgericht ten dienste van de patiëntenzorg en het patiëntgebonden wetenschappelijk onderzoek. Het Alzheimercentrum beoogt gecoördineerde en gestructureerde samenwerking binnen ziekenhuisafdelingen wat betreft de behandeling van de ziekte van

Noord-Holland

Alzheimer Café
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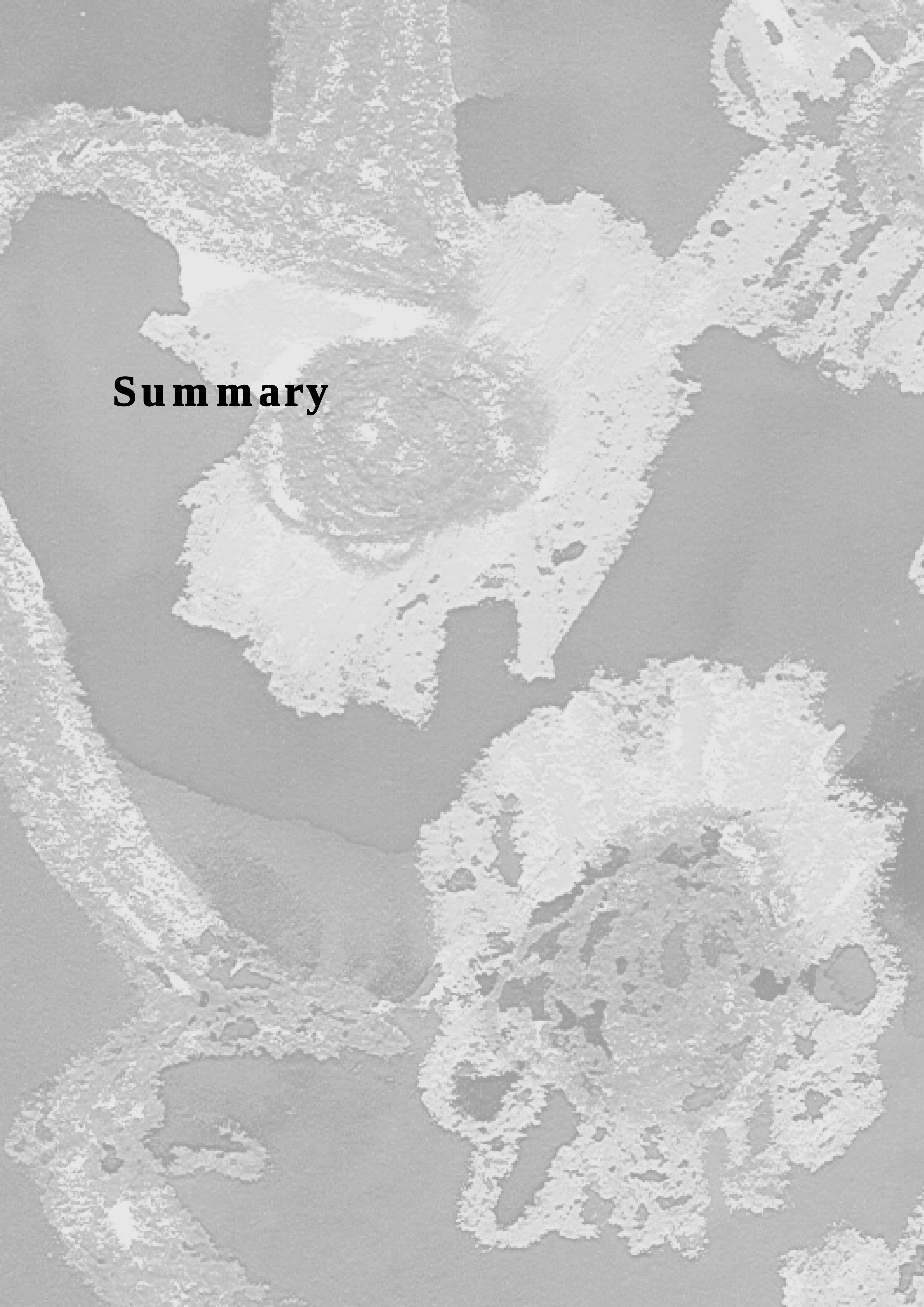
Boeken- en filmtips over dementie
Bijna iedereen kent wel (verhalen over) demente vaders, m...
Alzheimercentrum VUmc
Het Alzheimercentrum binnen het VU medisch centrum is opg...
Amsterdams Patiënten/Consumenten Platform
Het Amsterdams Patiënten/Consumenten Platform (APCP) is ...

meer links...

Figure 7. Links to relevant websites

Summary



This thesis reports on a study into the care and support needs of community-dwelling people with dementia and their informal carers. To inform people about available healthcare and welfare services that are useful to them, a DEMentia-specific Interactive Social Chart was developed, in short DEM-DISC. The development and evaluation of this system are also described in this thesis. This study was carried out in the framework of the Dutch FReeband User eXperience (FRUX) project.

Chapter 1 reports on the causes and aims of the study. Our society is ageing, and as a consequence the number of people with dementia will grow. The majority of the people with dementia live in their own home assisted by informal carers (mainly spouses or relatives) and in many cases also by professional care services. Because the incidence rate of dementia is expected to double every 20 years and the resources of the healthcare sector are not expected to increase at the same rate as the demand, an enormous strain will be put on informal cares and the available professional care. Care should be provided more efficiently and adequately in the future in order to secure sufficient support for people with dementia.

Taking care of a person with dementia has a high impact on informal carers. Many carers are burdened by the care and experience high levels of distress, anxiety and depression. Carer burden and stress, and unmet needs for professional support are known to be associated with nursing home admission and mortality of people with dementia. To enable people with dementia to stay in their own home for as long as possible it is important to meet their unmet care needs.

Dutch healthcare policy also aims to have people with dementia live in their own environment for as long as possible. With our ageing population, this means that care must be arranged more effectively. A better congruity between care and the needs of clients, in other words a change from a supply-driven to a demand-based healthcare system, can contribute to this. The client in the care system is given a (more) central position and care suppliers are encouraged to become more responsive towards the needs and wishes of their clients. In order to provide adequate and efficient demand-based care, it is necessary to gain insight into the needs of the individual care recipient. Although needs of people with dementia are studied comprehensively, researchers rarely consult them directly about their care needs.

In 2002, in accordance with their policy, the Dutch government opened the healthcare market to commercial parties who could operate and offer their services alongside the public services. Nowadays the offer of healthcare and welfare services is

comprehensive, very fragmented and changing continuously. There is a risk that clients, carers and referrers no longer see the wood for the trees, and therefore do not utilize the broad spectrum of available services in dementia care optimally. The need to create a continuum of flexible and transparent care and supportive services for the different stages of dementia is now generally recognized in the Netherlands.
Besides regular professional care, Information Communication Technology (ICT) is since the last decade seen as a promising means to support people with dementia and their carers. Various ICT devices to provide support for dementia symptoms were developed and have in the meantime been proven effective. But ICT applications providing information on the disease and available healthcare and welfare services are never tested on their efficacy, and in general are static and generic systems. A system that can provide tailored advice for specific care needs in dementia, and advises on available health and welfare services in a particular region would support people with dementia and their carers in meeting and alleviating their needs.

Chapter 2 describes the results of an exploratory literature review on the subjective needs of people with dementia. Electronic databases were searched for publications on subjective needs between January 1985 and July 2005, and additional papers were found by cross-referencing relevant publications. Extracts of publications on needs were classified according to problem areas of the (Dutch) National Dementia Program (NDP) and the quality of life domains. Subsequently the extracts were also classified as a "need" (an implicitly communicated felt state of deprivation), "want" (expression of a need) or "demand" (suitable solution to fulfil a need). Subjective needs as reported by people with dementia were found in 34 studies. The studies had various research aims, for example awareness and coping, and few studies focused specifically on the assessment of needs of people with dementia. The majority of the studies were based on small samples and were qualitative in nature. The results indicate that the most frequently reported needs of people with dementia were the need to be accepted and respected as they are, the need to find adequate strategies to cope with limitations, and the need to come to terms with their situation. Explicit wants or demands were expressed less frequently than needs. The high number of reported needs and the limited number of wants and demands shows that people with dementia often do not mention explicitly how they want their needs to be met. Most reported needs were not instrumental, but were related to well-being and coping.

Chapter 3 reports on the results of a large field study on the needs of community-dwelling people with dementia as reported by themselves and their informal carers. The study also provides insight into the service use, agreement on needs within patient-carer dyads, relationships between unmet needs and sociodemographic characteristics, and gaps between needs and availability of services. A large sample of 236

community-dwelling people with dementia and 322 informal carers were interviewed separately in their own homes, using the Camberwell Assessment of Need for the Elderly (CANE) to assess care needs.
People with dementia and carers reported that support was needed for many domains of daily living. Most unmet needs were experienced in the domains of memory, information, company, psychological distress and daytime activities; no, insufficient or inadequate support was provided for problems in these areas. The needs carers and people with dementia reported on a group level were quite similar, but people with dementia reported relatively fewer (unmet) needs than their carers; the agreement on needs within patient-carer dyads was low. Type and severity of dementia, living situation and informal carer characteristics were related to the number of reported (unmet) needs and to different care needs. Reasons for unmet needs were lack of knowledge about the existing service offer, a threshold to using services and insufficient service offer. These results provide good starting points to improve community care for people with dementia.

Chapter 4 describes the results of the study on the validity and reliability of the Dutch version of the CANE for use among community-dwelling persons with dementia and their informal carers. The data of the field study on needs in dementia were used to establish the construct validity. Criterion validity and test-retest reliability of the Dutch version of the CANE were established by conducting separate telephone interviews with 69 informal carers. The construct validity of the CANE was good among people with dementia and informal carers. Criterion validity could be studied for 76.9% of the CANE items, and conform the expectations all significant correlations were convergent. Test-retest reliability of the CANE varied from poor to very good and was best on domains where needs were explicit and problems well defined, such as physical health and household chores. The study shows acceptable construct and criterion validity and test-retest reliability of the CANE, and therefore supports the use of the Dutch version of the CANE among community-dwelling people with dementia and their carers.

Chapter 5 describes the development of a DEMentia-specific Digital Interactive Social Chart (DEM-DISC). Community-dwelling people with dementia and their informal carers experience a lot of problems and many of them experience unmet needs with regard to information on the disease and on the available care and welfare offer. They therefore tend not to fully utilize the broad spectrum of available care and welfare services. This can have very negative consequences; DEM-DISC aims to counteract these problems. DEM-DISC is a demand-oriented website for people with dementia and their carers, which is easy to use, accessible and provides users with general and customized information on healthcare and welfare services.

DEM-DISC is developed according to the human-centred design principles: people with dementia, informal carers and healthcare professionals were involved throughout the development process. DEM-DISC was developed from four perspectives. Within the *domain-specific content perspective* needs and available dementia care and welfare offer were identified. The formulations of the needs were based on the NDP and specific features of services were also inventoried to enable the system to provide customized advice. Within the *ICT perspective* DEM-DISC was built as a web-based system and the service ontology was developed and tested. Within the *user perspective* requirements of DEM-DISC were formulated and *demonstrators* of DEM-DISC were tested for the system's user-friendliness and usefulness. Within the *organizational perspective* research was done on a viable business model. The community and the governmental model were found to be the most viable to exploit DEM-DISC.

Finally, a first prototype of DEM-DISC was built with a simple interface, which included the service offer in the region of Amsterdam for five NDP problem areas. Users were supported to clarify their needs in three steps: from a need to a want to a demand. Each demand received an advice on available healthcare and welfare services, and additional information was given, tailored to the preferences of the user if required. Furthermore, the first DEM-DISC prototype contained links to national and regional dementia-related websites and daily news updates on dementia. The conclusion was that the human-centred design was a valuable method for the development of the DEM-DISC.

Chapter 6 reports on the results of the evaluation of the first prototype of DEM-DISC. This study was conducted among informal carers in Amsterdam. During a two-month intervention period the user-friendliness, usefulness and impact of the utilization of a first prototype of DEM-DISC on the daily life of people with dementia and their carers were evaluated within a pretest-posttest control group design.

Fourteen informal carers were provided with access to DEM-DISC in their own home, fourteen controls did not have access to DEM-DISC but could only consult their usual sources of information, like printed guides, regional newspapers, the internet, etc. Data were collected through separate interviews with people with dementia and carers at pretest and posttest, by digital logging of DEM-DISC use, short telephone interviews, and with a bottleneck checklist during the intervention period.

Although carers were not explicitly satisfied with this first prototype of DEM-DISC, they found it easy to learn to use DEM-DISC and thought the system was relatively user friendly. After only two months of DEM-DISC use they already reported a higher sense of competence than controls. People with dementia and informal carers in the DEM-DISC group also reported more *met* and fewer *unmet* needs.

These positive effects may be caused by the systematic and tailored individual way of information provisioning DEM-DISC offers. We recommend developing DEM-DISC further and conducting a randomized controlled trial into the impact of DEM-DISC use on patients and carers. The impact on nursing home admission and healthcare expenditure are also worth investigating.

Chapter 7 summarizes the main results from earlier chapters, reports on the main limitations of the studies, discusses scientific, psychogeriatric and societal relevance and considers recommendations for future research and psychogeriatric care that are derived from the results described in this thesis.

Despite the fact that a sample of community-dwelling people with dementia and informal carers was questioned comprehensively about their care needs, the results should be treated with some caution. A relatively large proportion of the non-response was caused by overburden of informal carers, and many people with dementia who lived alone could not be reached. These groups may experience different or more (unmet) care needs that could therefore be underrepresented in our study.

As the circumstances made it impossible to perform an RCT, and we therefore had to perform a pretest-posttest control group trial, the results of the evaluation of DEM-DISC cannot be directly generalized. The first reason is that only a small sample could be recruited due to the specific inclusion criteria, for example computer experience, and with the limited available time to recruit participants. This caused a selection bias: as compared to the control group, there were fewer spouses and more children of people with dementia (with computer skills) in the experimental group. In the analyses we controlled for these differences. Secondly, the DEM-DISC version under evaluation was a prototype, restricted to the city areas of Amsterdam Zuid and Amsterdam Zuideramstel, and it had the possibility to give advice for available care and welfare services on five of the fourteen problem areas of the NDP. Even though this prototype was evaluated by informal carers as relatively user friendly and useful and it seems to have some positive impact on the lives of people with dementia and their carers, the results can not be generalized to all carers with all types of needs living in different parts of the Netherlands.

The results of our field study on needs in dementia contribute to the knowledge on needs that community-dwelling people with dementia experience. Many studies have been conducted on needs in dementia, but they fail to report on the needs of people with dementia and their carers separately. Additionally we studied the agreement on needs within patient-carer dyads. We also showed that service offer was available for the most common unmet needs.

The development of DEM-DISC is unique and contributes to the growing knowledge on assistive technology of people with dementia and their carers. Information systems on dementia and care and welfare services are available, but were never evaluated with (potential) users on their user friendliness, usefulness and impact.

Professional carers in psychogeriatric care should take into account that the opinions of people with dementia and their carers are complementary. They should also pay attention to characteristics that are related to a higher risk for unmet needs, like having another type of dementia than Alzheimer's disease, severe dementia, separate households, and informal care provided by non-spouses, younger, female or burdened persons.

DEM-DISC may help to improve the dementia healthcare and welfare offer in a region by giving insight into the gaps in the existing offer for specific care needs. Because DEM-DISC is a demand-oriented system, care and welfare providers need to shift from supply-driven to a demand-oriented service offer that puts their (potential) clients first. The resulting insight into (un)met needs in dementia provides policy makers with the information they need to change the existing care system into a more demand-oriented system.

As DEM-DISC is developed with potential users, DEM-DISC is expected to give users an easy tool to make informed choices on the type of care that meet individual demands and to use available care more effectively. Targeting and alleviating unmet needs in time, may enable people to live in their own home for a longer period of time, thereby possibly postponing nursing home admission and even mortality. Furthermore the costs of health care could be reduced.

Successful implementation of DEM-DISC requires that it is further developed, using human-centred design principles. Before considering implementation on a large scale, the effects of DEM-DISC use should be studied with the fully developed version by means of an RCT. Only than can statements be made about the generalizability of possible effects. In addition to the effects of its use by informal carers, future studies should also focus on DEM-DISC use among people with dementia and professional carers and on how they experience its' user friendliness, usefulness and impact.

The results described in this thesis can support care professionals to better tailor their care to the needs and demands of their clients. To assess the needs of people with dementia, we recommend the systematic use of the CANE in dementia care practice.

With the development of DEM-DISC both dementia care providers and care users are being served: DEM-DISC procures dementia care providers with a tool to create and maintain a care chain in dementia practice, because it helps to identify needs and lacunas in the service offer in a region. By solving the unmet needs and filling the lacunas, a balanced continuum of dementia care in a region can be created that focuses on people with dementia in different stages of the disease. On the other hand, DEM-DISC provides user groups with relevant information on supportive services, it discloses the care offer in a region and makes the service offer easily accessible for potential users. It is therefore expected that DEM-DISC will ultimately contribute to a better quality of care, to more effective care use and, as a consequence, to a better quality of life for people with dementia.

Samenvatting

In dit proefschrift wordt verslag gedaan van een onderzoek naar de zorg- en ondersteuningsbehoeften van thuiswonende mensen met dementie en hun mantelzorgers. Om mensen te kunnen informeren over voor hen nuttige voorzieningen is een DEMentie specifieke Digitale Interactieve Sociale Kaart (DEM-DISC), kortweg de DementieWijzer, ontwikkeld. De ontwikkeling en evaluatie hiervan worden eveneens in dit proefschrift beschreven. Deze studie werd uitgevoerd in het kader van het Nederlandse FReeband User eXperience (FRUX) project.

Hoofdstuk 1 gaat in op de aanleiding en het doel van het onderzoek. Doordat onze maatschappij vergrijst, zal ook het aantal mensen met dementie in de toekomst toenemen. Het merendeel van de mensen met dementie woont thuis en ontvangt mantelzorg (voornamelijk van partners of familieleden) en in veel gevallen ook professionele hulp. Verwacht wordt dat het aantal mensen met dementie over twintig jaar verdubbeld zal zijn en dat de capaciteit van de gezondheidszorg niet in gelijke mate mee zal kunnen groeien. Hierdoor zullen mantelzorgers en de beschikbare professionele zorg enorm onder druk komen te staan. Om mensen met dementie in toereikende mate te kunnen ondersteunen zal zorg in de toekomst efficiënter en meer adequaat geboden moeten worden.

Zorgen voor iemand met dementie vraagt veel van mantelzorgers. Veel mantelzorgers zijn overbelast door de zorg en ervaren ernstige psychische klachten, angst en depressie. Het is bekend dat overbelasting door de zorg, stress en onvervulde zorgbehoeften gerelateerd zijn aan verpleeghuisopname en overlijden van mensen met dementie. Om mensen met dementie in staat te stellen zo lang mogelijk in hun eigen huis te blijven wonen is het belangrijk om onvervulde zorgbehoeften tegemoet te komen.
Het gezondheidsbeleid in Nederland is er ook op gericht om mensen met dementie zo lang mogelijk in hun eigen omgeving te laten wonen. Dat betekent dat met de groeiende groep ouderen de zorg doelmatiger zal moeten worden ingericht. Het beter aansluiten bij vragen van gebruikers, met andere woorden een omwenteling van een aanbodgestuurd naar een vraaggestuurd stelsel kan hiertoe bijdragen. Hierin krijgt de cliënt een meer centrale rol toebedeeld en worden zorgaanbieders aangemoedigd om beter tegemoet te komen aan de wensen en behoeften van hun cliënten. Maar om geschikte en efficiënte vraaggestuurde zorg te kunnen leveren is het nodig inzicht te verkrijgen in de behoeften van de individuele zorgvrager. Hoewel er uitgebreid on-

derzoek is gedaan naar behoeften van mensen met dementie, zijn zij zelf in studies zelden geraadpleegd over hun zorgbehoeften.
In lijn met het gezondheidsbeleid opende de Nederlandse regering in 2002 de gezondheidszorgmarkt voor commerciële partijen die hun diensten konden aanbieden naast het reguliere, publiekelijke aanbod. Hierdoor is het huidige aanbod van zorg- en welzijnsdiensten erg uitgebreid en gefragmenteerd. Het aanbod wijzigt ook continu, hierdoor bestaat het gevaar dat mensen met dementie, mantelzorgers en verwijzers door de bomen het bos niet meer zien en vervolgens het brede aanbod van beschikbare, dementiegerelateerde diensten niet optimaal benutten. In Nederland is het nu algemeen erkend dat er een keten (continuüm) van flexibele en transparante zorg en ondersteunende voorzieningen voor de verschillende stadia van dementie nodig is.
De laatste 10 jaar wordt Informatie en Communicatie Technologie (ICT), naast de gebruikelijke professionele zorg, als een veelbelovend middel gezien om mensen met dementie en hun mantelzorgers te ondersteunen. Van verscheidene ontwikkelde technologische hulpmiddelen die ondersteuning bieden bij dementiesymptomen is inmiddels bewezen dat ze effectief zijn. Maar ICT toepassingen om in de informatiebehoefte over dementie en beschikbare zorg- en welzijnsvoorzieningen te voorzien, zijn nooit wetenschappelijk onderzoekt op hun effectiviteit. Verder zijn deze toepassingen over het algemeen statisch en generiek. Een systeem dat advies op maat kan geven over specifieke zorgbehoeften en dat adviseert over beschikbare zorg- en welzijnsvoorzieningen in een regio zou mensen met dementie en hun mantelzorger kunnen ondersteunen bij het tegemoetkomen of verlichten van hun specifieke behoeften.

Hoofdstuk 2 beschrijft de resultaten van een verkennende literatuurstudie naar de subjectieve behoeften van mensen met dementie. Digitale databases werden doorzocht naar publicaties over subjectieve behoeften die zijn verschenen in de periode tussen januari 1985 en juli 2005, voorts werden aanvullende publicaties gevonden door de referenties van relevante publicaties door te kijken. Delen van de publicaties, handelend over subjectieve behoeften werden gecodeerd naar de probleemgebieden van het Landelijk Dementieprogramma (LDP) en de kwaliteit van leven domeinen. Vervolgens werd bij deze stukken tekst aangegeven of het een behoefte (een onbewust gecommuniceerd gevoel van gemis), een wens (een uiting van een behoefte) of een specifieke vraag (een passende oplossing om in een behoefte te voorzien) betrof. In 34 studies werden behoeften gevonden die door mensen met dementie zélf waren aangegeven. De studies hadden verschillende onderzoeksdoelen, zoals het verkrijgen van inzicht in het bewust zijn van en omgaan met de gevolgen van dementie. Slechts in enkele studies werd specifiek onderzoek verricht naar de behoeften van mensen met dementie. Uit de resultaten van de literatuurstudie bleek dat de behoefte om geaccepteerd en gerespecteerd te worden om wie men is, het vinden van de juiste strategieën om om te gaan met beperkingen, en de behoefte om de situatie te accepteren het meest gerapporteerd werden door mensen met dementie. Expliciete wensen of vragen werden minder vaak geuit dan algemene behoeften. Het hoge aantal algemene behoeften ten opzichte van de beperkte uitingen van wensen en specifieke vragen, laat zien dat mensen met dementie zelden expliciet aangeven hoe zij willen dat in hun behoeften wordt voorzien. De meest gerapporteerde behoeften waren niet instrumenteel van aard, maar gerelateerd aan welbevinden en het omgaan met de gevolgen van dementie.

Hoofdstuk 3 zet de resultaten uiteen van de grootschalige veldstudie naar de behoeften die thuiswonende mensen met dementie zelf en hun mantelzorgers ervaren. Het onderzoek geeft ook inzicht in het zorggebruik, de mate van overeenstemming van behoeften tussen patiënten en mantelzorgers, verbanden tussen behoeften en sociodemografische kenmerken, en lacunes tussen behoeften en het beschikbare zorgaanbod. Een grote steekproef van 236 mensen met dementie en 322 mantelzorgers is in hun thuissituatie geïnterviewd, waarbij gebruik is gemaakt van de Camberwell Assessment of Need for the Elderly (CANE) om zorgbehoeften in kaart te brengen.

Mensen met dementie en mantelzorgers gaven aan dat op veel gebieden van het dagelijks leven ondersteuning of hulp nodig was. De meest gerapporteerde onvervulde behoeften betroffen ondersteuning op het gebied van geheugenproblemen, informatievoorziening, gezelschap, psychisch lijden en dagbesteding. Hiervoor ontving men geen, onvoldoende of inadequate hulp. De behoeften die mensen met dementie en mantelzorgers noemden kwamen op groepsniveau redelijk overeen, hoewel mensen met dementie relatief veel minder (onvervulde) behoeften noemden dan mantelzorgers. De overeenstemming binnen patiënt-mantelzorgparen over ervaren behoeften was dan ook laag.

Het type en de ernst van dementie, woonsituatie, en mantelzorgkenmerken bleken samen te hangen met het aantal gerapporteerde (onvervulde) behoeften en met verschillen in zorgbehoeften. Het gebrek aan kennis over het bestaande zorgaanbod, het ervaren van een drempel om zorg te gebruiken en ontoereikende zorg werden genoemd als redenen voor onvervulde zorgbehoeften. De resultaten bieden een goed uitgangspunt om het bestaande zorgaanbod voor mensen met dementie te verbeteren.

Hoofdstuk 4 beschrijft de resultaten van het onderzoek naar de validiteit en betrouwbaarheid van de Nederlandse versie van de CANE onder thuiswonende mensen met dementie en hun mantelzorgers. Om de constructvaliditeit vast te stellen is gebruik gemaakt van de data van de veldstudie. Door middel van het afnemen van aparte telefonische interviews met 69 mantelzorgers konden de criteriumvaliditeit en de test-hertest betrouwbaarheid van de Nederlandse CANE bepaald worden. De constructvaliditeit van de CANE was goed voor mensen met dementie en mantelzorgers. De criteriumvaliditeit kon onderzocht worden voor 76.9% van de items, waarvan alle significante correlaties convergent bleken conform de verwachtingen. De test-hertest betrouwbaarheid van de CANE lag tussen slecht tot erg goed en was het hoogst voor expliciete behoeften en duidelijk omschreven problemen zoals fysieke gezondheid of het doen van het huishouden. De onderzoeksresultaten, die acceptabele construct- en criteriumvaliditeit en test-hertest betrouwbaarheid aantoonden, ondersteunen het gebruik van de Nederlandse versie van de CANE onder thuiswonende mensen met dementie en hun mantelzorgers.

Hoofdstuk 5 beschrijft de ontwikkeling van een DEMentie specifieke Digitale Interactieve Sociale Kaart (DementieWijzer). Thuiswonende mensen met dementie en hun mantelzorgers ondervinden veel problemen en veel van hen ervaren onvervulde behoeften met betrekking tot informatievoorziening over de ziekte en het beschikbare zorgaanbod. Hierdoor gebruiken zij het brede aanbod van voorzieningen niet optimaal, wat negatieve consequenties tot gevolg kan hebben. De DementieWijzer beoogt deze problemen tegen te gaan. De DementieWijzer is een gebruikersvriendelijke, gemakkelijk toegankelijke en vraaggestuurde website voor mensen met dementie en mantelzorgers die algemene informatie én informatie op maat biedt over beschikbare zorg- en welzijnsvoorzieningen.

De DementieWijzer is ontwikkeld volgens zogenaamde *human-centred design* principes: mensen met dementie, mantelzorgers en zorgprofessionals zijn actief betrokken tijdens het ontwikkelingsproces. De DementieWijzer is ontwikkeld vanuit vier verschillende perspectieven. Binnen het *domein specifieke inhoudsperspectief* zijn behoeften en het beschikbare zorg- en welzijnsaanbod voor dementie in kaart gebracht. De formuleringen van de behoeften werden gebaseerd op het LDP, daarnaast werden specifieke kenmerken van voorzieningen geïnventariseerd. Met deze gegevens is het mogelijk om informatie op maat te bieden voor gebruikers van de DementieWijzer. Binnen het *ICT-perspectief* is de DementieWijzer gebouwd als een internetsysteem en is de service ontologie (waarmee vraag en antwoord wordt gematched) ontwikkeld en getest. Binnen het *gebruikersperspectief* zijn enkele gebruikersvereisten voor de DementieWijzer geformuleerd en zijn *demonstrators* van de DementieWijzer getest op gebruikersvriendelijkheid en bruikbaarheid. Tot slot is binnen het *organisatieperspectief* onderzoek gedaan naar het meest levensvatbare business model om de DementieWijzer op de markt te brengen. Voor de exploitatie van de DementieWijzer werden het community-model en het overheidsmodel het meest geschikt bevonden.

Uiteindelijk is een eerste prototype van de DementieWijzer gebouwd, met een eenvoudige interface, waarin het service aanbod voor vijf LDP probleemgebieden werd opgenomen voor de regio Amsterdam. In drie stappen werd de gebruiker ondersteund om zijn behoeften te verduidelijken: van een algemene behoefte, naar een wens, naar een specifieke vraag. Op elke specifieke vraag volgde een advies over het beschikbare aanbod en aanvullende informatie hierover. Indien gewenst was dit advies toegesneden op de voorkeuren van de gebruiker. Hiernaast bevatte het eerste prototype van de DementieWijzer links naar nationale en regionale websites over dementie en was er dagelijks nieuws over dementie te vinden. De *human-centred design* methode bleek een waardevolle werkwijze om de DementieWijzer te ontwikkelen.

Hoofdstuk 6 doet verslag van de resultaten van de evaluatie van het eerste DementieWijzer prototype. Deze studie is uitgevoerd onder mantelzorgers in Amsterdam. Tijdens een interventieperiode van twee maanden zijn de gebruikersvriendelijkheid, de bruikbaarheid en de impact van het gebruik van het eerste DementieWijzer prototype op het dagelijks leven van mensen met dementie en mantelzorgers onderzocht. Dit is gedaan door middel van een pretest-posttest controlegroep design.
Veertien mantelzorgers kregen thuis toegang tot de DementieWijzer, veertien mantelzorgers in de controlegroep hadden geen toegang tot de DementieWijzer en konden uitsluitend hun gebruikelijke informatiebronnen raadplegen zoals papieren gidsen, regionale kranten, internet, etc. De dataverzameling vond plaats via individuele interviews met mensen met dementie en mantelzorgers bij aanvang en na twee maanden, via digitaal bijhouden (loggen) van het DementieWijzer gebruik, via korte telefonische interviews en het bijhouden van een knelpuntenlijst. Hoewel mantelzorgers niet uitgesproken tevreden waren over dit eerste prototype van de DementieWijzer leerden zij het systeem wel gemakkelijk te gebruiken en vonden zij het relatief gebruikersvriendelijk. Al na twee maanden DementieWijzer gebruik rapporteerden mantelzorgers een hoger gevoel van competentie dan de controle groep. Mensen met dementie en mantelzorgers in de experimentele groep rapporteerden meer tegemoetgekomen en minder onvervulde behoeften dan mensen met dementie en mantelzorgers in de controle groep.
De positieve effecten worden mogelijk veroorzaakt door de op het individu afgestemde wijze van informatievoorziening die de DementieWijzer biedt. Het verdient aanbeveling de DementieWijzer verder uit te breiden en een gerandomiseerde trial uit te voeren naar de impact van de DementieWijzer gebruik op zowel mensen met dementie en mantelzorgers, als ook de invloed op verpleeghuisopname en kosten van de gezondheidszorg.

Hoofdstuk 7 vat de belangrijkste bevindingen uit de eerdere hoofdstukken samen, gaat in op de belangrijkste methodologische beperkingen van de studies, bediscussieert de wetenschappelijke, psychogeriatrische en maatschappelijke relevantie en bespreekt aanbevelingen voor toekomstig onderzoek en de psychogeriatrische zorg praktijk.

Ondanks dat een grote steekproef thuiswonende mensen met dementie en mantelzorgers uitvoerig over hun zorgbehoeften is bevraagd, dienen de resultaten met enige voorzichtigheid te worden bezien. Een groot deel van de non-respons werd veroorzaakt door overbelaste mantelzorgers. Veel alleenwonende mensen met dementie konden niet worden bereikt. Deze groepen hebben mogelijk andere of meer (onvervulde) zorgbehoeften die nu ondervertegenwoordigd zijn in onze studie.

Omdat de omstandigheden het onmogelijk maakten een RCT uit te voeren en we aangewezen waren op het uitvoeren van een gecontroleerd onderzoek, dient gewaakt te worden voor al te gemakkelijke generalisatie van de resultaten van de evaluatie van de DementieWijzer. De eerste reden hiervoor was dat er slechts een kleine groep participanten kon worden gerekruteerd. Dit hield enerzijds verband met de specifieke inclusiecriteria, ondermeer ervaring met computers, en met de beperkte tijdsspanne om participanten te werven. Dit veroorzaakt een zekere selectiebias: in de experimentele groep namen vergeleken met de controlegroep bijvoorbeeld minder partners en meer kinderen (met computervaardigheden) van mensen met dementie deel. In de analyses werd voor deze verschillen gecorrigeerd. Ten tweede was de te evalueren DementieWijzer versie een prototype en beperkt tot de stadsdelen Amsterdam Zuid en Zuideramstel. De DementieWijzer kon alleen adviseren over zorg- en welzijnsdiensten voor vijf van de veertien LDP probleemgebieden. Hoewel het prototype als relatief gebruikersvriendelijk en bruikbaar is geëvalueerd door mantelzorgers en enige positieve impact op het dagelijks leven van mensen met dementie en mantelzorgers lijkt te hebben, kunnen de resultaten niet zondermeer worden gegeneraliseerd naar alle mantelzorgers met alle typen behoeften in alle delen van Nederland.

De resultaten van de veldstudie dragen bij aan de kennis van de subjectieve behoeften van thuiswonende mensen met dementie. Er is veel onderzoek gedaan naar behoeften bij dementie, maar deze studies hebben nagelaten om de meningen van mensen met dementie zelf en hun mantelzorgers apart te rapporteren. In onze studie werd ook onderzocht of de behoeften binnen patiënt-mantelzorger paren overeenkwamen en werd aangetoond dat er voor de meeste genoemde onvervulde behoeftes voorzieningen beschikbaar waren.

De ontwikkeling van de DementieWijzer is uniek en draagt bij aan de kennis over ondersteunende technologie voor mensen met dementie en hun mantelzorgers. Informatiesystemen over dementie, zorg- en welzijnsaanbod zijn wel beschikbaar, maar van geen enkel systeem is de gebruikersvriendelijkheid, bruikbaarheid of impact eerder wetenschappelijk geëvalueerd met (potentiële) gebruikers.

Zorgverleners in de psychogeriatrie dienen er rekening mee te houden dat de meningen van hun cliënten en mantelzorgers elkaar kunnen aanvullen. Ook moeten zij alert zijn op kenmerken die samenhangen met een groter risico op onvervulde behoeften, zoals het hebben van een ander type dementie dan Alzheimer, ernstige dementie en alleen wonen, of wanneer mantelzorg wordt gegeven door niet-partners, vrouwen, jongere of overbelaste personen.

Door inzicht te verschaffen in lacunes in de zorg in een regio kan de DementieWijzer mogelijk bijdragen aan de verbetering van het zorgaanbod. Omdat de DementieWijzer een vraaggestuurd systeem is, moeten zorgaanbieders een kentering maken van aanbodgestuurde naar vraaggestuurde zorg, waarbij hun (toekomstige) cliënt centraal komt te staan. De verworven inzichten in (onvervulde) behoeften bij dementie verschaffen beleidsmakers de benodigde informatie om het bestaande zorgstelsel te hervormen in een meer vraaggestuurd stelsel.

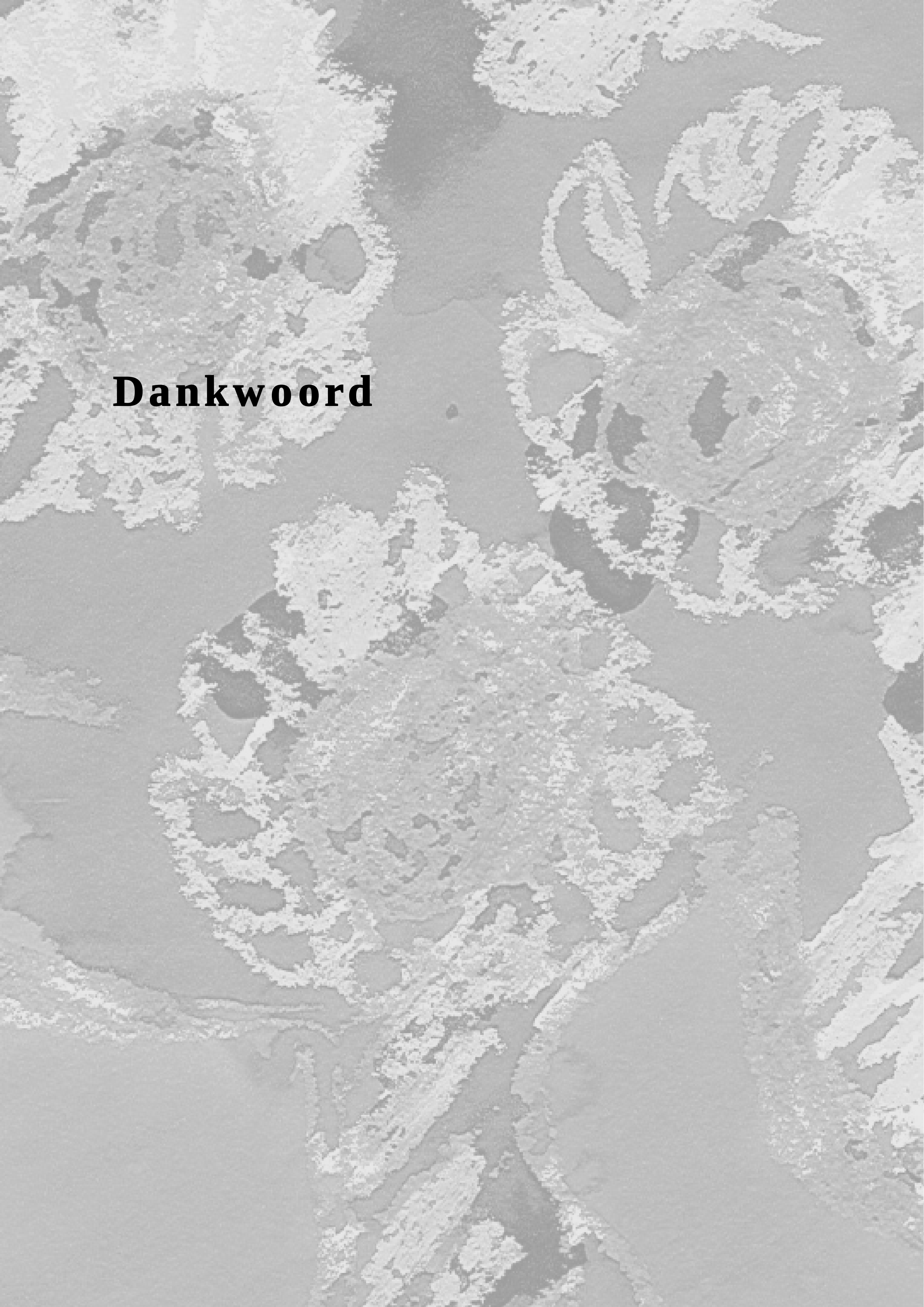
Omdat de DementieWijzer ontwikkeld is samen met potentiële gebruikers, wordt verwacht dat de DementieWijzer een gemakkelijk middel zal zijn waarmee gebruikers een weloverwogen keuze kunnen maken voor het type zorg dat tegemoet kan komen aan hun individuele behoeften. Hierdoor zal de beschikbare zorg ook meer efficiënt kunnen worden ingezet. Door het tijdig aanpakken en verlichten van onvervulde zorgbehoeften zal verpleeghuisopname en mogelijk zelfs overlijden kunnen worden uitgesteld en zullen mensen met dementie langer in hun eigen huis kunnen blijven wonen. Hierdoor zouden de kosten voor de gezondheidszorg kunnen verminderen.

Voor een succesvolle implementatie dient de DementieWijzer verder ontwikkeld te worden volgens *human-centred design* principes. Voordat grootschalige implementatie plaats kan vinden, zullen de effecten van het gebruik van de DementieWijzer met de uitontwikkelde versie dienen te worden bestudeerd in een RCT. Hiermee kunnen uitspraken gedaan worden over de generaliseerbaarheid van mogelijke effecten. In toekomstige studies dienen de effecten niet alleen onderzocht te worden onder mantelzorgers, maar ook onder mensen met dementie en professionele zorgverleners, ook bij hen zal gebruikersvriendelijkheid, en bruikbaarheid van de DementieWijzer moeten worden onderzocht.

De in dit proefschrift beschreven resultaten kunnen professionele zorgverleners helpen de zorg beter af te stemmen op de wensen en behoeften van hun cliënten. Het is aan te raden om de CANE systematisch in de praktijk te gebruiken om de specifieke behoeften van mensen met dementie te achterhalen.

Zowel zorgaanbieders als zorggebruikers hebben baat bij de ontwikkeling van de DementieWijzer: omdat met behulp van het systeem de zorgbehoeften en het zorgaanbod in een regio in kaart kan worden gebracht, kunnen zorgaanbieders de DementieWijzer gebruiken als een middel om een dementiezorgketen te ontwikkelen en in stand te houden. Door bestaande zorgbehoeften en lacunes in de zorg op te lossen, kan er een evenwichtig continuüm van zorg in een regio worden gecreëerd, waarbij de nadruk ligt op mensen met dementie in verschillende stadia van de ziekte. Anderzijds voorziet de DementieWijzer gebruikersgroepen van relevante informatie over ondersteunende voorzieningen en ontsluit het systeem het zorgaanbod op een laagdrempelige manier voor potentiële gebruikers. Hierdoor wordt verwacht dat de DementieWijzer zal bijdragen aan een betere kwaliteit van zorg en een betere kwaliteit van leven voor mensen met dementie.

Dankwoord



Try hard and learn… Dat geldt eigenlijk voor alles. Zeker ook voor de totstandkoming van dit proefschrift, waarvan ik nooit heb gedacht het te zullen schrijven. Het idee ooit te kunnen promoveren is tijdens mijn studie niet in mij opgekomen, zelfs niet toen ik na mijn afstuderen een 'doktersset' kreeg. Waarom ik dan toch een promotietraject ben ingestapt? Een duwtje in de juiste richting in combinatie met het juiste onderzoek deed het hem. En het resultaat hiervan ligt nu voor u.
Dit proefschrift is niet zondermeer tot stand gekomen en ik wil dan ook alle mensen bedanken voor hun onmisbare bijdragen, waarvan een aantal in het bijzonder.

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De leden van de leescommissie dr. E.J. Finnema, prof.dr. C.M.P.M. Hertogh, dr.ir. F. Moelaert-Hadidy, prof.dr. M.W. Orrell, prof.dr. F.R. Verhey en prof.dr. M.J.F.J. Vernooij-Dassen dank ik voor hun beoordeling van het manuscript van dit proefschrift.
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Martin Orrell, thank you for giving me the opportunity to work in London and to gain new experiences. It was definitely a good and educational period. I am happy you are

willing to oppose today. Chris Moniz, thanks for your support and friendship. And of course for introducing me to London and to your friends. The desk absolutely did it's job, Chapter 7 is the result of it.
I will not forget my London colleagues/friends, Claudia, Elisa, Sandeep, Jennifer, Amy, and Vasiliki. I loved working with you, thanks for all your interest and support. Claudia, I regret you cannot attend the promotion today. Good luck in Chile and hopefully we can visit you someday. Stay in touch.

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Oma, u staat als volwaardig laptopgebruiker op de foto. Ik geloof dat het een van de weinige foto's uit de reeks is, waarop de slappe lach niet is te zien. Bedankt voor het poseren. Alle andere (schoon)familie en vrienden, het was misschien niet altijd even duidelijk wat ik aan het doen was, maar bedankt voor jullie belangstelling. Het is eindelijk af.

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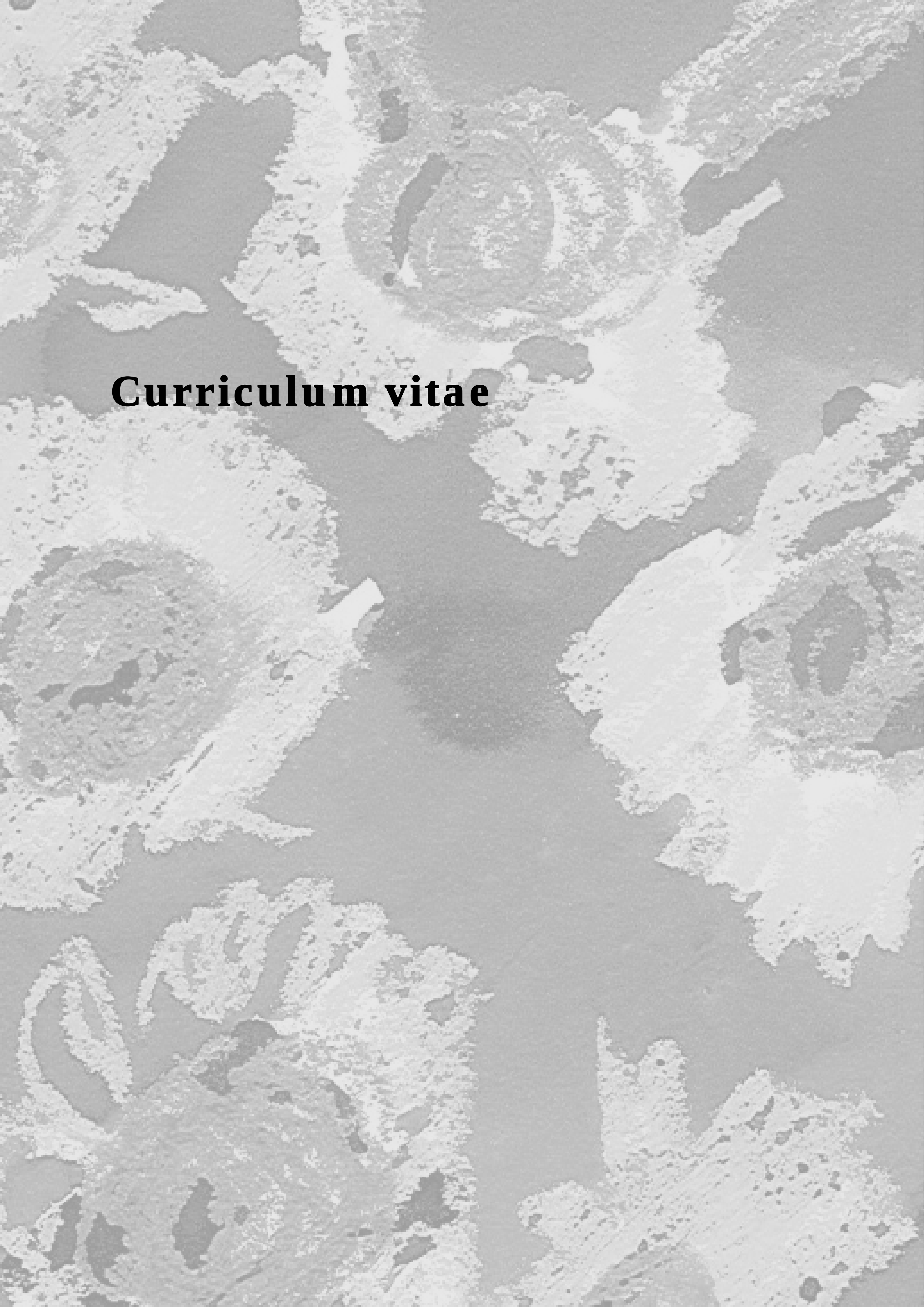
Curriculum vitae



Henriëtte van der Roest is op 26 augustus 1977 geboren in Laren. In 1995 behaalde zij haar VWO diploma aan het Christelijk College Stad en Lande te Huizen. Hierna begon zij de studie Psychologie aan de Vrije Universiteit in Amsterdam en studeerde in 2001 af in de Sociale Psychologie. Na werkzaam te zijn geweest in verschillende functies binnen de faculteit Geneeskunde van het VU medisch centrum begon zij in april 2005 bij de Academische afdeling Psychiatrie van het VU medisch centrum/GGZ Buitenamstel als junior onderzoeker. Hier deed zij in het kader van haar promotieonderzoek binnen het FRUX project, onderzoek naar de zorgbehoeften van thuiswonende mensen met dementie en hun mantelzorger en werkte zij aan de ontwikkeling en evaluatie van de DementieWijzer. Hiernaast was zij betrokken bij de helpdesk Ontmoetingscentra voor mensen met dementie en hun mantelzorgers en bij de behoeftepeiling naar een Inloophuis voor mensen met dementie in Amsterdam. Vanaf oktober 2008 tot en met januari 2009 werkte zij in Londen aan het University College London bij het Mental Health Department onder leiding van Professor Martin Orrell. Hier werkte zij mee aan het RemCare project, een nationale multicenter RCT naar het effect en de kosteneffectiviteit van gezamenlijke reminiscentie voor mensen met dementie en hun mantelzorgers. Momenteel is zij werkzaam als onderzoeker op het SHELTER project bij de afdeling Verpleeghuisgeneeskunde van het VU medisch centrum. Het SHELTER project is een Europese studie waarin een methode om de kwaliteit van verpleeghuiszorg in Europa te onderzoeken wordt gevalideerd. Vanaf 2007 maakt zij deel uit van INTERDEM, een internationaal netwerk van onderzoekers die zich bezighouden met de ontwikkeling van en onderzoek naar tijdige psychosociale interventies voor mensen met dementie.