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Care for vulnerable older persons: need, utilization and appropriateness

Zorg voor kwetsbare ouderen: behoefte, gebruik en passendheid

The study presented in this thesis was performed at the department of Public Health of the Erasmus Medical Center (Rotterdam, the Netherlands) in close collaboration with the Program on Aging of the Netherlands Institute for Mental Health and Addiction (Trimbos-instituut, Utrecht, the Netherlands) and the department of General Practice of the EMGO Institute (VU University Medical Center, Amsterdam, the Netherlands). The measurements for this study were conducted in the region West-Friesland, a northwestern region of the Netherlands in close collaboration with home care organization De Omring (Hoorn, the Netherlands).

The study was funded with a grant from the Netherlands Organization for Health Research and Development (ZonMw, project number:13550003).

Financial support for the publication of this thesis was kindly provided by:
Erasmus Medical Center
EMGO Institute
and
de Nederlandse Vereniging voor Gerontologie (NVG)

Cover design: Hidde van der Ploeg (sr.)
Cover photo: Eva van der Ploeg
Lay-out: Eva van der Ploeg
Printing: Ponsen & Looijen B.V., Wageningen, the Netherlands

ISBN: 978-90-9023878-4
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Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de
rector magnificus
Prof.dr. S.W.J. Lamberts
en volgens besluit van het College van Promoties.

De openbare verdediging zal plaatsvinden op
Woensdag 11 februari 2009 om 9:45
door
Eva Simone van der Ploeg
geboren te Laren

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Chapter 1

General introduction

The overall aim of this thesis is to evaluate care for vulnerable community-dwelling older persons (≥75). Care includes health care, but also home care, living care and psychosocial care. We focus on a chain of care decisions and actions including self-perceived care needs, care utilization and appropriateness of care. In this introductory chapter we provide general background on these concepts and on the group of vulnerable older persons. Research questions, methods and outline of this thesis will be addressed successively.

1.1 Background

In 2007 the Netherlands had a total population of 16,357,992 inhabitants of which 1,075,895 (6.5%) was 75 and over (http://statline.cbs.nl). Whereas the total population tripled over the last century the number of the persons aged 75 and over was multiplied by a factor 17 since 1900. This aging of the population continues in the future; it is estimated that in 2030 11% of the total population will be aged 75 and over. Not only do more persons grow old they also get older in absolute terms. Since 1950 men gained 7.4 years and women 9 years which makes the current life expectancy at birth 77.8 in men and 81.7 in women. Men spend on average 8.7 years and women 14.4 years with disabilities. In 2030 life expectancy at birth for men is estimated to be 80.2 and for women 83.1 years. The number of years in disability are expected to decrease in men over this period, whereas the trend in women is unclear.[1]

Aging of a population leads to an increase in the number of persons with certain (combinations of) diseases. For example the number of persons with cancer expected to grow with 50.5% between 2000 and 2020, the number of persons with diabetes with 48.1% and the number of persons with psychological problems with 44.1%.[2] More people will suffer from more than one disease; already 60% of persons over 65 years of age in the Netherlands suffer from two or more diseases. Multimorbidity leads to a higher risk of mortality, a poorer functional status and quality of life and increased use of health services.[3] Furthermore, impairments which influence daily functioning will be more prevalent, like problems with mobility, urine-incontinence and sensory problems. Concepts that are relatively new to describe the multiple problems that older persons often experience are vulnerability and frailty.[4,5]

1.1.1. Defining vulnerability

This thesis evaluates care for vulnerable persons aged 75 and over. Vulnerability is a state of poor functional health that resulted from an interplay of physical, psychological and social factors and leads to decreased reserves and diminished resistance to stressors. Vulnerability is related to frailty, a concept much discussed in the literature. Below we will shortly describe the existing literature on frailty and how vulnerability is related to frailty.

Frailty is commonly acknowledged as a syndrome amongst older persons, but it remains an enigmatic concept. Clinicians and patients apply the term frailty by

gestalt: They know it when they see it. It seems that the clinical definition is at odds with the research definition.[6] And even amongst researchers, in spite of a growing body of knowledge, there is no widely accepted definition.[7] There is only consensus on that frailty arises from many factors and that it is a state of vulnerability.[8] Frailty results from declines across multiple physiologic systems and leads to decreased reserve and resistance to stressors, and causes vulnerability to adverse health outcomes, like institutionalization, falls, disability, hospitalization, morbidity and mortality.[9,10] A consensus group of the American Geriatrics Society has settled on defining frailty as a physiological syndrome characterized by decreased reserve and diminished resistance to stressors.[9,11] A phenotype of physical frailty has been proposed as the combination of weight loss, fatigue, impaired grip strength, diminished physical activity and slow gait.[11] This precise characterization of frailty has been extremely useful for research[12,13], but this conceptualization of frailty as physiologic vulnerability can be problematic, partly because clinicians typically apply the word "frail" to functionally impaired older persons who are suffering from the cumulative effects of disease-related, psychosocial and environmental challenges.[8,11,14-16]

Even among researchers the AGS-consensus is not fully accepted as standard. For example, the Canadian Initiative on Frailty and Aging used another approach by accepting that a variety of definitions of frailty exists and should be classified. Frailty definitions were summarized as belonging to one of four classes: (1) physiological definitions; (2) definitions based on frailty as a complex syndrome; (3) frailty based on a balance model which combines the complex interrelationships between biological, behavioral and social pathways, and; (4) frailty defined on the basis of a geriatric syndrome, such as delirium and falls.[17] A recent study tried to map all existing definitions of frailty conducting a literature search and organizing expert meetings.[18] This resulted in a comprehensive model that integrated life course modifiers, diseases, frailty and adverse health outcomes. Frailty was described in terms of physical frailty, social frailty and psychological frailty. Again it emerged that some experts wanted to focus on physical frailty, whereas others wanted to include social and psychological factors as well.

The measure used in the current study includes physical, social and psychological items and thus is related to broad, generic definitions of frailty, e.g. the Groningen Frailty Indicator[19] and the nine frailty markers used in the Longitudinal Aging Study Amsterdam[20]. However, our measure also includes persons with milder forms of impaired functional health who consequently have slightly lower risks of adverse health outcomes than frail persons. More precisely, we define vulnerability as a poor functional health status that resulted from an interplay of physical, psychological and social factors and leads to decreased reserves and diminished resistance to stressors. Vulnerability was measured using COOP-WONCA charts[21] (see Box 1. for the operationalization of vulnerability of COOP-WONCA charts).

Box 1 Defining Vulnerability

A person is considered vulnerable when self reporting in the lowest quartile of 2 or more charts of the COOP-WONCA. Specifically this means that the person is characterized by 2 or more of the following symptoms:

1) fair to poor general health
2) only able to maintain very light physical activity during 2 minutes
3) a little or much worse health compared to 2 weeks ago
4) much difficulty with or not being able to performing one's usual activities or tasks
5) moderate to extreme emotional problems
6) moderate to extreme limitation in social activities

1.1.2. Self-perceived need

In the Netherlands and other Western European countries health care organizations work mostly supply-centered, which means that delivery of care is often determined by availability[22]. In the last two decades demographic developments in the Netherlands, like the increasing level of education and income, more attention for health and healthy lifestyles and increasing individualism, lead to more demanding individuals who want to have a say in the care they receive[23]. This lead to an increased interest in self-perceived needs assessment of individuals.

Need has commonly been defined as 'the ability to benefit in some way from health care[24,25]. More specifically as a state where (more) help with specific problems is required by care professionals, taking into account the views of persons themselves[26]. Bradshaw[27] distinguished four types of need: 1) normative need, the need for care as established by professional caregivers; 2) (self-)perceived need, the need as experienced by patients themselves; 3) expressed need, the explicit demand for care and support formulated by the patient; and 4) comparative need, which takes care utilization as starting point and looks if persons with the same health problems receive identical care. Availability might have been important in determining health care delivery, but how available resources were exactly allocated has mostly been based on symptomatology, diagnosis and disability (normative need) rather than on self-perceived patient need[28]. Care allocation based on presence of disability and diseases was rarely related to individuals subjectively perceived care needs[29-31]. For example, disability measures (e.g. Barthel Index[32]) do not take into account the impact of an individual's cultural and social background on their care needs[33]. Such a one-dimensional type of assessment can lead to over allocation of care when individuals are coping effectively by themselves or have sufficient support of relatives and friends[34]. On the other hand under-resourcing can occur when the person lacks readily identifiable symptoms or disabilities or when the individual does not seek assistance for needs[29].

For decades, an extensive number of unmet needs existed in older age groups unknown to their primary care physicians[35,36]. In 1990, the UK Department of Health was the first to introduce a contract of service for general practitioners (GPs), which required them to offer an annual multidimensional (needs) assessment to patients aged 75 years and older[37]. The evidence of benefit from such a whole population screening has always been thin, and the UK's '75 and over checks' had stalled long before they recently disappeared quietly from the new GP contract[38]. A very large randomized controlled trial showed that there are little or no benefits to quality of life or health outcomes from population screening[39]. Still, there is some evidence that needs assessment of older people followed by active management may improve survival and function[38], but there is lack of clarity on optimal approaches in general practice and currently no structured needs assessment tool is in widespread use. Although the UK contract specified broad areas for assessment, it gave little guidance on method, level, and nature of assessment[38]. Recently, a comprehensive and structured instrument was developed, the Camberwell Assessment of Need in the Elderly (CANE) to identify self-perceived met and unmet need in 24 care topics by interviewing older persons themselves[40]. A met need means that there is sufficient help to solve or significantly reduce the reported problem, whereas an unmet need means that there is no (sufficient) help to reduce the problem. CANE has been adapted from the Camberwell Assessment of Need used with adults with chronic mental illness[41] for use with older people in a mental health setting. Although some topics (e.g. psychotic symptoms and behavior problems) elicited very low responses when used in primary practice, CANE was found to be feasible in general practice to identify self-perceived needs not previously known by health professionals[42].

A small study using CANE (n=52) showed that for some topics half of a community-dwelling population over 75 years of age reported needs and on some topics up to 20% of older persons had unmet needs[42]. Most met needs were identified for Physical Health, Food, Household activities, Mobility/ falls and Eyesight/hearing impairment. Most unmet needs were reported by older persons for Eyesight/hearing impairment, Psychological distress (depression and anxiety symptoms), Incontinence, Information (on condition) and Company. Similar results for unmet needs were found in other CANE studies[38,43]. It was concluded though that many older persons tolerate unmet needs and seem reluctant to mention them to their general practitioner or acknowledge them unless asked directly[44]. Reasons for this restrained reporting differed per topic, for example for Information on condition (most identified unmet need in all studies) the authors suggested that older persons might prefer to accept as much as the doctor tells them instead of requesting additional information. For eyesight and hearing impairment it was suggested that older persons may attribute those difficulties to the aging process and think not much can be done. No studies have been identified using CANE in the Netherlands or focusing on vulnerable older persons.

1.1.3. Care utilization

Since the seventies the behavioral model developed by Andersen has come to dominate research on health care utilization in older persons. The initial model suggested that people's use of health care is a function of their disposition to use services combined with factors that enable use and their need for care[45]. Predisposing variables comprise demographic factors, (like age and gender), social structure factors (like education and ethnicity) and health beliefs (attitudes, values and knowledge about health and health care). In 1995 Andersen reviewed his model and added genetic factors, social networks and psychological characteristics like autonomy as possible predisposing variables[46]. In the original model enabling variables consisted of factors like income, health insurance status and travel/ waiting time. Andersen suggested that organizational measures and extent/ quality of social relationships should be added. Need variables are basic to this model and consist of people's own view of their general health and their experience of symptoms of illness, pain and worries[46,47]. A summary of research using this framework is found in Wolinsky[48]. Most but not all studies have shown that need variables, and especially worse functional health, are the main factors in explaining health care utilization in older persons (≥60 years of age)[49-57]. A very recent study found that in community-dwelling disabled older persons, lack of medication assistance in those needing medication support was associated with higher risk of hospitalization[58]. Thus, the association between need variables and different sorts of health care utilization is well established in both the general population as well as persons over 60 years of age. However, few studies have been done among persons aged 75 and over. An Israeli study in older persons showed that the demand for health services in a population with high levels of chronic disease and disability is driven primarily by health needs, rather than by extraneous factors such as income and education[54].

In the update of the model Andersen introduced the distinction between evaluated and self-perceived need[29]. Evaluated need represents professional judgment about a person's health status and his need for health care, whereas self-perceived need focuses on the experience of the person himself. A systematic review of 53 studies on chronically ill persons found an important role for evaluated need variables in predicting use, whereas the results for self-perceived need were mixed: four out of eight studies found that in multiple regression analyses controlled for assessed need variables, poor perceived health lead to more hospital admission, whereas the other four found no such association[47]. The association of self-perceived health with general practitioner visit was found more often (7 out of 9 studies). Self-perceived health was operationalized in these studies as a single measure asking the person to rate their overall health status. A study amongst frail older persons showed that frail persons who had an unmet need (i.e. receive no needed help) for ADL activities (like bathing, dressing) have higher admission rates than persons who reported a met need[59].

1.1.4. Appropriateness of care

Donabedian reported in 1980 that there are several definitions of quality or more accurately several variants of a single definition[60]. Characteristic of most definitions is the striving for an optimal balance between the actual care and expectations, guidelines and arrangements[61]. Donabedian also emphasizes three elements of quality of care: structure, process and outcome[62]. This so-called 'Donabedian's triad' of quality of care has generally been accepted as starting point for assessment and improvement of health care quality. Structure refers to facilities, equipment, services and manpower available[63]. Process refers to the actual process of care delivery by health care professionals, e.g. preventive measures, diagnostic tests and treatments[64]. Outcomes refers to changes in a patient's condition like physical function or ability for self-care[63]. The growing interest and commitment to quality of care was initiated by rising demands of governments to increase quality and provide evidence for effectiveness and efficiency. Patients, health economists and insurers also demanded value for money and increasing transparency and accountability with regard to the quality of care that is provided[65]. This thesis focuses on quality of care provided by general practitioners, because in the Netherlands they are the gateway to other care providers. Since the mid-80s quality policies for systematic quality assurance and improvement in general practice were developed and offered to GPs in the Netherlands[66]. For example, as part of a national guideline program, the Dutch College of General Practitioners (NHG) began developing practice guidelines in 1987[67]. The concern with and interest in quality of care resulted in the development and implementation of comprehensive quality of care assessment tools, the introduction of obligatory continuous medical education with accredited education programs, participation of GPs in obligatory peer review in local GP groups, and the introduction of a new certification system and so on[66,68,69]. Most of these initiatives have focused on the general population.

With the increase in life expectancy and aging in the baby boom generation, the Western world is becoming a region in which health care needs and costs are mainly driven by older persons, especially vulnerable older persons. For example, in 2000, American persons aged 65 and older had approximately four times the number of days of hospitalization as persons younger than 65[70]. Older persons also differ from younger persons in life expectancy, disease prevalence and comorbidity, social resources, goals of treatment, and preferences for care, which makes them particularly susceptible to adverse outcomes of substandard care[71] and complicates defining and measuring quality of care in this age group[72]. During the past quarter century, researchers, health care providers, insurers and governments have devoted considerable effort to improve and standardize quality of care for older persons[72]. The sum of this research is an emerging vision of optimal health care delivery for vulnerable older persons including the following principles: 1) care must be personalized to meet each patient's goals, values and resources; 2) care should be provided in accordance with best practices; 3) team care is essential; 4) care must be coordinated among those caring for patients; 5)

care must consider the resources and environment of the patient, and; 6) older persons must be included as active partners in their care as long as they are not to weak, mentally or physically[73].

Researchers at RAND and UCLA developed a comprehensive appropriateness method to asses quality of care for vulnerable persons aged 65 and older combining evidence and expert opinion which focuses on care processes (Assessing Care of Vulnerable Elders (ACOVE))[74]. The appropriateness method was developed as a pragmatic solution to the problem of trying to assess for what patients certain surgical and medical procedures are "appropriate." In this context, *appropriate* means that the benefits sufficiently exceed the risks and that the procedure is worth doing[74]. Appropriate care is described in quality indicators. A comparison of four systematic evidence based methods to develop and apply quality indicators in primary care showed that although the RAND method rarely includes patients and does not consider cost implications it is the only method that has evidence of predictive validity of the indicators[75]. For example, in a sample of 372 older persons 55% of the care provided was considered appropriate[76] and those receiving appropriate (or better-quality) care had a 10% higher survival over 3 years[71]. Another study amongst Medicare and Medicaid enrollees aged 75 and over that 65% of the care provided was appropriate[77]. This study also showed that many quality indicators (44 of 230) could not be tested in practice since the necessary information could not be abstracted using administrative data[77]. Care for geriatric conditions was much less optimal than care for general medical conditions[76]. Overall it should be concluded that current health care systems are unable to provide high-quality care for vulnerable older persons, particularly for conditions associated with aging (like dementia and falls) that have escaped most prior measurement efforts[67].

Furthermore, despite the development and wide promulgation of many guidelines and quality indicators, the effect on changing physician behavior seems limited[78]. Adherence to guidelines varies substantially between care providers. A wide range of factors has been identified as possible barriers to the implementation of guidelines and quality indicators. A review showed that many investigators have focused on characteristics of individual physicians to explain failure of guideline implementation[79]. Cabana and colleagues developed a framework in which the main barriers identified were classified into three main categories: barriers related to the physicians knowledge (lack of awareness of guideline and lack of familiarity with recommendations given in guideline), barriers that affect physicians' attitudes (lack of agreement with guideline, lack of self-efficacy i.e. the belief that one can actually perform the action mentioned in the guideline, lack of outcome expectancy and inertia of previous practice) and external barriers, like patient preferences, environmental barriers and lack of time[78].

1.2 Research questions

This thesis aims to show what kind of care vulnerable older persons themselves feel they need, what care they actually use and what health professionals think is appropriate care for them.

The research questions, addressed in this thesis, are:

1. What is the prognosis of vulnerability and to what number and type of self-perceived needs does it lead in community-dwelling older persons?

2. What kind of care do vulnerable older persons actually use, how is this related to self-perceived need and what will be the effect of the aging of the population on health care utilization in 2030?

3. What do health professionals consider to be appropriate general practitioner care for vulnerable older persons and what barriers exist in practice to provide this care?

1.3 Research methods

To answer the first two research questions (on vulnerability, need and utilization) we conducted a cross sectional cohort study in West-Friesland, a north western region of the Netherlands. To answer the third question (appropriateness of care) we conducted a nationwide panel-study followed by explorative interviews in general practice in West-Friesland.

1.3.1. Health care needs and utilization

A cross sectional study was done to establish care needs, utilization and possible determinants in vulnerable older people. This survey followed on a randomized controlled trial on the influence of demand-led home visits by nurses in primary care.[80] The current research started 18 months after the start of the RCT. Inclusion criteria were: aged 75 and over, vulnerable at baseline (and for Chapters 3 and 5 also at follow-up) and community-dwelling.

Description of RCT

The objective of the RCT was to evaluate the cost-effectiveness of systematic home visits by nurses to frail elderly.[80] The intervention consists of visits (at least five during 1.5 years) by trained community nurses to older persons living at home. The nurses assessed the health status and objective care need. Together with the patient they prioritized the care needs and developed care schemes to improve their health status. Persons in the control condition received their usual care.

Inclusion criteria for this RCT were:

- aged 75 and over;
- listed as general practitioner patient;
- living at home, and;
- being vulnerable.

Exclusion criteria were: living in a residential or nursing home (or being admitted to either one during the study), being terminally ill as determined by general practitioners or having dementia symptoms according to MMSE[81] or 7-Minute screen[82]. No persons were identified as being terminally ill in the community-dwelling population. Dementia symptoms were established in a two stage screening process. In stage one, patients received a postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE[83]). This questionnaire has been successful in distinguishing demented persons from a general population sample[83]. We used self-reports (with or without help from a proxy) instead of proxy reports. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE) and the 7 min screen (7 MS). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients[82]. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7 MS, were excluded from the RCT.

General practitioners provided the names and addresses of all listed persons aged 75 and over and living at home. All persons (n=2949) received a health survey including the COOP-WONCA charts[21] in order to identify the most vulnerable persons. 2171 persons were not vulnerable, 54 reported dementia symptoms, 66 provided no informed consent and 7 persons left the study for other reasons.

Description of current study

After 18 months older persons again completed a health survey including COOP-WONCA charts to establish if they were still vulnerable. They also self-reported on some of the health care utilization measures used. Next, they were visited by an interviewer who conducted the Camberwell Assessment of Need in the Elderly (see Self-perceived need). Some data were derived from the RCT to provide supplemental information, for example on risk indicators. The ethical committee of the VU medical center approved this study.

Sampling

The current research started 18 months after the start of the RCT at which time 465 persons were still in the study. Of those 24 died during our study, 12 were admitted to a residential home, 6 moved out of the region and 105 were no longer vulnerable. Of the 318 eligible older persons 34 were no longer willing to

participate and 17 quit for medical reasons. Another 50 could not be reached, had incomplete data or were lost due to other or unknown reasons. In total data of 217 older persons (68% of eligible subjects) were used in analysis for chapters 3 and 5. Chapter 2 only included persons in the experimental group because they completed all necessary measurements at baseline (n=149). Chapter 4 also included recovered persons (n=327).

Self-perceived care need

As mentioned above self-perceived need focuses on the older persons experience in spite of the judgment of a professional. The Camberwell Assessment of Need for the Elderly (CANE) was used to assess self-perceived care needs.[84] The CANE consists of four care domains, Environmental, Physical, Psychological and Social, with 24 topics in total (Table 1.). Environmental needs are for example if a person has a fitting living environment (for example adapted to some disability), if they can keep their houses clean and if they can eat the food they want. Physical needs include the actual health problems the person experiences, but also if the person has problems taking medication or mobility problems. Psychological needs include experiencing memory, mood and behavioral problems. Social needs include experiencing a lack of company or of an intimate relationship and having trouble getting through the day due to a lack of activities. The CANE has good content and construct validity and appropriate criterion validity. Reliability is high.[24] CANE was conducted by trained interviewers. For every topic the older person stated if he currently experienced a need. A distinction was made between a met and an unmet need. For a met need there is sufficient care, for an unmet need the care given does not suffice or no care was provided.

Table 1. Domains and topics of the Camberwell Assesment of Need in the Elderly.

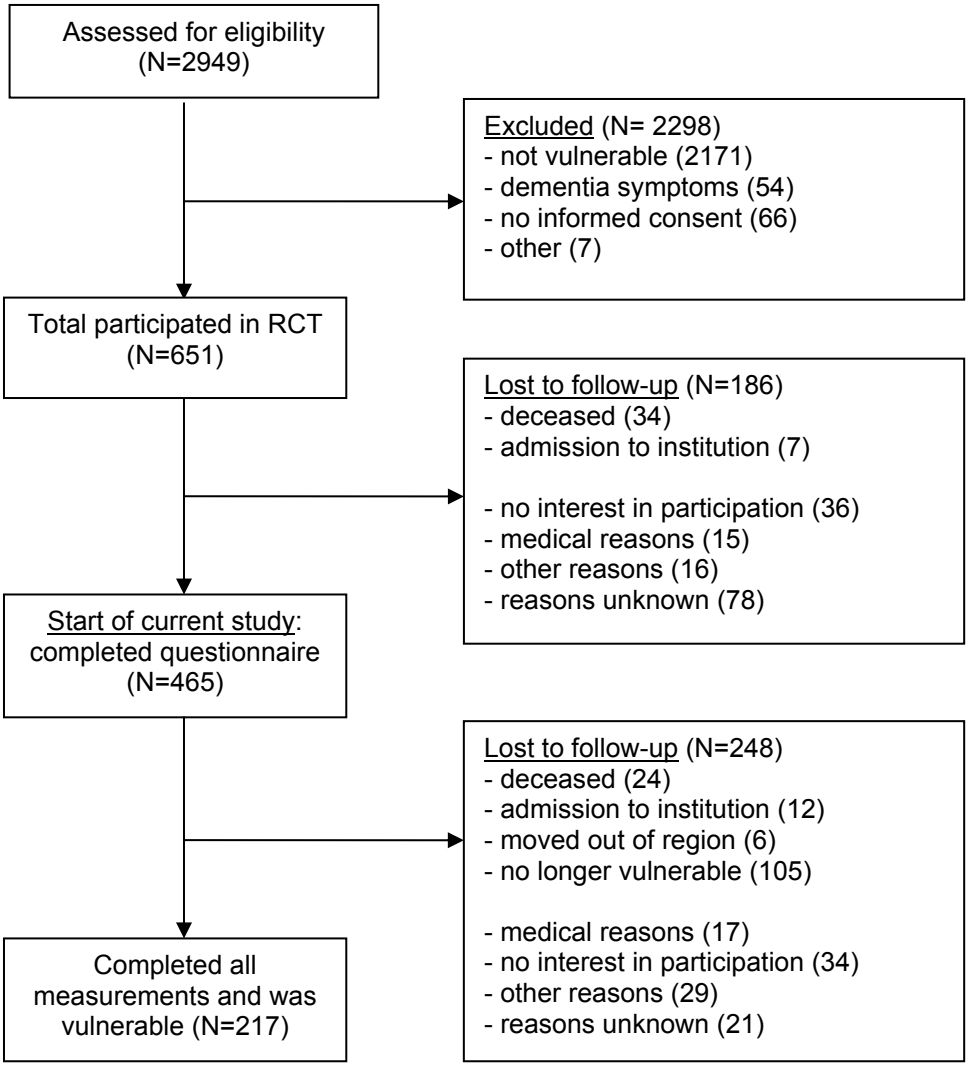
Environmental needs	*Physical needs*	*Psychological needs*	*Social needs*
Accommodation	Physical health	Psychological distress	Company
Household activities	Drugs		Intimate relationships
Food	Eyesight/hearing impairment	Memory	Daytime activities
Money		Behavior	Information
Benefits	Mobility/falls	Alcohol	Abuse/ neglect
Caring for someone	Self-care	Deliberate self-harm	
	Continence	Inadvertent self-harm	
		Psychotic symptoms	

Care utilization

The current study describes utilization of four types of health care, namely general practitioner visits, home care us and total and acute hospital admission. General practitioner visit is a combination of visits to the GP practice and home visits of the GP during the last 2 months. Visits of IADL home care (taking care of the persons

home and groceries) during the last week were noted. General practitioner visits and IADL-home care data were based on self-report whereas total and acute hospital admission data were abstracted from the registration record from the main hospital in the region. Total and acute hospital admission data for the last 5 years were abstracted.

Figure 1. Sampling of survey on care needs and utilization



1.3.2. Appropriateness of care

Appropriateness of care was first established as a theoretical concept. We asked health professionals, i.e. five general practitioners, two nursing home practitioners (medical doctors especially trained for working in a nursing home,) and two clinical geriatricians, to judge part of the American ACOVE-set[85] for validity in the Dutch health care situation. The focus was on general practitioner care and the following conditions were included: Continuity and Coordination of Care, Dementia, Depression, Diabetes, End of Life Care, Falls/Mobility, Medication Use and Undernutrition. The indicators which were judged valid by the Dutch experts were considered to (re)present appropriate care for Dutch vulnerable older persons. The theoretical indicators were partly tested in practice by interviewing 13 general practitioners on adherence to quality indicators and reasons of non-adherence. Three indicators for the conditions Type 2 Diabetes Mellitus and Depression were included in this explorative interview-study.

1.4 Outline of thesis

Chapters 2 to 4 focus on the description of vulnerable older persons in terms of vulnerability and self-perceived care needs. Chapters 5 and 6 focus on health care utilization and chapters 7 and 8 on appropriateness of care.

Chapter 2 describes the relationship of the vulnerability measure with some outcome measures and explores recovery from vulnerability and its determinants
Chapter 3 describes the number, type and determinants of self-perceived needs of vulnerable community-dwelling older persons.
Chapter 4 compares a measure of objective need with a measure of subjective need for use in older persons.

Chapter 5 focuses on health care utilization and the link between utilization and self-perceived need in comparison with predisposing, enabling and evaluated need variables.
Chapter 6 describes some future scenarios about the number of vulnerable older persons and health care utilization in 2030.

Chapter 7 describes a panel meeting of general practitioners, nursing home practitioners and clinical geriatricians; they discussed what appropriate GP care for a group of vulnerable older persons is and recorded this in quality indicators.
Chapter 8 describes the implementation of some of the quality indicators; general practitioners were interviewed to see if they actually adhered to care described in the quality indicators and to find out what reasons were of non-adherence.

Chapter 9 summarizes the findings of this thesis, discusses the methodology, proposes implication for care givers and policy makers and gives recommendations for future research.

Chapters 2 to 8 were written as separate publications in scientific journals. Some overlap between the chapters exists in the description of the methodology.

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Chapter 2

Recovery from vulnerability in Dutch community-dwelling persons aged 75 and over

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Submitted for publication

ABSTRACT

Objectives The aim of this study is to explore what proportion of vulnerable older persons is able to recover to a non-vulnerable state and to identify risk indicators that are associated with chronic vulnerability.

Methods 149 community-dwelling persons over 75 years of age in the Netherlands who were vulnerable as measured by COOP-WONCA charts were surveyed at baseline and after 18 months. Physical, lifestyle, psychological and social factors were measured at baseline to explore what risk indicators were related to chronic vulnerability.

Results 43 older persons (29%) had recovered from vulnerability after 18 months. The older a person was and the more depressive symptoms they reported the higher the risk of remaining vulnerable.

Discussion Almost one third of older persons was able to recover to a non-vulnerable state. As a consequence of the large loss to follow up it is likely that a selection bias occurred in this study with the most vulnerable persons leaving the study. When correcting for this bias recovery occurred in 15 to 25% of vulnerable persons. Depression might be reduced since it is highly prevalent (63%) and there is ample opportunity to improve the detection and treatment of depressive symptoms in older persons.

INTRODUCTION

Frailty is commonly acknowledged as a syndrome amongst older persons, but it remains an enigmatic concept. Clinicians often say "I know frailty when I see it, but I can't define it". This is not surprising given that in spite of a growing body of knowledge, there is no widely accepted definition[1]. There is only consensus on that frailty arises from many factors and that it is a state of vulnerability[2]. A consensus group of the American Geriatrics Society has settled on defining frailty as a physiological syndrome characterised by decreased reserve and diminished resistance to stressors, that results from declines across multivariate physiologic systems[3,4]. For this, a phenotype of physical frailty has been proposed as the combination of weight loss, fatigue, impaired grip strength, diminished physical activity and slow gait[3]. This precise characterization of frailty has been extremely useful for research[5,6], but this conceptualization of frailty as physiologic vulnerability can be problematic, partly because clinicians typically apply the word "frail" to functionally impaired older persons who are suffering from the cumulative effects of disease-related, psychosocial and environmental challenges[2,4,7-9].

Even amongst researchers the AGS-consensus is not completely accepted as standard. For example, the Canadian Initiative on Frailty and Aging used another approach by accepting that a variety of definitions of frailty exists and should be classified. Frailty definitions were summarised as belonging to one of four classes: (1) physiological definitions; (2) definitions based on frailty as a complex syndrome; (3) frailty based on a balance model (which adds social elements to the complex syndrome), and; (4) frailty defined on the basis of a geriatric syndrome, such as delirium and falls[10]. The definition of frailty in the current study falls into the third category; it is multifactorial and includes aspects of perceived health, mobility, recent change in health status, performing daily activities, but also emotional problems and performing social activities. To distinguish this type of frailty from the physical frailty as defined by Fried *et al.* we label our population as being "vulnerable".

Most investigators use a static measure of frailty although it is conceived as a dynamic state suggesting that not only a healthy person can become frail, but a frail person may be able to recover to a non-frail state[11]. To date, few studies are done on transitions from a non-frail to a frail status and only one on transitions between frail, pre-frail and non-frail states[3,12,13]. Transitions to states of greater frailty were more common (up to 43.3%) than transitions to states of lesser frailty (up to 23%) in community-dwelling persons of 70 and older[13]. The transition rate from being frail to non-frail was very low (0 to 9%). Gill et al. defined frailty as a combination of weight loss, fatigue, impaired grip strength, diminished physical activity or slow gait following the physical definition.

Our research focuses on the transition from vulnerability to a non-vulnerable state and looks into what risk indicators might be associated with remaining vulnerable. Vulnerability is a broad definition of frailty and includes both physiological,

psychological and social elements. For the purpose of identifying factors related to chronic vulnerability we examine physical, lifestyle, psychological and social risk indicators that predicted later life functional decline[14]. Research questions are; what proportion of older persons is able to recover from vulnerability? And are some groups at risk for remaining vulnerable?

METHODS

Design

This is a cohort study of community-dwelling vulnerable older persons in a north-western region of the Netherlands. Our study follows on a randomized controlled trial on the influence of demand-led home visits by nurses in primary care[15]. The objective of this RCT was to evaluate the (cost-)effectiveness of systematic home visits by nurses to vulnerable older persons. The intervention consists of visits (at least five during 1.5 years) by trained community nurses to older persons living at home. The nurses assessed health status and objective care need. Together with the person they prioritized the care needs and developed care schemes to improve their health status. Persons in the control condition received care as usual. The outcomes of this RCT were all negative. In the current study we only use persons from the experimental group, because they completed all necessary measurements at baseline. Preliminary analyses showed that slightly more persons in the control group recovered to a non-vulnerable state than in the experimental group. The ethical committee of the VU medical centre approved the study.

Participants

The research includes community-dwelling older persons who at the start were 75 years or older and were vulnerable. The sampling procedure of the RCT is described elsewhere[15]. Persons with dementia symptoms were excluded from the study. Dementia was established in a two stage screening process. In stage one, patients received a postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE)[16]. This questionnaire has been successful in distinguishing demented persons from a general population sample[16]. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE[17]) and the 7 min screen (7 MS[18]). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients[18]. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7 MS, were excluded from the study.

At the start of the RCT 651 persons were included in the study. 331 persons were allocated to the experimental group, which had measurements of risk indicators at baseline. This group was included in the analyses on factors associated with recovery from vulnerability. 27 persons died, 8 were admitted to a residential home

during our study and 1 person moved out of the region. Of the 295 eligible older persons 33 were no longer willing to participate, 6 thought the burden of the research was too high, 12 quit for medical reasons, 66 persons had incomplete RAI-data at baseline, 11 for other reasons and 18 persons quit for an unknown reason. In total 149 older persons (51%) were able and willing to complete all measurements.

Study variables

Vulnerability

Our study was embedded in a larger randomized controlled trial[15], which established vulnerability using COOP-WONCA charts[19]. Vulnerability was defined as being in the worst quartile of at least two out of six COOP-WONCA charts (Box 1.). In a pilot study the charts showed a high percentage of complete item response and they were easy to administer. The association of vulnerability with mortality and hospital admission is shown in Appendix A..

Box 1 Defining Vulnerability

A person is considered vulnerable when self reporting in the lowest quartile of two or more charts of the COOP-WONCA. All items had a range of 1 to 5, with 1 meaning good health or lack of problems and 5 meaning poor health or many problems. Per item the lowest quartile was calculated. Specifically a vulnerable person is characterized by two or more of the following symptoms:

1) fair to poor self-perceived health (score: 4 and 5)
2) only able to maintain very light physical activity during 2 minutes (score: 5)
3) little or much worse health compared to 2 weeks ago (score: 4 or 5)
4) much difficulty with or not being able to perform one's usual activities or tasks (score: 4 or 5)
5) moderate to extreme emotional problems (score: 3 to 5)
6) moderate to extreme limitation in social activities (score: 3 to 5)

Determinants

Unless stated otherwise risk indicators were measured using the Resident Assessment Inventory-Home care (RAI-HC), which is a structured and computerized multidimensional geriatric interview, which identifies problem areas in a direct and validated way[20,21]. RAI-HC was conducted by trained nurses.

Demography Birth date, gender, marital status and education were noted at baseline. Marital status had four categories, namely married, never married, divorced/ separated and widowed. Education levels were described in terms of low, middle and high education, with low signifying no or elementary education, middle referring to high school education and high to persons having bachelor and master degrees.

Physical factors Per person we counted the presence of 22 chronic somatic diseases to establish disease burden (multimorbidity). For specific chronic

diseases we included the top 10 of most prevalent diseases in older persons over 75 years of age in the Netherlands[22]. Cardiovascular disease (CVD) was composed of the RAI-HC items 'coronary artery disease' and 'peripheral artery disease'. Since persons with dementia were excluded in this study, dementia could not be included in the analysis although it is one of the most prevalent diseases in this age group. CVD, Arthritis, Auditory diseases, Cataract, Diabetes, Chronic heart failure, Pulmonary diseases (including COPD), Stroke and Osteoporosis were included.

For decreased body mass we asked if the person lost weight unintentional of over 5% of their body weight in the last month or over 10% in the last three months. We also asked if they were diagnosed as being obese. Lower extremity dysfunction is a precursor for disability. We used three self-report items taken from the Groningen Activity Restriction Scale (GARS), namely walking outdoors, climbing/ descending a stair and doing groceries[23]. Older persons having no difficulty with any of those activities were considered "not impaired" and those with difficulty in 1 or more of these activities as "impaired". Last, persons were asked if they had impaired vision.

Lifestyle factors To measure problems with alcohol use we asked the older person if other people ever advised them too drink less. We also asked if they were current smokers. For level of activity we used two measures: one for hours of activity (e.g. walking, cleaning home and physical exercise) and one to see if they still went outdoors. Hours of activity was labelled as "insufficient" if people were less than two hours active in the last three days. Going outdoors was established by asking how many days they left their houses each week; 0 or 1 time was considered to be "little activity", 2 or more days "sufficient activity".

Psychological factors Mild impaired cognition was established in a two stage screening process using the IQCODE[16], MMSE[17] and 7 MS[18] (the screening process is described in more detail under Participants). Older persons with a score of 3.6 and over, but with MMSE scores over 24 and less than 70% probability of having dementia according to 7 MS were considered to have mild impaired cognition. Depressive symptoms were measured using The Center for Epidemiologic Studies Depression (CES-D) scale[24]. A cut-off point of ≥16 of the total score on the 20 items was used to distinguish between persons with and those without clinically relevant symptoms of depression.

Social factors Loneliness was included as a social factor.

Self-perceived health was not included as a determinant, because it was an item used to determine vulnerability.

Statistical analysis

We used SPSS version 15.0 to analyze our data. Descriptive analyses for the subgroups of persons who were vulnerable and those who recovered were used to describe age, gender, marital status, education and overall and item scores on the COOP-WONCA. The presence of predictive factors was described in number and percentages of older persons in both groups having each factor. We used logistic regression analyses, controlled for gender, age, marital status and education to see if the groups differed from one another at baseline on the predictive factors.

Factors with p<.20 were added to a backward multiple regression analysis, which was again controlled for age, gender, marital status and education.

RESULTS

43 older persons (29%) had recovered from vulnerability after 18 months. Of the eligible persons the reasons of loss to follow "quit for medical reasons" (n=12) and "thought burden of research to high" (n=6) suggest that these 18 people did not recover from vulnerability after 18 months. If we correct for these 26 persons the percentage of recovery is 26%. We do not correct for the reason "admitted to institution" (n=8) because this study concerns vulnerability amongst community-dwelling persons.

Vulnerability

At baseline both persons with chronic vulnerability and recovered older persons on average reported being vulnerable on 3.0 out of 6.0 COOP-WONCA items (Table 1.). Recovered older persons reported better only on the item of perceived health. Chronic vulnerable older persons had 3.4 symptoms after 18 months, with worse scores on daily- and social activities compared to baseline. Recovered older persons improved on all items compared to baseline and to chronic vulnerable older persons resulting in 0.4 vulnerability symptoms after 18 months.

Table 1. Mean number of symptoms of vulnerability and scores per item on the COOP-WONCA charts for persons with chronic frail functional health (n=106) and recovered persons (n=43) at baseline and after 18 months.

	Chronic vulnerable persons M (SD)		Recovered persons M(SD)	
COOP-WONCA	baseline	18 months	baseline	18 months
Number of symptoms	3.0 (1.1)[a]	3.4 (1.2)[a,b]	3.0 (1.1)[c]	0.4 (.5)[b,c]
Items[±]				
Self-perceived health	4.0 (.5)[a]	3.9 (.4)[b]	3.8 (.5)[a,c]	3.0 (.6)[b,c]
Physical fitness	4.3 (.9)	4.4 (1.0)[a]	4.3 (.7)[b]	3.8 (.6)[a,b]
Changes in health status	3.2 (.7)	3.2 (.6)[a]	3.3 (.6)[b]	3.0 (.1)[a,b]
Daily activities	3.4 (.9)[a]	3.7 (.8)[a,b]	3.2 (.9)[c]	2.5 (.7)[b,c]
Mood	2.4 (1.2)	2.5 (1.2)[a]	2.4 (1.0)[b]	1.8 (.8)[a,b]
Social activities	2.4 (1.2)[a]	3.0 (1.3)[a,b]	2.6 (1.2)[c]	1.5 (.6)[b,c]

[±] Higher score means worse health, fitness or mood status (scale 1-5).

[a,b,c] Cells with the same superscript letter differ significantly from one another (read horizontal); comparisons are made within groups (scores on baseline and after 18 months) and between the two groups at the same time point

Risk indicators

Analysis per risk indicator, controlled for age, gender, marital status and education showed that the following persons were at greater risk to remain vulnerable: persons with a diagnosis of diabetes and persons with impaired lower extremity function (Table 2.). The older a person was the higher the risk of remaining vulnerable. The more symptoms of depression a person reported the higher the risk of remaining vulnerable. Diagnosis of CVD and mild cognitive impairment were related to remaining vulnerable as well (.05<p<.20). Backward multiple regression analysis with all risk variables with p<.20 controlled for gender, marital status and education resulted in a model containing age, diagnosis of diabetes, impaired lower extremity function and symptoms of depressive symptoms (Table 3.). The older persons are and the more depression symptoms they report the higher the chance that they remain vulnerable over time.

Table 2. Number and percentages of persons with chronic vulnerability (n=106) and recovered persons (n=43) having predictive factors at baseline. Logistic regression with vulnerability and predictive factors. Odds ratios describe the risk of remaining vulnerable after 18 months and are controlled for age, gender, marital status and education (age, gender, marital status and education controlled for each other).

	Chronic vulnerable persons n(%)	Recovered persons n(%)	Total population N (%)	OR (95% CI)
Demography				
Age				1.16* (1.02-1.32)
<80	52 (50)	22 (54)	74 (51)	
80-85	39 (37)	15 (37)	54 (37)	
>85	14 (13)	4 (10)	18 (12)	
Gender				
Female	86 (82)	30 (70)	116 (78)	2.06 (.69-6.16)
Marital status				.78 (.55-1.10)
Married	35 (40)	13 (32)	48 (38)	
Never married	6 (7)	7 (17)	13 (10)	
Divorced	5 (6)	1 (2)	6 (5)	
Widowed	41 (47)	20 (49)	61 (48)	
Education				1.42 (.58-3.48)
Low	75 (75)	24 (65)	99 (72)	
Middle	19 (19)	6 (16)	25 (18)	
High	6 (6)	7 (19)	13 (10)	
Physical factors				
Two or more diseases (multimorbidity)	82 (77)	27 (63)	109 (73)	1.42 (.58-3.48)

	Chronic vulnerable persons n(%)	Recovered persons n(%)	Total population N (%)	OR (95% CI)
Diagnosis of..				
Cardiovascular disease	32 (30)	9 (21)	41 (28)	2.18^{+} (.76-6.24)
Arthritis	46 (43)	20 (47)	66 (44)	1.03 (.44-2.41)
Auditory diseases	7 (7)	3 (7)	10 (7)	.53 (.09-3.32)
Cataract	28 (26)	11 (26)	39 (26)	.77 (.29-2.05)
Diabetes	22 (21)	4 (9)	26 (17)	3.78* (1.01-14.19)
Heart failure	24 (23)	8 (19)	32 (22)	1.32 (.48-3.80)
Pulmonary disease	22 (21)	10 (23)	32 (22)	.66 (.25-1.75)
Stroke	14 (13)	2 (5)	16 (11)	2.55 (.52-15.59)
Osteoporosis	23 (22)	6 (14)	29 (20)	1.12 (.37-3.37)
Unintended weight loss	5 (5)	1 (2)	6 (4)	1.06 (.10-10.85)
Obesity	18 (17)	3 (7)	21 (14)	2.30 (.57-9.27)
Impaired lower extremity function	62 (63)	14 (36)	76 (55)	2.71* (1.14-6.42)
Impaired vision	12 (11)	6 (14)	18 (12)	.52 (.14-1.85)
Lifestyle factors				
Problem with alcohol use	1 (1)	0 (0)	1 (1)	-
Smokes	12 (11)	2 (5)	14 (9)	2.71 (.50-14.85)
Hardly physical active	31 (29)	11 (26)	42 (28)	1.05 (.41-2.70)
Hardly ever going outdoors	18 (17)	4 (9)	22 (15)	1.33 (.32-5.44)
Psychological factors				
Symptoms of depression	62 (60)	19 (49)	81 (57)	1.09* (1.01-1.17)
Impaired cognition	28 (27)	3 (7)	31 (21)	2.71^{+} (.70-10.50)
Social factors				
Loneliness	23 (22)	9 (21)	32 (22)	.78 (.26-2.35)

*p<.05, **p<.01,***p<.001, $^{+}$ .05<p<.20

Table 3. Odds Ratios in logistic regression with single predictive factor controlled for age, gender, marital status and education (Model 1) and final model after backward multivariate logistic regression analyses (Model 2) with all predictive factors for chronic vulnerability after 18 months, corrected for gender, marital status and education.

	Model 1	Model 2
	OR (95%C.I.)	OR (95%C.I.)
Age	1.16* (1.02-1.32)	1.16* (1.00-1.34)
Physical factors		
CVD (0=no diagnosis, 1=diagnosis)	2.18^{+} (.76-6.24)	-
Diabetes (0=no diagnosis, 1=diagnosis)	3.78* (1.01-14.19)	3.52^{+} (.91-13.65)
Impaired lower extremity function (0=not impaired, 1=impaired)	2.71* (1.14-6.42)	2.38^{+} (.94-6.04)
Psychological factors		
Symptoms of depression (range 0-60, higher score means more symptoms)	1.09* (1.01-1.17)	1.08* (1.00-1.16)
Impaired cognition (0=not impaired, 1=impaired)	2.71^{+} (.70-10.50)	-
X^2		20.59**

*p<.05, **p<.01,***p<.001, $^{+}$ .05<p<.20

DISCUSSION

A quarter of vulnerable persons had recovered after 18 months. Persons with chronic vulnerability and recovered persons had the same amount of symptoms of vulnerability at baseline, but recovered older persons did perceive their health as somewhat better than chronic vulnerable older persons. The best model, corrected for gender, marital status and education predicting chronic vulnerability consisted of the factors age, diagnosis of diabetes, impaired lower extremity function and symptoms of depression. The older a person was and the more depressive symptoms they reported the higher the risk of remaining vulnerable.

A limitation of this study is that it follows on an RCT on the influence of demand-led home visits by nurses in primary care and the use of data on the experimental group of this RCT[15]. The intervention in this RCT consisted of visits (at least five during 1.5 years) by trained community nurses. The nurses assessed health status and objective care need. Together with the person they prioritized the care needs and developed care schemes to improve their health status. Persons in the control condition received care as usual. Although the intervention had no effect, we performed some preliminary analyses that showed that slightly more persons in the

control group recovered to a non-vulnerable state than in the experimental group. This means that the reported recovery in our study is not higher in the experimental group due to the RCT-intervention. Another concern is the large loss to follow up (49%). As was mentioned in the Results for part of this group we were able to link their reason for quitting to chronic vulnerability, but a large proportion of the reasons why persons were lost were unclear. As a consequence we were not able to establish if these persons remained vulnerable or recovered over time and if the current findings are representative for the total group of vulnerable persons. In the extreme case that all eligible persons who were lost to follow-up were still vulnerable after 18 months 15% of the sample would have recovered. (43/295, 43 is the number of vulnerable persons and 295 the number of eligible persons). Thus, a quarter might be an overestimation of persons who are able to recover from vulnerability, but still a significant group is able to recover.

This is one of the first studies to specifically look into transitions of a vulnerability and frailty to a better state. Gill et al.[13] looked into transitions between frail, pre-frail and non-frail states in a comparable group of community-dwelling persons over 70 years of age. He found a transition rate of only 0 to 9% from a frail to a non-frail state when using physical measures like weight loss, exhaustion, low physical activity, muscle weakness and slow walking speed to establish frailty. Despite these low numbers Gill et al. concluded that their findings suggested ample opportunity for the prevention and remediation of frailty. The current study found that a larger group was able to recover from vulnerability. This is probably due to the measurement of vulnerability; our definition was broader than the physical frailty definition and included psychological and social factors. Furthermore, the prevalence was higher and the measure was based on self report. It is possible that the recovery is partly due to response shifts; some individuals when experiencing changes in their health states may change their internal standards, values and conceptualzation of quality of life or in this case symptoms of vulnerability. However, a review on response shift found that overall the effect sizes of the response shift phenomena published to date are relatively small according to Cohen's criteria[25]. Thus, it is unlikely that response shifts will explain a large amount of the recovery rate found in this study. Another possibility is that some older persons actually are better able to cope with the problems that come with old age and thus are able to recover from vulnerability.

We explored if certain groups were at higher risk of remaining vulnerable. Surprisingly, no associations were found between diseases which are known to extensively burden patients like severe COPD and chronic heart failure. It is possible that these persons were lost to follow up or were not living in the community to begin with. In the community persons who were older and had more depressive symptoms were at higher risk of remaining vulnerable. Depression symptoms might be reduced; it is highly prevalent (63%) and there is ample opportunity to improve detection[26-28] and provide efficacious treatment, such as pharmacotherapy[29,30] and cognitive-behavioral therapy[31,32].

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Appendix A. Association of vulnerability with mortality and hospital admission

Since our measure of frailty/ vulnerability differed from more accepted definitions we explored the association of our measure with adverse health outcomes, namely mortality and total and acute hospital admission. Five years of follow up data on mortality and hospital admission were recorded for 2762 persons aged 75+ who responded to our initial health questionnaire (April 2003-February 2008). 651 of these persons were vulnerable according to our definition of scoring in the worst quartile on at least two out of six COOP–WONCA charts. Mortality data were based the municipality registrations. Hospital admissions were abstracted from the records of the main hospital in the region that covers over 95% of all hospital admissions. Data were abstracted for acute hospital admissions. We calculated a hazard ratio using Cox regression survival models to see if the two groups differed on "time to death". We calculated odds ratios using binary regression analysis to explore if persons with vulnerable persons were more often (acutely) admitted to hospitals. Adjusted HR for mortality is corrected for age, gender, depressive symptoms, body-mass index and disability. Adjusted OR for acute hospital admission was corrected for age, gender, presence of heart disease and disability. Table A. shows that vulnerability according to our definition is associated with higher mortality and more hospital admission rates. When correcting for certain important confounders the effect on mortality becomes not significant, but the association with acute hospital admission remains intact.

Table A. Number of vulnerable (n=651) and non-vulnerable (n=2111) persons who died or were acutely admitted to a hospital during the study. Odds ratios are calculated, controlled for age and gender.

	Vulnerable persons n (%)	Non-vulnerable persons n (%)
Deceased	183 (28)	443 (21)
HR (95% C.I.)	1.39 (1.17-1.65)***	
Adjusted HR (95% C.I.)	1.16 (0.93-1.44)	
Acutely admitted to hospital	338 (51)	849 (40)
OR (95% C.I.)	1.55 (1.30-1.84)***	
Adjusted OR (95% C.I.)	1.30 (1.06-1.60)*	

* p<.05, ** p<.01,*** p<.001

Chapter 3

Number, type and factors associated with self-perceived care needs in community-dwelling vulnerable older persons in the Netherlands

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ABSTRACT

Objectives To describe number and type of self-perceived care needs in community-dwelling vulnerable older persons and to explore what factors were associated with the presence of certain needs.

Methods 217 older persons were interviewed using the Camberwell Assessment of Need in the Elderly to describe care needs. Demographic variables, lifestyle factors, number of diseases and presence of specific diseases, level of depressive symptoms and level of disability were used in the analysis to explore associations between these factors and needs.

Results Older persons had on average 5.6 needs of which 0.4 were unmet. A majority had needs for the physical and environmental domains, but most needs were met. Few older persons had needs in the social domain and for psychological distress, but many of those were unmet. Level of activity was strongly associated with total number of needs and with needs for all four domains. Level of disability was associated with total and physical needs as well. Level of education was associated with total and social needs; little education led to more needs. Since the number of persons with social, psychological and unmet needs was small these associations should be interpreted with caution.

Discussion A majority reported needs in the physical and environmental domains. However the highest percentages of unmet need were reported on the psychosocial topics, which might signify a gap in health care. The number of unmet needs was low, which might be explained by good health care or underreporting. Disability showed a strong association with physical care needs, whereas the association of specific chronic diseases disappeared in the multivariate analysis. Furthermore, hours of activity also showed associations with total and physical needs, even in multivariate analysis controlled for disability. Hours of activity was also related to the other three domains describing non-physical needs. Thus, being inactive seems to be a strong indicator of the number of needs a person reports.

INTRODUCTION

In the Netherlands and other Western European countries health care organizations work mostly supply-centered, which means that delivery of care is often determined by availability[1]. In the last two decades demographic developments in the Netherlands, like the increasing level of education and income, more attention for health and healthy lifestyles and increasing individualism, lead to more demanding individuals who want to have a say in the care they receive[2]. This lead to an increased interest in self-perceived needs assessment of individuals. Need has commonly been defined as 'the ability to benefit in some way from health care[3,4]. More specifically as a state where (more) help with specific problems is required by care professionals, taking into account the views of persons themselves[5]. Bradshaw[6] distinguished four types of need: 1) normative need, the need for care as established by professional caregivers; 2) (self-)perceived need, the need as experienced by patients themselves; 3) expressed need, the explicit demand for care and support formulated by the patient; and 4) comparative need, which takes care utilization as starting point and looks if persons with the same health problems receive identical care.

Availability might have been important in determining health care delivery, but how available resources were exactly allocated has mostly been based on symptomatology, diagnosis and disability (normative need) rather than on self-perceived patient need[7]. Care allocation based on presence of disability and diseases was rarely related to individuals subjectively perceived care needs[8-10]. For example, disability measures (e.g. Barthel Index[11]) do not take into account the impact of an individual's cultural and social background on their care needs[12]. Such a one-dimensional type of assessment can lead to over allocation of care when individuals are coping effectively by themselves or have sufficient support of relatives and friends[13]. On the other hand under-resourcing can occur when the person lacks readily identifiable symptoms or disabilities or when the individual does not seek assistance for needs[8].

For decades, an extensive number of unmet needs existed in older age groups unknown to their primary care physicians[14,15]. However, during this period care allocation was mostly been based on symptomatology, diagnosis and disability rather than on self-perceived patient need[7]. Recently, a comprehensive and structured instrument was developed, the Camberwell Assessment of Need in the Elderly (CANE) to identify self-perceived met and unmet need in 24 care topics by interviewing older persons themselves[16]. A met need means that there is sufficient help to solve or significantly reduce the reported problem, whereas an unmet need means that there is no (sufficient) help to reduce the problem. CANE has been adapted from the Camberwell Assessment of Need used with adults with chronic mental illness[17] for use with older people in a mental health setting. Although some topics (e.g. psychotic symptoms and behavior problems) elicited very low responses when used in primary practice, CANE was found to be feasible in general practice to identify self-perceived needs not previously known by health

professionals[18]. A small study using CANE (n=52) showed that for some topics half of a community-dwelling population over 75 years of age reported needs and on some topics up to 20% of older persons had unmet needs[18]. Most met needs were identified for Physical Health, Food, Household activities, Mobility/ falls and Eyesight/hearing impairment. Most unmet needs were reported by older persons for Eyesight/hearing impairment, Psychological distress (depression and anxiety symptoms), Incontinence, Information (on condition) and Company. Similar results for unmet needs were found in other CANE studies[19,20].

The aim of this study is to describe the number of care needs in community-dwelling vulnerable older persons over 75 years of age, overall and for the 24 care topics. Furthermore, associations between care needs and possible determinants are explored. We aim to answer the following questions: do disability and care needs overlap as much as was assumed in earlier studies[7]? Does disability have a stronger association with the number of care needs than the presence of specific chronic diseases following the International Classification of Impairments, Disabilities and Handicaps[21,22]? Because several psychosocial models stress the importance of psychological health at advanced age[23], we also look at associations of depressive symptoms with self-perceived needs. Last we add risk factors of functional status decline in community-dwelling older people to see if these factors influence the number of care needs[24].

METHODS

Design

This is a cohort study of vulnerable community-dwelling elderly. Our study follows on a randomized controlled trial on the influence of demand-led home visits by nurses in primary care[25]. The objective of this RCT was to evaluate the (cost-)effectiveness of systematic home visits by nurses to vulnerable elderly in a northern region of the Netherlands. The intervention consists of visits (at least five during 18 months) by trained community nurses to older persons living at home. The nurses assessed health status and objective care need. Together with the person they prioritized the care needs and developed care schemes to improve their health status. Persons in the control condition received care as usual. The outcomes of this RCT were all negative. Preliminary analysis also showed no differences between the experimental and control group on the measures used in this study. The ethical committee of the VU medical centre approved the study.

Study sample

The research includes community-dwelling vulnerable older persons who were 75 years or older living in a northwestern region of the Netherlands. Our study was embedded in a larger randomized controlled trial[25], which established vulnerability using COOP-WONCA charts[26]. Vulnerability was defined as being in the worst quartile of at least two out of six COOP-WONCA charts (Box 1.).

Box 1 Defining Vulnerability

A person is considered vulnerable when self reporting in the lowest quartile of two or more charts of the COOP-WONCA. All items had a range of 1 to 5, with 1 meaning good health or lack of problems and 5 meaning poor health or many problems. Per item the lowest quartile was calculated. Specifically a vulnerable person is characterized by two or more of the following symptoms:

1) fair to poor self-perceived health (score: 4 and 5)
2) only able to maintain very light physical activity during 2 minutes (score: 5)
3) little or much worse health compared to 2 weeks ago (score: 4 or 5)
4) much difficulty with or not being able to perform one's usual activities or tasks (score: 4 or 5)
5) moderate to extreme emotional problems (score: 3 to 5)
6) moderate to extreme limitation in social activities (score: 3 to 5)

Sampling procedure

The sampling procedure of the RCT is described in more detail elsewhere[25]. Persons with dementia symptoms were excluded from the RCT. Dementia was established in a two stage screening process. In stage one, patients received a postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE)[27]. This questionnaire has been successful in distinguishing demented persons from a general population sample[27]. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE[28]) and the 7 min screen (7 MS[29]). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients[29]. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7 MS, were excluded from the study. The current research started 18 months after the start of the RCT at which time 465 persons were still in the study. Of those 24 died during our study, 12 were admitted to a residential home, 6 moved out of the region and 105 were no longer vulnerable. Of the 318 eligible older persons 34 were no longer willing to participate and 17 quit for medical reasons. Another 50 could not be reached, had incomplete data or were lost due to other or unknown reasons. In total data of 217 older persons (68% of eligible subjects) were used in analysis

Measures and measurements

Main outcomes measure: Subjective Care Need

The Camberwell Assessment of Need for the Elderly (CANE) was used to assess the self-perceived care needs[16]. The CANE consists of four care domains (Environmental, Physical, Psychological and Social) with five to seven topics each.

Environmental needs are for example if a person has a fitting living environment (for example adapted to some disability), if they can keep their houses clean and if they can get the food they want. Physical needs include the actual health problems the person experiences, but also if the person has problems taking medication or problems with walking. Psychological needs include experiencing memory, mood and behavioral problems. Social needs include experiencing a lack of company or of an intimate relationship and having trouble getting through the day due to a lack of activities. The CANE has good content, construct and consensual validity and appropriate criterion validity. Reliability is very high[17]. Although some topics (e.g. psychotic symptoms and behavior problems) elicited very low responses when used in primary practice, CANE was found to be feasible in general practice to identify self-perceived needs not previously known by health professionals[18]. For every topic the older person stated if there was a need that was met or unmet in the last month. A met need meant that there was sufficient help to solve or significantly reduce the reported problem, for example the older person has trouble cleaning her house, but a professional cleaner or informal caregiver helps out. An unmet need meant that there was no help or the help offered did not suffice in reducing the problem. For example, an older persons feels lonely and reports a need on Company, but does not know who to turn to or has a social worker coming in for conversation, but only once a month.

Determinants

Demography Birth date, gender, marital status and education were noted at the beginning of the CANE interview. Low education means no education or elementary education, middle means secondary education and high means bachelor or masters degree.

Disability The Groningen Activity Restriction Scale (GARS) is a non-disease-specific instrument to measure limitations in I(ADL) functioning[30]. It was developed in studies of Dutch samples consisting of older persons or chronically ill people. An overall score of the 18 items was calculated (range:18-72).

Chronic diseases The Resident Assessment Inventory - Home Care (RAI-HC) is a structured and computerized multidimensional geriatric interview, which identifies problem areas in a direct and validated way[31,32]. RAI-HC was conducted by trained nurses and interviewers. It is a generic instrument, including items on the presence of 22 chronic diseases. For separate chronic diseases we included the top 10 of most prevalent diseases in older persons over 75 years of age in the Netherlands.[33] Cardiovasculair disease (CVD) was composed of the RAI-HC items ‘coronary artery disease’ and ‘peripheral artery disease’. Since persons with dementia were excluded in this study, dementia could not be included in the analysis although it is one of the most prevalent diseases in this age group.

Depressive symptoms The Center for Epidemiologic Studies Depression (CES-D) scale is used to screen for depression[34]. A cut-off point of ≥16 of the total score on the 20 items was used to distinguish between older persons with and those without clinically relevant symptoms of depression.

Other risk indicators The risk indicators formulated by Stuck[24] were measured using RAI-HC except lower extremity functional limitations, which was considered superfluous, because we already included disability as a measure. For increased body weight a question on the presence of obesity was used; for decreased body weight a question on unintended weight loss. For low frequency of social contacts we used a question if the person felt lonely, which we considered more appropriate than the number of actual contacts, which does not consider the whishes of the person about having social contacts. Persons were asked if other people ever advised them to drink less as a measure of alcohol (ab)use. There was a question if the person smoked and if they had any trouble with vision. Poor perceived health was taken from the COOP-WONCA charts, with moderate and bad health considered as poor health. For level of activity we used two measures: one for hours of activity (e.g. walking, cleaning home and physical exercise) and one to see if they still went outdoors. Hours of activity was labelled as "insufficient" if people were less than two hours active in the last three days. Going outdoors was established by asking how many days they left their houses each week; 0 or 1 time was considered to be "little activity", 2 or more days "sufficient activity".

Data analysis

We used SPSS version 15.0 to analyze our data. Descriptive analyses were used to describe the number of care needs. Total number of needs was the sum of met and unmet needs for all topics. Logistic regression per factor controlled for age, gender, marital status and education, was used to see what factors were associated with overall care needs, unmet needs and with needs in the four domains. Factors with $p<.20$ were added to a multivariate logistic regression analyses. For the Psychological and Social domains and for unmet needs the number of persons with at least one need was very small and the assumption of linearity was not met. For each domain (and unmet needs) we split the group into older persons with no need and older persons with one or more needs. Then we used logistic regression to calculate odds ratios for the included factors. For total, Physical and Environmental needs we split the group into the worst quarter vs. the rest to have groups of the same size as the other domains and again calculated odds ratios using logistic regression.

RESULTS

Vulnerable older persons were on average 82.9 years of age and 77% was female (Table 1.). 55% was widowed, 36% married, 10% was divorced and 4% had never married at all. 72% of the older persons had little education, 20% finished secondary education and 8% obtained a bachelor or masters degree. Nobody reported problems with alcohol use, 11% smoked, 5% reported unintended weight loss and 14% overweight, 13% had problems with vision, 22% reported feeling lonely, 35% was less than 2 hours active in the last three days, 18% hardly went outdoors and 79% reported poor perceived health. 96% had at least one disease with a mean of 3.0 diseases (out of 24) per person. The prevalence of the top 10 of

Table 1. Descriptive details on demography, risk indicators, chronic diseases, ADL-functioning, depressive symptoms and care needs (n=217).

Variable	M (SD)	n (%)
Age	82.9 (3.9)	
<80 years of age		51 (24)
80-84 years of age		113 (52)
>85 years of age		53 (24)
Gender		
Female		168 (77)
Marital status		
Married		76 (36)
Unmarried		9 (4)
Divorced		10 (5)
Widowed		116 (55)
Education		
Low		150 (72%)
Middle		42 (20%)
High		16 (8%)
Risk indicators		
Overweight		30 (14)
Weight loss (>5%)		10 (5)
Feels lonely		47 (22)
Hardly physical active		76 (35)
Hardly going outdoors		44 (18)
Alcohol abuse		0 (0)
Poor perceived health		171 (79)
Smoking		23 (11)
Visual impairment		28 (13)
Number of diseases	3.0 (1.6)	
No disease		8 (4)
One disease		31 (14)
Two diseases		51 (24)
Three diseases		50 (23)
Four diseases		38 (18)
Five diseases		23 (11)
Six or more diseases		16 (7)
Diagnosis of..		
Cardiovascular disease		58 (27)
Arthritis		93 (43)
Auditory diseases		76 (35)
Cataract		36 (17)
Diabetes		43 (20)
Heart failure		40 (18)
Pulmonary disease		31 (14)
Stroke		25 (12)
Osteoporosis		45 (21)
Depressive symptoms		136 (63)
Disability (range 18-72)	38.6 (10.4)	

most prevalent diseases varied between 12 to 43%. A majority (63%) reported clinically relevant symptoms of depression.

Number and type of care needs

On average vulnerable older persons reported 5.6 needs, with 1.9 in the Environmental domain, 3.1 in the Physical domain, 0.2 in the Psychological domain and 0.4 in the Social domain (Table 2.). Almost all older persons reported at least one need in the Environmental (93%) and Physical (98%) domain, one quarter in the Social domain and 15% in the Psychological domain. A quarter reported at least one unmet need. Most needs were reported for Household activities (89%), Physical Health (80%), Mobility/falls (77%), Self care (68%) and Food (49%), but hardly any needs were unmet (1-4%) (Table 3.). One third reported needs on Medication use, but none of those were unmet. About a quarter reported needs on Money, Benefits and Eyesight/Hearing impairment, but again those were mostly met. Little needs were reported on Accommodation, Daytime Activities, Caring for someone and Memory and most were met. Although few persons reported needs for Intimate relationships (5%), Company (11%), Psychological distress (4%) and Information (7%), a large proportion of those needs was unmet (36-63%). Hardly any person reported a need for Behavioral problems, Alcohol use, Deliberate and Inadvertent self-harm, Psychotic symptoms, Abuse & neglect (0-1%).

Table 2. Number of care needs and percentage of older persons (n=217) having at least 1 care need in the specified domain.

	Number of care needs M (SD)	Number of older persons with 1 or more needs n(%)
Total care needs (24 topics)	5.6 (2.4)	216 (100)
Environmental needs (6 topics)	1.9 (1.1)	201 (93)
Physical needs (6 topics)	3.1 (1.3)	213 (98)
Psychological needs (7 topics)	.2 (.5)	32 (15)
Social needs (5 topics)	.4 (.7)	59 (27)
Unmet needs (24 topics)	.4 (1.00)	52 (24)

Determinants of care needs

Total number of needs In regression analysis per factor having many needs was related to level of education, hours of activity, perceived health, having problems with vision, having cataract or osteoporosis, number of chronic diseases and level of disability in daily functioning (ADL and IADL together). When all factors were added to a multivariate logistic regression analysis only the associations remained with level of education, level of activity and level of disability. Persons with little education, little activity and many disabilities reported more needs in total (Table 4a).

Table 3. Number and percentage of elderly (n=217) with one or more care needs and number and percentage of unmet care needs per topic.

Variable	Needs n (%)	Unmet needs n (%)[a]
Environmental needs		
Accommodation	15 (7)	3 (20)
Household activities	194 (89)	6 (3)
Food	107 (49)	1 (1)
Money	49 (23)	0 (0)
Benefits	46 (21)	7 (15)
Caring for someone	8 (4)	0 (0)
Physical needs		
Physical health	174 (80)	5 (3)
Medication use	71 (33)	0 (0)
Eyesight/hearing impairment	59 (27)	6 (10)
Mobility/falls	167 (77)	7 (4)
Self-care	148 (68)	4 (2)
Continence	55 (25)	6 (11)
Psychological needs		
Psychological distress	8 (4)	4 (50)
Memory	24 (11)	4 (17)
Behavior	1 (1)	0 (-)
Alcohol	0 (0)	0 (-)
Deliberate self-harm	2 (1)	1 (50)
Inadvertent self-harm	0 (0)	0 (-)
Psychotic symptoms	2 (1)	1 (50)
Social needs		
Company	23 (11)	9 (39)
Intimate relationships	11 (5)	7 (63)
Daytime activities	30 (13)	4 (13)
Information	15 (7)	9 (60)
Abuse/ neglect	3 (1)	1 (33)

[a] Percentages of unmet needs described are based on the total number of needs in that specific topic.

Table 4a. Multivariate logistic regression, controlled for age, gender, marital status and education for total, environmental and physical needs (n=217). Factors were included when logistic regression analysis with one factor controlled for age, gender, marital status and education was p<.20.

Variable	Total number of needs OR (95% CI)	Environmental needs OR (95% CI)	Physical needs OR (95% CI)
Age	1.04 (.89-1.20)	1.07 (.97-1.18)	.96 (.86-1.08)
Gender (female vs. male)	2.06 (.69-6.11)	.50 (.21-1.16)	1.53 (.61-3.83)
Marital status (1=married, 2=never married, 3=divorced, 4=widowed)	1.12 (.81-1.55)	1.13 (.88-1.46)	1.25 (.95-1.65)
Education (low to high, 3 cat)	.39** (.19-.79)	.85 (.49-1.45)	.66 (.36-1.19)
Overweight (0=no, 1=yes)	-	-	-
Weight loss (>5%) (0=no, 1=yes)	-	-	-
Feels lonely (0=no, 1=yes)	-	.54 (.25-1.19)	-
Hardly physical active (0=no, 1=yes)	8.70* (1.68-45.13)	3.75** (1.62-8.69)	2.90* (1.08-7.78)
Hardly ever goes outdoors (0=no, 1=yes)	-	2.00 (.67-5.96)	-
Poor perceived health (0=no, 1=yes)	.98 (.37-2.55)	-	1.11 (.46-2.65)
Smoking (0=no, 1=yes)	-	-	-
Visual impairment (0=no, 1=yes)	2.14 (.39-11.77)	-	2.16 (.56-8.43)
Number of diseases	1.26 (.89-1.78)	.95 (.74-1.22)	1.16 (.89-1.51)
CVD (0=no, 1=yes)	-	-	-
Arthritis (0=no, 1=yes)	-	-	.83 (.37-1.86)
Auditory diseases (0=no, 1=yes)	-	-	-
Cataract (0=no, 1=yes)	.33 (.10-1.13)	-	-
Diabetes (0=no, 1=yes)	-	1.63 (.69-3.85)	-
Heart failure (0=no, 1=yes)	-	-	-
COPD (0=no, 1=yes)	-	-	-
CVA/Stroke (0=no, 1=yes)	-	2.47 (.75-8.15)	-
Osteoporosis (0=no, 1=yes)	2.24 (.57-8.81)	2.18 (.85-5.63)	-
Depressive symptoms (scale 0 to 63, higher means more symptoms)	-	-	-
Disability	1.12*** (1.05-1.19)	1.03 (.99-1.06)	1.13*** (1.07-1.18)
R^2	42%	27%	38%

*p<.05, **p<.01,***p<.001

Table 4b. Multivariate logistic regression, controlled for age, gender, marital status and education for psychological, social and unmet needs (n=217). Factors were included when logistic regression analysis with one factor controlled for age, gender, marital status and education was p<.20.

Variable	Psychological needs OR (95% CI)	Social needs OR (95% CI)	Unmet needs OR (95% CI)
Age	.58 (.31-1.07)	.96 (.87-1.07)	.96 (.86-1.06)
Gender (female vs. male)	.00 (.00-.)	.55 (.23-1.36)	.33* (.14-.76)
Marital status (1=married, 2=never married, 3=divorced, 4=widowed)	.99 (.43-2.30)	1.11 (.84-1.46)	.87 (.66-1.14)
Education (low to high, 3 cat)	.05 (.00-5.45)	.45* (.23-.88)	.64 (.35-1.17)
Overweight (0=no, 1=yes)	-	-	-
Weight loss (>5%) (0=no, 1=yes)	-	4.40 (.91-21.36)	-
Feels lonely (0=no, 1=yes)	-	1.99 (.87-4.57)	2.34* (1.00-5.45)
Hardly physical active (0=no, 1=yes)	44.70* (1.26-1592.07)	2.12* (1.02-4.41)	-
Hardly ever goes outdoors (0=no, 1=yes)	-	-	-
Poor perceived health (0=no, 1=yes)	.04* (.00-.85)	-	-
Smoking (0=no, 1=yes)	-	-	-
Visual impairment (0=no, 1=yes)	-	1.62 (.62-4.23)	-
Number of diseases	1.62 (.76-3.46)	.93 (.71-1.21)	-
CVD (0=no, 1=yes)	-	1.92 (.82-4.47)	-
Arthritis (0=no, 1=yes)	.07 (.00-1.29)	-	-
Auditory diseases (0=no, 1=yes)	-	-	-
Cataract (0=no, 1=yes)	-	-	1.74 (.71-4.25)
Diabetes (0=no, 1=yes)	-	-	-
Heart failure (0=no, 1=yes)	-	-	-
COPD (0=no, 1=yes)	-	-	-
CVA/Stroke (0=no, 1=yes)	-	-	-
Osteoporosis (0=no, 1=yes)	-	2.62* (1.03-6.66)	2.25 (.95-5.38)
Depressive symptoms (scale 0 to 63, higher means more symptoms)	1.13 (.98-1.31)	1.04 (.99-1.08)	1.03 (.98-1.07)
Disability	-	-	-
R^2	54%	19%	13%

*p<.05, **p<.01,***p<.001

Environmental needs In analysis per factor having many environmental needs was related to feelings of loneliness, hours of activity, going outdoors, number of chronic diseases, having either diabetes, CVA or osteoporosis and level of disability. Multivariate analysis showed that persons with little hours of activity reported more environmental needs (Table 4a.).
Physical needs Analysis per factor showed an association between number of physical needs and hours of activity, perceived health, problems with vision, number of diseases, having arthritis and level of disability. When added to a multivariate analysis only the associations with hours of activity and level of disability remained. Persons with more disability and little hours of activity reported more physical needs (Table 4a.).
Psychological needs Having at least one psychological need was associated with hours of activity, perceived health, number of diseases, having arthritis and level of depressive symptoms. Multivariate analysis showed that persons with little hours of activity and poor perceived health reported more psychological needs(Table 4b.).
Social needs Having one or more social needs was associated with level of education, weight loss, feelings of loneliness, hours of activity, having problems with vision, number of diseases, having CVD or osteoporosis and level of depressive symptoms. Multivariate analyses showed that persons with little education, little activity and a diagnosis of osteoporosis reported more social needs (Table 4b.).
Unmet needs In analysis per factor having at least one unmet need was associated with feelings of loneliness, having cataract or osteoporosis and depressive symptoms. Multivariate analyses showed that males and persons who felt lonely reported more unmet needs(Table 4b.).

DISCUSSION
Vulnerable older persons reported on average 5.6 self-perceived needs but only 0.4 needs as being unmet. Many needs existed on physical health and household topics, such as Mobility/falls, Self care and Household activities, but almost all of these were met. A smaller number of older persons had needs on the social domain, such as Intimate relationships, Company and the psychological topic of Psychological Distress (depressive and anxiety symptoms). However, of those who had such a need between one and two thirds reported their need to be unmet. Level of activity was strongly associated with total number of needs and with needs for all four domains. Level of disability was also associated with total and physical needs. Level of education was associated with total and social needs; little education led to more needs. Poor perceived health led to more psychological needs and osteoporosis to more social needs. Reporting unmet needs was associated with being male and being lonely. Since the number of persons with social, psychological and unmet needs was small these associations should be interpreted with caution.

Most probably a selection bias arose because our study followed on a randomized controlled trial on the influence of demand-led home visits by nurses in primary

care[24]. Although all outcomes of this RCT were negative and the experimental and control group did not differ in their number of self-perceived needs, due to the 18 month follow up period a lot of older persons were lost. It seems that the most vulnerable people in this research were lost to follow-up. As a consequence the number of needs and especially unmet needs reported in this study might be an underestimation. Another limitation of this study is that it was cross-sectional and we can make no statements on causality. This study describes what factors co-occur with certain needs. Last, the factors included in the analysis to explore what associations existed with needs might seem to be quite similar to the need topics, for example depressive symptoms and psychological needs (and especially the topic psychological distress). We would like to stress that the difference between the two is the way in which they were established. To take the example of depressive symptoms, a total score of symptoms was calculated based on a self-report questionnaire with 20 items concerning depressive symptoms (e.g. sleep and mood problems), whereas a need was established by asking persons specifically if they experienced mood problems. 63% reported depressive symptoms using the self-report scale, whereas only 4% reported a need for psychological distress. Furthermore, in the multivariate analysis depressive symptoms were no longer associated with psychological needs.

Our finding that most needs were reported for environmental and physical need topics is comparable to another CANE-study[18]. The relatively many unmet needs reported for some psychosocial topics was also found in other studies using CANE[18-20]. It seems plausible that providing care concerning depressive feelings and loneliness is currently not optimal. This is emphasized by the current finding that 63% is identified as having clinically relevant symptoms of depression according to a self-report questionnaire, whereas 4% of older persons report an actual need for depression on CANE. Thus, the number of psychological and social needs presented here might just be the tip of the iceberg with already showing a pattern of relatively many unmet needs. Overall the number of unmet needs was low in the study population, which opposes previous findings that many unmet needs in older persons exist[14,15]. This might suggest that Dutch physicians and home care organizations supplemented with informal care do an excellent job in providing care. Another possibility is that older persons underreport on unmet needs. For example, because they are not aware of all possibilities in health care and base their care needs on the care they think is available to them or they may feel they should not complain.

Associations of specific chronic diseases with number of needs were found when conducting regression analysis including only a specific disease and the demographic variables. However, when added to the multivariate analysis most associations of chronic diseases disappeared, whereas level of activity and level of disability remained significantly associated. Thus, disability seems to show a stronger association with self-perceived care needs than the presence of particular chronic diseases[21,22]. Surprisingly, level of activity also showed strong associations

with total and physical needs, even when in multivariate analysis with disability and other factors. Furthermore, level of activity was also related to the other three domains describing non-physical needs. Thus, being inactive seems to be a strong indicator of the number of needs a person reports. Little education led also to more total and social needs. These persons might not as easily seek help for their health problems as more highly educated persons. It is encouraging that when asked specifically about care needs they do report problems.

Concluding, community-dwelling persons aged 75 and over reported several care needs, but most of those needs were met, meaning that help that reduces the problem was provided. The number of psychosocial needs was low, but for some topics relatively many needs were unmet, which might signify a gap in health care concerning depression symptoms and feelings of loneliness. The low number of unmet needs could be due to either the loss to follow-up of the most vulnerable persons, the presence of appropriate care in the study region or underreporting of unmet need. The exploration of factors associated with care needs showed that level of disability and level of activity are important indicators of the number of needs a person reports. Since the number of unmet, psychological and social needs was low in this group the analysis on associated factors for these needs should be interpreted with caution.

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Chapter 4

Comparison of subjective and objective need measures for use in persons aged 75 and over

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Submitted for publication

ABSTRACT

Objectives To compare a measure of subjective need with a measure of objective need in a population of persons aged 75 and over and to explore what underlies possible differences.

Methods 327 community-dwelling older persons (age ≥75) were interviewed, within four weeks with both an instrument to establish subjective need (Camberwell Assessment of Need in the Elderly) and an instrument to assess need in a more objective way (Resident Assessment Inventory).

Results For most domains ¾ of older persons reported consistently on CANE and RAI, meaning either presence or absence of need was reported on both. Agreement ranged from poor to substantial per need topic. On 11 of 18 domains persons more often reported a need on RAI. Agreement was lower when persons had impaired cognition and depressive symptoms. Depressed persons showed no pattern in reporting more needs on either RAI or CANE, whereas persons with impaired cognition reported less subjective needs.

Discussion Agreement on needs ranged from poor to substantial and was for most items fair or moderate. Disagreement occurred more often amongst persons with depressive symptoms and cognitive impairment. Care solely based on an objective measure of need can lead to over allocation of care and it does not take into account if a person has strong preferences about the care they would like to receive, but it can also point to lack of knowledge and embarrassment in older persons. We would advise health care professionals to supplement, but not replace, objective measures of need and health status with more subjective measures.

INTRODUCTION

In the Netherlands and other Western European countries health care organizations work supply-centered, meaning that care utilization is largely determined by availability[1]. In the last two decades demographic developments in the Netherlands, like the increasing level of education and income, more attention for health and healthy lifestyles and increasing individualism, lead to more demanding individuals who want to have a say in the care they receive[2]. This lead to a change in the focus on health care provision to beneficial outcomes on an individual level and increased the interest in needs assessment of individuals. Even before this development, research into the health needs of community-dwelling older persons already showed an extensive number of needs in older age groups unknown to their primary care physicians[3,4]. During this period care resources were generally allocated on the basis of disability levels and prevalence of chronic diseases[5]. Care allocation based on presence of disability and diseases was rarely related to the individuals subjectively perceived care needs[6,7]. For example, disability measures (e.g. Barthel Index[8]) do not take into account the impact of an individual's cultural and social background on their care needs[9]. Such a one-dimensional type of assessment can lead to over allocation of care when an individual is coping effectively by herself or has sufficient support of relatives and friends[10]. On the other hand under-resourcing can occur when the person lacks readily identifiable symptoms or disabilities or when the individual does not seek assistance for needs[7].

Interest in needs assessment arose because the focus in health care provision shifted to beneficial outcomes on an individual level and started to question how limited care resources could be allocated to obtain better outcomes for individuals[6,10]. Need has commonly been defined as 'the ability to benefit in some way from health care[11,12]. More specifically as a state where (more) help with specific problems is required by care professionals, taking into account the views of persons themselves[13]. Bradshaw[14] distinguished four types of need: 1) normative need, the need for care as established by professional caregivers, which seems closely related to care based on disability levels and prevalence of chronic diseases; 2) perceived need, the need as experienced by patients themselves; 3) expressed need, the explicit demand for care and support formulated by the patient; and 4) comparative need, which takes care utilization as starting point and looks if persons with the same health problems receive identical care.

The current study compares a measure of what we call subjective need (perceived need in Bradshaws' model), and a measure of objective need (normative need) in a population of community-dwelling older persons over 75 years of age in a northern region of the Netherlands. It is known that some factors make it harder for older persons to self-report. In a small sample cognitive impairment/ dementia lead to under-reporting of needs on Camberwell Assessment of Need in the Elderly by older persons in comparison with reports of staff and informal caregivers[9]. A symptom of depression can be poor concentration and memory difficulties[15], which

might lead to inconsistency in reporting as well. In this study we explore if cognitive functioning and symptoms of depression explain differences in objective and subjective needs. Thus, the research questions are: how does subjective need relate to objective need in this population? And to what extent does health status influence differences between subjective and objective need?

METHODS

Design

This is a cross-sectional study in a cohort of community-dwelling older persons. Our study followed on a randomized controlled trial on the influence of demand-led home visits by nurses in primary care[16]. Explorative analyses showed that the experimental and control group of the RCT did not differ on our outcome variables or any of the determinants. The ethical committee of the VU medical center approved both studies.

Study Sample

The research includes community-dwelling older persons who were 75 years or older living in a northwestern region of the Netherlands.

Sampling procedure

The sampling procedure of the RCT is described in more detail elsewhere[16]. Persons with dementia symptoms were excluded from the RCT. Dementia was established in a two stage screening process. In stage one, patients received a postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE)[17]. This questionnaire has been successful in distinguishing demented persons from a general population sample[17]. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE[18]) and the 7 min screen (7 MS[19]). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients[19]. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7 MS, were excluded from the study. The current research started 18 months after the start of the RCT at which time 465 persons were still in the study. Of those 24 died during our study, 12 were admitted to a residential home which excluded them from the study which focused on community-dwelling persons and 6 moved out of the region. Of the 423 eligible older persons 34 were no longer willing to participate and 17 quit for medical reasons. Another 45 could not be reached, had uncompleted data or were lost due to other or unknown reasons. In total data of 327 older persons (77% of eligible subjects) were used in analysis.

Measures and measurements

Subjective need

The Camberwell Assessment of Need for the Elderly (CANE) was used to assess the subjective care needs, which maps 24 topics of care need on four different domains, namely environmental, physical, psychological and social needs[20]. The CANE has good content, construct and consensual validity and appropriate criterion validity. Interrater and test-retest reliability is very high[21]. Although some topics (e.g. psychotic symptoms and behavior problems) elicited very low responses when used in primary practice, CANE was found to be feasible in general practice to identify self-perceived needs not previously known by health professionals[22]. The CANE interviews were conducted by independent interviewers. For every topic the older person stated if there was a need in the last month.

Objective need

The Resident Assessment Inventory - Home Care (RAI-HC) is a structured and computerized multidimensional geriatric interview, which identifies problem areas in a direct and validated way[23,24]. The RAI-HC is an interview that has been developed for assessing the health status and care needs of home-based frail elderly and disabled individuals. When performed by trained nurses using recommended protocols, it provides a valid measure of function in the frail home-based elderly[24]. It is a generic instrument, including items on communication/ hearing, vision, mood and behavior, social functioning, informal support services, physical functioning, continence, disease diagnosis, health conditions, preventive health measures, nutrition and hydration, dental status, skin condition and environment. The interview takes about 60 minutes to complete. RAI-HC was conducted by trained nurses. The nurses had an active role in identifying problem areas by observing and checking what older persons reported. For example nurses wanted to see all medication and if older persons reported that their home was clean and safe the nurses added their own impression of the house to the score.

Comparison

The RAI and CANE-interviews were done within four weeks of one another. A comparison was made on 18 of the 24 CANE topics. Topics of care need were only included in the analyses when RAI and CANE asked (nearly) identical questions. For the CANE topics of Caring for another, Information, the two Safety domains, Intimate relationships and Benefits no comparable items were identified in RAI. The CANE topics, matching RAI items and content of the domains are described in Appendix 1.

Determinants

Demography Date of birth, gender and marital status were noted at the beginning of the CANE interview. Education was noted at the beginning of the RCT.

Cognitive impairment Mild impaired cognition was established in a two stage screening process using the IQCODE[17], MMSE[18] and 7 MS[19] (the screening

process is described in more detail under Participants). Older persons with a score of 3.6 and over, but with MMSE scores over 24 and less than 70% probability of having dementia according to 7 MS were considered to have mild impaired cognition.
Depressive symptoms The Center for Epidemiologic Studies Depression (CES-D) scale was used to screen for depression[25]. A cut-off point of ≥16 of the total score on the 20 items was used to distinguish between older persons without and those with clinically relevant symptoms of depression.

Data analysis
We used SPSS version 15.0 to analyze our data. Descriptive statistics were used to describe age, gender, marital status, education and the number of persons who had impaired cognition or symptoms of depression. Descriptive statistics were also used to describe the number and percentage of persons that reported needs on either RAI and CANE. Crosstabs were used to describe the percentage of persons who reported a need on CANE and no need on RAI, persons who reported a need on RAI, but no need on CANE and persons who reported consistently. With consistently we mean they either reported a need on CANE and a need on RAI or they reported no need on both questionnaires. We calculated the number of needs with inconsistent reports by adding those reporting a need on CANE but no need on RAI and persons reporting a need on RAI, but no need on CANE. We also calculated Kappa to describe consistency. To see what factors underlie inconsistency in reporting needs we conducted separate t-tests with cognitive impairment (absent vs. present) and depressive symptoms (absent vs. present) as independent variables and number of inconsistent needs as outcome variable. We also conducted separate linear regression analysis with cognitive impairment and depressive symptoms, controlled for age, gender, marital status and education. To see if persons reported more needs on either CANE or RAI we repeated the same analysis with number of needs reported more on CANE or RAI as outcome variables.

RESULTS
Almost half of older persons was over 80 years of age (Table 1.). The mean age was 80.7 years. 73% was female. 54% was widowed, 36% married, 5% divorced and 5% never married. 70% had little education, 21% completed secondary school and 9% obtained a master or bachelor degree. 20% reported cognitive impairment and 53% clinically relevant symptoms of depression.

RAI-CANE comparison
Environmental needs For the needs for Accommodation, Household activities, Food and Money a majority of older persons reported consistently on RAI and CANE meaning they reported either a need on both or no need on both interviews (Table 2b.). Agreement was fair to moderate. More persons reported needs on CANE and not on RAI (CANE only) for Household activities. For Food and Money

more persons reported needs on RAI only. For Accommodation no clear pattern in inconsistency emerged.

Table 1. Demography details of older persons (n=327).

Variable	M (SD)	n (%)
Age	80.7 (3.7)	
<80 years of age		170 (52)
80-84 years of age		113 (35)
>85 years of age		43 (13)
Gender		
Female		239 (73)
Marital status		
Married		115 (36)
Unmarried, never married		16 (5)
Divorced/ separated		16 (5)
Widowed		172 (54)
Education		
Low		216 (70)
Middle		63 (21)
High		29 (9)
Mild impaired cognition		63 (20)
Depressive symptoms		171 (53)

Physical needs For Physical health, Medication, Eyesight/hearing impairment, Mobility, Self-care and Continence the majority reported consistently on RAI and CANE (Table 2b.). Agreement was slight to substantial with most agreement on the item Self-care. Many more needs were reported on CANE only than on RAI only for Mobility. For all other physical needs more needs were reported on RAI and not on CANE.

Psychological needs For Psychological distress, Memory, Psychotic symptoms, Behavioral problems and Alcohol abuse over three quarters of older persons reported consistently on RAI and CANE (Table 2b.). Agreement was poor for Psychotic symptoms and Behavioral problems, slight for Psychological distress and moderate for Memory. For Psychological distress, Memory and Behavioral problems more needs were reported on RAI only than on CANE only.

Social needs For Company, Daytime activities and Abuse/neglect over three quarters of older persons reported consistently (Table 2b.). No Kappa could be calculated for Abuse/ neglect. Agreement was slight for Daytime activities and fair for Company. No pattern of inconsistency emerged for Company.

Table 2a. Number and percentage of older persons (n=327) who report a need on CANE and/ or RAI.

Variable	Description of items	Need on CANE n(%)	Need on RAI n(%)
Environmental needs			
Accommodation	Inappropriately housed, e.g. adaptation for disabilities needed	17 (5)	16 (5)
Household activities	In need of domestic assistance	267 (82)	250 (77)
Food	Unable to prepare food or buy groceries, restricted diet or not able to swallow food	146 (45)	170 (52)
Money	Difficulty managing finances	61 (19)	74 (23)
Physical needs			
Physical health	Has physical ailment	256 (78)	289 (88)
Medication	Problems with side effects, compliance, dependency and abuse	106 (32)	168 (51)
Eyesight/hearing impairment	Difficulty with hearing what someone says in a quiet room, difficulty reading a newspaper or watching television, aids do not help sufficiently	102 (31)	141 (43)
Mobility/falls	Difficulty moving in own home, with transport or falls	230 (70)	145 (44)
Self-care	Difficulty with dressing, washing	202 (62)	78 (24)
Continence	Not able to manage incontinence independently	77 (24)	109 (33)
Psychological needs			
Psychological distress	Sad mood, anxious, frightened or extremely worried	11 (3)	50 (15)
Memory	Does not remember things that happened recently, often forgets where he/ she put things	30 (9)	54 (17)
Psychotic symptoms	Has hallucinations or delusional beliefs	2 (1)	3 (1)
Behavioral problems	Has behavioral problems like annoying, threatening or disturbing others	1 (0)	6 (2)
Alcohol abuse	Drinks excessively or has problems controlling drinking	0 (0)	1 (0)
Social needs			
Company	Few social contacts or feels lonely and isolated	32 (10)	31 (10)
Daytime activities	Difficulties with occupying self, limited social or leisure activities	36 (11)	42 (13)
Abuse/neglect	Is threatened or harmed by others or taken advantage of	0 (0)	7 (2)

Table 2b. Number and percentage of older persons (n=327) who report a need on CANE and/ or RAI.

Variable	Need on both CANE and RAI n(%)	No need on both CANE and RAI n(%)	Need on CANE, but no need on RAI n (%)	Need on RAI, but no need on CANE n (%)	Cohen's Kappa
Environmental needs					
Accommodation	5 (2)	299 (91)	12 (4)	11 (3)	.27
Household activities	231 (71)	41 (13)	36 (11)	19 (6)	.49
Food	122 (37)	133 (41)	24 (7)	48 (15)	.56
Money	35 (11)	227 (69)	26 (8)	39 (12)	.40
Physical needs					
Physical health	233 (71)	15 (5)	23 (7)	56 (17)	.15
Medication	63 (19)	116 (35)	43 (13)	105 (32)	.10
Eyesight/hearing impairment	62 (19)	149 (46)	39 (12)	76 (23)	.25
Mobility/falls	118 (36)	70 (21)	112 (34)	27 (8)	.19
Self-care	52 (16)	232 (71)	17 (5)	26 (8)	.62
Continence	54 (17)	195 (60)	23 (7)	55 (17)	.42
Psychological needs					
Psychological distress	5 (2)	271 (83)	6 (2)	45 (14)	.11
Memory	20 (6)	263 (80)	10 (3)	34 (10)	.41
Psychotic symptoms	0 (0)	322 (98)	3 (1)	2 (1)	-.01
Behavioral problems	0 (0)	320 (98)	1 (0)	6 (2)	-.01
Alcohol abuse	0 (0)	326 (100)	0 (0)	1 (0)	-
Social needs					
Company	7 (2)	271 (83)	25 (8)	24 (7)	.25
Daytime activities	6 (2)	255 (78)	30 (9)	36 (11)	.04
Abuse/neglect	320 (98)	0 (0)	7 (2)	0 (0)	-

Table 3. Number of needs reported differently on RAI and CANE or reported more on either CANE or RAI controlled for age, gender, education and marital status.

	Number of needs differently reported on RAI and CANE M (SD)	OR (95% CI)	Number of needs reported more on CANE M (SD)	OR (95% CI)	Number of needs reported more on RAI M (SD)	OR (95% CI)
Cognitive functioning		2.15** (1.39-3.32)		1.10 (.79-1.52)		1.96** (1.33-2.89)
Not impaired (0)	2.8 (1.6)		1.5 (1.2)		1.3 (1.4)	
Impaired (1)	3.6 (1.5)		1.6 (1.1)		2.0 (1.6)	
Depressive symptoms		1.53* (1.07-2.18)		1.17 (.90-1.53)		1.30 (.94-1.79)
No depressive symptoms (0)	2.7 (1.4)		1.4 (1.0)		1.3 (1.2)	
Clinically relevant depressive symptoms (1)	3.2 (1.7)		1.6 (1.2)		1.6 (1.5)	

*p<.05, **p<.01

Abuse/neglect was only reported on CANE (7%) and never on RAI (0%). For Daytime activities slightly more persons reported needs on RAI only than on CANE only.

Determinants

The number of times that a persons reported not consistent on CANE and RAI was related to cognitive impairment and symptoms of depression (Table 3.). Persons with clinically relevant depressive symptoms reported inconsistently on 3.2 needs, whereas persons with no symptoms reported inconsistently on 2.8 needs. No pattern was found for reporting more needs on either RAI or CANE. Persons with mild impaired cognition reported inconsistently on 3.6 needs on average, whereas a cognitively intact person on 2.8 needs. This difference was due to the fact that persons with mild impaired cognition reported more needs on RAI than on CANE than cognitively intact persons (2.0 vs. 1.3 needs).

DISCUSSION

Discrepancies existed in objective and subjective need. Inconsistency per topic ranged from 0 to 45% of persons. Agreement ranged from poor to substantial with Psychotic symptoms and Behavioral problems on the lower end and Self-care as the topic with best agreement. On 11 of the 18 topics older persons more often objective than subjective needs were identified (e.g. for Medication). On the other

hand more subjective than objective needs were reported for Mobility, Household activities and Abuse/ neglect. For the needs of Accommodation, Psychotic symptoms, Alcohol abuse and Company the inconsistency in reporting was equally distributed between either more needs on CANE or more needs on RAI. Inconsistency in scores was related to impaired cognition and symptoms of depression. Depressed persons reported more often inconsistently, but showed no pattern in reporting more on either RAI or CANE. Persons with mild impaired cognition reported less needs on CANE.

A limitation of this study is that RAI was always conducted before CANE due to requirements of the RCT this study followed on. It is highly unlikely that in the four week period between the interviews health needs reduced greatly in this group of older persons. Still, nurses who conducted RAI made a care plan to improve care in certain problem areas. Although four weeks is a short period to make large improvements (e.g. for many aids or treatments waiting lists exist) we can not exclude the option that some persons' health did get better during this period and partly explained why less needs were reported on CANE. Future studies should vary the order in which RAI and CANE are conducted to see if this influences the results. Another limitation of this study is that our measure of objective need was not a strict measure of normative need, because the patient was sometimes consulted to obtain information. This probably leads to an underestimation of the differences between subjective and objective need.

The discrepancies are surprising considering that the items taken from RAI were (nearly) identical to the CANE domains and the fact that the interviews were done within four weeks of one another. Most of the time more needs were identified with RAI than with CANE. This difference might be due to the role of the persons who conducted RAI and CANE. Independent interviewers, with no medical background, conducted CANE and were instructed to just note what the older person told them, whereas the nurses who conducted RAI added their own observations and impressions to their score. For example for Medication, CANE-interviewers just noted if the person reported a need or no need for this topic, whereas RAI-nurses asked the person to show them all medications which they then carefully wrote down. An analysis of number and combination of medication could lead to identifying this as a problem area (i.e. a need). Another example is Physical Health. The nurses conducting RAI noted any diagnoses of pathologies and limitations they knew of and checked the unknown items with the older person while in the CANE interview a general question was asked if the person had any physical ailments. With CANE it is likely that a person who did not experience negative consequences of a chronic diseases (e.g. well controlled high blood pressure) does not report this, while most likely the nurse already has this information or the person herself remembers when specifically asked.

Seen in this light the two measures actually complement each other; RAI objectively identifies problems, whereas CANE adds information if the older persons actually experiences a problem.
It seems that especially for community-dwelling persons a measure of subjective need can provide additional information to more objective measures, because no one, except maybe a spouse (if present), but not even a child (living separately), visiting nurse or general practitioner would be aware of all things relevant to these persons. For eleven topics more needs were identified using RAI, which might point to the assumption that the one-dimensional type of assessment that maps objective needs seems to lead to over allocation of care when an individual is coping effectively by herself or has sufficient support of relatives and friends[10]. Off course, caution is needed for some domains, e.g. medication use, for which older persons often lack knowledge on interactions and side effects; in this case the way they feel is an indicator of their health, but can not replace an objective evaluation of medication (e.g. because interaction of medication might not directly influence one's health perception, but can have severe consequences later on). It is also possible that a person does not report certain needs due to feelings of embarrassment or to social desirability response bias, i.e. the tendency to act (answer) in ways that people believe others find acceptable and approve of[26].

An exception were older persons with depressive symptoms and/ or cognitive impairment. It seems that depressed persons are not stable in what they score; they show no tendency of either having more needs on RAI or CANE, they just have more inconsistent scores than non-depressed persons. Cognitively impaired persons report less needs on CANE, a finding also reported in a study in a small sample in the UK that found that cognitive impairment/ dementia lead to underreporting of needs on CANE by older persons themselves compared to staff and informal caregivers[9]. When assessing need it should be taken into account that persons with impaired cognition and depressive symptoms might not be able to correctly judge their health status and ask for appropriate support. The use of proxies could supplement these older persons report of needs[9].

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Appendix 1. Specific RAI items used to compare with CANE topics and the cut off points chosen.

CANE topics	Items RAI	Content of RAI items	Need on RAI, when...
Environmental needs			
Accommodation	o1i	Summarizes the accommodation items of: too little light, problems with the floor, the bathroom the kitchen, central heating, safety and entrance to house and rooms.	A problem exists on one or more of these items.
Household activities	h1ba	Ability to perform normal domestic work.	Person needs some to very much help performing tasks.
Food	h1aa+h1fa+l1a	Ability to prepare meals, buy groceries and occurrence of unintended weight loss of over 5% in last 30 days or over 10% in last 180 days.	Person need some to very much in preparing meals, buying groceries and/or person reports weight loss.
Money	h1ca	Problems with managing money.	Managing can not be done independently.
Physical needs			
Physical health	j1ac	Summarizes 28 items on presence or absence of chronic diseases/ functional limitations.	Presence of one or more chronic diseases/ limitations.
Medication	h1da+ q4+ q3	Problems with medication management and intake and question if some physicians has made an overview of all medication.	When help is given with management, when intake is not as prescribed and/or no physician has made overview.
Eyesight/hearing impairment	d1+c1+c2	Problems with sight, hearing and speech.	Either sight was limited to very limited; hearing was a bit to very difficult and person was sometimes t hardly ever understood by others.
Mobility/falls	h2c+k5+h1ga	Problems with walking within the home, number of recent falls and problems with transportation.	Walking and transportation can not be performed independently and/or person recently fell 1 or more times.

Self-care	h2j+h2i+h2e+h2f	Problems with washing one self, nail care and dressing the upper and the lower body.	Person need some to very much help on one or more of these items.
Continence	i1a+i3	Incontinence of urine or feces.	Continent with catheter and all levels of incontinence for either urine or feces.
Psychological needs			
Psychological distress	e1a+e1c+e1e+e1f	Feelings of depression, anxiety, worry and sadness in last 3 days.	Presence of one or more of those feelings.
Memory	b1a	Problems with short term memory.	Persons has problems with memory.
Psychotic symptoms	k3f+k3g	Presence of hallucinations or delusional thoughts	Person has either hallucinations or dellusional thoughts.
Behavioral problems	e3b+e3c+e3d	Shows verbally, physically or other inappropriate behaviors	Person shows one or more of those behaviors.
Alcohol abuse	k7a+k7b	Others say person should drink less or persons experiences problems because of drinking.	Person experiences problems or advice was given.
Social needs			
Company	e1i	Decrease in social contact in last 3 days.	Person has decreased contact.
Daytime activities	f2	Decrease in social activities in last 90 days.	Decreased occurred and this decrease was not desirable.
Abuse/neglect	k9d	Person is neglected, abused or maltreated.	Either one is present.

Chapter 5

Impact of self-perceived need on health care utilization in vulnerable community-dwelling older persons

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ABSTRACT

Objectives To establish what type of self-perceived needs are related to certain forms of health care utilization and see how much of utilization is explained by self-perceived need when added to a model of predisposing, enabling and evaluated need variables.

Methods 217 vulnerable community-dwelling older persons were interviewed using the Camberwell Assessment of Need in the Elderly to establish self-perceived need on 24 topics. They also self-reported on number of general practitioner visits and minutes of IADL home care. Total and acute hospital admission data were derived from hospital registration.

Results Persons with needs for their physical health or an unmet need for depression and anxiety more often visited the GP than persons with no need. Persons with a met need for money less often visited the GP and also used less IADL care. Persons with a met need for physical health or an unmet need for information were more often admitted to a hospital. Persons with met needs of physical health and medication or unmet needs for self care were more often acutely admitted to hospitals. Predisposing and enabling variables together explained about 7 to 10% of GP care, home care and hospital admission. Need variables added 23 to 19% explained variance of which 9 to 17% was due to self-perceived need variables.

Discussion Self-perceived need is strongly associated with health care utilization, especially for hospital admission this is somewhat surprising, because admission is often mostly associated with specific diseases and disabilities. Most associations of self-perceived need with health care utilization were obvious, except that money needs actually lead to less GP visits and less home care. Depression needs lead to more visits to the GP and lack of information lead to more hospital admission.

INTRODUCTION

Since the seventies the behavioral model developed by Andersen has come to dominate research on health care utilization in older persons. The initial model suggested that people's use of health care is a function of their disposition to use services combined with factors that enable use and their need for care[1]. Predisposing variables comprise demographic factors, (like age and gender), social structure factors (like education and ethnicity) and health beliefs (attitudes, values and knowledge about health and health care). In 1995 Andersen reviewed his model and added genetic factors, social networks and psychological characteristics like autonomy as possible predisposing variables[2]. In the original model enabling variables consisted of factors like income, health insurance status and travel/ waiting time. Andersen suggested that organizational measures and extent/ quality of social relationships should be added. Need variables are often seen as main determinants of health care utilization and consist of people's own view of their general health and their experience of symptoms of illness, pain and worries[2,3].

A summary of research using this framework is found in Wolinsky[4]. Most but not all studies have shown that need variables, and especially worse functional health, are the main factors in explaining health care utilization in older persons (≥60 years of age)[5-13]. A very recent study found that in community-dwelling disabled older persons, lack of medication assistance in those needing medication support was associated with higher risk of hospitalization[14]. Concluding, the association between need variables and different sorts of health care utilization is well established in both the general population as well as persons over 60 years of age. However, few studies have been done among persons aged 75 and older. An Israeli study in this group showed that the demand for health services in a population with high levels of chronic disease and disability is driven primarily by health needs, rather than by extraneous factors such as income and education[10].

In the update of the model Andersen introduced the distinction between evaluated and self-perceived need[2]. Evaluated need represents professional judgment about a person's health status and his need for health care, whereas self-perceived need focuses on the experience of the person himself. A systematic review of 53 studies on chronically ill persons found an important role for evaluated need variables in predicting use, whereas the results for self-perceived need were mixed: four out of eight studies found that poor perceived health lead to more hospital admission, whereas the other four found no such association[3]. The association of self-perceived need with general practitioner visit was found more often (7 out of 9 studies). A study amongst vulnerable older persons showed that vulnerable persons who live without help for ADL activities (like bathing, dressing) while having unmet ADL-needs have higher rates of admissions than when their needs are met[15].

The current study describes utilization of four types of health care, i.e. general practitioner visits, IADL home care and total and acute hospital admissions in

vulnerable older persons in the Netherlands. In contrast to earlier studies on health care utilization we used a comprehensive measure to establish self-perceived need on 24 topics instead of presenting perceived need as a single measure of perceived health or quality of life[3]. The main questions are: which self-perceived needs are related to health care utilization? And how do self-perceived needs relate to predisposing, enabling and evaluated need in explaining health care utilization?

METHODS

Design

This is a cross-sectional study in a cohort of vulnerable community-dwelling older persons. Our study followed on a randomized controlled trial (RCT) on the influence of demand-led home visits by nurses in primary care[16]. The outcomes of this RCT were all negative. Preliminary analysis also showed no differences between the experimental and control group on the measures used in this study. The ethical committee of the VU medical center approved the study.

Research sample

The research includes community-dwelling older persons in a northwestern region of the Netherlands who at the start of the RCT were 75 years or older and were vulnerable. Our study was embedded in a larger randomized controlled trial[16], which established vulnerability using COOP-WONCA charts[17]. Vulnerability was defined as being in the worst quartile of at least two out of six COOP-WONCA charts (Box 1.).

Box 1 Defining Vulnerability

A person is considered vulnerable when self reporting in the lowest quartile of two or more charts of the COOP-WONCA. All items had a range of 1 to 5, with 1 meaning good health or lack of problems and 5 meaning poor health or many problems. Per item the lowest quartile was calculated. Specifically a vulnerable person is characterized by two or more of the following symptoms:

1) fair to poor self-perceived health (score: 4 and 5)
2) only able to maintain very light physical activity during 2 minutes (score: 5)
3) little or much worse health compared to 2 weeks ago (score: 4 or 5)
4) much difficulty with or not being able to perform one's usual activities or tasks (score: 4 or 5)
5) moderate to extreme emotional problems (score: 3 to 5)
6) moderate to extreme limitation in social activities (score: 3 to 5)

Sampling procedure

The sampling procedure of the RCT is described in more detail elsewhere[16]. Persons with dementia symptoms were excluded from the RCT. Dementia was established in a two stage screening process. In stage one, patients received a

postal health questionnaire, including a self-report version of the short Informant Questionnaire on Cognitive Decline (IQCODE)[18]. This questionnaire has been successful in distinguishing demented persons from a general population sample[18]. Patients with an IQCODE score of 3.6 and over (strongly suggesting cognitive decline) proceeded to stage two. In stage two, they were assessed at home with the Mini Mental State Examination (MMSE[19]) and the 7 min screen (7 MS[20]). The MMSE is the most widely used brief screening test of mental status, and the 7MS has shown to be a useful tool for discriminating demented and cognitively impaired patients from cognitively intact patients[20]. Patients who scored less than 24 on the MMSE or who had a probability of having dementia of 70% or more according to the 7 MS, were excluded from the study. The current research started 18 months after the start of the RCT at which time 465 persons were still in the study. Of those 24 died during our study, 12 were admitted to a residential home, 6 moved out of the region and 105 were no longer vulnerable. Of the 318 eligible older persons 34 were no longer willing to participate and 17 quit for medical reasons. Another 50 could not be reached, had incomplete data or were lost due to other or unknown reasons. In total data of 217 older persons (68% of eligible subjects) were used in analysis.

Measures and measurements

Main outcomes measures; Health care utilization

General practitioner visits and IADL-home care data were based on self-report whereas total and acute hospital admission data were abstracted from registration record from the main hospital in the region. General practitioner visit is a combination of visits to the GP practice and home visits of the GP during the last 2 months. Visits of IADL home care (taking care of the persons home and groceries) during the last week were noted. Total and acute hospital admission data for the last 5 years were abstracted.

Determinants

Unless noted otherwise the variables were measured using RAI-HC. The Resident Assessment Inventory - Home Care (RAI-HC) is a structured and computerized multidimensional geriatric interview, which identifies problem areas in a direct and validated way[21,22]. RAI-HC was conducted by trained nurses. Nurses had an active role in identifying problem areas by observing and checking what older persons reported, for example by reviewing all medication.

Predisposing variables Birth date, gender and education were noted. Low education means no education or elementary education, middle means secondary education and high means bachelor or masters degrees. We also asked if the person lived alone. As a measure of social network we asked the older person to estimate the number of good contacts they had without further defining “good”, but leaving this open to the older persons own interpretation of “good”. As a measure of health beliefs older persons were asked if they believed their functional status could improve.

Enabling variables Older persons were asked if they had an informal caregiver.

Evaluated need variables RAI-HC includes items on the presence of 22 chronic diseases, which were counted to establish multimorbidity. RAI-HC automatically calculates so-called CAPS, which are problem areas based on the sum of item scores relevant to the domain. We included the following CAP-domains as measures of evaluated need: ADL/ Rehabilitation potential (CAP1), HADL improvement (CAP2a), Communicative impairment (CAP5), Cognitive impairment (CAP8), Depression and Anxiety (CAP10), Pain (CAP18), Medication use (CAP26).
Self-perceived need variables The Camberwell Assessment of Need for the Elderly (CANE) was used to assess self-perceived care needs[23] The CANE consists of four care domains, Environmental, Physical, Psychological and Social, with five to seven topics each. The CANE has good content, construct and consensual validity and appropriate criterion validity. Reliability is very high[24]. CANE was conducted by trained interviewers. For every topic the older person stated if there was a need that was met or unmet in the last month. A met need meant that there was sufficient help to solve or significantly reduce the reported problem, for example the older person has trouble cleaning her house, but a professional cleaner or informal caregiver helps out. An unmet need meant that there was no help or the help offered did not suffice in reducing the problem. For example, an older persons feels lonely and reports a need on Company, but does not know who to turn to or has a social worker coming in for conversation, but only once a month.

Data analysis
We used SPSS version 15.0 to analyze our data. Descriptive analyses were used to describe health care utilization and predisposing, enabling, evaluated need and self-perceived need variables. First, we conducted ONE-way ANOVA's to describe the mean number of visits, minutes of help and times of admission for persons with no need, a met need and an unmet need per self-perceived need topic. To establish if these groups differed in their health care utilization we conducted ordinal regression analyses with the no need group as reference category. A condition to conduct ordinal regression analysis is that outcome variables have no groups containing less than ten persons. To satisfy this condition we had to group persons with high utilization together. Persons who visited the GP four or more times were put in one group (n=14). So were persons who were admitted seven or more times to hospital (n=14) or four or more times acutely (n=11). Groups for minutes of IADL-care were generally small, so all persons receiving care were taken together (n=51).

We conducted separate ordinal regression analysis for blocks of predisposing and enabling variables, evaluated need variables and self-perceived need variables to establish R^2 for the separate models. For the self-perceived need variables we only added those variables that had $p<.20$ in the separate ordinal regression analysis mentioned above. Next, we did a stepwise ordinal regression analysis starting with the predisposing and enabling variables and manually adding first the evaluated need variables and then the self-perceived need variables. R^2, R^2-change and X^2 were noted for each step.

RESULTS

Descriptives

Predisposing and enabling variables

Vulnerable older persons were on average 82.9 years of age (Table 1.). Three quarters was female and 63% lived alone. Social networks on average consisted of 12 persons with a range from 0 to 100 persons. 72% of the older persons had little education, 20% finished secondary education and 8% obtained a bachelor or masters degree. 3% believed that their functional status could improve. 39% had no informal caregiver.

Table 1. Descriptive details on predisposing, enabling and need variables and health care utilization (n=217).

Variable	M (SD)	Range	n (%)
Predisposing variables			
Age	82.9 (3.9)	77-97	
Sex - female			168 (77)
Living alone			135 (63)
Social network (number of persons)	11.9 (15.8)	0-100	
Educational level			
Low			150 (72)
Middle			42 (20)
High			16 (8)
Belief that functional status can improve			6 (3)
Enabling variables			
No Informal caregiver			82 (39)
Evaluated need variables			
Multimorbidity	3.0 (1.6)	0-9	
ADL/Rehabilitation potential (CAP1)			44 (20)
HADL improvement (CAP2a)			31 (14)
Communicative impairment (CAP5)			89 (41)
Cognitive impairment (CAP8)			52 (24)
Depression and anxiety (CAP10)			28 (13)
Pain (CAP18)			152 (70)
Medication use (CAP26)			24 (11)
Health care utilization			(≥1)
GP visit (last 2 months)	1.3 (1.6)	0-10	124 (57)
Number of IADL home care visits (minutes per week)	48.4 (84.4)	0-360	92 (42)
All hospital admission (in last 5 years)	2.9 (3.9)	0-38	168 (79)
Acute hospital admission (in last 5 years)	1.0 (1.4)	0-9	105 (49)

Evaluated need variables
Older persons had on average 3 diseases with over three quarters reporting two or more diseases. For few persons (11-14%) problem areas were identified for the RAI-CAPS HDL improvement, depression and anxiety and medication use. Slightly more persons (20%) had problems with recovery from ADL impairment. About a quarter had problems with cognition, almost half with impaired communication and over two thirds with pain.

Table 2. Number and percentage of elderly (n=217) with one or more care needs and number and percentage of unmet care needs per topic.

Variable	Needs n (%)	Unmet needs n (%)[a]
Environmental needs		
Accommodation	15 (7)	3 (20)
Household activities	194 (89)	6 (3)
Food	107 (49)	1 (1)
Money	49 (23)	0 (0)
Benefits	46 (21)	7 (15)
Caring for someone	8 (4)	0 (0)
Physical needs		
Physical health	174 (80)	5 (3)
Medication use	71 (33)	0 (0)
Eyesight/hearing impairment	59 (27)	6 (10)
Mobility/falls	167 (77)	7 (4)
Self-care	148 (68)	4 (2)
Continence	55 (25)	6 (11)
Psychological needs		
Psychological distress	8 (4)	4 (50)
Memory	24 (11)	4 (17)
Behavior	1 (1)	0 (-)
Alcohol	0 (0)	0 (-)
Deliberate self-harm	2 (1)	1 (50)
Inadvertent self-harm	0 (0)	0 (-)
Psychotic symptoms	2 (1)	1 (50)
Social needs		
Company	23 (11)	9 (39)
Intimate relationships	11 (5)	7 (63)
Daytime activities	30 (13)	4 (13)
Information	15 (7)	9 (60)
Abuse/ neglect	3 (1)	1 (33)

[a] Percentages of unmet needs described are based on the total number of needs in that specific topic.

Self-perceived need variables

Most needs were reported for Household activities (89%), Physical Health (80%), Mobility/falls (77%), Self care (68%) and Food (49%), but hardly any needs were unmet (1-4%) (Table 2.). One third reported needs on Medication use, but none of those were unmet. About a quarter reported needs on Money, Benefits and Eyesight/Hearing impairment, but again those were mostly met. Little needs were reported on Accommodation, Daytime Activities, Caring for someone and Memory and most were met. Although few persons reported needs for Intimate relationships (5%), Company (11%), Psychological distress (4%) and Information (7%), a large proportion of those needs were unmet (36-63%).

Table 3a. Mean number of GP visits in the last 2 months and average minutes of IADL home care in last week. p derived from ordinal regression analyses with "no need" as reference category.

Self perceived need[a]	Persons with need n (N=217)	Number of GP visits M(SD)	Minutes of home care M(SD)
Environmental needs			
Accommodation – no need	202 (93)	1.3 (1.3)	49.0 (83.3)
Persons with met need	12 (6)	1.0 (1.4)	50.0 (111.0)
Persons with unmet need	3 (1)	1.3 (1.2)	.0 (.0)
Household activities – no need	23 (11)	1.3 (1.1)	15.7 (51.9)
Persons with met need	188 (87)	1.2 (1.6)	54.0 (87.6)*
Persons with unmet need	6 (3)	2.0 (2.5)	.0 (.0)
Food – no need	110 (51)	1.4 (1.4)	53.6 (88.3)
Persons with met need	106 (49)	1.1 (1.7)$^{+}$	43.4 (80.5)
Persons with unmet need	1 (0)		
Money – no need	168 (77)	1.4 (1.6)	55.4 (89.0)
Persons with met need	49 (23)	.7 (1.1)**	24.5 (61.1)*
Persons with unmet need	0 (0)		
Benefits	164 (76)	1.3 (1.6)	46.1 (84.9)
Persons with met need	39 (18)	.9 (1.1) $^{+}$	56.9 (83.7)
Persons with unmet need	7 (3)	1.9 (1.8)	51.4 (87.8)
Caring for someone else	209 (96)	1.3 (1.6)	47.7 (84.2)
Persons with met need	8 (4)	1.4 (1.3)	67.5 (93.2)
Persons with unmet need	0 (0)		
Physical needs			
Physical health – No need	43 (20)	.9 (1.4)	44.7 (76.4)
Persons with met need	169 (78)	1.3 (1.6)*	50.8 (87.3)
Persons with unmet need	5 (2)	2.4 (2.3)*	.0 (.0)
Medication use	146 (67)	1.3 (1.6)	52.7 (85.0)
Persons with met need	71 (33)	1.2 (1.5)	39.4 (82.9)$^{+}$
Persons with unmet need	0 (0)		
Eyesight/hearing impairment	158 (73)	1.4 (1.6)	86.4 (50.0)
Persons with met need	53 (24)	1.0 (1.4)$^{+}$	49.2 (82.2)
Persons with unmet need	6 (3)	.7 (.8)	.0 (.0)

Self perceived need[a]	Persons with need n (N=217)	Number of GP visits M(SD)	Minutes of home care M(SD)
Mobility/falls	49 (23)	1.4 (1.6)	53.6 (84.2)
Persons with met need	160 (74)	1.2 (1.5)	48.1 (85.5)
Persons with unmet need	7 (3)	1.9 (2.3)	25.7 (68.0)
Self care	69 (32)	1.2 (1.3)	38.7 (82.2)
Persons with met need	144 (66)	1.3 (1.7)	54.5 (86.0)$^{+}$
Persons with unmet need	4 (2)	2.5 (2.5)	.0 (.0)
Continence	162 (75)	1.2 (1.7)	45.1 (78.3)
Persons with met need	49 (23)	1.3 (1.3)	61.9 (103.6)
Persons with unmet need	6 (3)	1.3 (.8)	30.0 (73.5)
Psychological needs			
Psychological distress	208 (96)	1.2 (1.5)	47.6 (84.4)
Persons with met need	4 (2)	2.3 (1.0)$^{+}$	105.0 (90.0)$^{+}$
Persons with unmet need	4 (2)	3.0 (2.6)*	45.0 (90.0)
Memory	193 (89)	1.3 (1.6)	50.7 (86.0)
Persons with met need	20 (9)	1.1 (1.4)	36.0 (73.9)
Persons with unmet need	4 (2)	.0 (.0)	.0 (.0)
Social needs			
Company	193 (89)	1.2 (1.5)	51.3 (86.5)
Persons with met need	14 (6)	.9 (1.3)	30.0 (65.5)
Persons with unmet need	9 (4)	2.1 (2.5)	20.0 (60.0)
Intimate relationships	206 (95)	1.2 (1.5)	49.0 (85.1)
Persons with met need	4 (2)	1.8 (1.0)	60.0 (84.9)
Persons with unmet need	7 (3)	2.3 (2.1)$^{+}$	25.7 (68.0)
Daytime activities	187 (86)	1.3 (1.6)	53.0 (87.4)
Persons with met need	26 (12)	.9 (1.1)	23.1 (59.0)$^{+}$
Persons with unmet need	4 (2)	1.8 (2.9)	.0 (.0)
Information	199 (92)	1.3 (1.6)	49.8 (85.7)
Persons with met need	6 (3)	1.3 (1.2)	40.0 (72.7)
Persons with unmet need	9 (4)	1.4 (1.6)	40.0 (79.4)

$^{+}$ .05<p<.20, *p<.05, **p<.01,***p<.001, (*, **, *** and $^{+}$ were added to regression analysis)
[a] Need topics with n<5 were removed from the analyses (Behavioral problems. Alcohol problems, Deliberate and Inadvertent self-harm, Psychotic symptoms and Neglect/abuse).

Health care utilization

57% visited the general practitioner in the last two months with a range from 1 up to 10 visits (Table 1.). 42% had IADL home care with a range of 60 to 360 minutes per week. Half of older persons were acutely admitted to the hospital at least once in the last five years. When including non-acute admissions this number rose to over three quarters of older persons.

Relationship with health care utilization

Visits to General Practitioner

Persons who had problems with their physical health more often visited the GP regardless if the need was met or unmet (Table 3a.). Person with depression and/

or anxiety problems (Psychological distress) who did not seek help or received insufficient help also more often visited the GP than persons with no need. When a person reported receiving sufficient help with management of their finances (Money) they still visited the GP less than persons with no financial need. Predisposing and enabling variables together explained 8% of the variance (Table 4.). Need variables added 23% of which 15% was due to self-perceived need variables (total R^2=31%).

Visits of IADL home care

Persons who reported sufficient help for their need for support for household activities self-evidently used more IADL care per week than persons with no such need (Table 3a.). Again persons with a met need for money used less IADL care. Predisposing and enabling variables together explained 10% of the variance (Table 4). Need variables added 25% of which 14% was due to self-perceived need variables (total R^2=35%).

Table 3b. Mean number of admission to a hospital (total and acute) in the last five years. p derived from ordinal regression analyses with "no need" as reference category.

Self perceived need[a]	Persons with need n (N=217)	Number of hospital admissions in last 5y	Number of acute hospital admissions in last 5y
Environmental needs			
Accommodation – no need	202 (93)	2.9 (4.0)	1.0 (1.5)
Persons with met need	12 (6)	3.1 (2.1)	.5 (.7)
Persons with unmet need	3 (1)	1.5 (2.1)	.0 (.0)
Household activities – no need	23 (11)	2.9 (2.3)	.7 (.9)
Persons with met need	188 (87)	2.9 (4.1)	1.0 (1.6)
Persons with unmet need	6 (3)	3.3 (2.3)	1.3 (1.0)$^{+}$
Food – no need	110 (51)	2.9 (3.2)	.9 (1.4)
Persons with met need	106 (49)	2.8 (4.5)$^{+}$	1.0 (1.6)
Persons with unmet need	1 (0)		
Money – no need	168 (77)	2.9 (3.2)	1.0 (1.4)
Persons with met need	49 (23)	2.8 (5.7)$^{+}$	1.0 (1.8)
Persons with unmet need	0 (0)		
Benefits	164 (76)	2.9 (3.0)	1.0 (1.4)
Persons with met need	39 (18)	2.9 (6.4)	.8 (1.4)$^{+}$
Persons with unmet need	7 (3)	1.7 (1.2)	1.0 (1.1)
Caring for someone else	209 (96)	2.9 (3.9)	1.0 (1.5)
Persons with met need	8 (4)	1.8 (2.0)	.8 (1.4)
Persons with unmet need	0 (0)		
Physical needs			
Physical health – no need	43 (20)	1.2 (1.3)	.4 (.7)
Persons with met need	169 (78)	3.4 (4.2)***	1.1 (1.6)*
Persons with unmet need	5 (2)	2.2 (2.8)	.4 (.5)

Self perceived need[a]	Persons with need n (N=217)	Number of hospital admissions in last 5y	Number of acute hospital admissions in last 5y
Medication use	146 (67)	2.5 (2.5)	.8 (1.3)
Persons with met need	71 (33)	3.8 (5.7)[+]	1.4 (1.8)**
Persons with unmet need	0 (0)		
Eyesight/hearing impairment	158 (73)	3.0 (4.2)	1.0 (1.5)
Persons with met need	53 (24)	2.6 (2.4)	.9 (1.5)
Persons with unmet need	6 (3)	3.2 (5.1)	1.8 (2.2)
Mobility/falls	49 (23)	2.6 (2.2)	.8 (1.2)
Persons with met need	160 (74)	3.0 (4.3)	1.0 (1.6)
Persons with unmet need	7 (3)	2.9 (2.1)	1.3 (1.1)
Self care	69 (32)	2.4 (2.7)	.8 (1.4)
Persons with met need	144 (66)	3.1 (4.3)	1.0 (1.5)
Persons with unmet need	4 (2)	3.5 (2.1)[+]	2.0 (1.4)*
Continence	162 (75)	2.8 (3.2)	.9 (1.3)
Persons with met need	49 (23)	3.2 (5.7)	1.1 (1.9)
Persons with unmet need	6 (3)	2.7 (2.3)	1.3 (1.4)
Psychological needs			
Psychological distress	208 (96)	2.9 (3.9)	1.0 (1.5)
Persons with met need	4 (2)	2.3 (2.2)[+]	.3 (.5)
Persons with unmet need	4 (2)	3.5 (2.6)	1.5 (1.3)
Memory	193 (89)	3.1 (4.0)	1.0 (1.6)
Persons with met need	20 (9)	1.6 (1.5)[+]	.5 (.6)[+]
Persons with unmet need	4 (2)	1.3 (1.5)	.3 (.6)
Social needs			
Company	193 (89)	3.0 (4.0)	1.0 (1.6)
Persons with met need	14 (6)	2.6 (2.0)	.7 (.7)
Persons with unmet need	9 (4)	1.6 (1.4)	.4 (.5)
Intimate relationships	206 (95)	2.9 (3.9)	1.0 (1.5)
Persons with met need	4 (2)	2.0 (2.4)	.3 (.5)
Persons with unmet need	7 (3)	2.4 (2.4)	1.1 (1.2)
Daytime activities	187 (86)	3.0 (4.1)	1.0 (1.6)
Persons with met need	26 (12)	2.0 (1.5)	.7 (.8)
Persons with unmet need	4 (2)	1.3 (.5)	.8 (.5)
Information	199 (92)	2.9 (3.9)	.9 (1.4)
Persons with met need	6 (3)	2.3 (1.8)	.3 (.5)
Persons with unmet need	9 (4)	4.6 (3.3)[+]	2.1 (3.1)

[+] .05<p<.20, *p<.05, **p<.01,***p<.001, (*, **, *** and [+] were added to regression analysis)
[a] Need topics with n<5 were removed from the analyses (Behavioral problems. Alcohol problems, Deliberate and Inadvertent self-harm, Psychotic symptoms and Neglect/abuse).

Total hospital admission

Older persons with a met need for Physical health were more often admitted to a hospital than persons with no need (Table 3b.). So were persons with an unmet need for Information, meaning that persons who did not receive information on their health status or who did not understand the information were more often admitted

to a hospital. Predisposing and enabling variables together explained 10% of the variance (Table 4.). Need variables added 31% of which 18% was due to self-perceived need variables (total R^2=41%).

Acute hospital admission
Older persons with a met need for Physical health or Medication (problems with management, adherence and side effects) or an unmet need for Self care were more often acutely admitted to a hospital than persons with no need (Table 3b.). Predisposing and enabling variables together explained 7% of the variance (Table 4.). Need variables added 23% of which 9% was due to self-perceived need variables (total R^2=30%).

Table 4. Hierarchical multivariate ordinal regression analysis of predisposing, enabling, evaluated and self-perceived need variables on number of visits to the general practitioner in the last 2 months, minutes of IADL care in the last week and hospital admission in the last 5 years.

	Separate R^2	R^2- total	R^2-change	X^2
GP visit				
Predisposing + enabling variables	8%	8%		15.31
Evaluated need variables	8%	16%	+8%	31.47*
Self perceived need variables	16%	30%	+14%	65.48**
IADL care				
Predisposing + enabling variables	10%	10%		11.26
Evaluated need variables	10%	21%	+11%	31,33*
Self perceived need variables	20%	35%	+14%	54.75**
All hospital admission				
Predisposing + enabling variables	10%	10%		19.97*
Evaluated need variables	12%	23%	+13%	48.71***
Self perceived need variables	20%	41%	+18%	100.96***
Acute hospital admission				
Predisposing + enabling variables	7%	7%		13.69
Evaluated need variables	15%	21%	+14%	41.13**
Self perceived need variables	13%	30%	+9%	62.44**

*p<.05, **p<.01,***p<.001

DISCUSSION

Persons with needs for their physical health or an unmet need for depression and anxiety more often visited the GP than persons with no need. Persons with a met need for money less often visited the GP and also used less IADL care. Persons with a met need for physical health or an unmet need for information were more often admitted to a hospital. Persons with met needs for physical health and

medication or unmet needs for self care were more often acutely admitted to hospitals. Predisposing and enabling variables together explained about 7 to 10% of GP care, both kinds of home care and hospital admission. Need variables added 19 to 23% explained variance of which 9 to 17% was due to self-perceived need variables.

A limitation of this study is that it is cross sectional and that we can not establish a causal relationship between the variables and health care utilization. When discussing the results (below) we will take this into account. Furthermore, the loss to follow-up was substantial (32%). Most probably the most vulnerable persons were lost in this study and thus the amount of health care utilization presented in Table 1. is an underestimation. This loss might also have weakened the associations of predisposing, enabling, evaluated need and self-perceived need with health care utilization. The loss to follow-up also lead to a small number of persons with unmet needs. Although the analysis takes this small number into account we should interpret these results with caution. We tried to follow the Andersen-Newman model as precisely as possible, but its classification sometimes seemed illogical especially for social factors. Why is living alone a predisposing variable and having an informal caregiver an enabling variable? Because predisposing and enabling variables were analyzed together this did not pose a problem in the current study. It should be noted that little enabling factors were measured in our study. Organization factors were missing, which most probably are the most important enabling variables[2]. This might explain the lack of association of enabling factors with health utilization although in many other studies, even when including characteristics of services, no associations were found either[3].

In contrast to earlier studies on health care utilization we used a comprehensive measure to establish self-perceived need on 24 topics instead of including one item describing perceived health, subjective health or perceived need for care as a need measure[3,9-13]. So we did not ask older persons how they rated their health, but if they experienced a need/ problem in specific care areas. This distinction made it possible to identify specific areas of need that were associated with health care utilization. This lead to the identification of some obvious relationships of self-perceived need and health care utilization, like persons who reported a met need for household activities also using much more IADL care than persons with no such need. Another example is the association between physical health needs and GP visits: persons with a met need (who would need check-ups every now and then) visited the GP more often than persons with no need and persons with an unmet need (thus, with uncontrolled health problems) even went more often. Persons who were unable to take good care of themselves (in terms of hygiene) were more often admitted to hospitals. The same goes for persons who reported that they did not receive or did not understand the information about their health state. It is possible that more or clearer information might lead to less hospital admissions, but it is also possible that persons with more complex health problems are more often admitted

to hospital and that the complexity of the problems leads to problems with information. Another curious finding is that persons with money problems, although they report sufficient help for this problem still visit the GP less and use less IADL home care. Another interesting relationship is that of physical health and medication management needs with hospital admission. Persons with met need are more often admitted than persons with no need. This might be due to this study being cross-sectional, maybe the hospital admissions lead to better health or medication management. Last, persons with an unmet need for depression and anxiety more often visit their GP than persons with no need. Most likely this is related to underdiagnosis of depression; these persons will present with physical or vague health complaints, which the GP does not recognize as a consequence of being depressed.

Self-perceived need is strongly associated with health care utilization. Especially for acute and total hospital admission this is somewhat surprising. We hypothesized that hospital admission would be related to evaluated need because it is care "that will be provided after a patient has presented to a medical care provider"[2]. Although evaluated need variables had strong association with total and especially with acute hospital admission, self-perceived need variables added substantially to the explained variance. A question that remains unanswered is if the strong influence of self-perceived need is a finding specific to this target group of vulnerable persons over 75, who by definition are already at greater risk of adverse health outcomes like institutionalization, hospitalization and mortality or if it applies to other groups as well?

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Chapter 6

The effect of demographic changes and changes in the prevalence of depressive symptoms on vulnerability and health care utilization in community-dwelling older persons in 2030

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ABSTRACT

Objectives This study estimates the number of vulnerable persons and their health care utilization in 2007. It also estimates this population and utilization in 2030 using six scenarios. The first scenario is based on changes in age, gender, marital status and education over time. Five scenarios describe changes in vulnerability and health care utilization as a consequence of reducing depressive symptoms by improving detection and/ or treatment.

Methods This study linked results from a cohort study in a northwestern region of the Netherlands with population projections from Statistics Netherlands. Vulnerability is measured with COOP-WONCA charts. Four measures of health care utilization are included, namely, general practitioner visits (GP visits), home care concerning domestic tasks (IADL home care) and total and acute hospital admission.

Results The prevalence of vulnerability in the total population aged 75 and over was 29%. Due to the aging of the population the absolute number of vulnerable older persons will rise with 74% to almost half a million in 2030. When the number of depressed persons is reduced using several reduction-scenarios the number of vulnerable persons may consequently be reduced with 2 to 29%. The effect of this reduction on health care utilization in the total population aged 75 and over may then lead to a reduction of 0 to 2% for IADL home care, 0 to 3% for GP visits, 0 to 5% for total hospital admissions and 0 to 6% for acute hospital admissions. Only the 100%-detection scenario and the 100%-combination scenario led to small improvements in health care utilization in the total population aged 75 and over.

Discussion Although this study has limitations and the numbers should not be interpreted rigidly, it shows that the aging of the Dutch population will lead to almost a doubling of the number of vulnerable persons and consequently also a doubling of their health care utilization. This is alarming, since the Dutch health care system is already strained and in its current form will not be able to tackle the increase in (vulnerable) older persons and their health care utilization. Reducing depressive symptoms by improving detection and treatment may lead to large reductions in vulnerability, but small reductions of health care utilization in the total population aged 75 and over.

INTRODUCTION

In 2007 the Netherlands had a total population of 16,357,992 inhabitants of which 1,075,895 (6.5%) was 75 years of age and older (http://statline.cbs.nl). Whereas the total population tripled over the last century the number of older persons was multiplied by a factor 17 since 1900. This aging of the population continues in the future, with prognosis showing that in 2030 11% of the total population will be aged 75 and older. Aging of a population leads to an increase in the number of persons with certain (combinations of) diseases. Furthermore, impairments which influence daily functioning will be more prevalent, like problems with mobility, urine-incontinence and sensory problems. A concept that is relatively new to describe the multiple problems that older persons often experience is frailty[1]. Frailty is an important concept in health care because it leads to adverse health outcomes like institutionalization, falls, disability, hospitalization, morbidity and mortality[2,3]. So far, there is no widely accepted definition of frailty[4]. A consensus group of the American Geriatrics Society has settled on defining frailty as a physiological syndrome characterised by decreased reserve and diminished resistance to stressors, that results from declines across multiple physiologic systems[2,5]. The definition used in the current study is multifactorial and includes both physical and psychosocial factors. To distinguish this type of frailty from the physical frailty as defined by Fried *et al.* we label our population as being “vulnerable”.

Depression is a common disorder among older persons and it has been estimated that in 2020 depression will become the second leading cause of disability[6]. About 3% of older persons have a severe depression and another 10±15% have a mild to moderate depression[7,8]. Prevalence of depressive symptoms in older persons ranges from 18 to 35%[9-13]. Depression is not only highly prevalent in late life it has also an unfavorable prognosis[14] and considerable impact on the quality of life of patients[15]. Furthermore, it is associated with increased mortality[16], higher demands on caregivers and higher service use[17] and considerable economic costs[18]. It also showed a strong association with physical frailty[19] and is seen as an important factor in the cycle of frailty[20]. Although effective treatments, such as pharmacotherapy[21,22] and cognitive-behavioral therapy[23,24] are available, only few older persons receive adequate treatment for depression[25,26].

It is estimated that approximately one third of all depressed persons currently receives efficacious treatment, which leads to 13% averted burden of depression in the total population[27]. Averted burden of disease was defined as a reduction in Disability Adjusted Life Years (DALY’s). Averted DALY’s were calculated by multiplying the number of persons receiving efficacious treatment with the change in disability weight due to this efficacious treatment. Disability weights change because treatment leads to persons changing from severe or modest depression states to less severe states (or even a non-depressed state) and thus to a reduction in disability. If all persons who present themselves to physicians with depressive symptoms (55% of all persons with depression) would be recognized and receive optimal treatment this would lead to a reduction in burden of

depression of 36%[27]. Another study in 14 world regions[28] showed that 10 to 30% of the burden of depression can be reduced if 50% of all persons with depression received optimal treatment.

Summarizing, depressive symptoms in individuals and consequently burden of depression on a national level could be reduced when detection and treatment improve. Since depressive symptoms is a risk factor for developing and remaining vulnerable and both depressive symptoms and vulnerability lead to higher levels of health care utilization, we hypothesize that better detection and treatment of depressive symptoms could reduce the number of vulnerable persons and their health care utilization. The current study describes the Dutch community-dwelling population aged 75 and over in 2007 and estimates the size and composition of this population in 2030 in terms of age, gender, marital status, education, vulnerability and depressive symptoms. It also presents the impact of five scenarios describing reductions in depressive symptoms on vulnerability and health care utilization in 2030.

METHODS

The research question can be divided in three sub-questions. First, what are the effects of the aging of the population and other demographic changes on the number of community-dwelling vulnerable persons aged 75 and over in 2030? Second, what is the effect of this change on health care utilization in vulnerable persons and in the total population aged 75 and over in 2030? Last, if depressive symptoms in this population are reduced, what is the effect on number of community-dwelling vulnerable persons and their health care utilization in 2030? The methods are divided according to these three questions.

Effect demographic changes on vulnerability

First, we established the prevalence rate of vulnerability by age, gender, marital status and education and by depression status in a dataset concerning community-dwelling persons aged 75 and over in West-Friesland, a northwestern region of the Netherlands (the dataset and some of its characteristics are described in more detail in Appendix A). Table 1. describes the prevalence of vulnerability stratified for age, gender, marital status and education in this region. Prevalence of vulnerability increases gradually with age from a quarter in persons aged 75 to 80 to almost 50% in persons aged 90 and over. Females are more often vulnerable than males and widowers more often than married persons. Last, the higher the education the lower the prevalence of vulnerability. We used population projections of Netherlands Statistics to estimate population numbers by age (75 and over), gender, and marital status in 2030[29]. As these population projections did not include education, we added this variable on the basis of the level of education amongst persons currently aged 50 to 65 to the population projections[30]. The number of vulnerable persons in 2030 was estimated by applying the prevalence rates of vulnerability by age, gender, marital status and education to the population

projections. We used .R version 2.6.1 (The R Foundation for statistical Computing) for the analysis.

Table 1. Prevalence of vulnerability stratified by age, gender, marital status, education and depressive symptoms. p is based on independent t-test with 75-80, men, married persons, high education and absence of depressive symptoms as reference group.

	n	Number and percentage of vulnerable persons	p
Total population	2780	824 (30%)	
Age[†]			
75-80 (reference)	1315	321 (24%)	
80-85	1020	311 (30%)	**
85-90	331	140 (42%)	***
90+	93	43 (46%)	***
Gender			
Male (reference)	1056	260 (25%)	
Female	1724	564 (33%)	***
Marital status[†]			
Married (reference)	1250	324 (26%)	
Never married	104	28 (27%)	
Divorced/ separated	74	27 (36%)	
Widowed	1149	384 (33%)	***
Education[†]			
Low	1768	560 (32%)	**
Middle	542	143 (26%)	
High (reference)	272	63 (23%)	
Depressive symptoms[†]			
Present	845	505 (60%)	***
Absence (reference)	1877	298 (16%)	

* p<.05, ** p<.01, *** p<.001

[†] The numbers for the categories do not all sum up to 2780 due to missing data.

Effect vulnerability on health care utilization

The West-Friesland study also provided us with data on health care utilization in vulnerable older persons, stratified by age, gender, marital status and education (described in Appendix A). Four measures of health care utilization among vulnerable persons were studied, namely general practitioner visits (GP visits), home care concerning household activities (IADL home care) and acute and total hospital admissions. Table 2. describes health care utilization in both vulnerable and non-vulnerable persons in this study. Health care utilization of the total

population is not described; the over-representation of vulnerable persons in this study would lead to an overestimation of health care utilization in the total population. Vulnerable persons generally make more use of health services than non-vulnerable persons. Supplementary analysis showed that within the vulnerable population age, gender, marital status and education were not significantly associated with the use of health services (not in Table). Furthermore, the analysis used to explore these associations were based on small numbers of persons. Therefore, we will not include these variables in the calculation of health care utilization. Thus, health care utilization is calculated by multiplying the number of vulnerable and non-vulnerable persons with the accessory amount of health care utilization.

Table 2. Average health care utilization in vulnerable and non-vulnerable persons in 2007. p is based on independent t-tests comparing vulnerable with non-vulnerable persons.

	Non-vulnerable population	Vulnerable population	p
n	105	217	
GP visits per year M (SD)	5.9 (6.7)	8.0 (10.5)	*
Total hospital admission in last 5 years M (SD)	1.8 (2.0)	2.9 (3.6)	**
Acute hospital admission in last 5 years M (SD)	.6 (1.0)	1.0 (1.5)	**
Hours of IADL help per year M (SD)	32.9 (72.2)	41.2 (72.7)	

* p<.05, ** p<.01, *** p<.001

Effect of depression-intervention on vulnerability and health care utilization
The prevalence of depressive symptoms in the total population aged 75 and over is 31% (not in Table). Of the non-depressed persons 16% is vulnerable and of the depressed persons 60% (Table 1). The relative risk of being vulnerable when being depressed compared to persons who are not depressed is 3.77. The population attributable risk is 46%, meaning that 46% of vulnerability is a consequence of being depressed.

Based on the literature on maximal health gain[27,28] in depression we decided to develop five scenarios that aim to reduce depressive symptoms. The calculation of the percentages used in each scenario is shown in Appendix B. Two scenarios describe improvement in treatment, two more describe improvement in detection and one combines optimal detection with optimal treatment. The 100%-treatment scenario describes the reduction in depression when all persons who currently receive efficacious treatment would received optimal treatment (reduction in depressive symptoms of 8%). The 50%-treatment scenario describes the same

effect when not all but only half of those persons receive optimal treatment (4% reduction). The 50%-detection scenario describes what happens if 50% of all persons with depression received current care (8% reduction). The 100%-detection scenario describes the effect of all depressed persons receiving current care (32% reduction). Last, the 100%-combination scenario describes the consequences of all persons with depression being detected and receiving optimal care (60% reduction). We again used .R to calculate the number of vulnerable persons and their health care utilization after the reduction in depressive symptoms. The effect of the reduction can be quantified as the potential impact fraction (PIF): the proportional change in expected incidence as a consequence of a specified change in exposure level[31]. In this case, the expected reduction in number of vulnerable persons and their health care utilization as a consequence of a reduction in depressive symptoms.

Assumptions

When estimating the effect of demographical changes and an intervention on a population, questions may arise for which an evaluation may not provide direct answers. For this study, we made the following supplementary assumptions.

1. The estimate of the current averted burden of depression percentage is based on analysis in a single study in Australia. Most input variables used in this study were based on findings in international reviews and meta-analysis. Thus, we assumed that this calculation would more or less apply to the Netherlands.
2. The reduction of burden due to better detection and treatment estimates were conducted on the general population level and not separately for older persons. We assumed that approximately the same improvement in detection and treatment was possible in older persons.
3. Depressive symptoms was included as a binary outcome in this study (absence vs. presence of clinically relevant depressive symptoms). We assumed that the reduction in burden of depression would lead to a similar reduction in persons with clinically relevant symptoms of depression.
4. We also assumed that the prevalence of vulnerability and depressive symptoms would apply to the total Dutch population of older persons. And that the subsample of vulnerable older persons was representative of the whole vulnerable Dutch population aged 75 and over.
5. Since CBS provided no data on education in this old population we assumed that the distribution of education in the West-Friesland sample was representative of the Dutch population aged 75 and over in 2007. Furthermore, we applied education levels of persons currently aged 50 to 65 to the population aged 75 and over in 2030.

Outcome variables

Vulnerability Since this study was embedded in a larger randomized controlled trial[32], we adopted the measure of vulnerability used in the RCT, which established

vulnerability using COOP-WONCA charts[33,34]. Vulnerability was defined as being in the worst quartile of at least two out of six COOP-WONCA charts (Box 1.).

Health care utilization Four measures of health care utilization among vulnerable persons were studied, namely general practitioner visits (GP visits), home care concerning domestic activities (IADL home care) and acute and total hospital admissions. GP visits and IADL-home care data were based on self-report whereas total and acute hospital admission data were abstracted from the registration record of the main hospital in the region. GP visits is a combination of visits to the GP practice and home visits of the GP during the last 2 months. Visits of IADL home care during the last week were noted. Total and acute hospital admission data for the last 5 years were abstracted.

Box 1 Defining Vulnerability

A person is considered vulnerable when self reporting in the lowest quartile of two or more charts of the COOP-WONCA. All items had a range of 1 to 5, with 1 meaning good health or lack of problems and 5 meaning poor health or many problems. Per item the lowest quartile was calculated. Specifically a vulnerable person is characterized by two or more of the following symptoms:

1) fair to poor self-perceived health (score: 4 and 5)
2) only able to maintain very light physical activity during 2 minutes (score: 5)
3) little or much worse health compared to 2 weeks ago (score: 4 or 5)
4) much difficulty with or not being able to perform one's usual activities or tasks (score: 4 or 5)
5) moderate to extreme emotional problems (score: 3 to 5)
6) moderate to extreme limitation in social activities (score: 3 to 5)

Risk factors

Demography Age, gender, marital status and education were included as demographic variables. Marital status had 4 categories, namely married, never married, divorced/ separated and widowed. Education level was described in terms of low, middle and high education, with low signifying no or elementary education, middle referring to high school education and high to persons having college or university education.

Depression Depressive symptoms were measured using The Center for Epidemiologic Studies Depression (CES-D) scale[35]. It consists of 20 items and the total score ranges between 0 and 60. A cut-off point of ≥16 is commonly used to distinguish between persons with and those without clinically relevant symptoms of depression. At this cutoff the sensitivity was 100% and the specificity 88% for major depressive disorders in a representative elderly Dutch population[36].

RESULTS

Table 3. Percentages of Dutch population aged 75 and over in 2007 and 2030 in terms of age, gender, marital status (data from CBS) and education (data from baseline study and data on persons currently aged 50 to 65).

	2007	2030
75 and over compared to general population	6%	10%
% within population aged 75 and over:		
75-80	44%	36%
80-85	32%	37%
85-90	17%	18%
90+	8%	9%
Gender		
Female	63%	59%
Marital status		
Married	47%	49%
Unmarried	7%	6%
Divorced/ separated	5%	10%
Widowed	40%	34%
Education		
Low	68%	53%
Middle	21%	31%
High	11%	16%

Effect demographic changes on vulnerability

The number of persons aged 75 and over is projected to increase strongly between 2007 and 2030 from 6% to 10% of the total community-dwelling population (Table 4.). The distribution within this older population in age categories remains approximately the same, although the group of persons aged 80 to 85 relatively increases due to the aging of the baby boom generation (Table 3.). As a consequence the group of 75 to 80 year olds shows a relative decrease. The male-female distribution slightly changes over time with relatively more men in 2030 than in 2007. Marital status also changes slightly between 2007 and 2030; in 2030 relatively more persons are married and divorced and less persons are widowed, the percentage of persons that have never married remains the same. Larger differences will occur for education level; in 2030 more older persons will have middle and high education compared to less persons with low education. These changes in demography lead to a 74%-increase in number of vulnerable persons to almost half a million in 2030 (Table 4.).

Effect vulnerability on health care utilization
Number of GP visits, IADL home care visits and hospital admission amongst vulnerable persons shows the same increase as a consequence of this absolute increase in vulnerable persons. The health care utilization of the total population increased with 76% as a consequence of the aging of the population (Table 4.).

Effect of depression-intervention on vulnerability and health care utilization
The results of the five scenarios describing various reductions in depressive symptoms are shown in Table 4.. If only treatment is improved (50% and 100%-treatment scenarios) the number of vulnerable persons shows a small reduction (2 to 4%). Both acute and total hospital admission decrease by 1%, but no effect is found on number of GP visits and hours of IADL home care used. If detection is increased to 50% of all persons (50%-detection scenario) this leads to a small reduction in vulnerable persons (4%). Again hospital admission are reduced by 1% and no effect is found on GP visits and IADL home care. The effect of detecting all depressed persons (100%-detection scenario) has a larger effect: the number of vulnerable persons is reduced by 16%. Consequently, health care utilization in the total population aged 75 and over is a bit more reduced: 1% for IADL home care, 2% for both GP visits and total hospital admissions and 3% for acute hospital admissions. Last, optimal detection and optimal treatment combined (100%-combination scenario) leads to 29% reduction in vulnerable persons. Consequently IADL home care in the total population aged 75 and over is reduced with 2%, GP visits with 3%, total hospital admissions with 5% and acute hospital admissions with 6%.

Table 4a. Changes in number of vulnerable persons and their health care utilization (x 1 million) as a consequence of different scenarios: a description in 2007 (Scenario 2007), a prognosis based on demography changes in 2030 (Demography scenario 2003) and two scenarios describing consequences of reductions in depressive symptoms.

	Scenario 2007	Demography scenario 2030	50% - treatment scenario 2030 (5%reduction)	100% - treatment scenario 2030 (9% reduction)
Total Dutch population	16.36	16.98	16.98	16.98
Total Dutch community dwelling population	16.16	16.77	16.77	16.77
Total vulnerable community dwelling population aged 75+	.29	.50 (+ 74%)	.49 (- 2%)	.48 (- 4%)
Total non-vulnerable community dwelling population aged 75+	.65	1.16	1.17	1.17
Total community dwelling population aged 75+	.94	1.66 (+76%)	1.66	1.66

Number of GP visits per year amongst vulnerable older persons	2.29	3.99 (+ 74%)	3.89 (- 2%)	3.81 (- 4%)
Number of GP visits per year amongst non-vulnerable persons	3.86	6.87	6.94	7.00
Number of GP visits per year amongst total population aged 75 and over	6.15	10.86 (+ 76%)	10.83 (- 0%)	10.81 (- 0%)
Number of hospital admissions per year amongst vulnerable older persons	.83	1.45 (+ 74%)	1.41 (- 2%)	1.38 (- 4%)
Number of hospital admissions per year amongst non-vulnerable persons	1.69	2.09	2.12	2.13
Number of hospital admissions per year amongst total population aged 75 and over	2.52	3.54 (+ 76%)	3.53 (- 0%)	3.51 (- 1%)
Number of acute hospital admissions per year amongst vulnerable older persons	.29	.50 (+ 74%)	.49 (- 2%)	.48 (- 4%)
Number of acute hospital admissions per year amongst non-vulnerable persons	.39	.70	.71	.71
Number of acute hospital admissions per year amongst total population aged 75 and over	.68	1.20 (+ 76%)	1.20 (- 0%)	1.19 (- 1%)
Hours of IADL care per year amongst vulnerable older persons	11.79	20.53 (+ 74%)	20.04 (- 2%)	19.64 (- 4%)
Hours of IADL care per year amongst non-vulnerable persons	21.55	38.30	38.70	39.02
Hours of IADL care per year amongst total population aged 75 and over	33.34	58.84 (+ 76%)	58.74 (- 0%)	58.66 (- 0%)

Table 4b. Changes in number of vulnerable persons and their health care utilization (x 1 million) as a consequence of different scenarios: a prognosis based on demography changes in 2030 (Demography scenario 2003) and three scenarios describing consequences of reductions in depressive symptoms.

	Demography scenario 2030	50% - detection scenario 2030 (9% reduction)	100%-detection scenario 2030 (32% reduction)	100%-combination scenario 2030 (60% reduction)
Total Dutch population	16.98	16.98	16.98	16.98
Total Dutch community dwelling population	16.77	16.77	16.77	16.77
Total vulnerable community dwelling population aged 75 and over	.50 (+ 74%)	.48 (- 4%)	.42 (- 16%)	.35 (- 29%)
Total non-vulnerable community dwelling population aged 75 and over	1.16	1.17	1.24	1.31
Total community dwelling population aged 75 and over	1.66 (+76%)	1.66	1.66	1.66
Number of GP visits per year amongst vulnerable older persons	3.99 (+ 74%)	3.81 (- 4%)	3.36 (- 16%)	2.83 (- 29%)
Number of GP visits per year amongst non-vulnerable persons	6.87	7.00	7.33	7.72
Number of GP visits per year amongst total population aged 75 and over	10.86 (+ 76%)	10.81 (- 0%)	10.69 (- 2%)	10.55 (- 3%)
Number of hospital admissions per year amongst vulnerable older persons	1.45 (+ 74%)	1.38 (- 4%)	1.22 (- 16%)	1.03 (- 29%)
Number of hospital admissions per year amongst non-vulnerable persons	2.09	2.13	2.24	2.35
Number of hospital admissions per year amongst total population aged 75 and over	3.54 (+ 76%)	3.51 (- 1%)	3.46 (- 2%)	3.38 (- 5%)

Number of acute hospital admissions per year amongst vulnerable older persons	.50 (+ 74%)	.48 (- 4%)	.42 (- 16%)	.35 (- 29%)
Number of acute hospital admissions per year amongst non-vulnerable persons	.70	.71	.75	.78
Number of acute hospital admissions per year amongst total population aged 75 and over	1.20 (+ 76%)	1.19 (- 1%)	1.17 (- 3%)	1.13 (- 6%)
Hours of IADL care per year amongst vulnerable older persons	20.53 (+ 74%)	19.64 (- 4%)	17.29 (- 16%)	14.60 (- 29%)
Hours of IADL care per year amongst non-vulnerable persons	38.30	39.02	40.89	43.04
Hours of IADL care per year amongst total population aged 75 and over	58.84 (+ 76%)	58.66 (- 0%)	58.18 (- 1%)	57.64 (- 2%)

DISCUSSION

This study aimed to describe the number of vulnerable persons in the Dutch population aged 75 and over in 2007 and 2030 based on demographic changes and to establish reductions in these numbers as a consequence of reducing the burden of depression. We also looked at (changes in) health care utilization in the total population aged 75 and over as a consequence of the changes in number of vulnerable persons. Although some demographic changes occur between 2007 and 2030 the effect on prevalence of vulnerability is small. This can be explained by the fact that the different changes have opposite effects; some changes lead to more vulnerable persons (e.g. more 80 to 85 year olds) and others to less vulnerable persons (e.g. more males, less persons with low eduction). Thus, over time the prevalence of vulnerability remains approximately the same. However, a large increase in absolute numbers of vulnerable persons has occured by 2030; this is a direct consequence of the aging of the population. The five scenarios describing a reduction in persons with depressive symptoms led to a substantial reduction in number of vulnerable persons (2 to 29%). As a consequence the health care utilization within this group reduced with the same percentage, but the impact on the utilization of the total population aged 75 and over was much smaller (0 to 6%).

The results of this study are dependent on the quality of the data used and the assumptions made.

Uncertainty in the data

The results presented in this paper were sensitive to one kind of data uncertainty. Based on the West-Friesland studies we cannot be sure that depression causes vulnerability, because it was a cross-sectional study. However, depression showed strong associations with physical frailty[19] and is seen as an important factor in the cycle of frailty[20]. It was also an important factor associated with recovery from vulnerability (Chapter 2 of this thesis) and yet another study showed that high positive affect lead to lower risk of developing frailty in non-frail older Mexican Americans[37].

Uncertainty in the assumptions

In the analysis a number of assumptions were made, which are subject to discussion. We will discuss every assumption and its consequences below.

1. The current reduction in burden of depression (13%) was based on a single Australian study[27] since no other data were available. Most input variables used in this study were based on findings in international reviews and meta-analysis. Furthermore, the findings in the same study on the possible reduction in burden as a consequence of optimal depression care were similar to those found in fourteen other world regions (30%)[28]. Although the 13% will approximate the Dutch situation, the burden currently averted might be slightly higher or lower in the Netherlands.
2. The percentages of reduced burden of depression as a consequence of better detection and treatment was based on better treatment of depression in the general population and not specifically in older persons. A couple of studies found that about one quarter[38-40] of older persons were recognized as being depressed by their physician. This is slightly lower than the 32% used in this study. No reviews and meta-analysis were identified that described the possibilities of better treatment in older persons compared to adults and in the studies on the total population no distinction was made between older persons and adults. Since a special analysis was conducted for younger adults in one of the studies[27] it seems that in this study they considered the effect on older persons similar as on adults. However, it is possible that, for example due to multi-morbidity, the percentage of reduction in depression burden as a consequence of better treatment is lower in older persons than in adults. Thus, slightly more gain could be obtained in older persons due to even worse current detection in this group. However, difficulties with treatment in this group might lead to less gain in the end.
3. Depressive symptoms was included as a binary outcome in this study (absence vs. presence of clinically relevant depressive symptoms). We assumed that the reduction in burden of depression would lead to a similar reduction in persons with clinically relevant symptoms of depression.

However, not only the persons who become non-depressed as a consequence of treatment might profit from the scenarios proposed. Many persons might transfer from severe depression states to less severe depression states as well and contribute to a reduction in disability and burden as well. This might have lead to an underestimation of the effect of the reduction in depressive symptoms on both the number of vulnerable older persons and health care utilization

4. We assumed that the prevalence of vulnerability and depressive symptoms in the total Dutch population would be the same as in the West-Friesland sample. Unfortunately, we can not compare the finding for vulnerablity to other studies since no other studies using this measure of vulnerability are available. The prevalence of depressive symptoms (31%) was high compared to other studies in older populations. Other studies showed a prevalence of depressive symptoms in older persons of 18 to 35%[9-13]. If the prevalence in the total Dutch population is actually lower than in West-Friesland this would lead to slightly smaller numbers of vulnerable persons and health care utilization. However, the percentages reduction in vulnerable older persons and health care utilization as a consequence of better detection and treatment of depressive symptoms will remain the same, because the decreases are relative. Second, the sample in West-Friesland might suffer from some selection bias. Since the predictions on vulnerability were based on a dataset containing 2506 persons and the demographic variables showed a similar pattern to the nationwide (CBS)[41] data on all persons aged 75 and over we feel these estimates are quite robust. The predictions on health care utilization are based on a dataset containing 217 vulnerable persons (and 105 non-vulnerable persons). The loss-to-follow-up was 32% and it is likely that the most vulnerable persons left the study due to the burden of participation and medical reasons. This could have let to an underestimation of health care utilization in this group.
5. Last, we assumed that education in the total population was equal to that in the larger West-Friesland sample, which might have led to an over or underestimation of education level. However, it is well known that the current population aged 75 and over has had a low education and the two thirds of persons in West-Friesland who had no or only primary education might be quite accurate.

Possibilities for further analysis

It would be useful to repeat this exercise for several other health variables which can be targeted to compare possible reductions in vulnerability and utilization. A next step would be to estimate the costs of an intervention program targeting depressive symptoms in older persons and perform a cost-effectiveness analysis. Such an analysis would help decision-makers to set priorities and to decide whether to invest in depression reduction in older persons.

Concluding, although this study has limitations and the numbers should not be seen rigidly, it shows that the aging of the Dutch population will lead to almost a

doubling of the number of vulnerable persons and consequently also a doubling of their health care utilization. This finding is alarming, since the Dutch health care system is already strained and in its current form will not be able to tackle the increase in (vulnerable) older persons and their health care utilization. This study showed that targeting depressive symptoms may lead to a substantial reduction in vulnerable older persons and their utilization, but a more modest reduction in health care utilization in the total population aged 75 and over. Still, this small contribution is a starting point to tackle the large increase of older persons that awaits us. Future studies should look into the contribution of the reduction of other diseases, impairments and disabilities on vulnerability and health care utilization.

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Appendix A. Description of West-Friesland-datasets

This study combines results from a cohort study in a northwestern region of the Netherlands and data from Statistics Netherlands (CBS, statline.cbs.nl). The cohort study was embedded in a larger randomized control trial[41] and provided us with two datasets. One concerning information on a large (baseline) population of persons aged 75 and over (the 75+-dataset) and one concerning a subgroup of vulnerable persons aged 75 and over (the vulnerable-dataset).

Sampling procedure

The 75+-dataset included community-dwelling older persons who at the start were 75 years or older and were vulnerable. 2949 older persons responded to the appeal to participate in the randomized controlled trial. 2780 persons completed all measures necessary for this study and were included in our description and projections of vulnerability.

The vulnerable-dataset included 465 vulnerable persons at the start. Of those 24 died during our study, 12 were admitted to a residential home, 6 moved out of the region and 105 were no longer vulnerable. Of the 318 eligible older persons 34 were no longer willing to participate and 17 quit for medical reasons. Another 50 could not be reached, had incomplete data or were lost due to other or unknown reasons. In total data of 217 older persons (68% of eligible subjects) were used in analysis on health care utilization.

Appendix B. Calculation scenarios

The current percentage of persons receiving efficacious treatment (32%) was directly derived from the study by Andrews et al. [27]

We calculated the percentage depression reduction in persons who received treatment for both current and optimal care. If 13% of depression burden is reduced in the total population as a consequence of 32% depressed persons receive treatment, this is due to 41% depression in persons we are treated (13/32*100). We did the same for optimal treatment (21/32*100=65%).

Proportional reduction in depression as compared to current situation is calculated by subtracting the % Depression reduction in the current situation from the % Depression reduction in scenario and divide this by the % Depressive symptoms that is not reduced in the current situation (87%).

Scenario	% Depression reduction in total population	% Depression reduction in persons who received treatment	% of depressed persons in the total population that is being treated	Proportional reduction in depression as compared to current situation
Current situation	13%	41%	32%	-
50%-treatment scenario	17%	52%	32%	+ 5%
100%-treatment scenario	21%	65%	32%	+ 9%
50%-detection scenario	21%	41%	50%	+ 9%
100%-detection scenario	41%	41%	100%	+ 32%
100%-combination scenario	65%	65%	100%	+ 60%

Chapter 7

Developing quality indicators for general practice care for vulnerable older persons; transfer from US to the Netherlands

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Published in: Quality and Safety of Health Care, 2008, 17, 291-295

ABSTRACT

Background Measurement of the quality of health care is a first step for quality improvement. To measure quality of health care a set of quality indicators is needed. We describe the adaptation of a set of systematically developed US quality indicators for health care for vulnerable older persons in the Netherlands. We also compare the US and the Dutch set to see if quality indicators can be transferred between countries as has been done in two studies in the UK, with mixed results.

Method 108 US quality indicators on GP care for vulnerable older persons, covering eight conditions, were assessed by a panel of 9 clinical experts in the Netherlands. A modified version of the RAND/UCLA appropriateness method was used. The panel members received US literature reviews, extended with more recent and Dutch literature, summarizing the evidence for each quality indicator.

Results 72 indicators (67% of US set) were (nearly) identical in the Dutch and US sets. For some conditions this percentage was much lower. For Undernutrition only half of the US indicators were included in the Dutch set. For Depression many indicators were discarded or changed in a significant way, resulting in that only five of the original seventeen indicators (29%) are the same in the Dutch and the US set.

Conclusions Quality indicators can be transferred between countries, but with caution, because in two of the three studies on transferring indicators between the US and Europe 33-44% of the indicators was discarded. For some conditions in the current study this percentage is much higher. For Undernutrition there is hardly evidence and differences between the indicator-sets can be attributed to differences in expert opinion between the countries. For Depression it seems that different evidence is considered important in the US and in the Netherlands, of which the Dutch body of knowledge is not known in the US.

INTRODUCTION

Practice patterns and the quality of care vary considerably. Moreover, clinicians become more interested in having objective information about their practices and patients want to know more about the quality of care available to them[1]. Researchers at RAND and UCLA developed a method to asses the quality of care (Box 1.)[2]. A comparison of four systematic evidence based methods to develop and apply quality indicators in primary care showed that although the RAND method rarely includes patients and does not consider cost implications it is the only method that has evidence of predictive validity of the indicators[3]. It is also said to be the only systematic method which combines both expert opinion and evidence[3,4]. This method has been used to develop quality indicators for health care for many conditions in the US and UK[5,6].

Quality indicators have been used to show that effective health care is delivered in only 50% of the cases in the US general population[7]. The same percentage was found for a group of vulnerable older persons[8]. For this particular group the development of quality indicators seems even more important, because 60% of the people over 65 years of age in the Netherlands suffer from two or more diseases[9]. This comorbidity leads to a higher risk of mortality, a poorer functional status/ quality of life and increased use of health services[10]. Moreover, it has been shown that better performance on process quality measures is strongly associated with better survival among community-based vulnerable older persons[11].

The Assessing Care of Vulnerable Elders (ACOVE) project, initiated by the RAND organization, developed a comprehensive set of quality-assessment tools for vulnerable older persons[12]. Vulnerable older persons were defined as persons aged 65 and older who are at increased risk of functional decline and mortality over two years[13].

Box 1. Steps in the RAND method of developing quality indicators

(1) Comprehensive literature reviews are commissioned for each of the conditions by experts in the field and a preliminary set of indicators are recommended by the author on the basis of the literature review and after consulting with clinical experts.
(2) Expert clinicians are recruited from professional organisations and invited to join panels for a two stage process to rate the indicators.
(3) Draft indicators and literature reviews are sent by post to the panel members who rate them in terms of their validity as measures of quality. The panel members give each indicator two ratings on a continuous scale of 1-9.
(4) First round scores are fed back to panellists for a second round of scoring in a two-day face to face panel meeting. Each panellist is told his or her own score and the mean score and distribution across the whole panel. All indicators are discussed, modified where necessary, and re-scored.
(5) Second round scores are used to select only those indicators rated highly for validity by the panel members.

This set was used as basis for the assessment of health care for vulnerable older persons[8]. It also served as starting point for the development of a UK set of quality indicators for vulnerable older persons; 86% of the US indicators were valid for use in England[6]. The conclusion was that there is potential for transfer of quality indicators between countries. The current study wants to extend this finding by doing a comparable study in yet another country, the Netherlands. It is limited to care provided by the general practitioner, who in the Netherlands is the "gateway" to all care providers.

The aim of this study is to develop a set of quality indicators for vulnerable older persons in the Netherlands based on the ACOVE quality indicators. We also define vulnerable older persons as aged 65 and over and at increased risk and functional decline or death over 2 years. The aim is not to develop an all-inclusive, comprehensive set of indicators, but merely to identify the most important quality indicators per condition. A second objective is to draw conclusions about transferability of indicators between countries by comparing the indicators in the final Dutch set to the indicators in the original US set.

METHODS

Selection of conditions

During the initial development of the ACOVE-indicators a Clinical Committee selected the 22 conditions most important to vulnerable older persons based on prevalence, impact on health and quality of life, effectiveness of available interventions and feasibility of collecting data[12]. In the updated ACOVE-version four conditions were added[14]. The current research could only organize one panel meeting (due to limited means) during which eight conditions could be discussed. We focus on eight of those 26 conditions that are associated with the development of frailty, an important concept in health care because it leads to adverse health outcomes, institutionalization, falls, disability, hospitalization, morbidity and mortality[15,16]. Dementia, Depression, Diabetes (as a major chronic disease in this age group), End of Life Care, Falls/Mobility, Medication Use and Undernutrition are all components in the cycle of frailty[16]. Continuity and Coordination of Care was added, because it was considered the starting point of providing care.

Literature reviews

The ACOVE-3 literature reviews were finished in fall 2005. The Dutch panel meeting was in November 2006; by then the reviews were over one year old. It was decided to update the reviews, using Dutch GP's, specialists and/or researchers with a specific interest in each condition. They were asked to do a literature search to add international papers that were published in the intermediate year and papers published in Dutch magazines. The Dutch reviewers were asked to advice on the validity of the US indicators in the Netherlands. They were also invited to comment on removal and addition of indicators. These comments were added to the reviews so the panelists could consider them before rating the validity of the indicators.

Selection of expert panel
The aim was to compose a panel of eight GP's (one of each university), two nursing home practitioners and two clinical geriatricians. GP's had to practice and be affiliated to a Department of General Practice at one of the universities in the Netherlands. The last criterion made them more likely to be up-to-date on scientific publications and guidelines. All panelists needed to have generic knowledge on care for older persons, which distinguished them from the reviewers, who had to be specialized in one topic. In the end five GP's, two nursing home practitioners (medical doctors) and two clinical geriatricians participated in the panel meeting.

Rating the indicators
The same method as in the RAND/UCLA process was used to develop a set of Dutch indicators. The panel members were sent the original ACOVE-3 set of indicators, the supporting literature and the input of the Dutch reviewers by mail. Panelists were asked to rate each indicator on a continuous 9-point scale in terms of its validity in the Dutch health care system with 1 being "not at all valid" and 9 "extremely valid". Panelists were instructed to consider an indicator valid if:

- there was adequate scientific evidence and/ or professional consensus to support a link between the process described in the indicator and health benefits for patients;
- the health benefits of the process described in the indicator are this large that not delivering the mentioned care would be considered bad care;
- most factors determining adherence to the indicator are under the control of the GP and not only of the patient himself.

Because our aim was to identify the most important quality indicators per condition we instructed panelists also to consider how important each indicator was compared to the other ones. The first round scores for validity were fed back to the panel during a two-day face-to-face meeting. All the indicators were discussed, first round scores for validity were presented, the wording of the indicators was modified where necessary, and each indicator was then individually re-rated in a second rating round. New indicators could be proposed during the meeting; they were also discussed and rated.

Comparison of Dutch and US indicators
The second round ratings were used to select the set of Dutch indicators. For some indicators the chairman (HR) proposed to discard the indicator based on the panel discussion; when the panel agreed on this proposal the indicator was discarded right away. All other indicators were scored the same way as in the first round and analyzed to see if the panelists scores corresponded with each other. We used the same cut off points as the US set (validity score ≥7) without disagreement within the panel (disagreement meaning three or more of the nine ratings for an indicator being in both the top and bottom third of scores). For each indicator in the US set we identified whether there was an exact or near equivalent indicator in the Dutch set. We also listed the main outcomes of the discussions prior to the discarding of indicators to try and identify reasons and underlying themes for discarding.

RESULTS

The original US set on GP care consisted of 108 indicators for the eight conditions included in this research. All US indicators, the final Dutch set and reasons for discarding or changing can be viewed in Appendix A at the end of this thesis. To the original set changes were made by discarding, adding and changing indicators (Table 1.).

Table 1. Results per condition

Condition	Number of indicators in starting set	Number of discarded indicators	Number of added indicators	Number of indicators in final Dutch set	Number of significantly changed indicators	Number of nearly identical indicators
Continuity & coordination of care	13	1	1	13	-	12 (92%)
Dementia	17	5	1	13	-	12 (75%)
Depression	17	8	1	10	4	5 (29%)
Diabetes	10	3	-	7	-	7 (70%)
End of Life Care	8	2	-	6	-	6 (75%)
Mobility/Falls	12	3	-	9	-	9 (75%)
Medication Use	23	6	-	17	-	17 (74%)
Undernutrition	8	4	2	6	-	4 (50%)
Total	**108**	**32**	**5**	**81**	**4**	**72 (67%)**

Discarded indicators

32 indicators (30% of the original set) were discarded because they were not considered to be valid in the Dutch situation according to the panel (Table 2. and 3.). For Undernutrition half of US indicators were discarded, because there was too little evidence to support them, the indicator was considered not important enough and there was no agreement on the indicators validity amongst the panelists (meaning an “indeterminate”-score). For Depression also half of the indicators were discarded; mostly because the panel did not agree on its validity in the Dutch situation. All reasons for discarding point to a different opinion of experts in the US and the Netherlands. For example, for the indicators with too little evidence in the form of published RCT’s, the US panel still agreed to include the indicator in the set based on their opinion about the importance of the indicator, while in the Netherlands they did not agree with this decision.

Table 2. Reasons why indicators were discarded per condition (N=32).

Condition	Medication is not available in the Netherlands	No evidence for effectiveness	Dutch panelists did not agree with one another on validity	Is considered not important enough by Dutch panel to be a QI in this set	Other
Continuity and coordination of care	-	-	-	1	-
Dementia	-	1	-	1	3
Depression	-	2	6	-	-
Diabetes	-	3	-	-	-
End of Life Care	-	-	1	1	-
Mobility/Falls	-	-	3	-	-
Medication Use	2	1	-	3	-
Undernutrition	-	1	2	1	-
Total	2 (6%)	8 (25%)	12 (38%)	7 (22%)	3 (9%)

Table 3. Examples of discarded, changed and new indicators.

Discarded indicators
Dementia **IF** a vulnerable elder is newly diagnosed with dementia **AND** has risk factors for HIV, **THEN** HIV and syphilis testing should be offered. *Reason:* Not considered important enough to be in a set of QI's, because the number of vulnerable elders with (risk factors for) HIV in the Netherlands is so small that this indicator is considered not relevant.
Depression **ALL** vulnerable elders should have documentation of a screen for depression during the initial evaluation and annually thereafter. *Reason:* There is no evidence for an effect of screening.
End of Life Care **IF** a vulnerable elder is diagnosed with lung cancer or cancer metastatic to lung, NYHA Class III-IV congestive heart failure, or oxygen dependent pulmonary disease, **THEN** a self-reported assessment of dyspnea should be documented in the outpatient chart. *Reason:* The panelists did not agree with one another on the validity of this indicator.
Medication Use **IF** a vulnerable elder receives ketoralac **THEN** it should not be prescribed for >5 days. *Reason:* Medication not available in the Netherlands.
Undernutrition **IF** a vulnerable elder is prescribed oral nutritional supplements, **THEN** the supplements should be used between meals rather than with meals. *Reason:* Not considered important enough to be in a set of QI's, because to the Dutch panel this is a minor detail.

Changed indicators	
US indicator	**Dutch indicator**
Depression	
IF a vulnerable elder has depression associated with bereavement, **THEN** he or she should be treated with an antidepressant medication with or without interpersonal psychotherapy.	**IF** a vulnerable elder has depression associated with bereavement, **THEN** he or she should be treated with interpersonal psychotherapy with or without antidepressant medication. *Difference:* Emphasis on therapy instead of medication.
New indicators	
Continuity and coordination of care **IF** a GP first suspects an elder to be vulnerable or obtains crucial information on aggravation of (determinants of) vulnerability, **THEN** the physician should document an estimation of health needs and demands, to be followed by an intervention plan to be coordinated by a clearly identified professional.	
Dementia **IF** an elder is vulnerable and the care-giver burden is high, **THEN** the GP should have a pro-active attitude towards cognitive dysfunction or dementia.	
Depression **IF** a vulnerable elder has comorbid dementia or a chronic somatic disease, **THEN** an existing depression should still be treated.	
Undernutrition **IF** a vulnerable elder has an advanced stage of COPD, **THEN** the GP should monitor the elder's body weight and recommend energy-enriched food. **IF** a vulnerable elder is at risk of, or suffering from, decubitus, **THEN** the physician should consult a dietician.	

Added indicators

In total five new indicators were added by the panel (Table 3.). For Undernutrition two indicators were added, both concerning risk factors for undernutrition. The indicator on COPD concerning undernutrition is based on the Dutch GP guideline on COPD. For Depression an indicator was added concerning the treatment of depression if the older person also has a somatic disease. For Dementia an indicator on a pro-active attitude towards cognitive dysfunction and dementia of vulnerable older persons was added. Last, for Continuity and Coordination of Care an indicator on the development of an intervention plan was added.

Changed indicators

Thus, 76 indicators (70%) of the original US set were included in the Dutch set. To half of the indicators for Depression major changes were made by the Dutch reviewers based on their (expert) opinion even before the panel scored the indicators. In three indicators the follow-up period was shortened, while in another the period of continuing successful treatment was extended. Electroconvulsive therapy was removed as treatment option. Watchful waiting was added to the first

treatment options after diagnosis of depression. There was a tendency to include the patient in making treatment decisions. In four indicators the focus on medication as the first/ main treatment was changed: psychotherapy was considered equally important. Some of the changed indicators were still discarded by the panel, but four of the indicators included in the final set were changed in a major way by the Dutch reviewers. These indicators were not considered identical to the US indicators, resulting in that only five of the original seventeen indicators (29%) for Depression are the same in the Dutch and the US set.

DISCUSSION

The ACOVE-3 indicators were a good starting point to develop a set of quality indicators on appropriate GP care for vulnerable older persons in the Netherlands, but still only a starting point. The current research showed that the adaptation of quality indicators should always be done in the described systematical way, because the transferability between countries is limited and differs per condition. Only 72 of 108 indicators (67%) were (nearly) identical in both sets. Undernutrition and Depression had much lower percentages of agreement on validity in the two countries. Half of the US indicators on Undernutrition were discarded. For Depression only 29% of the indicators were identical in both sets due to major changes and discarding of indicators.

In the UK 86% of the quality indicators for care for vulnerable older persons were (nearly) identical to the US set[6]. In the current study this percentage is lower and for some conditions much lower. However, a study on quality indicators for care for the general population found 56% agreement between the UK and US[5]. There are two major advantages for using an already existing set, even when major changes are made to the indicators. First of all the development of quality indicators is resource intensive; it saves a lot of work to adapt instead of produce new literature reviews. Moreover, using the US set as starting point a comparison can be made between the indicator set of both countries. But, the current study shows that indicators can not simply be transferred between countries. The differences between the Dutch and US sets are partly due to methodological issues. For example our aim was to develop a set with the most important indicators per condition instead of a comprehensive, all-inclusive set like in ACOVE. The role of the Dutch chair was also a bit different, because he proposed discarding of indicators before the panel rated them for the second time. Most other differences were due to different emphasis on or different interpretation of the existing literature for some conditions and lack of literature for other conditions. For Dementia, Depression and Diabetes Dutch guidelines for general practitioners existed. Those guidelines were present during the panel meeting and were consulted and followed when appropriate. The reason to deviate from the guidelines was that the panelists thought care for this specific group is different from the general population. For Dementia the guideline, which off course concerns an older target group, largely overlapped with the US indicators. For Diabetes two indicators were discarded based on recommendations in the Dutch guideline.

Furthermore, for Depression the RAND literature review was not considered to be a good starting point for the panel to assess the quality indicators on validity. The Dutch reviewers concluded that the review was thoroughly done (although only based on Northern American literature), but differed from the current opinion dominating in the Netherlands. In their opinion the RAND review was too focused on medication as first/main treatment option. This emphasis is not justified by the existing evidence: a review showed that there is no difference in treatment effect of antidepressant drug treatment and psychotherapy[18]. However, this review was published in a Dutch journal, meaning the RAND-reviewers could have no knowledge of it. Still, another, international published, review showed that intervention studies, cognitive-behavioral therapy and interpersonal psychotherapy combined with antidepressant medication have the largest base of evidence in support of their efficacy for late life depression[19]. Yet another review noted that comparisons of psychotherapy and pharmacotherapy must be interpreted with caution, in part because medication studies are more likely to use a credible active placebo, which may lead to smaller adjusted effect sizes in medication studies[20]. This review also concluded that given that psychotherapy and pharmacotherapy did not show strong differences in effect sizes, treatment choice should be based on other criteria, such as contraindications, treatment access, or patient preferences. For vulnerable older persons this means that their greater sensitivity to side effects of antidepressant medication and the fact that they often use different sorts of medication, which can lead to interaction between medications should be taken into account[21]. The Dutch reviewers and panel also considered patient preferences to be of importance in treatment decisions. Concluding, there seems to be a cultural difference in the treatment of Depression between the US and the Netherlands. In the US antidepressants are considered to be the first/ main treatment option. In the Netherlands this choice is not as clear cut. As one of the Dutch reviewers put it “we consider it important to start treatment, any treatment (if applicable based on patient preferences), monitor this treatment and make changes if it has no effect”.

For the conditions other than Dementia, Depression and Diabetes no Dutch guidelines existed. The agreement between the US and Dutch panel was on most conditions still rather good. But for Undernutrition a lot of differences in expert opinion led to little indicators being transferred from the US to the Netherlands. There was no guideline for Undernutrition in the Netherlands nor in the US; in the RAND-review there was sometimes little evidence in the form of RCT’s to support some indicators, which were then included based on expert opinion. The Dutch panel discarded two indicators, because of lack of evidence. This indicates a difference in expert opinion between the two countries. In contrast, the Dutch panel also discarded an indicator on screening the weight of all older persons, which was backed by a lot of evidence (and by the Dutch reviewers), because most Dutch GP’s did not think it is feasible to weight every person on every visit and document this. Last, the indicator on taking multivitamins was considered superfluous,

because another indicator advised vitamin D supplementation, which was considered the most important supplementation. Although these two indicators were not discarded because of lack of evidence, the discarding can be attributed to a difference in expert opinion between the two countries.

Five new indicators were added to the Dutch set. Most had something to do with a more pro-active attitude of the GP towards vulnerable older people. This was a recurring theme during the panel meeting, but the panel found it hard to express this necessity in indicators. The adding of these indicators was not supported by published evidence, but expressed to need of all panelists to draw attention to the special treatment these older persons need from their GP. This brings us to the main limitation of our study. When adding new indicators the panelists were asked not to consider the possibility of implementation of the indicator. Our aim was to develop a quality indicator set with the most important indicators included. Although the Dutch panel was clear on adding indicators on “pro-active attitudes of the GP”, these indicators should be made measurable before implementation. We want to emphasize that this research is only the start of developing a set of quality indicators, from now on discussion and implementation should further sharpen the set.

Concluding, the current study shows that the transferability between countries of quality indicators is possible, but with caution. There have now been three attempts at transferring US-developed indicators into European countries, and the number of indicators discarded or greatly modified has been substantial (33-44%)[5,6]. This still means that more than half of US-developed indicators have been judged valid, supporting the concept that the majority of quality indicators will be acceptable in other health care settings. Because of the savings in resources, practitioners and policy makers interested in developing quality indicators should view our results as encouraging starting with rigorously developed quality indicators in countries other than their own. Still, the results also suggest that it is likely that in most attempts at transferability, a thorough process of review will result in clinically important changes in quality indicators. Furthermore, researchers should realize that culture differences in medical practice exist.

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Chapter 8

Self reported adherence to Depression and Type 2 Diabetes Mellitus quality indicators for vulnerable older persons and reasons for non-adherence amongst Dutch general practitioners

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ABSTRACT

Objectives Our aim is to establish to what extent general practitioners adhere to care for vulnerable older persons formulated in depression and type 2 diabetes mellitus quality (T2DM) indicators and to explore what barriers lead to non-adherence.

Methods 13 general practitioners in a northern region of the Netherlands were interviewed on three important quality indicators for both depression and T2DM. They were asked in what percentage of cases they provided the care as mentioned in the indicator and what reasons were that they did not provide such care.

Results Self-reported adherence to three depression indicators ranged on average from 39 to 98%. For T2DM indicators the averages per indicator were 64% or higher. Main reasons for not providing care were that the patient had severe health problems or withdrew from care for other reasons, that the GP's under-registrated, that patients had problems understanding the GP, that a cut off point was set too low and that there was too little time.

Conclusions Self-reported adherence to quality indicators and reasons for non-adherence differed between conditions and specific indicators. Adherence for T2DM indicators was generally higher and the barriers identified were carefully balanced decisions on the general practitioners' part, whereas overall adherence to depression indicators was lower and the barriers identified might point to possible improvements in general practice. When developing guidelines or quality indicators for vulnerable older persons the special situation for some subgroups (e.g. persons with short life expectancy) should be carefully considered.

INTRODUCTION

With the increase in life expectancy and aging in the baby boom generation, the Western world is becoming a region in which health care needs and costs are mainly driven by older persons, especially vulnerable older persons. It is a challenge to provide good health care to this population with multivariate diseases, limitations and disability. To achieve criteria of optimal health care many guidelines and quality indicators have been developed, but despite wide promulgation, guidelines and quality indicators have had a limited effect on changing physician behavior[1]. The study reported here focused on the quality of type 2 diabetes mellitus (T2DM) and depression care for vulnerable older persons. Several guidelines on T2DM, its treatment and prevention of complications have been published[2]. Adherence to these guidelines varied substantially between care providers. For example, adherence to yearly examinations of HbA_{1c} ranged from 16 to 100% and rates for feet examination ranged from 25 to 67%[3-9]. For vulnerable older persons adherence of 42 to 80% to yearly measure HbA_{1c} was found[10,11]. The studies on vulnerable older persons were based on the first version of the Assessing Care for Vulnerable Elders (ACOVE) quality indicators[12]. In the same study indicators for Depression care for vulnerable older persons were tested. Adherence to depression indicators also varied widely, from 0 to 90%[11]. A wide range of factors has been identified as possible barriers to the implementation of guidelines and quality indicators. A review showed that many investigators have focused on characteristics of individual physicians to explain failure of guideline implementation[13]. Cabana and colleagues developed a framework in which these barriers are classified into three main categories: barriers related to the physicians knowledge (lack of awareness of guideline and lack of familiarity with recommendations given in guideline), barriers that affect physicians' attitudes (lack of agreement with guideline, lack of self-efficacy i.e. the belief that one can actually perform the action mentioned in the guideline, lack of outcome expectancy and inertia of previous practice) and external barriers, like patient preferences, environmental barriers and lack of time[1].

The current study focuses on quality of depression and T2DM care for vulnerable older persons provided by general practitioners in the Netherlands and reasons why practitioners did not adhere to quality indicators. We define vulnerable older persons as persons aged 65 and older who are at increased risk of functional decline or death over 2 years[14]. Quality indicators were developed by adapting the ACOVE-3 quality indicators to the Dutch situation[15,16]. We considered several methods to establish adherence and reasons for non-adherence. So far, chart abstraction has been used most[11], but this seems to lead to an imperfect reflection of care provided[17-19]. For example, in 5 out of 17 Depression indicators for vulnerable older persons no data were available on adherence, because the event, for which a treatment or other action was formulated in a quality indicator, was not found in the chart[11]. Although poor registration is related to poor process of care[20] we want to avoid a discussion on the quality of registration and instead focus on a discussion on quality of care. To this end we designed an explorative interview

which we conducted to a group of general practitioners. Our aim was to establish if general practitioners adhere to care formulated in depression and T2DM quality indicators and to explore what barriers exist when they report non-adherence.

METHODS

Design

We designed a practice based, explorative interview study to enable us to examine adherence to quality indicators and reasons for non-adherence in general practice. Interviews in clinicians' consultation rooms allowed a detailed discussion of their usual practice in relation to the quality indicators.

Selection of indicators

During the panel meeting 108 quality indicators were developed for in total eight conditions[16]. For the current study we focused on six indicators and two conditions. As mentioned above we selected the conditions of depression and T2DM. Two senior staff members of the department of General Practice (GN, MW)) were asked to identify the three most important indicators per condition (Box 1.).

Box 1. Quality Indicators chosen for interviews

Depression

1. **IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the general practitioner should immediately provide information on the target symptoms for depression.
2. **IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the general practitioners record should document on the day of diagnosis:
    - presence or absence of suicidal ideation;
    - presence or absence of psychosis;
    - presence or absence of past history of mania or hypomania;
    - presence or absence of anxiety.
3. **IF** a vulnerable elder has thoughts of suicide, **THEN** the medical record should document, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.

Diabetes

1. **IF** a vulnerable elder has diabetes, **THEN** glycated hemoglobin should be measured at least annually.
2. **IF** a vulnerable elder has diabetes, **THEN** a foot exam should be performed annually.
3. **IF** a diabetic vulnerable elder has a persistent (on 2 consecutive visits) elevation of systolic BP >140 mm Hg, **THEN** the general practitioner should initiate an intervention (pharmacologic, lifestyle, compliance, etc.) or there should be documentation of a reversible cause/other justification for the elevation or a reason why an intervention was not done.

Participating General Practitioners
We made a selection of 17 general practitioners in the northwest of the Netherlands. In the region where the interviews took place a special Diabetes Center has been set up, which provides protocolized care based on the Dutch T2DM guideline coordinated by nurses at the center or the assistants of the general practitioner. Four GPs were not willing to participate, because they had no time for the interview. Of the 13 interviewed GPs five were female and eight male. Six worked in the principal town in the region, seven in the surrounding villages. The average age was 48 (range: 34-61 years).

Interviews
For each indicator we formulated a statement. For example the first indicator for Depression (Box 1) was reformulated as "With a vulnerable older person who just received a diagnosis of a new depression episode I will directly talk about the symptoms of depression". On the answering sheet a line was drawn below each statement. The line had a range from 0 to 100% with 50% clearly marked. The general practitioners put a cross on the number of cases in which they provided the care as formulated in the statement. The general practitioners filled out this form before or during the interview. At the beginning of each interview attention was drawn to the definition of the target group of vulnerable older persons. The GPs were shown a table that gave a description of the target population (Appendix 1.) and the interviewer stated that they should keep in mind that the interview concerned a subgroup of older persons. During the interview the target group was sometimes mentioned again, especially when the interviewer felt that the GP was talking about the general population instead of the subgroup or if she was unsure what group the GP was talking about. The GPs differed in their way of answering; some started to comment directly on the indicator and reasons why they not always provided the care mentioned, others first named the percentage. Either way the GPs were always asked to provide a percentage of number of cases in which they provided the care mentioned and reasons why they did not provide care. In the case that they said they provided the care in 100% of cases the interviewer suggested reasons why some persons were missed (mostly taken from other interviews) to see if they had not overlooked anything. When the discussion on an indicator was finished the interviewer repeated the percentage given and checked if this still held after all that was said. She also summarized the main reasons that were given for not providing care to check if she had understood correctly. At the end of the interview the GPs were asked if they had any comments or wanted to return to any of the indicators. The interviewer made notes during the interview and typed in the answers directly after each interview.

Data analysis
The percentages were entered in a data file in SPSS 15.0. Descriptive analysis were done to describe the mean, standard deviation, range and quartiles per indicator. Two researchers (HPvH and EvdP) individually grouped the reasons for

non-adherence in categories of barriers why physicians did not adhere to guidelines[1]. They then compared and discussed deviating scores to reach consensus on all barriers mentioned.
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RESULTS

Table 1. Mean, minimum and maximum and quartiles of percentage of cases in which the GP provides the care mentioned in the quality indicator.

	M (SD)	Min	Max	1st quartile	2nd quartile	3rd quartile
Depression						
Provide information on target symptoms	74.7 (20.8)	30	100	50	80	90
Record presence and absence suicide, psychosis, (hypo)mania and anxiety	38.8 (25.7)	0	80	25	50	70
Document suicide plans or refer to psychiatric hospital	97.7 (7.5)	75	100	100	100	100
Type 2 Diabetes Mellitus						
Annually measure HbA_{1c}	93.8 (9.1)	75	100	90	99	100
Annually perform foot exam	87.7 (18.3)	50	100	85	99	99
Start intervention or document why not when diabetic has persistent elevated of systolic BP	63.5 (35.4)	0	100	50	80	95

Depression

1. *If a vulnerable elder receives a diagnosis of a new depression episode, then the general practitioner should immediately provide information on the target symptoms for depression.*

On average GPs said that they discussed symptoms of depression in 74% of the cases (Table 1.). The minimum percentage mentioned was 30% and the maximum 100%. The main reasons for not talking about depressive symptoms was that GPs felt that some subgroups should not be burdened with this information, mostly because of cognitive impairment or dementia (Table 2a.). Four general practitioners did no agree with the content of the quality indicator. The external

barriers of patient preferences and lack of time were also mentioned. Once a GP mentioned a bad relationship with the older person as a barrier. Examples of answers (for all indicators) are given in Table 3..

2. *If a vulnerable elder receives a diagnosis of a new depression episode, then the general practitioners record should document on the day of diagnosis:*

- *presence or absence of suicidal ideation;*
- *presence or absence of psychosis;*
- *presence or absence of past history of mania or hypomania;*
- *presence or absence of anxiety.*

On average GPs said that they recorded suicide, psychosis, (hypo)mania and anxiety in 39% of the cases (Table 1.). The minimum percentage mentioned was 0% and the maximum 80%. The main reason for non-adherence was lack of agreement with the indicator (Table 2a.). More specifically most GPs had a problem documenting both presence and absence off all aspects. They felt this made no sense and that there was no time to register everything. Twice it was mentioned that the prevalence/ incidence of the suicide, psychosis and mania is so low it is not worth asking everybody. Twice inertia of previous practice was the reason. One GP said it was sometimes a problem that Dutch persons stay with their GP for a long period: “It can happen that an intern points out that a certain person has a major depression and might have had it for a long time”.

3. *If a vulnerable elder has thoughts of suicide, then the medical record should document, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.*

Two GPs said they had never encountered an older person who seriously considered suicide. On average the other GPs said that they asked if the person had immediate plans for suicide or referred in 98% of the cases (Table 1.). Ten GPs reported this in 100% of cases. One GP reported 75%. This GP did not agree with the indicator, because he felt that people have the right of self determination, especially at this age: “If they are very old and depressed I think they should be allowed to end their lives. Off course it is very important that the depression has a chronic character and that the person is able to make such a decision. But I will not interfere with a so-called balance-suicide; when they exactly know what they are doing”.

Table 2a. Barriers that were mentioned to explain why depression-care recorded in the quality indicators was not provided in 100% of cases per indicator and in total.

	Provide information on symptoms	Suicide, psychosis, mania, anxiety	Suicide plans	Total Depression
Barriers related to physicians' knowledge				
Lack of awareness of guideline	-	-	-	-
Lack of familiarity with recommendations given in guideline	-	-	-	-
Barriers related to physicians' attitudes				
Lack of agreement with guideline	15	12	1	28
1 - with content	4	2	1	7
2 - with obligation to register	-	7	-	7
3 - specific subgroups should not be burdened with intervention	11	3	-	14
a - Short life expectancy	-	-	-	-
b - Cognitive impairment/ dementia	8	-	-	8
c - Lighter cases (of depression)	-	3	-	3
d - Polypharmacy	-	-	-	-
e - Low intelligence	2	-	-	2
f - High age	-	-	-	-
g - Persons who deny disease	1	-	-	1
Lack of self-efficacy	-	-	-	-
Lack of outcome expectancy	-	2	-	4
Inertia of previous practice	-	2	-	4
External barriers				
Patient preferences	1	-	-	1
Lack of time	3	3	-	6
Other	1	1	2	4
Patient-physician relationship	1	-	-	1
Never occurred		1	2	3
Unclear	-	-	-	-

Type 2 Diabetes

1. *If a vulnerable elder has diabetes, then glycosylated hemoglobin should be measured at least annually.*

On average the GPs' assistants measured glycosylated hemoglobin (HbA_{1c}) at least annually in 94% of the persons with diabetes (Table 1.). The minimum percentage mentioned was 75% and the maximum 100%. 8 GPs reported a score of 99% or higher (not in Table). Non adherence was mostly due to the patient preferring not to be treated and GPs felt that some persons (with short life expectancy) should not be burdened with the measurement (Table 2b.).

2. *If a vulnerable elder has diabetes, then a foot exam should be performed annually.*

On average the GPs assistants performed a foot examination annually in 88% of the cases (Table 1.). The minimum percentage mentioned was 50% and the maximum 100%. 7 GPs reported 99 or 100% (not in Table). The reasons for not providing care were most of the time exactly the same as for the first Diabetes indicator: again some persons preferred not to be checked and GPs felt that some persons (with short life expectancy) should not be burdened with the examination (Table 2b.). Additionally, two GPs in a rural area (far away from the Diabetes Center, so some persons went to their GP instead) said they only checked feet when the person reported problems with their feet, which implies lack of agreement with the indicator.

3. *If a diabetic vulnerable elder has a persistent (on 2 consecutive visits) elevation of systolic BP >140 mm Hg, then the general practitioner should initiate an intervention (pharmacologic, lifestyle, compliance, etc.) or there should be documentation of a reversible cause/other justification for the elevation or a reason why an intervention was not done.*

On average GPs said they started an intervention or registered why not in 64% of the diabetics with a systolic blood pressure over 140 mm Hg (Table 1.). Scores differed largely between GPs, with a range from 0 to 100%. 10 GPs did not agree with the indicator, mostly because they thought the cut of point was set to low. Some said 145 mm Hg was better and others would only react to a pressure over 160 mm Hg. Four GPs had problems with the obligation to register a reversible cause or other justification for not starting an intervention. Short life expectancy, comorbidity and polypharmacy were mentioned as reasons not to start an intervention.

Table 2b. Barriers that were mentioned to explain why diabetes-care recorded in the quality indicators was not provided in 100% of cases per indicator and in total.

	Annually measure HbA_{1c}	Annually perform foot exam	Elevated of systolic BP	Total T2DM
Barriers related to physicians' knowledge				
Lack of awareness of guideline	-	-	-	-
Lack of familiarity with recommendations given in guideline	-	-	-	-
Barriers related to physicians' attitudes				
Lack of agreement with guideline	5	8	17	30
1 - with content	-	2	6	8
2 - with obligation to register	-	-	4	4
3 - specific subgroups should not be burdened with intervention	5	6	7	18
a - Short life expectancy	5	6	2	13
b - Cognitive impairment/ dementia	-	-	2	2
c - Lighter cases (of depression)	-	-	-	-
d - Polypharmacy	-	-	2	2
e - Low intelligence	-	-	-	-
f - High age	-	-	1	1
g - Persons who deny disease	-	-	-	-
Lack of self-efficacy	-	-	-	-
Lack of outcome expectancy	-	-	-	-
Inertia of previous practice	-	-	-	-
External barriers				
Patient preferences	6	6	1	13
Lack of time	1	1	1	3
Other	1	1	1	3
Patient-physician relationship	-	-	-	-
Never occurred	-	-	-	-
Unclear	1	1	1	3

Table 3. Examples of answers given by general practitioners.

Barriers	**Example of answer**
Lack of agreement	1. I think a systolic pressure of 140 is wonderful! In this group it should not be lower. That would be harmful. With a pressure over 160 I would start considering an intervention 2. With 85% of the depressed elderly I will talk about suicide, psychosis, anxiety and mania. The problem is registering. I believe that I will remember things. Registering what people do not have often happens for the wrong reason, namely juridical-defensive. To me that's incorrect. Registering everything would not change my treatment policy. 3. I am always watchful if a person with diabetes has a systolic blood pressure above 140 and will always start an intervention. Except for persons with severe dementia; you can still help those people, but you become less inventive with this group. Furthermore, I would not want to burden them any more.
External barriers	
Patient preferences	We are very active in calling patients for diabetes check-up. If a patient does not show up for a third or fourth time we tend to stop sending out notices. Every time we schedule an hour for their check-up; it is a burden for our practice if they do not show up. Why they do not show? I think they feel it is not necessary… they will say "I am fine". Sometimes I think they just deny their health problems.
Lack of time	I visit some persons at home. I will check their glucose, their blood pressure and once in a while check a leg, but sometimes there is no time for the glycosylated hemoglobine. In those cases it will be measured next year.
Lack of outcome expectancy	I hardly ask if persons consider suicide or are psychotic. I am not sure why. It makes me think of an ringing alarm that you switch of without further thought of what might be going on. In this group depressive symptoms are very common, whereas the prevalence of suicide and psychosis is really low.
Other – Patient-physician relationship	I have a counseling contact with my patients, they depend on me. Labeling a person as depressed can disrupt our relation. It is considered to be a disqualification amongst elderly.
Unclear	There is a small group that slips through. I have to be honest; I do not check if every diabetic I see was checked by our practice-assistant for glycosylated hemoglobine.

DISCUSSION

Self-reported adherence to quality indicators and reasons for non-adherence differed between conditions and specific indicators. For depression, adherence was very high (mean 98%) for talking about suicide plans or referral to a psychiatric hospital when an older person had thoughts of suicide, a bit lower (75%) for talking about target symptoms after a new diagnosis of depression and much lower (39%) for documenting presence or absence of suicide thoughts, psychosis, (hypo)mania and anxiety. For T2DM, adherence was very high (respectively 94% and 88%) for annually measuring HbA_{1c} and performing foot examinations. The number for both HbA_{1c} measurement and foot examination was higher than found in most studies, including those targeting vulnerable older persons[3-11]. Adherence was lower (64%) for starting an intervention (or documenting a reason why not) when an older diabetic had consistently elevated systolic blood pressure over 140 mm Hg. The main reasons for non-adherence in both depression and diabetes care were mostly related to physician attitude and external barriers; the underlying reasons differed between the two conditions.

A limitation of using interviews to obtain data is the problem of social desirability response bias, i.e. the tendency to answer in ways that people believe others find acceptable and approve of[21]. Since answers were given concerning self-determination, not feeling like informing the patient, having no time, just missing some people and admitting the physician-patient relation is not too good seems to imply that many GPs answered in a sincere and honest way. This was also the impression of the interviewer. Another limitation of the chosen research method is that the adherence percentages given are estimations. We did not ask practitioners to actually count the number of cases they encountered and the number of cases in which they provided the care as mentioned in the indicator. This might sometimes have led to recall bias, but this could lead to both under- and overestimation of the adherence percentages. Furthermore, general practitioners who take the time to participate in studies on quality of care probably are above average in terms of quality of care, which leads to an overestimation of adherence percentages. Despite these limitations we still feel we can form a notion of which indicators lead to difficulties in providing care, because the limitations apply equally to all quality indicators included in this study.

The use of an explorative interview can be considered a strength as well, because we were not dependent on the quality of charts, which in earlier studies led to an imperfect reflection of care provided[17-19]. For example, for the Assessing Care of Vulnerable Elders indicators 0% adherence was found for both discussing depressive symptoms and for recording suicide and psychosis risk when using medical record review[11]. This might be partly due to the fact that only 13 cases with a new depression episode were identified (to compare; for diabetes indicators 43 to 85 incident cases were identified). For the indicator of talking about suicide plans or

referral no cases (i.e. persons who considered suicide) were identified at all. The prevalence of depression is low and the incidence of suicide and psychosis is even lower. Trying to obtain these numbers from a chart is like trying to find a needle in a haystack, especially when one focuses only on care provided in the last year, like in the ACOVE study. When interviewing GPs, they could recall and use events from their whole working career and report what they did. The percentage of adherence obtained with an interview might give a more realistic view on what is actually going on in depression care.

Another advantage of using an interview was that general practitioners were not restricted in the number and type of barriers they could mention. So far, mostly quantitative studies on reasons why physicians do not follow guidelines have been done (115 of the 120 included in the review by Cabana[1]). 90 of those studies (78%) only included 1 or 2 possible barriers to providing care. Most barriers reported by general practitioners in the current study were easily fitted into the categories of barriers identified in those 120 studies[1]. But we were also able to make some refinements within the categories, especially for the barrier of lack of agreement with the indicator. Sometimes the GPs did not agree with the medical content (e.g. the level of blood pressure mentioned), but the obligation to register was another barrier. An important finding, probably specific to vulnerable older persons, was that many times the GPs agreed with the indicator for most vulnerable older persons, but not for certain subgroups. The main reasons that a GP felt certain subgroups should not be burdened any further were short life expectancy and cognitive impairment. The original ACOVE-quality indicators were evaluated to measure if different indicators would apply to patients with advanced dementia and poor prognosis (expected survival < 6 months)[22]. Respectively 40% and 34% of indicators were excluded for persons with advanced dementia and poor prognosis. Content analysis revealed that indicators aimed at care coordination, safety or prevention of decline, or short-term clinical improvement or prevention with nonburdensome interventions were hardly ever excluded (10% and 2% for respectively advanced dementia and poor prognosis), but indicators directed at long-term benefit or requiring interventions of moderate to heavy burden were usually excluded (84% and 81%). Furthermore, when testing the ACOVE-indicators for adherence in a group of vulnerable older persons it was stated that not providing care because of poor prognosis could not to be considered inappropriate care[11]. Thus, when short life expectancy was mentioned in our study as a reason not to provide care we should not consider this to be poor care. Cognitive impairment/ dementia were only mentioned as barriers for the indicator of providing information on the target symptoms of depression. We feel it is doubtful if this can be considered good care: although it is clear why it is not useful to provide this information to persons with impaired cognition, GPs could provide the information to a spouse, child or other caregiver. Another important reason in the ACOVE-study to consider not-provided care as good care was patient preferences[11].

Summarizing, adherence for T2DM indicators was generally higher and the barriers identified were carefully balanced decisions on the general practitioners' part, whereas overall adherence to depression indicators was lower and the barriers identified might point to possible improvements in general practice, e.g. they can take more time to ask and inform about depression and involve caregivers when the person is cognitively impaired. It is possible that the presence of a Diabetes Center in the region lead to better care, because it systematically implemented the Dutch guidelines on Diabetes care (which were closely related to the quality indicators). Another option is that general practitioners have more difficulties in treating a psychological ailment. We would also recommend that when developing guidelines or quality indicators for vulnerable older persons the special situation for some subgroups (e.g. persons with short life expectancy) should be carefully considered: does this indicator also apply to this subgroup or do we have to add a sub-indicator which states how to handle special cases? This might lead to a large amount of extra indicators, but the group of vulnerable older persons is seemingly too diverse to make indicators that apply to all. Even when strongly supported by practice general practitioners should always consider the individual before providing indicator-based care. We also like to stress the importance of ongoing discussion on the differences between theoretically developed indicators and everyday practice. An example is the treatment of a vulnerable older diabetic who presents himself with a systolic blood pressure above 140 mmHg. Both the Dutch guideline, developed for the general population[23] and the ACOVE-indicators mention this cut-off point, but many general practitioners in our study did not agree with the value. Another study also stated that another cut-off point should be used for this group, e.g., 160 mm Hg for patients over 60 years of age[2] (Dijkstra, 2004). This quality indicator should be subject to further discussion. The findings in practice should be fed back to quality of care researchers.

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Appendix 1. Characteristics of vulnerable older persons (sheet from RAND, not published).

Age group (total=100%)	**(%)**	**ADL disability, % that has problems with...**	
65-74	25	Making phone calls	11
75-84	45	Light housework	31
85+	30	Preparing meals	25
Marital status (total=100%)		Shopping	43
Married	42	Managing finances	22
Widowed	47		
Divorced/ separated	7	**Medical Condition**	**(%)**
Never married	4	Arthritis	72
Sexe (total=100%)		Hypertension	63
Male	33	Difficulty with Vision	58
Female	67	Difficulty with Hearing	53
		Diabetes Mellitus	23
Functional limitation (total=100%)		Swallowing difficulty	22
None	11	Emphysema	20
One	13	Other heart condition	17
Two	20	Osteoporosis	16
Three or more	56	Myocardial Infarction or Angina	13
		Cancer (other than skin)	8
ADL disability, % that has problems with...		Stroke history	8
Bathing	24	Alzheimer's disease	5
Dressing	16	Psychiatric diagnosis	5
Eating	5	Partial paralysis	5
Chair transfer	5	History hip fracture	3
Toileting	8	Parkinson's disease	3
Walking	19		
		Poor to fair self-rated health	54

Chapter 9

General Discussion

This thesis evaluates what kind of care vulnerable older persons themselves feel they need, what care they actually use and what health professionals think is appropriate care for them.

The research questions, addressed in this thesis, are:

1. What is the prognosis of vulnerability and to what number and type of self-perceived needs does it lead in community-dwelling older persons?
2. What kind of care do vulnerable older persons actually use, how is this related to self-perceived need and what will be the effect of the aging of the population on health care utilization in 2030?
3. What do health professionals consider to be appropriate general practitioner care for vulnerable older persons and what barriers exist in practice to provide this care?

In the following section we will summarize the findings of the studies presented in Chapters 2 to 8 and answer the research questions. We subsequently present methodological considerations, a literature perspective and end with recommendations for health practitioners, policy makers and researchers.

9.1 Summary of findings

1. What is the prognosis of vulnerability and to what number and type of self-perceived needs does it lead in community-dwelling older persons?

Vulnerability is defined as a poor functional health status that resulted from an interplay of physical, psychological and social factors and leads to decreased reserves and diminished resistance to stressors. Almost one third of persons aged 75 and over considered to be vulnerable in this study. About 15 to 25% of these persons recovered to a non-vulnerable status within 18 months. Thus, over three quarters remain vulnerable. The older a person is and the more depression symptoms they report the higher the risk that they remain vulnerable over time.

Self-perceived needs were described using the Camberwell Assessment of Need in the Elderly[1]. On average vulnerable older persons reported 5.6 needs (out of 24 need topics) and 0.4 of those were unmet needs. Almost all persons reported at least one need in the physical and environmental domains (e.g. having a physical ailment or being able to perform domestic tasks). However the highest percentages of unmet needs were reported on psychosocial topics, like the need for company or suffering from depression symptoms. We also explored risk indicators associated with the number of needs reported. Especially, being physically inactive was associated with more needs in total and for all four care domains separately. Last, we compared needs reported on CANE with needs as assessed by community nurses using the Resident Assessment Inventory-Home Care[2]. Agreement ranged from poor to substantial per need-topic and was lower when persons had impaired cognition or clinically relevant symptoms of depression.

2. What kind of care do vulnerable older persons actually use, how is this related to self-perceived need and what will be the effect of the aging of the population on health care utilization in 2030?
About half of vulnerable older persons visited the general practitioner (GP visits) in the last two months with a range from 1 up to 10 visits. 42% received home care concerning domestic tasks (IADL home care) with a range of 1 to 6 hours per week. About half of older persons was acutely admitted to the hospital at least once in the last five years. When including non-acute admissions this number rose to over three quarters of persons. Vulnerable persons made more use of health services than non-vulnerable persons.

Self-perceived need was strongly associated with GP visits, IADL home care and acute and total hospital admission even when added to a model with predisposing, enabling and evaluated (objectively established) need variables. Most associations of self-perceived need with health care utilization were obvious, for example persons with a met need for domestic tasks self-evidently used more IADL home care per week than persons with no such need. More striking findings were that persons with an unmet need for depression more often visited the GP and that a lack of information on health condition was associated with hospital admission.

We also estimated the number of vulnerable older persons and their health care utilization in 2030. Although the use of epidemiological modeling has its limitations and the numbers should not be interpreted rigidly, the model shows that aging of the Dutch population will lead to approximately doubling of the number of vulnerable persons and consequently doubling of their health care utilization. Reducing depression symptoms by improving detection and treatment will lead to large reductions in number of vulnerability, but small reductions in health care utilization in the total population aged 75 and over.

3. What do health professionals consider to be appropriate general practitioner care for vulnerable older persons and what barriers exist in practice to provide this care?
In cooperation with health professionals, we developed a set of quality indicators describing appropriate care for vulnerable older persons for the conditions Continuity and Coordination of care, Depression, Dementia, End of life care, Type 2 Diabetes Mellitus, Medication use, Mobility and falls and Undernutrition. The American ACOVE indicators[3] were a good starting point to develop this set. When strong scientific evidence was provided by many studies US and Dutch experts agreed on the appropriateness of the quality indicator. For Depression large differences in appropriateness of care between the US and Dutch set existed; in the US there is a focus on medication as first/main treatment option, whereas in the Netherlands this is not the first treatment option by all means.

To test the indicators in practice who conducted explorative interviews with 13 general practitioners on adherence to diabetes and depression quality indicators

and barriers to provide appropriate care for these conditions. Adherence for diabetes indicators was generally higher and the barriers identified were carefully balanced decisions on the general practitioners' part (e.g. not wanting to burden a persons with short life expectancy), whereas overall adherence to depression indicators was lower and the barriers identified might point to possible improvements in general practice.

9.2 Methodological considerations

In this paragraph we will discuss the limitations of the methods used in the described studies.

9.2.1. Question 1: vulnerability and self-perceived need

Internal validity

Loss to follow-up

The loss to follow-up was large in this study and may have led to selection bias by drop out of the most vulnerable persons. Although it is difficult to get and keep such a vulnerable group in research, this was partly due to the burden of the study. Participating older persons had to fill out a long questionnaire and participate in two interviews that lasted from 30 to 90 minutes per interview. The burden was too high for some persons to continue in the study and others just had enough. Some quitted because of medical reasons. Another study based on data of the same RCT as the current study showed that general practitioners identified more persons with dementia among the non-responders than among the responders[4]. All in all, it is plausible that the most vulnerable persons in this study were not included at the start or lost to follow up. This probably lead to an underestimation of number of needs (and especially unmet needs) and to an overestimation of the percentage of persons that were able to recover from vulnerability. The prevalence of vulnerability was established at baseline and thus, was not influenced by the loss to follow-up.

External validity

Follow-up on RCT

A limitation in gathering the data is that the current study followed on a randomized controlled trial to evaluate preventive effects of demand-led home visits by nurses in primary care[5]. A possible consequence of following up on this trial was that the study population of the current study could consist of two different groups of vulnerable older persons. If the home visits had an effect on the health status and objective care need of vulnerable older persons, the groups would differ in objective care need and most probably also in subjective care need and health care utilization. However, all outcomes of this RCT were negative. Furthermore, we checked these possible implications by comparing the mentioned outcomes (and many other factors, e.g. demography) in the control and experimental groups. No differences between the groups were found.

Representativeness of the sample
The loss to follow-up had some effect on the representativeness of our study population. The consequences of this selection bias are mentioned under Loss to follow-up.

This study took place in West-Friesland, a northwestern region of the Netherlands. This region is characterized by a good health care infrastructure and the no-nonsense attitude of its inhabitants. A study among persons aged 65 and older in several regions of the Netherlands showed that older persons in West-Friesland were relatively in good health and showed a strong tendency to participate in society[6]. This might implicate that the prevalence of vulnerability and the number of self-perceived needs are higher in other parts of the Netherlands.

Probably the description of number and type of self-perceived need can not be generalized to other countries. It is known that many older persons in the Netherlands consider some topics, like depression and money problems as taboo, which might lead to underreporting on needs for those topics. The current study confirms this general knowledge, since 63% reported depression symptoms on a screening questionnaire, whereas only 4% reports having problems concerning depression when directly asked by an interviewer. In different countries different taboos might exist, which could lead to a difference in reporting certain self-perceived needs. We have no reason to believe that risk indicators of self-perceived need, how self-perceived need relates to objective need and recovery from vulnerability and its risk indicators will be different in other populations/ countries other then the effect of the loss of the most vulnerable persons in our study (which is described above).

Definition of vulnerability
Our definition of frailty/ vulnerability deviated from other, more accepted, definitions of frailty, especially from the definition describing physical frailty. Vulnerability in this study has a broader definition including a psychological and a social item and was based on self-report. The main advantage of this measure was that it was easy to administer and showed large item-response. Furthermore, it shows some of the same characteristics as frailty (like increasing prevalence with age) and is related to important health outcomes like hospital admission and general practitioners visits. However, our results can not be generalized to persons who are defined as being frail. First of all, the prevalence of frailty is lower. Other consequences of the use of a measure of frailty may be a lower recovery rate and a larger amount of self-perceived needs. This differences will be the largest when a physical frailty is used as measure. Furthermore, since psychological factors are not included in such a definition the proportion of persons with depression symptoms may be smaller.

9.2.2. Question 2: Health care utilization

Since data on health care utilization were gathered in the same study as the data on vulnerability and self-perceived need the same issues of internal and external validity apply to those results. Below we will shortly describe the consequences of the issues mentioned above for the findings concerning health care utilization.

Internal validity

Loss to follow-up

As a consequence of the loss to follow-up the most vulnerable persons may have left the study. This might have led to an underestimation of the amount of health services used by vulnerable older persons. Our projection on health care utilization among vulnerable persons in 2030 would then also be an underestimation.

External validity

Follow-up on RCT

As mentioned before we checked if the control and experimental group of the RCT differed on our outcome (and other) measures. They approximately reported the same amount of health care utilization and thus the follow-up on the RCT had no impact on our findings.

Representativeness of sample

The specific characteristics of the region of West-Friesland might have led to an underestimation of health care utilization compared to the total Dutch population aged 75 and over. An additional consideration when generalizing the findings of this study to international settings is the good health infrastructure in the Netherlands. Enabling factors, like attainability of health services are not a major factor in health care utilization in the Netherlands. Enabling factors might be more important in determining health care utilization in more spacious/ less inhabited countries.

Definition of vulnerability

Persons who are frail probably have a worse health status than persons who are vulnerable. Thus, they would make more use of health services than reported in this study.

9.2.3. Question 3: Appropriateness of care

Internal validity

Information bias

An important limitation of the appropriateness studies was that we are not sure that all panelists and interviewed practitioners had the same target group in mind. This form of information bias could have worked two ways. First, persons had a much frailer group in mind then proposed; this could have lead to discarding quality indicators as inappropriate. Second, persons could have envisioned the total group of older persons, thereby maybe accepting indicators as appropriate which would not apply to vulnerable persons. Since the panel consisted of nine experts the

effect of the information bias might have leveled out between persons, but we can not be sure it did nor can we establish in which direction the bias could have worked. For the practitioners that were interviewed on adherence and barriers to provide appropriate care this could also have been a problem. The interviewer provided and discussed a fact sheet describing the population with all of them and all physicians seemed to have a clear idea about vulnerable older persons, but still this might slightly differ between practitioners.

External validity
Because of the savings in resources, practitioners and policy makers in all countries interested in developing quality indicators should consider using rigorously developed quality indicators in countries other than their own, although a thorough process of review is always necessary. In every country different clinically important changes will be made to quality indicators. Countries with a similar health care system as the Netherlands (like the U.K.) could consider using Dutch instead of American quality indicators as a starting point, which might lead to less discarding and changing of quality indicators. Another universal finding is that when developing guidelines or quality indicators for vulnerable older persons the special situation for some subgroups (e.g. persons with short life expectancy) should be carefully considered. The percentages of adherence to quality indicators can not be generalized to other populations, because it is based on thirteen interviews only. It does give an impression of which indicators lead to difficulties in providing care and possible barriers which are not specific to these region.

9.3 Literature perspective
An extensive body of literature exists on the different topics discussed in this thesis, like frailty[7-12], (self-perceived) care needs[13-18] and health care utilization[19-21] (this is only a selection of many references). The main addition to the literature of the current study is that it integrates the concepts of frailty/ vulnerability, older persons, self-perceived need, care utilization and appropriateness of care.

9.3.1. Vulnerability
This is one of the first studies to specifically look into transitions of a vulnerable or frail health status to a non-vulnerable/ frail state. Gill et al. looked into transitions between frail, pre-frail and non-frail states in a comparable group of community-dwelling persons over 70 years of age[22]. They found a transition rate of only 0 to 9% from a frail to a non-frail state when using physical measures like weight loss, exhaustion, low physical activity, muscle weakness and slow walking speed to establish frailty. Despite these low numbers Gill et al. concluded that their findings suggested ample opportunity for the prevention and remediation of frailty. This study found that a larger group was able to recover from vulnerability. This is probably due to the measurement of frailty/ vulnerability; our definition included psychological and social factors and was based on self report. Seemingly, recovery from vulnerability is more likely than recovery from physical frailty. We also explored if certain groups were at higher risk of remaining vulnerable. In

community-dwelling persons it appears that persons who were older and had more depression symptoms were at higher risk of remaining vulnerable. Even though our definition deviates from physical frailty the analysis of risk indicators actually shows overlap with the cycle of frailty in which chronic diseases, disability and depression amongst others are identified as factors that cause or maintain frailty[23].

9.3.2. Self-perceived need and health care utilization

This study describes how a comprehensive measure of self-perceived need (CANE) relates to a more objective measure of need (RAI-HC). The most important conclusion of this study is that lack of agreement between the two measures was partly due to health status. Persons with depression symptoms more often have different scores on the two measures. Persons with cognitive impairment report less self-perceived need compared to assessment of need by trained nurses.

In earlier studies perceived- or subjective need variables have often been included as measures of need, but hardly any explicit self-perceived need variables. A systematic review on health care utilization in chronically ill persons using generic definitions of self-perceived need found an important role for evaluated need variables in predicting use, whereas the results for self-perceived need were mixed: four out of eight studies found that poor perceived health lead to more hospital admission, whereas the other four found no such association[21]. Our study looked at a comprehensive measure of self-perceived need and showed strong associations of certain self-perceived need topics and general practitioner visits, use of IADL help and total and acute hospital admission. As shown in the review measures of evaluated (objectively established) need were important as well, especially for hospital admissions, but self-perceived need topics added much explained variance even for these outcomes. Since self-perceived need shows strong associations with use of health services it seems that more attention should be paid to patients' health care needs by policymakers, physicians and society at large as was suggested in an earlier study[24]. However self-perceived need should not replace more objectively established measures of need for we can not determine if care solely based on self-perceived need would prove to be appropriate care.

Last, our study on estimating number of vulnerable older persons and their health care utilization in 2030 added information to other studies trying to describe the consequences of the aging of the Dutch population (e.g. the report by van den Berg[25]). Specifically, we show that the number of vulnerable older persons will increase with 74% to half a million in 2030. Consequently, health care utilization will almost double as well. The study also shows that the reduction of persons who are depressed will lead to a large reduction in number of vulnerable persons, but smaller reductions in the health care utilization of the total population aged 75 and over.

9.3.2. Appropriateness of care

The study on development of quality indicators showed that the transferability between countries of quality indicators is possible, but with caution. It was the third attempt to transfer US-developed indicators into European countries, and in two of these the number of indicators discarded or greatly modified has been substantial (33-44%)[26,27]. This still means that more than half of US-developed indicators have been judged valid, supporting the concept that the majority of quality indicators will be acceptable in other health care settings. Because of the savings in resources, practitioners and policy makers interested in developing quality indicators should view our results as encouraging starting with rigorously developed quality indicators in countries other than their own. Still, the results also suggest that it is likely that in most attempts at transferability, a thorough process of review will result in clinically important changes in quality indicators.

Most barriers reported by general practitioners in the current study were easily fitted into the categories of barriers identified in a review (including 120 studies).[28] But we were able to make some refinements within the categories, especially for the barrier of lack of agreement with the indicator. Sometimes the GPs did not agree with the medical content (e.g. the level of blood pressure mentioned), but the obligation to register was another barrier. An important finding, probably specific to vulnerable older persons, was that many times the GPs agreed with the indicator for most vulnerable older persons, but not for certain subgroups. The main reasons that a GP felt certain subgroups should not be burdened any further were short life expectancy and cognitive impairment. The original ACOVE-quality indicators were also evaluated to measure if different indicators would apply to patients with advanced dementia and poor prognosis (expected survival < 6 months).[29] Respectively 40% and 34% of indicators were excluded for persons with advanced dementia and poor prognosis. Content analysis revealed that indicators aimed at care coordination, safety or prevention of decline, or short-term clinical improvement or prevention with nonburdensome interventions were hardly ever excluded (10% and 2% for respectively advanced dementia and poor prognosis), but indicators directed at long-term benefit or requiring interventions of moderate to heavy burden were usually excluded (84% and 81%). Furthermore, when testing the ACOVE-indicators for adherence in a group of vulnerable elders it was stated that not providing care because of poor prognosis could not to be considered inappropriate care.[29] Thus, although ACOVE and the current study developed quality indicators for the whole group of vulnerable older persons careful considerations should be made when dealing with these specific subgroups.

9.4 Recommendations

Vulnerability is highly prevalent in persons aged 75 and over and most vulnerable persons remain vulnerable over time. Our estimation of number of vulnerable persons and their health care utilization in 2030 shows an enormous increase in number of vulnerable persons and their health care utilization as a consequence of the aging of the Dutch population. This finding is alarming, since the Dutch health

care system is already strained and in its current form will not be able to tackle the increase in (vulnerable) older persons and their health care utilization. Reducing depression symptoms has a large effect on the number of vulnerable persons, but a much smaller effect on health care utilization in the total population aged 75 and over. The number of unmet needs among vulnerable older persons identified in this study was low. However, we would like to add some notes to this finding. First, we wonder if for some topics the persons in this study underreported. Especially for psychosocial topics we feel (unmet) needs were not reported. Secondly, another study showed that the population studied (in West-Friesland) is quite healthy compared to older populations in other Dutch regions. We already described the selection bias due to the loss of the most vulnerable persons during this study. Thus, the number of unmet needs might be higher in the Dutch vulnerable population aged 75 and over. Furthermore, even if care is quite good, there is still ample opportunity for improvement. Based on the findings of this thesis we are able to make some recommendations to practitioners, policymakers and researchers to reduce these problems.

9.4.1. General practitioners & policymakers

A main concern for policymakers is how vulnerability and its adverse health outcomes can be reduced, especially with the aging of the population in mind. The focus should be on how to prevent vulnerability and its health outcomes. However, our study did not look into prevention of vulnerability. We identified some groups that are at higher risk of remaining vulnerable once they have reached this state, but it is not clear if the same risk indicators apply to the development of vulnerability. Currently, many interventions are available that target specific functions and competences to prevent disability that may also prevent vulnerability from occurring, like fall prevention and cognitive training, the establishment of health centres for the elderly and providing support for informal caregivers (respite care). However, the availability of these services is scattered and in general the effectiveness of these interventions is unclear[30-38]. More research is needed to explore how vulnerability can be prevented. Another option would be to reduce the adverse outcomes of vulnerability, like institutionalization, hospitalization and mortality. A concern for general practitioners is how to identify and treat vulnerable older persons in a growing population of older persons. However, detection and treatment of vulnerable persons by GPs should be preceded by the development of methods to both identify and effectively treat vulnerable persons (see 9.4.2. Recommendations for Future research). In the future, general practitioners could play a major role in conducting these screening and treatment methods.

Another recommendation based on this thesis is that more attention should be paid to depression symptoms in this group. Difficulties with depression was a recurring theme:
1) It was highly prevalent with 63% of vulnerable persons reporting clinically relevant symptoms of depression;

2) Relatively many unmet needs were identified for this condition and we felt that the number of needs (4% compare to the 63% on the screening list) reported was only the tip of the iceberg;
3) Depressed persons had inconsistent scores when comparing an objective with a subjective measure of needs;
4) When persons reported a need for Depression it led to more health care utilization, especially to more GP visits;
5) Depression symptoms was a risk indicator for remaining vulnerable and not being able to recover to a non-vulnerable status.
6) Last, it also was a problematic condition in the development and testing of quality indicators. First, the Dutch expert panel who adapted US indicators to the Dutch situation discarded and changed many US indicators. When three Depression indicators where tested in general practice self reported adherence was lower than for diabetes and barriers identified were related to possible improvements in practice.

It seems that many aspects of care for vulnerable persons would profit from better treatment and detection, and clearness on appropriateness of care for depression. Better depression care for vulnerable older persons would start with greater awareness of the high prevalence and the consequences of depression in this group amongst general practitioners. Recently an appendix of the Dutch guideline on depression has been written concerning older persons. This appendix should be widely dispersed and an ongoing discussion on providing depression care for this group should be initiated. The Dutch College of General Practitioners (NHG) could play a major part in this discussion. Again screening the total older population should be considered since underdetection of depression is highly prevalent in this group (only a quarter is recognized). Underdetection happens for several reasons: 1) older persons are less likely to report depression[39,40]; 2) recognition of depressive symptoms is often hampered by physical diseases[41], and; 3) symptoms indicative of depression in the oldest adults may be dismissed as natural consequences of the frequently occurring adverse life events and illnesses.[42] Systematic screening could reduce these problems of detection, but it is unclear if screening leads to a reduction in the number of persons with depression. Two reviews showed that although most trials demonstrated that screening and feedback to primary care providers improved detection rates and some studies improved the rates of depression-specific treatments, robust differences in symptom outcomes were not shown[43,44]. Currently, about one third of the general population receives efficacious depression treatment[45]. A recent Dutch study among community-dwelling older persons showed that antidepressant use increased over the past 15 years, but that still only a minority of the more severely depressed persons used antidepressants[46]. Unützer[47] extensively described how primary care for older adults with depression could be improved, including aspects of patient (and informal caregiver) education and activation, provider education and support and the tracking of treatment outcomes.

9.4.2. Future research

Although this thesis gave some insight in self-perceived needs, utilization and appropriateness of care for vulnerable older persons, some questions remain unanswered and some answers triggered new questions. This leads to the following recommendations for future research:

- Prevention of vulnerability could possibly lead to better health outcomes for the total population aged 75 and over. A Dutch study showed that two serum endocrine and inflammatory markers were associated with incident frailty[48]. Future studies should look at what (other) risk factors are related to developing vulnerability and if reducing the prevalence of these risk factors really prevents a person from becoming vulnerable.
- Since no criterion standard exists to diagnose frailty correctly in a heterogeneous group of older persons[49,50], a first step would be to test and compare different measures on feasibility and the group they identify. An explorative comparison of four measures showed that the use of frailty criteria is feasible in a group of geriatric inpatients, but that the various criteria gave highly different selections of patients[51]. More research should be done to set a standard how to measure complex concepts like frailty and vulnerability.
- When an appropriate (and easy-administrable) method of establishing vulnerability is identified a next step would be to explore the effects of screening for vulnerability in the community-dwelling population. What is the best way to screen this population? One could think of screening in general practice or health centers. However, vulnerability might be characterized by no show, thus, other methods (sending letters, home visits) should be considered. A comparison of methods would be best. Furthermore, it should be studied if screening for vulnerability will actually lead to a reduction in adverse health outcomes in this group.
- The finding that older persons are able to recover from vulnerability should be further explored. Is it a long lasting improvement or is it a matter of months before the recovered persons become vulnerable again? And can more groups that are at higher risk of remaining vulnerable be identified?
- An intervention tool box for vulnerable older persons should be developed taking into account possible interactions between interventions. This will be a long process of selecting interventions for the tool box, testing its feasibility, efficiency and effectiveness, probably changing the content of the tool box et cetera. Based on this study depression symptoms should be included in the tool box by all means.
- Methods should be developed and evaluated to improve treatment and especially detection of depression symptoms in older persons in primary care.
- The prevalence of unmet needs was very low in our population. Further research is needed to explore the reasons for this low prevalence; is it the same in other Dutch regions? Is care in West-Friesland good or does underreporting play a role?
- Since we were only able to translate quality indicators for eight out of 26 conditions to the Dutch situation for the general practitioner setting, future research should aim at translating all other conditions as well to obtain a complete set of quality indicators for vulnerable older persons in the Netherlands. For all conditions

the indicators should be revised for specific subgroups like persons with short life expectancy. Last, quality indicators should also be developed for different settings, for example for hospitals.
- Although our interviews provided us with a lot of information we were only able to talk about 6 indicators in half an hour. Reviewing our 108 indicators would take 9 hours in total with 18 more conditions to go. Thus, a method should be developed how to test quality indicators in practice that does not burden practitioners, but also does not suffer from problems with the quality of registration files.

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Appendix I

Quality Indicators (Supplement Chapter 7)

#US	US-indicator	#NL	NL-indicator	Reason for changing or discarding
	Continuity and coordination of care			
	-	**1**	**IF** a general practitioner first suspects an elder to be vulnerable or obtains crucial information on aggravation of (determinants of) vulnerability, **THEN** the physician should document an estimation of health needs and demands, to be followed by an intervention plan to be coordinated by a clearly identified professional. (**NEW**)	
1	**ALL** vulnerable elders should be able to identify a physician or a clinic to call for medical care or know the telephone number/other mechanism to reach this source of care.	**-**	**-**	Considered not important to be in QI set; in the Netherlands everybody has a general practitioner.
2	**IF** a vulnerable elder outpatient is prescribed a new chronic disease medication, and s/he has a follow-up visit with the prescribing physician, **THEN** 1 of the following should be noted at the follow-up visit: • Medication is being taken • Patient was asked about the medication (e.g., side effects, adherence, availability) • Medication was not started because it was not needed or changed.	**2**	**IF** the general practitioner prescribes a vulnerable elder a new chronic disease medication, and s/he has a follow-up visit with this physician, **THEN** 1 of the following should be noted at the follow-up visit: • Medication is being taken; • Patient was asked about the medication (e.g., side effects, adherence, availability); • Medication was not started because it was not needed or it was changed.	

3	**IF** a vulnerable elder is under the outpatient care of ≥2 physicians, and one physician prescribed a new chronic disease medication or a change in prescribed medication, **THEN** the non-prescribing physician should acknowledge the medication change at the next visit.	**3**	**IF** a vulnerable elder is under the outpatient care of ≥2 physicians, and a physician other then the GP prescribed a new chronic disease medication or a change in prescribed medication, **THEN** the general practitioner should acknowledge the medication change at the next visit.	
4	**IF** an outpatient, vulnerable elder was referred to a consultant and revisited the referring physician, **THEN** the referring physician's medical record should acknowledge the consultant's recommendations, include the consultant's report, or indicate why the consult did not occur.	**4**	**IF** a vulnerable elder was referred to a medical specialist and after is seen again by the v, **THEN** the general practitioners record should acknowledge the medical specialist's recommendations, include the specialist's report, or indicate why the visit to the specialist did not occur.	
5	**IF** an outpatient vulnerable elder was given an order for a diagnostic test, THEN 1 of the following should be documented at the follow-up visit: • Result of the test initialed/acknowledged • Note that the test was not needed/reason why it will not be performed • Note that the test is pending .	**5**	**IF** a vulnerable elder was given an order for a diagnostic test by the general practitioner, THEN 1 of the following should be documented at the follow-up visit: • Result of the test initialed/acknowledged; • Note that the test was not needed/reason why it will not be performed; • Note that the test is pending.	

6	**IF** a vulnerable elder misses a required preventive care event that is recurrent with a specific periodicity, **THEN** there should be medical record documentation of a reminder that the preventive care is needed within one full interval since the missed event.	**6**	**IF** a vulnerable elder misses a needed preventive care event that is recurrent with a specific periodicity (e.g. influenza vaccination or annual control of diabetics), **THEN** there should be general practitioners record documentation of a reminder that the preventive care is needed within one full interval since the missed event.	
8	**IF** a vulnerable elder is discharged from a hospital to home and survives ≥ 4 weeks after discharge, **THEN** a physician visit or telephone contact should be documented within 6 weeks of discharge **AND** the medical record acknowledge the recent hospitalization.	**7**	**IF** a vulnerable elder is discharged from a hospital to home and survives ≥ 4 weeks after discharge, **THEN** a general practitioner visit or telephone contact should be documented within 6 weeks of discharge **AND** the general practitioners record should acknowledge the recent hospitalization.	
9	**IF** a vulnerable elder is discharged from a hospital to home and received a new chronic disease medication or a change in medication prior to discharge, **THEN** the outpatient medical record should document the medication change within 6 weeks of discharge.	**8**	**IF** a vulnerable elder is discharged from a hospital to home and received a new chronic disease medication or a change in medication prior to discharge, **THEN** the general practitioners record should document the medication change at most 3 days after receiving the information from the hospital.	

12	**IF** a vulnerable elder is discharged from a hospital to home or a nursing home and the hospital medical record specifies a follow-up appointment for a physician visit or a treatment (e.g., physical therapy or radiation oncology), **THEN** the medical record should document that the visit/treatment took place, that it was postponed, or not needed.	**10**	**IF** a vulnerable elder is discharged from a hospital to home and the discharge summary requests the general practitioner to take certain actions, **THEN** the general practitioners record should document the follow-up on the requested actions.	
13	**IF** a vulnerable elder is discharged from a hospital to home, **THEN** there should be a discharge summary in the outpatient medical record.	**9**	**IF** a vulnerable elder is discharged from a hospital to home, **THEN** there should be a discharge summary in the general practitioners record.	
15	**IF** a vulnerable elder is discharged from a nursing home to home, **THEN** there should be a discharge summary in outpatient medical record.	**11**	**IF** a vulnerable elder is discharged from a nursing home to home, **THEN** there should be a discharge summary in general practitioners record.	
16	**IF** a vulnerable is new to a primary care practice, **THEN** the medical record should contain medical records from a prior care source, a request for such medical records, or an indication that such records are unavailable.	**12**	**IF** a vulnerable elder is new to a general practitioners practice, **THEN** the general practitioners record should contain general practitioners records from a prior care source, a request for such general practitioners records, or an indication that such records are unavailable.	
17	**IF** a vulnerable elder is deaf or does not speak English, **THEN** an interpreter or translated materials should be utilized to facilitate communication.	**13**	**IF** a vulnerable elder is not able to understand the general practitioner due to language barriers or deafness, **THEN** an interpreter (e.g. an informal caregiver) or translated materials should be present to facilitate communication.	

	Dementia			
1	**IF** a vulnerable elder is new to a primary care practice or inpatient service, **THEN** there should be a documented assessment of cognitive ability and functional status.	**1**	**IF** a vulnerable elder new to a general practitioners practice presents with possible signs of cognitive dysfunction and/or deficient mental or functional status, **THEN** there should be a documented assessment of cognitive ability and functional status.	
2	**ALL** vulnerable elders should be evaluated annually for changes in memory and function.	**2**	**ALL** cognitive vulnerable elders should be evaluated at regular time intervals (the timing between assessments depending on cognitive status) for changes in memory and functional status.	
3	**IF** a vulnerable elder screens positive for dementia, **THEN** the physician should document an objective cognitive evaluation that tests ≥2 cognitive domains.	**5**	**IF** a vulnerable elder tests positive for dementia, **THEN** the general practitioner should document an objective cognitive evaluation that assesses ≥2 cognitive domains.	
4	**IF** a vulnerable elder screens positive for dementia, **THEN** the physician should review the patient's medications (including over-the-counter) for any that may be associated with mental status changes.	**3**	**IF** a vulnerable elder tests positive for dementia, **THEN** the general practitioner should review the patient's medications (including over-the-counter) for any that may be associated with mental status changes.	
5	**IF** a vulnerable elder screens positive for dementia and is taking medications that are commonly associated with mental status changes in the elderly, **THEN** the physician should discontinue or justify continuing these medications.	**4**	**IF** a vulnerable elder tests positive for dementia and is taking medications that are commonly associated with mental status changes in the elderly, **THEN** the general practitioner should discontinue or justify continuing these medications.	

6	**IF** a vulnerable elder is newly diagnosed with dementia, **THEN** a clinician should perform a neurologic examination that includes evaluation of gait, motor function, and reflexes.	**6**	**IF** a vulnerable elder is newly diagnosed with dementia, **THEN** a general practitioner should perform a neurologic examination that includes evaluation of gait, motor function, and reflexes.	
7	**IF** a vulnerable elder is newly diagnosed with dementia, **THEN** complete blood count, thyroid testing, electrolytes, liver function tests, glucose, blood urinary nitrogen, and serum B_{12} tests should be done.	**7**	**IF** a vulnerable elder is newly diagnosed with dementia, **THEN** Hb, Ht, MCV, BSE, glucose, TSH and creatinine tests should be done and, if indicated, tests on electrolytes, folic acid, vitamin B1, vitamin B6, vitamin B12, and liver function.	
8	**IF** a vulnerable elder is newly diagnosed with dementia **AND** has risk factors for HIV, **THEN** HIV and syphilis testing should be offered.	**-**	**-**	Considered not important to be in QI set; hardly any elderly have HIV.
9	**IF** a vulnerable elder is diagnosed with dementia with recent onset symptoms (2-3 years), **THEN** the clinician should order neuroimaging.	**8**	**IF** a vulnerable elder is diagnosed with dementia with recent onset symptoms (2-3 years), **THEN** the general practitioner should refer the patient to a specialist if: • The diagnosis of dementia cannot be made with certainty; • The diagnosis of dementia is clear, but it has a) a conspicuous course; b) conspicuous symptoms; c) indications of deviations which can be treated with specialist treatment. • Medical treatment for Alzheimers disease is wished for. There is a need for the specialists advice.	
11	**IF** a VE with mild to moderate dementia has vascular or stroke risk factors, **THEN** s/he should receive stroke prophylaxis.	**-**	**-**	Other: should be under conditions CVA/stroke.
	IF a VE with dementia has a caregiver, **THEN** the caregiver should be screened for depression.	**-**	**-**	Other: concerns informal caregiver, not vulnerable elder herself.

	IF a VE with dementia has a caregiver who screens positive for depression, **THEN** there should be documentation that the caregiver was advised to seek care/was already under care.	**-**	**-**	Other: concerns informal caregiver, not vulnerable elder herself.
12	**IF** a VE with dementia has a caregiver, **THEN** the patient and/or caregiver should be given information on the following: • Dementia diagnosis, prognosis, and associated behavioral symptoms • Home occupational safety • Community resources	**9**	**IF** a vulnerable elder with dementia has a caregiver, **THEN** the general practitioner should give the patient and/or caregiver information on the following: • Dementia diagnosis, prognosis, and associated behavioral symptoms; • Home occupational safety; • Suitability to drive a vehicle; • Possibility of medication with cholinesterase inhibitors or other agents that might affect dementia symptoms or course without affording cure; • Community resources; • Care/ help for the informal caregiver.	
13	**IF** a VE has dementia, **THEN** s/he should be screened annually for behavioral and psychological symptoms of dementia (BPSD).	**10**	**IF** a vulnerable elder has dementia, **THEN** s/he should be screened after at regular time-intervals for psychotic affective disorders and/or behavioral problems (including BPSD).	

15	**IF** a VE with dementia is treated for BPSD, **THEN** there should be documentation that a behavioral intervention was tried first/concurrently **OR** if treated first with a pharmacologic intervention that the problem was severe.	**11**	**IF** a vulnerable elder with dementia is treated for psychotic affective disorder and/or behavioral problems, **THEN** the general practitioners record should contain documentation that a psycho-social intervention was tried first/concurrently, OR if treated first with a pharmacologic intervention that the problem was severe.	
16	**IF** a VE with dementia and BPSD is newly treated with an antipsychotic, **THEN** there should be a documented risk-benefit discussion.	**12**	**IF** a vulnerable elder with dementia and psychotic affective disorder and/or behavioral problems is newly treated with an antipsychotic, **THEN** there should be a documented risk-benefit discussion.	
	IF a VE has dementia, **THEN** a physical exercise program should be prescribed.	**-**	**-**	Not enough evidence exists to support this indicator.
	-	**13**	**IF** an elder is vulnerable and the care-giver burden is high, **THEN** the general practitioner should have a pro-active attitude towards cognitive dysfunction or dementia. (**NEW**)	

	Depression			
1	**ALL** vulnerable elders should have documentation of a screen for depression during the initial evaluation and annually thereafter.	**-**	**-**	Not enough evidence exists to support this indicator.
3	**IF** a vulnerable elder presents with one of the following symptoms (and the symptom has not previously been documented as a chronic condition): • sad mood, feeling down • insomnia or difficulties with sleep • apathy or loss of interest in pleasurable activities • complaints of memory loss • unexplained weight loss of greater than 5% in the past month or greater than10% in the past year • unexplained fatigue or low energy **THEN** the patient should be asked about depression, treated for depression, or referred to a mental health professional within two weeks of presentation.	**-**	**-**	No agreement between Dutch panelists: some feel that firsy attention should be paid to somatic reasons for the occurrence of the mentioned symptoms.
4	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the medical record should document at least three of the nine Diagnostic and Statistical Manual (DSM-IV) target symptoms for major depression within 2 weeks of diagnosis.	**1**	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the general practitioner should immediately provide information on the target symptoms for depression.	

5	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the medical record should document on the day of diagnosis: • presence or absence of suicidal ideation • presence or absence of psychosis • past history of mania or hypomania • an evaluation of cognition.	**2**	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the general practitioners record should document on the day of diagnosis: • presence or absence of suicidal ideation; • presence or absence of psychosis; • presence or absence of past history of mania or hypomania; • presence or absence of anxiety.	
6	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the medical record should document screening for the following co-morbid conditions (documented within one month of the depression diagnosis or during the 3 months prior to diagnosis): • hypothyroidism for women over age 50 • substance dependence or abuse.	**3**	**IF** a vulnerable elder receives a diagnosis of a new depression episode, **THEN** the general practitioners record should document screening for the following co-morbid conditions (documented within one month of the depression diagnosis or during the 3 months prior to diagnosis): • cardiovascular risk factors; • hypothyroidism for women over age 50; • substance dependence or abuse; • Parkinsonism; • dementia.	
7	**IF** a vulnerable elder has thoughts of suicide, **THEN** the medical record should document, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.	**4**	**IF** a vulnerable elder has thoughts of suicide, **THEN** the medical record should document, on the same date, that the patient either has no immediate plan for suicide, or that the patient was referred for evaluation for psychiatric hospitalization.	

8	**IF** a vulnerable elder is diagnosed with depression, **THEN** antidepressant treatment, psychotherapy, or electroconvulsive therapy should be offered within 2 weeks after diagnosis unless there is documentation within that period that the patient has improved, or unless the patient has substance abuse or dependence, in which case treatment may wait until six weeks after the patient is in a drug or alcohol free state.	**5**	**IF** a vulnerable elder is diagnosed with depression, **THEN** psychotherapy, or antidepressant treatment, should be offered within 2 weeks after diagnosis unless there is documentation (e.g. "watchful waiting") within that period that the patient has improved, or unless the patient has substance abuse or dependence, in which case treatment may wait until six weeks after the patient is in a drug or alcohol free state.	Major change; psychotherapy and antidepressant treatment switched, deletion of electroconvulsive therapy and adding of 'watchful waiting'.
9	**IF** a vulnerable elder is started on an antidepressant medication, **THEN** the following medications should not be used as first- or second-line therapy: tertiary amine tricyclics (amitriptyline, imipramine, doxepin, clomipramine, trimipramine); monoamine oxidase inhibitors (unless atypical depression is present); benzodiazepines; or stimulants (except methylphenidate).	**-**	**-**	Not enough evidence exists to support this indicator.
10	**IF** a vulnerable elder has depression with psychotic features, **THEN** he or she should be referred to a psychiatrist **AND** should receive treatment with a combination of an antidepressant and an antipsychotic, or with electroconvulsive therapy.	**6**	**IF** a vulnerable elder has depression with psychotic features, **THEN** he or she should be urgently referred to a mental health specialist or emergency department specialised in mental health care.	
11	**IF** a vulnerable elder has depression associated with bereavement, **THEN** he or she should be treated with an antidepressant medication with or without interpersonal psychotherapy.	**-**	**-**	No agreement between Dutch panelists.

12	**IF** a vulnerable elder with a history of cardiac disease is started on a tricyclic medication, **THEN** a baseline electrocardiogram should be performed prior to initiation of or within 3 months prior to treatment.	**-**	**-**	No agreement between Dutch panelists; this is not in accordance with the Dutch guideline on depression.
15	**IF** a vulnerable elder is newly treated for depression, **THEN** the following should be documented at the first follow-up visit to the same physician or to a mental health provider within 4 weeks of treatment initiation: • degree of response to at least 2 of the 9 Diagnostic and Statistical Manual (DSM-IV) target symptoms for major depression • medication side effects, if he or she is taking antidepressant medications.	**-**	**-**	No agreement between Dutch panelists.
16	**IF** a vulnerable elder is newly treated for depression and has suicidal ideation at an outpatient visit, **THEN** at the next follow-up visit, which must occur within 1 week, documentation should reflect asking about suicide risk.	**-**	**-**	No agreement between Dutch panelists.
17	**IF** a vulnerable elder has no meaningful symptom response after 6 weeks of treatment, **THEN** one of the following treatment options should be initiated by the 8th week of treatment: medication dose should be optimized or changed, or the patient should be referred to a psychiatrist (if initial treatment was medication); or medication should be initiated or referral to a psychiatrist should be offered (if initial treatment was psychotherapy alone).	**7**	**IF** a vulnerable elder has no meaningful symptom response after 4-6 weeks of treatment, **THEN** the general practitioner should asses the reason for non-respons, reconsider the diagnosis, check compliance of the elder and eventually switch to another treatment.	Major change; focus not on medication.

18	**IF** a person age 75 or older responds only partially after 12 weeks of treatment, **THEN** one of the following treatment options should be instituted by the 16th week of treatment: switch to a different medication class or add a second medication to the first (if initial treatment includes medication); add psychotherapy (if the initial treatment was medication); try medication (if initial treatment was psychotherapy without medication); consider electroconvulsive therapy; or refer to a psychiatrist.	**-**	**-**	No agreement between Dutch panelists.
19	**IF** a vulnerable elder has responded to antidepressant medication, **THEN** the he or she should be continued on the drug at the same dose for at least 4 months, and he or she should make at least 1 clinician contact (office visitor phone) during that time period.	**8**	**IF** a vulnerable elder has a diagnosis of depression for the first time and responds to the chosen therapy, **THEN** he or she should be continued on the same treatment for at least 6 months during which the general practitioner provides adequate monitoring.	Major change; focus not on medication.
20	**IF** a vulnerable elder has experienced three or more episodes of depression, **THEN** the he or she should receive maintenance antidepressant medication with the same type and dose of medication for at least 12 months with at least 4 office or telephone visits for depression during that period.	**9**	**IF** a vulnerable elder has experienced three or more episodes of depression, **THEN** he or she should receive continuing treatment for at least 12 months during which the general practitioner provides adequate monitoring.	Major change; focus not on medication.
		10	**IF** a vulnerable elder has comorbid dementia or a somatic disease, **THEN** an existing depression should still be treated. (**NEW**)	

	Diabetes			
1	**IF** a vulnerable elder has diabetes, **THEN** glycated hemoglobin should be measured annually.	**1**	**IF** a vulnerable elder has diabetes, **THEN** glycated hemoglobin should be measured at least annually.	
2	**IF** a vulnerable elder has an elevated HgbA1c, **THEN** a therapeutic intervention should occur: • HgbA1c 9-10.9%: Within 3 months • HgbA1c ≥11%: Within 1 month	**2**	**IF** a vulnerable elder has a fasting glucose level between 4 and 7 mmol/l, **THEN** the general practitioner should initiate a therapeutic intervention within 3 months or should document why this did not happen.	
3	**IF** a diabetic vulnerable elder does not have established renal disease and is not receiving an ACE inhibitor or ARB, **THEN** a test for proteinuria should be done annually.	**3**	**IF** a diabetic vulnerable elder does not have established renal disease and is not receiving an ACE inhibitor or ARB, **THEN** a test for creatinine clearance should be done annually.	
4	**IF** a diabetic vulnerable elder has proteinuria, **THEN** an ACE inhibitor or ARB should be prescribed.	**-**	**-**	Not enough evidence exists to support this indicator.
5	**IF** a vulnerable elder has diabetes, **THEN** a foot exam should be performed annually.	**4**	**IF** a vulnerable elder has diabetes, **THEN** a foot exam should be performed annually.	
6	**IF** a diabetic, vulnerable elder is not blind, and did not have retinopathy on a previous examination, **THEN** s/he should have a retinal eye examination performed by a specialist every 2 years.	**5**	**IF** a diabetic, vulnerable elder is not blind, and did not have retinopathy on a previous examination, **THEN** s/he should have a retinal eye examination or fundus photography performed every 2 years.	
7	**IF** a vulnerable elder has diabetes, **THEN** blood pressure should be measured at each primary care visit.	**6**	**IF** a vulnerable elder has diabetes, **THEN** the general practitioner should measure the blood pressure annually or for deviant values every 3 months.	

8	IF a diabetic vulnerable elder has a persistent (on 2 consecutive visits) elevation of systolic BP >130 mm Hg, THEN an intervention (pharmacologic, lifestyle, compliance, etc.) should occur or there should be documentation of a reversible cause/other justification for the elevation.	**7**	**IF** a diabetic vulnerable elder has a persistent (on 2 consecutive visits) elevation of systolic BP >140 mm Hg, **THEN** the general practitioner should initiate an intervention (pharmacologic, lifestyle, compliance, etc.) or there should be documentation of a reversible cause/other justification for the elevation or a reason why an intervention was not done.	
9	**IF** a diabetic vulnerable elder is not on anticoagulant/antiplatelet therapy, **THEN** daily aspirin should be prescribed.	**-**	**-**	Not enough evidence exists to support this indicator. Dutch guideline deviates from US indicator; this document mentions that it is not sure if this therapy is effective and safe for diabetes-elderly based on publications in Heart and JAMA.
10	**IF** a diabetic vulnerable elder has fasting LDL >130 mg/dl, **THEN** a pharmacologic or lifestyle intervention should be offered.	**-**	**-**	Not enough evidence exists to support this indicator and deviant from Dutch guideline.

	End of Life Care			
1	**IF** a vulnerable elder dies with metastatic cancer, dementia, or a progressive incurable disease, **THEN** there should be evidence within 6 months prior to death that they received a comprehensive assessment including: • Pain and other symptoms • Spiritual and existential concerns • Caregiver burdens/need for practical assistance • Advance care planning	**1**	**IF** a vulnerable elder dies with a progressive incurable disease (for example metastatic cancer, or dementia) **THEN** there should be evidence within 6 months prior to death that they received a comprehensive assessment including: • Pain; • Anxiety, depression; • Vomiting and dyspnea; • Spiritual and existential concerns; • Caregiver burdens/need for practical assistance; • Wishes concerning medical treatment and care at the end of life; • A discussion about and if possible the determination of a surrogate decision maker.	
13	**IF** a vulnerable elder is diagnosed with lung cancer or cancer metastatic to lung, NYHA Class III-IV congestive heart failure, or oxygen dependent pulmonary disease, **THEN** a self-reported assessment of dyspnea should be documented in the outpatient chart.	**-**	**-**	No agreement between Dutch panelists.
14	**IF** a vulnerable elder with metastatic cancer or oxygen dependent pulmonary disease has dyspnea refractory to non-opiate medications, **THEN** opiate medications should be offered.	**2**	**IF** a vulnerable elder with metastatic cancer or oxygen dependent pulmonary disease has dyspnea refractory to non-opiate medications, **THEN** opiate medications should be offered.	

15	**IF** a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, **THEN** the chart should document dyspnea care and follow-up.	**3**	**IF** a vulnerable elder who had dyspnea in the last 7 days of life died an expected death, **THEN** the general practitioners record should document a dyspnea policy (including interventions).	
17	**IF** a vulnerable elder who was conscious during the last 7 days of life died an expected death, **THEN** the medical record should contain documentation about presence/absence of pain during the last 7 days of life.	**4**	**IF** a vulnerable elder who was conscious during the last 7 days of life died an expected death, **THEN** the general practitioners record should document a pain policy (including interventions).	
	IF a cognitively intact vulnerable elder who was conscious during the last 7 days of life died an expected death, **THEN** the medical record should contain documentation about a discussion of spirituality or how the patient was dealing with death or religious feelings.	**-**	**-**	Considered not important to be in QI set; in the Netherlands this is not an issue to be addressed by the general practitioner.
21	**IF** a vulnerable elder is a caregiver for a spouse/significant other/dependent that is terminally ill or has very limited function, **THEN** the vulnerable elder should assessed for caregiver financial, physical, and/or emotional stress.	**5**	**IF** a vulnerable elder is a caregiver for a spouse/significant other/dependent that is terminally ill or has very limited function, **THEN** the vulnerable elder should be assessed for caregiver financial, physical, and/or emotional stress.	
22	**IF** a vulnerable elder's spouse/significant other dies, **THEN** the vulnerable elder should be assessed for depression or thoughts of suicidality within 6 months	**6**	**IF** a vulnerable elder's spouse/significant other dies, **THEN** the vulnerable elder should be assessed for depression or thoughts of suicidality within 6 months.	

	Falls/ mobility			
1	**ALL** vulnerable elders should have documentation that they were asked annually about the occurrence of recent falls.	**-**	**-**	No agreement between Dutch panelists.
2	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of a basic fall history (circumstances, medications, chronic conditions, mobility, alcohol intake) within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	**1**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year, **THEN** the general practitioner should document a basic fall history (including type and circumstances of the falls, and possible contributing factors like medication, chronic conditions, alcohol intake) within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	
3	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of orthostatic vital signs (blood pressure and pulse) within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	**-**	**-**	No agreement between Dutch panelists.
4	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of receipt of an eye exam in the past year, or evidence of visual acuity testing within 3 months of the reported history.	**2**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year, **THEN** the general practitioner should document receipt of an eye exam in the past year, or evidence of visual acuity testing within 3 months of the reported history.	

5	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of a basic gait, balance, and strength evaluation within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	**3**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year, or has worsening difficulty with ambulation, balance, or mobility, **THEN** the general practitioner should document a basic gait, balance, and strength evaluation within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	
7	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of an assessment of cognitive status in the past 6 months or within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	**4**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year, **THEN** the general practitioner should document an assessment of cognitive status in the past 6 months or within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	
8	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year, **THEN** there should be documentation of an assessment and modification of home hazards recommended in the past year or within 3 months of the reported history.	**5**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year, **THEN** the general practitioner should document an assessment and modification of home hazards recommended in the past year or within 3 months of the reported history.	

9	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year and is taking a benzodiazepine, **THEN** there should be documentation of a discussion of related risks and assistance offered to reduce/discontinue benzodiazepine use.	**6**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year and is taking a benzodiazepine, **THEN** the general practitioner should document a discussion of related risks and assistance offered to reduce/discontinue benzodiazepine use.	
	IF a vulnerable elder reports a history of two or more falls (or one fall with injury) in the past year, **THEN** there should be documentation of footwear review at least once in the past year, or no more than three months from when the history of falls is reported to the provider.	**-**	**-**	No agreement between Dutch panelists.
11a	**IF** a VE demonstrates decreased balance/proprioception or increased postural sway AND does not have an assistive device, **THEN** an evaluation/prescription for an assistive device should be offered within 3 months.	**7**	**IF** a vulnerable elder demonstrates decreased balance/proprioception or increased postural sway AND does not have an assistive device, **THEN** an evaluation/prescription for an assistive device should be offered within 3 months.	
11b	**IF** a VE reports a history of ≥ 2 falls (or 1 fall with injury) in the past year AND has an assistive device, **THEN** there should be documentation of an assistive device review in the past 6 months or within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	**8**	**IF** a vulnerable elder reports a history of ≥ 2 falls (or 1 fall for which the elder visits the general practitioner) in the past year AND has an assistive device, **THEN** there should be documentation of an assistive device review in the past 6 months or within 3 months of the reported history (or within 4 weeks, if the most recent fall occurred in the past 4 weeks).	

12	**IF** a VE is found to have a problem with gait, balance, strength, or endurance, **THEN** there should be documentation of a structured/supervised exercise program offered in the past 6 months or within 3 months of noting the problem.	**9**	**IF** a vulnerable elder is found to have a problem with gait, balance, strength, or endurance, **THEN** there should be documentation of a structured/supervised exercise program offered in the past 6 months or within 3 months of noting the problem.	
	Medication use			
1	**IF** a vulnerable elder is prescribed a drug, **THEN** the prescribed drug should have a clearly defined indication.	**1**	**IF** a vulnerable elder is prescribed a drug, **THEN** the prescribed drug should have a clearly defined indication.	
2	**IF** a vulnerable elder is prescribed a drug, **THEN** the vulnerable elder (or a caregiver) should receive appropriate education about its use.	**2**	**IF** a vulnerable elder is prescribed a drug, **THEN** the vulnerable elder (or a caregiver) should receive appropriate education about its use.	
3	**ALL** vulnerable elders should have an up-to-date medication list readily available in the medical record, accessible by all healthcare providers, and including over-the-counter medications.	**3**	**ALL** vulnerable elders should have an up-to-date medication list readily available in the general practitioners record, accessible by all healthcare providers, and including, if known, over-the-counter medications.	
4	**IF** a VE is prescribed an ongoing medication for a chronic medical condition, THEN there should be a documentation of response to therapy.	**4**	**IF** a vulnerable elder is prescribed an ongoing medication for a chronic medical condition, **THEN** there should be a documentation of response to therapy.	
5	**ALL** vulnerable elders should have an annual drug regimen review.	**5**	**ALL** vulnerable elders should have an annual drug regimen review.	
6	**IF** a vulnerable elder is prescribed warfarin, **THEN** an international normalized ratio (INR) should be determined within 4 days after initiation of therapy and at least every 6 weeks thereafter.	**6**	**IF** a vulnerable elder is prescribed an oral anticoagulant by the Dutch Thrombosis Service or otherwise, **THEN** this should be clearly marked in the general practitioners record.	

7	**IF** a vulnerable elder is prescribed an ACE inhibitor, **THEN** s/he should have serum creatinine and potassium monitored within 2 weeks after initiation of therapy and at least yearly thereafter.	**7**	**IF** a vulnerable elder is prescribed an ACE inhibitor, **THEN** s/he should have serum creatinine and potassium monitored within 2 weeks after initiation of therapy and at least yearly thereafter.	
8	**IF** a vulnerable elder is prescribed a loop diuretic, **THEN** he or she should have electrolytes checked within 2 weeks after initiation and at least yearly thereafter.	**8**	**IF** a vulnerable elder is prescribed a loop diuretic, **THEN** s/he should have electrolytes checked within 2 weeks after initiation and at least yearly thereafter.	
10	**IF** a vulnerable elder is taking a benzodiazepine (>1 month), **THEN** there should be annual documentation of discussion of risks and attempt to taper and discontinue the benzodiazepine.	**9**	**IF** a vulnerable elder is taking a benzodiazepine (>2 weeks), **THEN** the general practitioner should stop or taper this treatment, unless documented discussion with the patient provides counterarguments.	
11	**ALL** VEs should not be prescribed any medication with strong anticholinergic effects if alternatives are available.	**10**	**ALL** vulnerable elders should not be prescribed any medication with strong anticholinergic effects if alternatives are available.	
12	**IF** a vulnerable elder does not require seizure control, **THEN** barbiturates should not be used.	**-**	**-**	Considered not important to be in QI set; situation hardly ever occurs in the Netherlands.
13	**IF** a vulnerable elder requires analgesia, **THEN** meperidine should not be prescribed.	**-**	**-**	Considered not important to be in QI set; situation hardly ever occurs in the Netherlands.
14	**IF** a vulnerable elder receives ketoralac **THEN** it should not be prescribed for >5 days.	**-**	**-**	Medication is not available in the Netherlands.
15	**IF** a VE receives prescription pharmacological treatment for back or neck pain, **THEN** for >1 week. cyclobenzaprine, methocarbamol, carisoprodol, chlorzoxasone, orphenadine, tizanidine, or metaxolone should not be prescribed.	**-**	**-**	Considered not important to be in QI set; situation hardly ever occurs in the Netherlands.

16	**IF** a vulnerable elder has had a recent stroke or myocardial infarction, has peripheral arterial disease, or acute coronary syndrome that will be treated medically or with a percutaneous angioplasty, and the patient requires antiplatelet therapy, **THEN** clopidogrel should be prescribed rather than ticlopidine.	**-**	**-**	Medication is not available in the Netherlands.
17	**IF** a vulnerable elder has iron deficiency anemia, **THEN** no more than 1 tablet daily of low-dose oral iron should be prescribed	**-**	**-**	Not enough evidence exists to support this indicator. Some studies show that iron supplementation has negative effects.
18	**IF** a vulnerable elder is started on an antipsychotic drug, **THEN** there should be documentation of an assessment of response within 1month.	**11**	**IF** a vulnerable elder is started on an antipsychotic drug, **THEN** the general practitioner should document a first assessment of response within 1 week.	
	NSAID and ASA Use			
20	**IF** a vulnerable elder is prescribed an NSAID (non-selective or selective), **THEN** gastrointestinal bleeding risks should be discussed and documented.	**12**	**IF** a vulnerable elder is prescribed a NSAID (non-selective or selective), **THEN** the general practitioner should document a discussion or consideration of gastrointestinal bleeding risks.	
21	**IF** a vulnerable elder is prescribed low-dose (≤ 325 mg/day) aspirin, **THEN** the vulnerable elder should be advised of the associated gastrointestinal bleeding risks.	**13**	**IF** a vulnerable elder is prescribed low-dose (≤ 325 mg/day) aspirin, **THEN** the general practitioner should consider the associated gastrointestinal bleeding risks and advise the vulnerable elder accordingly.	

22	**IF** a vulnerable elder is prescribed chronic high-dose acetaminophen (≥ 3 grams/day) OR a vulnerable elder with liver disease is prescribed chronic acetaminophen **THEN** s/he should be advised of the risk of liver toxicity.	**14**	**IF** a vulnerable elder is prescribed chronic high-dose acetaminophen (≥ 3 grams/day) OR a vulnerable elder with liver disease is prescribed chronic acetaminophen **THEN** s/he should be advised of the risk of liver toxicity	
	IF a vulnerable elder is prescribed an NSAID, **THEN** the medical record should indicate whether or not s/he has a history of 1) gastrointestinal bleeding or ulcers and 2) renal insufficiency **AND**, if a history is present, justification of NSAID use should be documented.	**15**	**IF** a vulnerable elder is prescribed an NSAID, **THEN** the GP record should indicate whether or not s/he has a history of 1) gastrointestinal bleeding or ulcers and 2) renal insufficiency or 3) heart failure **AND**, if a history is present, the general practitioner should document justification of NSAID use.	
23	**IF** a vulnerable elder is treated with a non-selective NSAID (or a COX-2 selective NSAID and a daily aspirin) AND the vulnerable elder has risk factors for gastrointestinal bleeding, **THEN** s/he should be treated concomitantly with either misoprostol or a proton pump inhibitor.	**16**	**IF** a vulnerable elder is treated with a NSAID, **THEN** s/he should be treated concomitantly with either misoprostol or a proton pump inhibitor.	
	IF a vulnerable elder is treated with daily NSAIDs (selective or nonselective) AND the vulnerable elder has risk factors for developing renal insufficiency, THEN a serum creatinine should be assessed at baseline and at least once in the first year following the initiation of therapy.	**17**	**IF** a vulnerable elder is treated with daily NSAIDs (selective or nonselective) AND the vulnerable elder has risk factors for developing renal insufficiency, **THEN** serum creatinine should be assessed at baseline and at least once in the first year following the initiation of therapy.	

	Undernutrition			
1	**ALL** vulnerable elders should be weighed at each primary care visit and weights documented in the medical record.	**-**	**-**	No agreement between Dutch panelists.
2	**ALL** vulnerable elders should be recommended to take 1-2 multivitamins daily.	**-**	**-**	Not enough evidence exists to support this indicator.
3	**ALL** vulnerable elders in stable health states should take 800 IU (or equivalent) of vitamin D supplementation daily.	**1**	**ALL** vulnerable elders in stable health states should take 800 IU (or equivalent) of vitamin D supplementation daily.	
5	**IF** a vulnerable elder has involuntary weight loss of ≥ 10% of body weight in ≤1 year, **THEN** weight loss (or a related disorder) should be documented in the medical record as recognition of undernutrition as a potential problem.	**2**	**IF** a vulnerable elder has involuntary weight loss of ≥ 10% of body weight in ≤1 year, **THEN** the general practitioner should document weight loss (or a related disorder) as recognition of undernutrition as a potential problem.	

6	**IF** a vulnerable elder has involuntary weight loss of ≥10% in ≤1 year or hypoalbuminemia (<3.5 g/dL), **THEN** s/he should be evaluated for potentially reversible causes of poor nutritional intake including assessment of: • Dental status (e.g., reference to dentition, gum health, dental referral) • Food security (e.g., financial status, social work referral) • Food-related functional status (e.g., ability to feed, prepare meals) • Appetite and intake (e.g., 72-hour calorie count, dietitian referral) • Swallowing ability (e.g., bedside swallowing study, swallowing study referral) • Dietary restrictions (e.g., low salt or low protein diet).	**3**	**IF** a vulnerable elder has involuntary weight loss of ≥10% in ≤1 year or hypoalbuminemia (<3.5 g/dl), **THEN** s/he should be evaluated for potentially reversible causes of poor nutritional intake including assessment of: • Dental status (e.g., reference to dentition, gum health, dental referral); • Food security (e.g., financial status, social work referral); • Food-related functional status (e.g., ability to feed, prepare meals); • Appetite and intake (e.g., 72-hour calorie count, dietitian referral); • Swallowing ability (e.g., bedside swallowing study, swallowing study referral); • Dietary restrictions (e.g., low salt or low protein diet).	

7	**IF** a vulnerable elders has involuntary weight loss of ≥10% in ≤1 year or hypoalbuminemia (< 3.5 g/dL), THEN s/he should be evaluated for potentially relevant comorbid conditions, including assessment of: • Medications associated with decreased appetite (e.g., digoxin, SSRIs, amphetamines) • Depression (e.g., Geriatric Depression Scale or other screen) • Cognitive impairment (e.g., MMSE or other dementia screen) • Thyroid function • Work up for cancer, diabetes, malabsorption (e.g., exam of lymph nodes, breast, abdomen, prostate; CBC, erythrocyte sedimentation rate, and comprehensive metabolic panel)	**4**	**IF** a vulnerable elders has involuntary weight loss of ≥10% in ≤1 year or hypoalbuminemia (< 3.5 g/dl), THEN s/he should be evaluated for potentially relevant comorbid conditions, including assessment of: • Medications associated with decreased appetite (e.g., digoxin, SSRIs, amphetamines); • Depression; • Cognitive impairment; • Thyroid function; • Cancer, diabetes, malabsorption (e.g., exam of lymph nodes, breast, abdomen, prostate; CBC, erythrocyte sedimentation rate, and comprehensive metabolic panel).	
11	**IF** a vulnerable elder is prescribed oral nutritional supplements, **THEN** the supplements should be used between meals rather than with meals.	**-**	**-**	Considered not important to be in QI set; not relevant.
	IF a vulnerable elder sustains a hip fracture, **THEN** the patient should receive oral multinutrient supplements.	**-**	**-**	No agreement between Dutch panelists.
		5	**IF** a vulnerable elder has an advanced stage of COPD, **THEN** the general practitioner should monitor the elder's body weight and recommend energy-enriched food. (**NEW**)	
		6	**IF** a vulnerable elder is at risk of, or suffering from, decubitus, **THEN** the general practitioner should consult a dietician. (**NEW**)	

Care for vulnerable older persons: need, utilization and appropriateness

Currently 6.5% of the total Dutch population is aged 75 and over. Due to the aging of the population this number will rise to 11% in 2030. Aging of a population leads to an increase in the number of persons with certain diseases and in the number of persons with multi-morbidity (two or more chronic diseases). Furthermore, impairments which influence daily functioning will be more prevalent, like problems with mobility, urine-incontinence and sensory problems. A concept that is relatively new to describe the multiple problems that older persons often experience is vulnerability/frailty. Vulnerability in this thesis is defined as a poor functional health status that resulted from an interplay of physical, psychological and social factors and leads to decreased reserves and diminished resistance to stressors. Consequently, if the health status of a vulnerable person further diminishes, because of worsening of an already existing problem or the occurrence of a new problem, it will easily lead to adverse health outcomes, like mortality and admission to hospital, residential care or nursing homes.

The overall aim of this thesis is to evaluate care for vulnerable community-dwelling older persons aged 75 and over. Care includes health care, but also home care, living care and psychosocial care. We focus on a chain of care decisions and actions including self-perceived care needs, care utilization and appropriateness of care. More particularly, this thesis describes the kind of care vulnerable older persons themselves feel they need, what care they actually use and what health professionals think is appropriate care for them. Chapters 2, 3 and 4 focus on vulnerability and self-perceived need. Chapters 5 and 6 on current health care utilization and in 2030 and its link with self-perceived need. Chapter 7 and 8 concern appropriateness of care for vulnerable older persons.

About one third of persons aged 75 and over is vulnerable according to our definition. **Chapter 2** explores the prognosis of vulnerability and groups that are possibly at risk of remaining vulnerable. This study shows that between 15 and 25% of persons recovered to a non-vulnerable status. The older a person is and the more depressive symptoms they report the higher the risk that a person remains vulnerable as well. **Chapter 3** describes the type and number of self-perceived needs vulnerable older persons report using the Camberwell Assessment of Need in the Elderly (CANE) interview. A majority reported needs in the physical and environmental domains. However the highest percentages of unmet needs were reported on the psychosocial topics, which might signify a gap in health care. The overall number of unmet needs was low, which might be explained by good health care or underreporting. This study also explored risk indicators of total number of needs and presence of environmental, physical, psychological and social needs. The most important risk indicator is the hours that a person is active (e.g. walking, cleaning home and physical exercise); persons who are less than two hours active in the last three days report more needs in total and for all domains of need separately. In **Chapter 4** we compared a measure of self-perceived need with a measure of objectively established need. Agreement

ranged from poor to substantial and was lower when persons had impaired cognition and depressive symptoms.

The link between self-perceived need and health care utilization in vulnerable older persons was described in **Chapter 5**. Self-perceived need was strongly associated with general practitioner visits, home care concerning domestic tasks and acute and total hospital admission even when added to a model with predisposing, enabling and evaluated (or objective) need variables. Most associations of self-perceived need with health care utilization were obvious, for example persons who reported sufficient help (i.e. a met need) for support for household activities self-evidently used more IADL care per week than persons with no such need. More striking were the findings that unmet needs for depression was associated with more GP visits and lack of information on a physical condition with to more hospital admission. **Chapter 6** aimed to predict the number of vulnerable older persons and their health care utilization in 2030. Although the use of epidemiological modeling has its limitations and the numbers should not be interpreted rigidly, it shows that the aging of the Dutch population will lead to approximately a doubling of the number of vulnerable persons and consequently also a doubling of their health care utilization. Targeting depressive symptoms by improving detection and treatment will lead to large reductions in vulnerability, but small reductions of health care utilization in the total population aged 75 and over.

Chapter 7 describes the development of a set of quality indicators describing appropriate care for vulnerable older persons for the conditions Continuity and Coordination of care, Depression, Dementia, End of life care, Type 2 Diabetes Mellitus, Medication use, Mobility and falls and Undernutrition. The American ACOVE indicators were a good starting point to develop a this set. Most differences were due to different emphasis on or different interpretation of the existing literature for some conditions and lack of literature for other conditions. For Depression large differences in appropriateness of care between the US and Dutch set existed; in the US there is a focus on medication as first/main treatment option, whereas in the Netherlands this is not the first treatment option by all means. **Chapter 8** describes the outcomes of explorative interviews with 13 general practitioners on adherence to diabetes and depression quality indicators and barriers to provide appropriate care for these conditions. Adherence for diabetes indicators was generally higher and the barriers identified were carefully balanced decisions on the general practitioners' part (e.g. not wanting to burden a persons with short life expectancy), whereas overall adherence to depression indicators was lower and the barriers identified might point to possible improvements in general practice.

In **Chapter 9** the findings are summarized and discussed. We concluded that vulnerability is highly prevalent in persons aged 75 and over and most vulnerable persons remain vulnerable over time. Vulnerable older persons report many needs, but little unmet needs. They make more use of health services than non-vulnerable

persons. Our estimation of number of vulnerable persons and their health care utilization in 2030 shows an enormous increase in number of vulnerable persons and their health care utilization as a consequence of the aging of the Dutch population. This finding is alarming, since the Dutch health care system is already strained and in its current form will not be able to tackle the increase in (vulnerable) older persons and their health care utilization. Reducing depressive symptoms has a large effect on the number of vulnerable persons, but a much smaller effect on health care utilization in the total population aged 75 and over. We were able to develop a set of quality indicators describing appropriate care for this group and test some indicators in practice. One of the conclusions was that within the group of vulnerable older persons a distinction should be made for persons with severe health problems (severe dementia or short life expectancy). Agreement on Depression indicators was low between the US and the Netherlands, but also between Dutch general practitioners.

This study had some limitations. First, the most vulnerable persons were lost to follow-up. Second, the region where the study was conducted might be slightly healthier that other Dutch populations. Both these limitations are associated with an underestimation of number of needs and use of health services and an overestimation of the recovery-percentage. Our definition of vulnerability is different from other frailty definitions; persons who are physically frail might have a worse health condition which than leads to more needs and care utilization. Last, for the study on appropriateness we can not be sure if all health professionals had the same group in mind when formulating or judging indicators for vulnerable older persons.

The main recommendations in this thesis are:
1) in view of the approaching aging of the population, vulnerability and its adverse health outcomes should be reduced, and;
2) depressive symptoms should be better detected and treated in vulnerable persons.

Vulnerability is highly prevalent and related to adverse health outcomes. Prevention of vulnerability or its consequences would reduce the burden on both individuals, health services and communities. This study made a start at identifying factors that might influence the outcomes of vulnerability: being active was related to self-perceived needs of vulnerable persons and depressive symptoms was related to recovery from vulnerability and the one factor that could be reduced. This study did not provide information on how to prevent vulnerability itself; more research is needed to study prevention at this level. Difficulties with depression was a recurring theme in this thesis. Relatively many unmet needs were identified for this condition and we felt that the number of needs reported was only the tip of the iceberg. Depressed persons also had inconsistent scores when comparing an objective with a subjective measure of needs; it seems that either the persons themselves or the health professionals (who conducted the objective need

measure) are not able to validly judge their needs. When persons reported a need for Depression it led to more health care utilization, especially to more GP visits. When we reduced depressive symptoms in a epidemiological model this led to small reductions in health care utilization. Furthermore, it was a risk indicator for remaining vulnerable and not being able to recover to a non-vulnerable status. As mentioned above it also was a problematic condition in the development and testing of quality indicators. It seems that many aspects of care for vulnerable persons would profit from better treatment and detection, and clearness on appropriateness of care for depression.

Zorg voor kwetsbare ouderen: behoefte, gebruik en passendheid

Op dit moment is 6,5% van de Nederlandse bevolking 75 jaar of ouder. Door de vergrijzing van de bevolking zal dit percentage stijgen tot 11% in 2030. Met de vergrijzing gaat een toename gepaard van het aantal mensen met bepaalde ziekten of combinaties van ziekten. Ook het aantal mensen met beperkingen die hun functioneren beïnvloeden – bijvoorbeeld problemen met mobiliteit en vallen, met incontinentie en met gehoor en gezicht – zal toenemen. Een concept dat relatief nieuw is om de meervoudige problemen te beschrijven die ouderen ervaren, is kwetsbaarheid. In dit proefschrift is kwetsbaarheid gedefinieerd als een slechte functionele toestand, die het gevolg is van een ongelukkig samenspel van lichamelijke, psychologische en sociale factoren. Kwetsbaarheid leidt tot een gebrek aan reserves om externe stressoren het hoofd te bieden. Als de toestand van een kwetsbaar persoon verslechtert, bijvoorbeeld door het verergeren van een bestaand probleem of het ontstaan van een nieuw probleem, leidt dit vaak tot negatieve uitkomsten als opname in een ziekenhuis of verpleeghuis en zelfs tot overlijden.

Doel van dit proefschrift is de zorg te evalueren voor kwetsbare thuiswonende ouderen (75 jaar en ouder). Met zorg bedoelen we niet alleen gezondheidszorg, maar ook zorg ten aanzien van huisvesting, huishouden en psychosociale problemen. We richten ons hierbij op een keten van zorgbeslissingen en zorgacties, namelijk zorgbehoefte, zorggebruik en passendheid van verleende zorg. Specifieker gesteld: dit proefschrift beschrijft welke zorg ouderen zelf zeggen te willen, welke zorg ouderen daadwerkelijk gebruiken en welke zorg professionals passend voor ouderen vinden. De hoofdstukken 2, 3 en 4 richten zich op kwetsbaarheid en zorgbehoefte. De hoofdstukken 5 en 6 op zorggebruik in de huidige situatie en in 2030 én de link tussen zorgbehoefte en zorggebruik. De hoofdstukken 7 en 8 beschrijven passende zorg voor kwetsbare ouderen. Hoofdstuk 9 ten slotte vat de bevindingen samen en bediscussieert deze.

Bijna een derde van de mensen van 75 en ouder is kwetsbaar volgens de definitie die in dit proefschrift wordt gebruikt. **Hoofdstuk 2** verkent de prognose van kwetsbaarheid en groepen die mogelijk meer kans maken kwetsbaar te blijven. Deze studie laat zien dat 15 tot 25% van de ouderen in staat is om van kwetsbaarheid te herstellen. Naarmate een persoon ouder is en meer depressiesymptomen rapporteert, neemt de kans ook toe dat deze persoon kwetsbaar blijft. **Hoofdstuk 3** beschrijft het soort en het aantal zorgbehoeftes die ouderen zelf rapporten als ze worden geïnterviewd met de Camberwell Assessment of Need in the Elderly (CANE-interview). Nagenoeg iedereen geeft aan behoeftes te hebben voor fysieke en omgevingsfactoren, zoals het hebben van een lichamelijke ziekte of het nodig hebben van hulp in de huishouding. Relatief de meeste onvervulde (niet verholpen) behoeftes worden gerapporteerd voor psychosociale onderwerpen, zoals depressie en behoefte aan gezelschap. Dit duidt wellicht op een lacune in de zorg. In zijn totaliteit is het aantal onvervulde behoeftes dat wordt gerapporteerd zeer laag. Dit kan gerelateerd zijn aan goede zorgverlening, maar ook te maken hebben met onderrapporteren door de ouderen.

In deze studie is ook bekeken welke factoren geassocieerd zijn met het rapporteren van behoeftes. De belangrijkste factor is of iemand fysiek actief is of niet. In **hoofdstuk 4** vergelijken we de meting van subjectieve zorgbehoefte (de CANE) met een meer objectieve meting van zorgbehoefte ingevuld door verpleegkundigen. Overeenstemming per item varieert van slecht tot substantieel. Er treden meer verschillen in scores op als ouderen problemen rapporteren met cognitie of depressiesymptomen.

Verbanden tussen zorgbehoefte en zorggebruik zijn beschreven in **hoofdstuk 5**. Subjectieve zorgbehoefte (wederom volgens de CANE) vertoont sterke associaties met het aantal keren dat een persoon de huisarts bezoekt, de hoeveelheid thuiszorg die wordt benut en het aantal malen dat een persoon wordt opgenomen in het ziekenhuis, al dan niet acuut. De meeste verbanden zijn voor de hand liggend, zoals de bevinding dat mensen die een vervulde behoefte aangeven voor hulp in het huishouden ook meer thuiszorg gebruiken dan mensen die geen behoefte rapporteren. Meer opvallende bevindingen zijn dat mensen met een onvervulde behoefte voor depressie vaker de huisarts bezoeken en dat mensen die een gebrek aan informatie ervaren over hun lichamelijke conditie (of hun ziekte), vaker worden opgenomen in het ziekenhuis. In **hoofdstuk 6** doen we een poging om het zorggebruik te voorspellen van de groep thuiswonende, kwetsbare 75-plussers in 2030. Hoewel het gebruik van epidemiologische modellen zijn beperkingen kent en de getallen niet al te rigide moeten worden geïnterpreteerd, laat de voorspelling zien dat de vergrijzing leidt tot bijna een verdubbeling van het aantal kwetsbare ouderen, en dus ook van hun zorggebruik. Symptomen van depressie zijn sterk gerelateerd aan kwetsbaarheid. Als we erin slagen het aantal ouderen met klinisch relevante symptomen van depressie drastisch terug te brengen – door betere herkenning en behandeling – leidt dit weliswaar tot een enorme afname van het aantal kwetsbare personen, maar slechts tot een matige afname van zorggebruik door de totale groep 75-plussers.

Hoofdstuk 7 geeft de ontwikkeling weer van een set kwaliteitsindicatoren die passende zorg voor kwetsbare ouderen beschrijven voor de condities Continuïteit en coördinatie van zorg, Depressie, Dementie, Terminale zorg, Diabetes, Medicijngebruik, Mobiliteit en vallen, en Ondervoeding. De in Amerika ontwikkelde ACOVE-indicatoren vormden een goede basis voor de ontwikkeling van een Nederlandse set. Verschillen tussen de Amerikaanse en Nederlandse set zijn met name toe te schrijven aan afwijkende interpretaties van bestaande literatuur of aan een gebrek aan literatuur. De grootste verschillen bestaan voor de conditie Depressie: in Amerika worden antidepressiva als eerste en belangrijkste behandeling gezien, terwijl in Nederland meerdere opties worden afgewogen en de mening van de depressieve oudere daarbij belangrijk is. **Hoofdstuk 8** beschrijft vervolgens het toetsen van enkele van de ontwikkelde indicatoren in de huisartspraktijk. In interviews met dertien huisartsen is uitgevraagd hoe vaak huisartsen zich houden aan enkele indicatoren van de condities Diabetes en Depressie en wat de redenen zijn om af te wijken van de beschreven passende

zorg. In het algemeen worden de indicatoren voor Diabetes beter gevolgd dan die voor Depressie. Bovendien zijn de redenen om ze voor Diabetes niet op te volgen vaak gerelateerd aan zorgvuldige afwegingen door de huisarts (bijvoorbeeld het niet willen belasten van een oudere met een korte levensverwachting), terwijl de redenen om niet-passende Depressiezorg te verlenen vaak minder weloverwogen zijn.

In **hoofdstuk 9** worden de bevindingen samengevat en bediscussieerd. We concluderen dat kwetsbaarheid veel voorkomt onder 75-plussers en dat de meeste mensen kwetsbaar blijven als ze het eenmaal zijn. Kwetsbare ouderen rapporteren veel behoeftes, maar weinig onvervulde behoeftes. Wel maken ze meer gebruik van zorgvoorzieningen dan niet-kwetsbare personen. Onze schatting van het aantal kwetsbare ouderen en hun zorggebruik in 2030 laat een enorme toename zien in aantallen kwetsbaren, en dus hun zorggebruik, als gevolg van de vergrijzing. Dit is alarmerend, omdat het Nederlandse gezondheidssysteem momenteel al onder druk staat. Het is zeer de vraag of het deze toename aankan. Het terugbrengen van het aantal depressieve mensen onder de kwetsbare ouderen leidt tot een kleine afname van zorggebruik binnen de totale groep van 75-plussers. We hebben een set van kwaliteitsindicatoren ontwikkeld die passende zorg voor kwetsbare ouderen beschrijven en hebben enkele van deze indicatoren in de praktijk getest. Een van conclusies is dat binnen de groep kwetsbare ouderen een uitsplitsing moet worden gemaakt naar mensen met ernstige gezondheidsproblemen (zoals ernstige dementie of een lage levensverwachting) en mensen met minder ernstige gezondheidsproblemen. Overeenstemming over Depressie-indicatoren was laag: tussen Amerika en Nederland, maar ook tussen Nederlandse huisartsen.

De beschreven studies hebben enkele beperkingen. Allereerst zijn de meest kwetsbare personen uit de studie weggevallen als gevolg van de duur van de studie. Verder staat de regio waar de studie plaatsvond bekend als enigszins gezonder dan andere Nederlandse regio's. Deze twee beperkingen zijn beide geassocieerd met een onderschatting van het aantal (onvervulde) zorgbehoeftes en het zorggebruik én een overschatting van het aantal mensen dat in staat is te herstellen van kwetsbaarheid. Onze definitie van kwetsbaarheid wijkt af van definities, gebruikt in andere studies; mensen die kwetsbaar zijn volgens een meer fysieke definitie hebben waarschijnlijk een slechtere gezondheid, en dus meer zorgbehoeftes en zorggebruik. Als laatste kunnen we er wat betreft de studies over passendheid van zorg niet zeker van zijn dat alle deelnemende artsen dezelfde groep in gedachten hebben gehad bij hun beoordeling van de indicatoren.

De belangrijkste aanbevelingen op basis van de bevindingen in dit proefschrift zijn de volgende.
1. Met het oog op de aanstaande vergrijzing dienen zowel kwetsbaarheid als de negatieve gevolgen daarvan te worden teruggebracht.

2. Depressiesymptomen bij kwetsbare ouderen moeten beter worden herkend en behandeld.

Kwetsbaarheid komt veel voor en is gerelateerd aan negatieve uitkomsten. Preventie van kwetsbaarheid of van de negatieve uitkomsten zou de last verminderen voor zowel individuen als zorgverleners en de maatschappij als geheel. Deze studie heeft een begin gemaakt met het identificeren van factoren die mogelijk gerelateerd zijn aan de negatieve consequenties van kwetsbaarheid; actief zijn is gerelateerd aan het aantal zorgbehoeftes dat kwetsbare ouderen rapporteren en depressiesymptomen zijn gerelateerd aan herstel van kwetsbaarheid. Deze studie heeft niet bekeken hoe kwetsbaarheid zelf is te voorkomen; toekomstig onderzoek is nodig om de mogelijkheden hiervan te bestuderen. Problemen met depressie(symptomen) zijn een terugkerend thema in dit proefschrift. Relatief veel onvervulde behoeftes werden voor dit item gerapporteerd. Bovendien hebben we het gevoel dat het aantal behoeftes dat voor Depressie wordt gerapporteerd slechts het topje van de ijsberg is. Depressieve personen hebben inconsistente scores op de subjectieve en objectieve maat van zorgbehoefte. En dat wijst erop dat de ouderen zelf of hun zorgverleners (die de objectieve maat afnamen) hun behoeftes niet goed kunnen inschatten. Als ouderen een behoefte voor Depressie rapporteren, maken ze vaker gebruik van zorgvoorzieningen en dan met name van de huisarts. Het terugbrengen van depressie in het epidemiologische model leidt dan ook tot een kleine afname van zorggebruik. Vervolgens is depressie ook nog eens gerelateerd aan mogelijk herstel van kwetsbaarheid. Als laatste – en zoals al eerder vermeld – is het een moeizame conditie voor het ontwikkelen van kwaliteitsindicatoren en de implementatie daarvan. Het lijkt erop dat vele aspecten van zorg voor kwetsbare ouderen zouden profiteren van het verbeteren van de herkenning en de behandeling van depressie en depressiesymptomen.

Dankwoord

Dit boekje is tot stand gekomen in samenwerking met vele anderen. De meeste mensen die ik hieronder bedank, beschikken over meer kwaliteiten dan ik vermeld, maar ik richt me op de meest in het oog springende.

Beste Henk (Rigter), zonder jou was het project er sowieso niet geweest. Ik ben blij dat je het hebt geïnitieerd en ZonMw hebt kunnen overtuigen van onze aanpak met het prachtig geschreven voorstel. Toen het project meer van je vroeg dan jouw agenda je toestond, heb je besloten een stap terug te doen. Pas later in mijn project heb ik me gerealiseerd wat een onconventionele stap dat was. Dat verdient alle waardering. Ook daarna heb je overigens met betrokkenheid en precisie mijn stukken becommentarieerd.
Hein en Marja, uiteindelijk is mijn dagelijkse begeleiding een duobaan voor jullie beiden geworden, omdat jullie elkaar (en mij) zo goed aanvullen. Hein (van Hout), voor mij ben je de man van de eindeloze stroom ideeën. Ideeën voor onderzoeksvragen, ideeën voor net iets andere invalshoeken voor een artikel, ideeën voor nieuwe artikelen, ideeën voor tijdschriften om artikelen in te dienen, ideeën voor vervolgonderzoek. Het was fijn om naar jou te luisteren, een en ander te noteren en te overdenken. Zo werd altijd helder welke van jouw goede ideeën het beste paste in mijn project. Marja (Depla), bij jou is het sleutelwoord precisie. Je wist me altijd te vragen wat dan precies de definitie was van 'zusenzo' en je nam geen genoegen met een 'ik geloof'-antwoord. Dat heeft me scherper gemaakt op dit vlak, een kwaliteit die ik in de toekomst zeker nodig zal hebben. Hetzelfde geldt voor je vraag om consequentie in mijn stukken. Je hebt heel vaak de puntjes op de i gezet.
Giel (Nijpels), van jou zullen me twee dingen altijd bijblijven. Allereerst het feit dat je een prachtige onderzoeksinfrastructuur in West-Friesland en veel goodwill hebt opgebouwd. Het noemen van je naam heeft deuren geopend die ik zelf nooit had kunnen openen. Zo namen dertien huisartsen een halfuur de tijd om met mij te praten over hun oudere patiënten: een unicum in Nederlands onderzoeksland! Het tweede is je enthousiaste, zeer positieve manier van stukken becommentariëren met veel aandacht voor de dingen die goed waren en vervolgens kritische aanvullingen.
Johan (Mackenbach), na de stap terug van Henk, ben jij betrokken geraakt bij mijn project. Ik heb veel van je geleerd. Op de eerste plaats heb je door jouw rust mij veel rust gegeven. Tijdens vergaderingen en het becommentariëren van stukken legde je altijd de vinger op de zere plek, maar op een diplomatieke wijze. Overleggen waren vaak intens en leidden tot rode wangen aan mijn kant, omdat ik zo hard moest nadenken. Maar altijd resulteerden ze in een verbetering in onderzoeksopzet of artikel. Het was een groot genoegen met je te werken en ik hoop dat het in de toekomst nog eens een vervolg krijgt.

Naast het onderzoeksteam moet ik nog enkele mensen bedanken voor hun begeleiding. Allereerst Anne Margriet (Pot), juist als relatieve buitenstaander heb je me enorm geholpen door op sommige momenten een luisterend oor en advies te geven. Verder heb je me, ondanks mijn detachering, volledig laten meedraaien in

het Programma Ouderen en mij kansen geboden om allerlei dingen te doen die niet gebruikelijk zijn voor jonge onderzoekers, zoals het organiseren van de Ti-dag en het schrijven van een acquisitieaanvraag. Ik hoop dat je je enthousiasme voor het werken met jonge mensen altijd houdt, want het is stimulerend en inspirerend. Jacobijn Gussekloo en Pim Assendelft, we hebben alleen samengewerkt in de opstartfase van het appropriateness-deel, maar wat mij betreft was dat aangenaam en gaf het me de sturing die ik toen nodig had. Bedankt daarvoor. Last but not least, Paul (Shekelle). Working with Americans is always a pleasure due to their unlimited supply of ideas and enthusiasm, but you combined this with a refreshing, un-American openness and honesty. It was great to meet you in both Leiden and Santa Monica (with the unforgettable weather and beach). After talking to you I felt 'bubbly' and eager to take all actions we had just decided on. Although I still believe I chose the best suited post-doc job, I do regret not getting to work with you at RAND.

Natuurlijk ben ik ook veel dank verschuldigd aan alle kwetsbare ouderen in West-Friesland die ondanks hun vaak slechte gezondheidstoestand bereid waren vele vragen, zowel schriftelijk als mondeling, te beantwoorden. Ik heb met veel plezier enkele interviews mogen bijwonen en genoten van de diversiteit van deze groep ouderen. Ik zal nooit de dag vergeten dat ik bij meneer Wolf binnen liep en we direct vrienden waren. Ook al is dat weer lang geleden; ik hoop hem op mijn promotie te kunnen verwelkomen. Dat ik sowieso bij de ouderen terecht kon was te danken aan de thuiszorgorganisatie De Omring, en in het bijzonder Mini van der Horst, die ook de verpleegkundigen leverde om het RAI af te nemen. Via de VU werd dit team aangevuld met interviewers om de CANE af te nemen. Zonder Marja Tames, Gonny van der Ploeg, Tineke Sijm, Louise Schenk, Ank Putters, Evelyn Mus-Mulder, Annie Vertelman, Corine Grooteman, Gerda List, Gesina Kroeze, Marga Smal, Nel Truyens en Marian van Schagen was het nooit gelukt om alle data te verzamelen. Bedankt voor alle geduld en inzet! Vanuit de VU is de logistiek van de survey gecoördineerd: ik wil Evelyn Mus-Mulder, Paulien Hoekstra en Willemijn Tybout hiervoor bedanken. Hoewel het een contact op afstand was waren jullie altijd bereid mijn vragen te beantwoorden en dingen voor me uit te zoeken. Bovendien hadden jullie vaak al een oplossing als een probleem net de kop op stak. Het was voor mij een fijn gevoel dat ik dit met gerust hart aan jullie heb over kunnen laten. Als laatste heb ik ook samengewerkt met Nelleke van 't Veer en Danielle Jansen die aanverwant onderzoek deden in dezelfde regio. Ook jullie waren altijd bereid prangende vragen te beantwoorden, maar het was vooral ook gezellig om jullie af en toe te zien! Van het ErasmusMC ben ik met name Else van den Engel en Anja Bik veel dank verschuldigd voor het maken en verzetten van mijn afspraken met Johan en het verwerken van mijn reisdeclaraties. En natuurlijk de praatjes voorafgaand aan die afspraken. Als ze niet beschikbaar waren, was altijd Sonja Deurloo er nog. Op een gegeven moment ben ik je gewoon mailtjes blijven sturen, omdat ik altijd blij werd van jouw enthousiaste en soms knotsgekke reacties. Als laatste wil ik Caspar Looman en Gerard Borsboom bedanken voor de ondersteuning en het meedenken bij de modelbouw.

Voor ik bij het bedanken van mijn collega's op mijn daadwerkelijke werkplek (het Trimbos-instituut) kom wil ik nog een uitstap maken naar alle artsen en onderzoekers die hebben mee gewerkt aan de panelbijeenkomst en de daarop volgende interviews. Allereerst wil ik de voorbewerkers van de dossiers bedanken voor hun heldere input en aanvullingen: Annet Wind, Professor Verhey, Giel Nijpels, Professor Storms, mevrouw van Haastregt, mevrouw Emmelot-Von, Professor van Binsbergen, mevrouw de Groot, de heer de Smet, mevrouw van der Heijden en de heer van Delden. In het bijzonder wil ik Aartjan Beekman en Harm van Marwijk bedanken. Niet alleen waren zij bereid een keer samen te komen om de speciale conditie Depressie door te spreken ook gedurende de rest van mijn onderzoek zijn ze altijd bereid geweest mijn vragen over Depressie te beantwoorden. Dit is een belangrijke bijdrage aan dit proefschrift geweest. Heel erg bedankt! Dan de 9 panelleden die bereid waren op een hutje (nou ja, hutje) op de hei anderhalve dag over passende zorg voor kwetsbare ouderen te praten. Met veel plezier heb geluisterd naar de discussies tussen Annet Wind, Olga Lackamp, Janny Dekker, Erik Frölke, Hub Peeters, Ton Bakker, Jan Eefsting, Jos van Campen en Marcel Olde Rikkert. Het was zo inspirerend dat ik me zelfs georiënteerd heb of het nog mogelijk is om medicijnen naast mijn werk te studeren. Helaas is de opleiding daar niet op ingesteld en blijf ik dus voorlopig onderzoeker. Ook de 13 huisartsen in de regio West-Friesland die de tijd en moeite namen om een half uur of soms langer met mij over hun oudere patiënten te praten ben ik erkentelijk. Dokters Wolfe, Banis, Wybenga, Harmse, Seelt, den Boer, Verschoor, van Assema, Klaassen, Koeman, Kuijs, Bakker en Toppers; hartelijke dank voor de tijd en interessante gesprekken. Als laatste wil ik de leden van de commissie, Prof. dr. Robbert Huijsman, Prof. dr. Patrick Bindels, Prof. dr. Dorly Deeg, dr. Ticia van der Cammen, Prof. dr. Ewout Steyerberg en Prof. dr. Anne Margriet Pot, bedanken voor hun bereidheid zitting te nemen in de commissie en voor de tijd en moeite die ze hebben genomen om zich in mijn proefschrift te verdiepen.

Bij het Trimbos heb ik me thuis gevoeld bij het Programma Ouderen. Lange tijd heb samengewerkt met Anne Margriet Pot, Jacomine de Lange, Marja Depla, Selma te Boekhorst, Bernadette Willemse, Marjolein Veerbeek, Laura Dorland, Dieneke Smit, Gerda Hellwich en Jorien Bax. Gekscherend werd er altijd geroepen dat er een man nodig was in deze club en hoewel dat vast ook leuk zou zijn, moet ik zeggen dat er eigenlijk niet zo veel miste in deze groep bijzondere vrouwen! Vergaderingen waren vaak inspirerend, bijkletsen gebeurde vervolgens tijdens de lunch. Ook waren er flink veel borrels. Het gaat me niet lukken om iedereen op te noemen die daarbij wel eens is aangeschoven, maar graag noem ik de supergezellige harde kern van Maaike, Lex, Leonie, Matthijs, Jasper, Marko, Marjoliek en Wiljo. Lex wil ik nog even in het bijzonder bedanken, met name ook voor de venijnige squash-partijtjes na het werk, die we dan naarstig goed probeerden te maken met bananenbier en Ethiopische pannenkoeken. En natuurlijk: Maaike, mijn mede-organisator van de borrels. Altijd zaten we er keurig als eersten en wachten beleefd tot een ieder weer op huis was aangegaan waarna wij het licht uitdeden. In de tussentijd kletsen we elkaar en de anderen de oren van

de kop en werd er veel gegiecheld. Maaike, bedankt voor organisatie en gezelligheid. Ik kan alleen maar hopen dat ik down under weer zo'n maatje vind om de gezelligheid te kanaliseren. Als laatste wil ik mijn kamergenootjes bij het Trimbos bedanken voor een waanzinnige tijd. Mijn hart brak bijna toen Renata me na ongeveer anderhalf jaar ging verlaten, maar gelukkig stapte Selma in dat gat om het te vullen. Sel, we hebben alle lief en leed van de wereld gedeeld op ons zolderkamertje. Ik vond het heel bijzonder om je zwangerschap en de geboorte van Tobias van zo dichtbij mee te maken, maar het allerleukst was onze reis naar Japan, samen met Bas, om een congres bij te wonen en vakantie te vieren. Wat was dat bijzonder! Renata, we zijn nog niet aan zo'n mooi reisje toegekomen, maar hopelijk gebeurt dat nog eens. Je was in ieder geval de beste kamergenoot die ik me kon wensen toen ik bij Ti begon. Je nam me meteen op sleeptouw en rekende me het helemaal niet aan dat ik de eerste dag al met een banaan liep te zwaaien alsof ik James Bond junior was. Hoewel we ook goed en over alles konden praten was de humor wel wat ons het meeste bond. Iedere dag dat jij binnen kwam en direct een goede of slechte grap maakte was een mooie dag.

Dit begint inmiddels het langste dankwoord ooit te worden, dus ten aanzien van mijn privé heb ik besloten het ook maar enigszins werkgerelateerd te houden. Met uitzondering van mijn Vis&Wijn cluppie dat een speciale vermelding verdiend. Lieve Sanne, Tanja, Eliza, Jasper en Guy, ik heb enorm genoten van al onze etentjes. Het begin was even wennen, maar daarna is het altijd bijzonder geweest, misschien juist omdat we zo'n bijeengeraapt zooitje waren? Het etentje in het Amstel Hotel dit jaar om ons 5 jarig jubileum te vieren was een absoluut hoogtepunt: een avond om niet snel te vergeten! Bedankt voor 5 (en inmiddels al weer een half) jaar gezelligheid, goede gesprekken, slappe lachen, vissen en wijnen. Marinka, jij stopte met het cluppie, maar gelukkig bleven we met ons tweeën leuke dingen doen, waar wederom vis, wijn en gezelligheid sleutelwoorden waren. Met goede vriendinnen Eva, Evelien, Channa en later ook Judith hebben we een aio-intervisie-groep opgericht. Naast alle andere gezelligheid kwamen we eens in de twee maanden samen om te praten over ons werk met al zijn aspecten. Wederom moet ik lekkere hapjes en drankjes vermelden, maar ook inhoudelijk waren de middagen kwalitatief hoogstaand. Ze gaven stof tot nadenken, maar ook moed tot handelen! Meiden, bedankt. Ik zal jullie allen missen down under!

Nu kom ik toch bij de allernaasten aan. Lieve Luca, ik kan me geen betere vrouw wensen voor mijn grote broer. Je bent intelligent, grappig, de beste gastvrouw en kok ever en vooral ook superlief. Ik weet niet eens waar te beginnen met dingen te herinneren: chocoladefondue op Uilenstede, dolfijnen en later heel veel walvissen kijken, cocktails drinken of alleen maar kijken hoe jij een computerspelletje met een lullig badeendje speelt; het was allemaal even leuk. Ik zie er erg naar uit zo veel dichterbij je te komen wonen en weer meer te genieten van je gezelschap, kookkunsten en gegrinnik. Dan mijn paranimfen: naast de mensen die mij inspireerden om onderzoek te gaan doen ook meteen twee van de belangrijkste mensen in mijn leven. Lieve Evelien, het begon allemaal bij Sociale Cognitie waar

we aan de praat raakten over serieuze zaken en en passant de Sander-fanclub oprichten. Vervolgens mochten we onder de vleugels van Johan leuk onderzoek uitvoeren met het gooien van pennen enzo. Ik vrees dat ze op de afdeling Sociale Psychologie van de VU het nog wel eens hebben over die twee meisjes die luidlachend over de gang liepen en onderzoek kennelijk echt heel leuk vonden! Tegelijkertijd vertrokken we naar het buitenland voor studie en stage: de afstand Madrid-Berkeley bracht ons alleen maar dichterbij elkaar. Wekelijks kletsten we bij over wat we nu weer mee hadden gemaakt. Na de studie hebben we nog veel mooie reisjes samen gemaakt en ook heel veel koffie (met iets lekkers? met iets lekkers!) gedronken. Stockholm, Madrid, New York; het was allemaal even leuk. Ik zal je echt vreselijk missen als ik straks vertrek, maar hopelijk kom je snel langs! Enneh... in ons rijtje ontbreekt ook nog een bezoekje aan San Francisco en omstreken! Dan mijn grote broer, Hidde, ik zou eigenlijk precies het zelfde kunnen schrijven als jij over mij deed toen je jouw proefschrift afrondde. Ik ben superblij met onze band: lekker gek doen en lachen, maar als het moet opeens zeer serieus. Je bent in de laatste jaren alleen maar belangrijker voor me geworden; door met je te werken werd me duidelijk wat ik zelf wilde doen en toen ik er aan begonnen was heb je me altijd enorm gesteund. Ik ben blij dat ik je straks niet meer hoef te missen, maar vaak langs kan komen in Sydney. Je bent een schat. Als laatste wil ik mijn ouders bedanken. Pap en mam, jullie hebben ons opgevoed tot onafhankelijke, eigenwijze mensen. Dat levert wel eens tegenwind op, maar maakt ook dat ik enorm van het leven geniet en echt doe wat ik wil. Met veel plezier denk ik terug aan het warme en vooral ook humorvolle nest waarin ik ben opgegroeid. Dat heeft me een geweldige basis gegeven waardoor ik veel aankan. Ik ben jullie daar zo dankbaar voor! Als ik er nog iets aan toe kan voegen... Pap, ook heel erg bedankt voor het mooie kaft ontwerp. De samenwerking ging voorspoedig en ik ben blij met resultaat. Lieve mam, je bent mijn steun en toeverlaat met heel grote luisterende oren en altijd goed en relativerend advies; lang leve de telefoon!

About the author

Eva Simone van der Ploeg was born on the 23th of October 1977 in Laren, the Netherlands. She attended primary school at 'De Levensboom' in Blaricum and high school (athenaeum) at the 'OSG Huizermaat' in Huizen. After graduation she enrolled in the Journalism and Communication College in Utrecht. She graduated within four years with specializations in written press, foreign affairs and sports. With one more year of government study-funding left, she enrolled in the first year of Psychology at the 'Vrije Universiteit' in Amsterdam. After passing the propaedeutical exam she took a one year break to travel through Russia, China and southeastern Asia. After returning she resumed her Psychology studies. In 2004 she graduated cum laude, majoring in Social Psychology. During her studies she did an internship at the University of California, Berkeley, where she participated in research on emotions (mainly joy and laughter). In 2004 she started working on her PhD thesis at the Department of Public Health of the Erasmus Medical Center in Rotterdam. During the last four years she obtained a masters degree in public health at the Netherlands Institute of Health Sciences in Rotterdam. From March 2009 on she will work as a Research Fellow at the Aged Mental Health Unit at Kingston Centre, Monash University in Melbourne, Australia.