Nurse-led multifactorial care in community-dwelling older people

Outcomes on daily functioning, experiences and costs

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Publication date
2017
Document Version
Final published version
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The work described in this thesis was financially supported by ZonMw (no. 313020201) and is part of the Dutch National Care for the Elderly Programme.

The printing of this thesis was financially supported by the Academic Medical Center - University of Amsterdam.

For reasons of consistency within this thesis, some terms have been standardised throughout the text. As a consequence the text may differ from the articles that have been published.

ISBN: 9789082738308

Cover & Lay-out: Mijn Proefschrift | www.mijn-proefschrift.nl
Published by: ProefschriftMaken | www.proefschriftmaken.nl

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ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex
ten overstaan van een door het
College voor Promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op vrijdag 13 oktober 2017, te 11:00 uur

door

Marjon van Rijn
geboren te Naaldwijk

Promotiecommissie:

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Chapter

1

General introduction

Optimal care for older people is one of the greatest challenges in healthcare [1]. Worldwide, the proportion of older people (≥ 65 years) will rise from 426 million older people in 2010 (8% of the total world population) to one billion older people in 2050 (16% of the total word population) [2]. In the Netherlands, the proportion of older people will rise from 2.6 million in 2010 (16% of the total Dutch population) to 4.8 million in 2050 (27% of the total Dutch population) [2]. In this ageing population it is a challenge to prevent or postpone new disabilities and to improve the years spent in good overall health [1].

The onset of new disabilities in older people

Ageing is often accompanied by multiple chronic conditions (MCC) and the onset of new disabilities in daily functioning [3]. Disability is defined as difficulty in carrying out (instrumental) activities of daily living ((I)ADL), essential for self-care and living independently at home, such as bathing, dressing and cooking [4]. In developed societies, around 20% of people aged 70 years or older, and 50% aged 85 years and older has one or more difficulties in basic ADLs [5]. The annual onset of new disabilities in people aged 75 and older is estimated around 12% and many of them recover from those disabilities, yet more are prone to developing new disabilities in the following year [6]. Disability in older people can be caused by several modifiable factors. In the literature, risk factors for new disabilities that may be amenable by interventions are multifactorial: previous disability, depression, comorbidity, polypharmacy, obesity, reduced social contact, physical inactivity and visual impairment [7-10]. Disability in older people is associated with an increased risk of institutionalisation [11], increased healthcare utilisation and costs [12] and poor quality of life [13].

Interventions to prevent or postpone disability in community-dwelling older people

The onset of new disabilities in community-dwelling older people might be prevented or postponed by multifactorial interventions. However, the effectiveness of those multifactorial interventions remain controversial [14-17]. Previous meta-analyses and reviews demonstrated that interventions with beneficial effects on daily functioning include screening a population that is at risk of functional decline, comprehensive geriatric assessment (CGA), and multiple follow-up visits [18-20]. In the past decades, such comprehensive care programs to prevent or postpone disability in community-dwelling older have become common practice in several Western countries such as the United Kingdom [21]. However, until 2008, such programs had not been implemented nor evaluated on a large scale in the Netherlands yet.

Towards improved primary care for older people in the Netherlands

In 2008, the Health Council of the Netherlands stated that the current

healthcare provision for older people was inadequate, fragmented and not designed to meet the needs of older people with MCC [22, 23]. Hence, in 2008 the Dutch Government launched the National Care for the Elderly Programme [22], that aimed to improve the quality of care for older people by developing coordinated and integrated care that is better suited to the individual needs and preferences of older people. In 2009, a second report of the Health Council focused specifically on daily functioning of older people [24]. It was suggested that a more preventive approach in primary care (proactive care), compared to the demand driven care for older people (reactive) is needed to maintain daily functioning and timely identify values, needs and preferences of community-dwelling older people. For that reason, the FIT (Functiebehoud in Transitie) study started in 2010 with the aim to improve primary care for community-dwelling older people in the Netherlands [25].

The FIT study

Design of a cluster randomised trial

As part of the National Care for the Elderly Programme, a cluster randomised controlled trial (RCT) was designed and initiated in order to evaluate the effects of nurse-led multifactorial care to prevent or postpone new disabilities in community-dwelling older people. A theoretical framework designed by the UK Medical Research Council (MRC) [26] was used that includes the development, piloting, evaluation and implementation of a complex intervention (Figure 1).

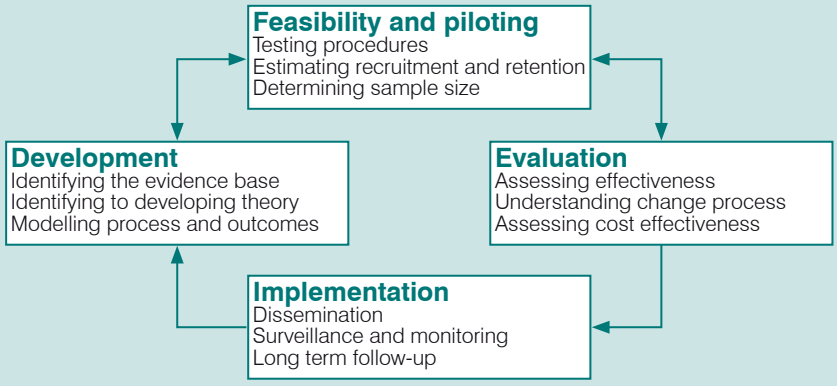

Figure 1. Key elements of the development and evaluation process (Craig P et al. BMJ. 2008)

We designed a three-step FIT care model (Figure 2). The first step was the selection of the target population. From the literature, it appears that older people with no or only mild disabilities were most likely to benefit from interventions to postpone disability [18]. Therefore we needed a self-reporting, generic, easy-to-apply, and validated instrument for primary care to identify older people at increased risk of functional decline. We modified and validated the Identification of Seniors At Risk (ISAR) screening questionnaire to identify older people at increased risk of functional decline in primary care [27]. This resulted in the ISAR-Primary Care (ISAR-PC) screening instrument. The second step in the FIT care model was a comprehensive geriatric assessment (CGA), including recognition and prioritisation of geriatric conditions by older people. The third step was to make an individually tailored care and treatment plan including multifactorial interventions coordinated by a trained community-care registered nurse (CCRN).

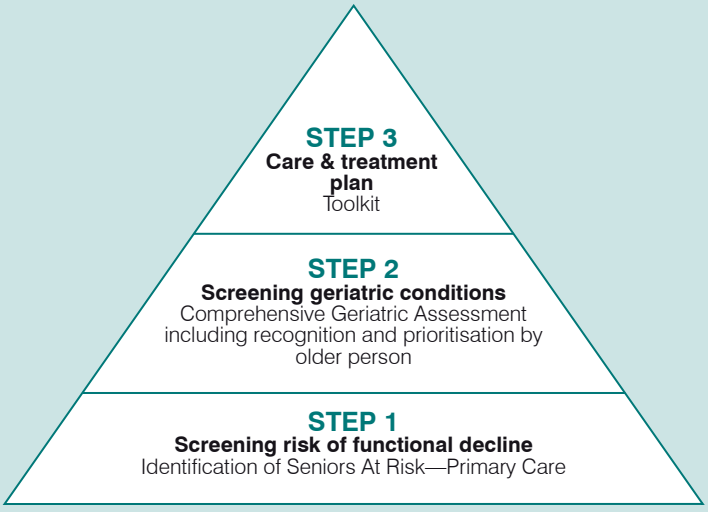

Figure 2. Fit care model

In 2010 we started our trial in the region of Noord-Kennemerland and IJmuiden [28]. Twenty-four general practices participated in this RCT, of which eleven were assigned to the intervention group and thirteen were assigned to the control group. All participants were screened with the ISAR-PC screening instrument according to step 1 of the FIT care model. Step 2 and 3 were part of the intervention and consisted of a CGA, value clarification, recognition and prioritisation of identified geriatric condition by the older person, and, if favored by the older person, individually tailored multifactorial interventions coordinated by a trained CCRN with multiple follow-up home visits.

Community dwelling older peoples' values, health priorities and experiences with nurse-led multifactorial care

Comprehensive geriatric assessment (CGA) is an important part of the FIT care model. CGA is a multidisciplinary, systematic procedure addressing the physical, psychological, functional and social conditions of older people to identify existing geriatric conditions. This assessment facilitates shared decision making and drafting of a tailored care and treatment plan [29, 30]. The CGA starts with five questions about what is perceived important in terms of ageing, worries, the future, healthy ageing and quality of life. The presence of MCC in older people influences their goals, preferences and expectations of medical treatment [31]. Therefore, especially for older people with MCC, it is necessary to explore their preferences before starting treatment.

After addressing these five questions, the CCRN systematically assessed potential physical, psychological, functional and social geriatric conditions and the participants' priorities and goals. Little is known regarding the prevalence of identified geriatric conditions and the extent to which geriatric conditions are recognised as relevant problems by community-dwelling older people. This limits our understanding of the needs community-dwelling older people have and the choices they may like to make with regard to care and treatment.

Minimal important change and minimal detectable change in daily functioning

In daily practice (as part of a CGA) and in research (as an outcome measure), the Katz-activities of daily living (ADL) index score and the Lawton instrumental activities of daily living (IADL) scale are frequently used as self-reporting instruments to identify daily functioning [32]. However, the interpretability of these instruments is unknown. To determine the interpretability of the Katz-ADL index score and the Lawton IADL scale the smallest change in score on activities of daily living (ADL) and instrumental activities in daily living (I) ADL functioning that is perceived as important by the older person and the smallest change in (I)ADL that can be detected by the instruments (beyond measurement error), are important [33].

Assessment of per capita healthcare costs of older people

Nurse-led multifactorial care in primary care may enable reductions in healthcare utilisation as it has the potential to prevent hospitalisation and early admission to a nursing home, which are important drivers of healthcare costs and are associated with changes in ADL and IADL functioning. Therefore, it is important to identify the 'high cost' group, specify major cost drivers and study the association between healthcare costs and transitions in disability in community-dwelling older people in the Netherlands. Acute hospitalisation in older people is associated with changes in ADL and IADL functioning [34].

Acutely hospitalised older people are at high risk for poor outcomes during hospital stay and after discharge, such as functional decline and mortality [35]. In the past two decades, interventions to identify acutely admitted older patients who are at risk for functional decline and to achieve medication reconciliation have contributed to a decline in the in-hospital mortality of older patients and reduced length of hospital stay (LOS) in the Netherlands from weeks to days [36-38]. However, the influence of improved treatment strategies and new patient safety procedures on the in-hospital and 30-day post-discharge mortality for the most common acute diagnoses in older patients is still unknown.

Aims of this thesis

The overall aim of this thesis is to improve primary care for community-dwelling older people in the Netherlands. First, by improving the general health and daily functioning of community-dwelling older people; second, by exploring the experiences of older people with nurse-led multifactorial care; and third by assessing per capita healthcare costs of older people. Consequently, the following research questions were formulated:

1. What are the effects of nurse-led multifactorial care on the onset of new disabilities in community-dwelling older people?
2. What are personal views of community-dwelling older people in terms of ageing, worries, the future, healthy ageing and quality of life and how do multiple chronic conditions affect those personal views?
3. What is the prevalence of geriatric conditions in community-dwelling older people at increased risk of functional decline and what CGA-identified geriatric conditions do older people recognise as relevant problems?
4. What are community-dwelling older peoples' experiences and views on nurse-led comprehensive geriatric assessment and care coordination?
5. What are the minimal important change and the minimal detectable change of the Katz-ADL index score and the Lawton IADL scale in community-dwelling older people?
6. What is the association between healthcare costs and transitions in functional disability in community-dwelling older people?
7. What are the changes over time in the in-hospital mortality and mortality from discharge to 30 days post-discharge for the most frequently encountered hospital diagnoses (acute myocardial infarction, heart failure, stroke, chronic obstructive pulmonary disease, pneumonia and hip fracture) in acutely admitted older patients?

Outline of this thesis

In **chapter 2** the effects of nurse-led multifactorial care on the onset of new disabilities in community-dwelling older people are presented. **Chapter 3** describes how multiple chronic conditions affect patients preferences and the process of shared decision making in community-dwelling older people and **chapter 4** reports on the prevalence and recognition of geriatric conditions identified by community-dwelling older people with an increased risk of functional decline. **Chapter 5** presents the experiences of older people living at home, regarding nurse-led comprehensive geriatric assessment and care coordination. **Chapter 6** focusses on the accuracy and clinical meaning of (changes in) scores of the Katz-ADL index score and Lawton IADL scale in community- dwelling older people. **Chapter 7** presents the costs associated with transitions in disability in a population of community-dwelling older people. **Chapter 8** provides an overview of changes in hospital mortality and 30-day post discharge mortality between 2000 and 2009 in older patients acutely hospitalised in the Netherlands. Finally, **chapter 9** presents a general discussion of the main findings of this thesis, including its strengths and limitations and implications for clinical practice, education and research.

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Chapter

2

Effects of nurse-led multifactorial care to prevent disability in community-living older people: cluster randomised trial

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PLoS One. 2016;11(7)

Abstract

Background: To evaluate the effects of nurse-led multifactorial care to prevent disability in community-living older people.

Methods: In a cluster randomised trail, 11 practices (n = 1,209 participants) were randomised to the intervention group, and 13 practices (n = 1,074 participants) were randomised to the control group. Participants aged 70 years were at increased risk of functional decline based on a score 2 points on the Identification of Seniors at Risk-Primary Care, ISAR-PC. Participants in the intervention group received a systematic comprehensive geriatric assessment, and individually tailored multifactorial interventions coordinated by a trained community-care registered nurse (CCRN) with multiple follow-up home visits. The primary outcome was the participant's disability as measured by the modified Katz activities of daily living (ADL) index score (range 0–15) at one year follow-up. Secondary outcomes were health-related quality of life, hospitalisation, and mortality.

Results: At baseline, the median age was 82.7 years (IQR 77.0–87.1), the median modified Katz-ADL index score was 2 (IQR 1–5) points in the intervention group and 3 (IQR 1–5) points in the control group. The follow-up rate was 76.8% (n = 1753) after one year and was similar in both trial groups. The adjusted intervention effect on disability was -0.07 (95% confidence interval -0.22 to 0.07; p = 0.33). No intervention effects were found for the secondary outcomes.

Conclusions: We found no evidence that a one-year individualised multifactorial intervention program with nurse-led care coordination was better than the current primary care in community-liv-ing older people at increased risk of functional decline in The Netherlands.

Trial Registration: Netherlands Trial Register NTR2653

Introduction

The need to prevent disability and functional decline in later life is increasingly urgent with the ageing of society, the increase of multimorbidity and growing strain on limited resources [1]. Disability is defined as difficulty of or dependence in (instrumental) daily activities essential for independent living [2]. The occurrence of new physical disabilities is often called functional decline [3]. Older individuals consider prevention of disability as a patient-relevant outcome [4]. Progressive disability is associated with loss of quality of life [5], loss of independence [6], and high healthcare utilisation [7].

It has been suggested that a proactive, integrated care provision for community-dwelling older people is needed to address complex care needs, enable independent living and improve quality of life [8-10]. Earlier meta-analyses and reviews demonstrated that interventions including a comprehensive geriatric assessment (CGA), multifactorial interventions, and multiple follow-up visits had beneficial effects on overall functioning, especially for the relatively young, pre-frail subjects [11-14]. Nevertheless, more recent primary care studies on complex elderly care showed neutral findings [15-21]. Despite controversies over the effectiveness of multifactorial interventions to prevent functional decline [11-13, 22-24], different proactive strategies are already part of national policies in several Western countries, including the United Kingdom and Denmark [25].

In 2008, the Dutch government launched the National Care for the Elderly Programme (NCEP) stimulating innovative healthcare projects focused on older people with multifactorial care needs to promote physical, mental and social health and wellbeing [26]. Designing an intervention to prevent or postpone disability and functional decline, we aimed to target those who were likely to benefit most; a younger pre-frail population [2, 11, 12, 27]. Furthermore, to enhance the benefit of the target population, we identified those at increased risk of functional decline, and combined this with interventions based on current evidence or guidelines, patient-centered care, and nurse-led care coordination [2, 11, 12, 27, 28]. In a cluster randomised trial, which is part of the NCEP, we studied the effects of a systematic CGA, and nurse-led care coordination of individualised multifactorial interventions with multiple follow-up visits on preventing disability in community-living older people at increased risk of functional decline.

Materials and Methods

The protocol for this study[28] and CONSORT checklist are available as supporting information (File A-1 and File A-2). We provide a summary of the materials and methods in the current article because a more extensive description is published in the study protocol [28].

Design and setting

Between December 2010 and May 2014 we conducted a cluster randomised trial with a 1-year intervention and a 2-year follow-up in the north-west of the Netherlands. We invited 95 general practices who had not implemented nurse-led care coordination for community-living older people to participate. Twenty-four general practices were willingly to participate and were randomised. Community-care registered nurses (CCRN) provided the multifactorial intervention program to participants from practices allocated to the intervention group. The control group received no extra care or information besides usual care. The trial was registered at Trial Registration NTR2653. (http://www.trialregister.nl)

Participants

All participating general practitioners (GP) selected their patients aged 70 years and over from their electronic medical record and excluded those who had a life expectancy of less than three months, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad, or lived in a nursing home. The selected persons received a self-reporting questionnaire, including a screening instrument: Identification of Seniors At Risk-Primary Care (ISAR-PC) (Text A-1) [29]. ISAR-PC was developed to identify community-living older persons at increased risk of functional decline. It comprises three dichotomous items (age, dependence in instrumental activities of daily living (IADL), and impaired memory). ISAR-PC discriminates moderately and is well calibrated (Area under the receiver operating characteristics curve (AUC) range 0.63–0.64 in an independent validation cohort; p-value for calibration range 0.09–0.78; 34% of those screened were identified at increased risk (score 2). ISAR-PC was validated in Dutch. All eligible participants signed a written informed consent before inclusion. The study has been approved by the Medical Ethics Committee of the Academic Medical Center, University of Amsterdam, The Netherlands (protocol ID MEC10/182).

Randomisation and blinding

An independent statistician performed the computerised cluster randomisation, stratified on the basis of socio-economic status, number of participants and general practices in both study groups [28]. Participants were blinded for the study intervention by applying a postponed informed consent procedure to prevent selection bias [30]. All outcome assessors were blinded to treatment allocation and were not otherwise involved in the study.

Intervention

The participants in the intervention group received a systematically administered CGA, an individually tailored care treatment plan (CTP) consisting of multifactorial interventions, and nurse-led care coordination with multiple follow-up visits. The CGA, CTP and follow-up visits were conducted

by the same CCRN. In total, 15 experienced CCRNs, employed by one home-care organisation, participated in the intervention. All CCRNs followed a formal 10-day training in providing integrated elderly care in the community, prior to the start of the study (more information of the training is provided in Text A-2). The CCRN conducted the CGA during a home visit. The CGA focused on somatic, psychological, functional and social domains, representing conditions such as urinary incontinence, memory problems, fall risk, and loneliness. The physical examination and performance tests of the CGA included measurement of body mass index, blood pressure and pulse (all geriatric conditions are described in Text A-3) [28]. The participants were asked whether they recognised the identified conditions as relevant problems, whether they desired (additional) care or treatment for them, and in case of multiple problems, which one(s) should have priority in the CTP. To create uniformity, further diagnostic assessments and interventions came from a toolkit containing standardised evidence-based protocols and were developed by a multidisciplinary expert panel (examples of possible diagnostics and interventions are described in Text A-3) [28]. Possible interventions were referral to a GP, referral to a paramedic, giving advice, follow-up visit by the CCRN. Subsequently, the CCRN discussed the yield of the CGA with the GP, and a CTP was created in which all actions expected of the participant, CCRN and/or GP were specified. The CCRN evaluated the CTP during several follow-up visits [28].

Nurse-led care coordination consisted of elements of case management, self-management and patient-centered care, which were derived from several chronic care models [4, 28, 31, 32]. During the intervention, the CCRN worked in close collaboration with the GP and maintained contact with other healthcare professionals (e.g., occupational therapists, physiotherapists, etc.) and the participant's caregiver(s).

To meet the demands and needs of older persons, in accordance with NCEP study guidelines, a panel of elderly people was actively involved in the design and evaluation of the study [26].

Care as usual

The participants from general practices randomised to the control group received usual care (Text A-4). Throughout the study, we monitored all participants' resources utilisation (Table 1 Baseline variables of participants).

Baseline data collection and measurements of outcomes

The baseline assessment included demographics, socio-economic status score, comorbidities, disability (modified Katz-ADL index score) [33], health-related quality of life (EQ-5D) [34], emotional wellbeing subscale (RAND-36) [35], self-perceived quality of life [36], healthcare utilisation (hospitalisation, after-hours primary care) [36], and incidence of falls within 12 months. Socio-economic status score (SES) was based on income, employment and educational level, calculated for the postal code of the participants' residence by the

Table 1. Distribution of baseline variables of participants with an ISAR-PC score ≥ 2, by study arm (n = 2283)

Characteristics	Intervention group	Control group
	N= 1209	N= 1074
	N(%)	N(%)
Age, in years, median (IQR)	82.6 (76.8-86.8)	82.9 (77.3-87.3)
Female sex	789 (65.2)	671 (62.7)
Caucasian	1141 (95.4)	1022 (96.5)
Level of education		
primary school or less	255 (21.4)	281 (26.6)
secondary education	760 (63.7)	648 (61.4)
college or university	179 (15.0)	127 (12.0)
Socio-economic status		
low (≤1SD)	57 (4.7)	78 (7.3)
intermediate	931 (76.9)	890 (83.2)
high (≥1SD)	223 (18.4)	102 (9.5)
Married/living together	561 (46.7)	489 (46.0)
Living situation		
independent, alone	530 (44.1)	467 (43.9)
independent, together	535 (44.5)	442 (41.6)
home for elderly	138 (11.5)	154 (14.5)
Multimorbidity (≥2)	997 (83.2)	856 (80.6)
Polypharmacy (≥3)	830 (69.3)	748 (70.7)
Modified Katz-ADL index (range 0-15), (median (IQR))	2 (1-5)	3 (1-5)
Katz-ADL (range 0-6), median (IQR)	1 (0-1)	1 (0-1)
IADL scale (range 0-7), median (IQR)	1 (0-3)	2 (0-3)
EuroQol-5D (range -0.33-1.0), mean (SD)	0.75 (0.21)	0.72 (0.22)
Psychological health status (Rand-36) (range 4-100), mean (SD)	71.4 (17.4)	70.3 (17.6)
Quality of Life (range 0-10), mean (SD)	7.2 (1.3)	7.2 (1.2)
Healthcare utilisation in past 12 months		
hospital admission (≥1)	306 (26.1)	264 (25.6)
GP after hours (≥1)	232 (20.1)	175 (17.2)
home care (physical)	193 (17.0)	149 (14.7)
home care (instrumental)	654 (56.3)	523 (51.9)
day care	26 (2.2)	36 (3.5)
Falls (≥1) in past 12 months	418 (34.9)	344 (32.7)
Identification of seniors at risk-primary care (range 0-7.5), median (IQR)	4 (3-5)	4 (3-5)

Values are numbers (percentages) unless stated otherwise

Netherlands Institute for Social Research (SCP). In both groups, participants received similar self-reporting questionnaires at baseline and at six-month intervals, for two years.

Primary and secondary outcomes

The primary outcome was participants' change in disability measured with the 15-item modified Katz-ADL index score at one year follow-up [33]. This index is a combination of six basic ADL items based on the Katz-ADL index (bathing, dressing, toileting, transfer, incontinence and eating), seven instrumental ADL (IADL) items based on the Lawton Scale (housekeeping, meal preparation, shopping, telephone use, transportation, medication use, budgeting), and two additional items (grooming and walking). Scores range from zero to 15 points with higher scores indicating more dependence [33]. We determined the (mean) smallest meaningful change to be -0.5 points on the modified Katz-ADL index score based on previous research [12].

The secondary outcomes were the participants' change in health-related quality of life (EQ-5D), emotional wellbeing subscale (RAND-36), self-perceived quality of life, healthcare utilisation, number of falls at all follow-up moments, and all-cause mortality. The EQ5D is a five-dimension scale to estimate preference-based health-related quality of life values. Possible health states were converted in a utility score, using a Dutch general population validation study [37]. Self-perceived quality of life was assessed using a Cantril's Ladder where respondents rated their present quality of life on a scale between zero and ten [36]. All outcome measures were validated for the Dutch population [36].

Adherence to the study protocol

The intervention group's adherence to the protocol was based on 1) the percentage of participants that received both the CGA and their personalised care and treatment plan; 2) the percentage of the CGAs that the CCRN discussed with the GP; and 3) the percentage of participants that received an evaluation of the CTP after one year.

Sample size calculation

The sample size was based on observational data from primary care practices from a prospective cohort study (mean modified Katz-ADL score 2.70, SD 2.55) [29], which would represent an effect size of 0.20. With an assumed intracluster coefficient (ICC) of 0.015 and an expected cluster size of 100 participants per practice, the design effect was estimated at 2.50 (1+100*0.015). Using a two-sided alpha of 0.05 and power of 80%, 1,025 participants were needed in each group. The final target sample of participants was increased to 1,281 per treatment group to allow for a dropout rate of 20% within one year [28].

Statistical analyses

Analyses were performed according to the intention-to-treat principle. Baseline characteristics of participants were described for the two study groups. Mixed linear and negative binomial regression models with a random intercept for participants were used for continuous (modified Katz-ADL index score, EQ-5D, Rand 36, self-perceived quality of life) and count data (number of hospital admissions, after-hours primary care contacts, and falls), respectively. An additional random intercept at the GP level did not improve model fit (likelihood-ratio test $p = 0.20$). Linear mixed regression models employed robust standard errors to account for skewness in the outcome variable [38]. The models were adjusted for confounding variables, which were selected on the basis of causal diagrams for the various outcomes. All adjustment variables concerned baseline values of (i) the outcome variable, (ii) age, (iii) sex, (iv) (three levels of) education, and (v) (three levels of) socio-economic status [39]. Based on the likelihood-ratio test ($p_{interaction} < 0.05$) interaction terms for treatment $\times$ time were added, to assess whether the treatment effect, if any, varied over time. Kaplan-Meier curves were used to estimate survival rates and compared using the log-rank test.

Post-hoc analyses were performed by adding interaction terms for treatment $\times$ levels of education (high and intermediate), treatment $\times$ socio-economic status (low and intermediate), treatment $\times$ levels of age (75–79 years, 80–84 years, 85–89 years, and 90 years and over), and treatment $\times$ baseline disability (tertiles of the Katz score) to the fully adjusted model ($p_{interaction} < 0.05$). In the treatment group, we visually explored the mean change on the modified Katz-ADL index between baseline and one year as a function of the number of home visits, the number of interventions, and the variation among the 15 community care nurses in the intervention group.

To assess the impact of missing data, we performed a sensitivity analysis. We created ten imputation sets by multiple imputation using chained equations and predictive mean matching (PMM) in STATA 13 [40]. Missing values were imputed separately for each study group. We then repeated the fully adjusted mixed regression models on the ten sets and combined the estimates using Rubin's rule. We used IBM SPSS, Version 20.0 (IBM Corp. 2011) and STATA 13 (StataCorp. 2013. College Station, TX) for data analysis.

Results

Eleven practices were randomised to the intervention group and 13 practices were randomised to the control group. Screening with ISAR-PC resulted in 35.2% (1209/3430) of the participants in the intervention group and 33.2% (1074/3238) of the participants in the control group (Figure 1 Flow chart). The follow-up rates after one year were 77.4% (936/1209) in the intervention group and 76.1% (817/1074) in the control group (Figure 1 Flow chart). The characteristics of the participants and general practices are shown in

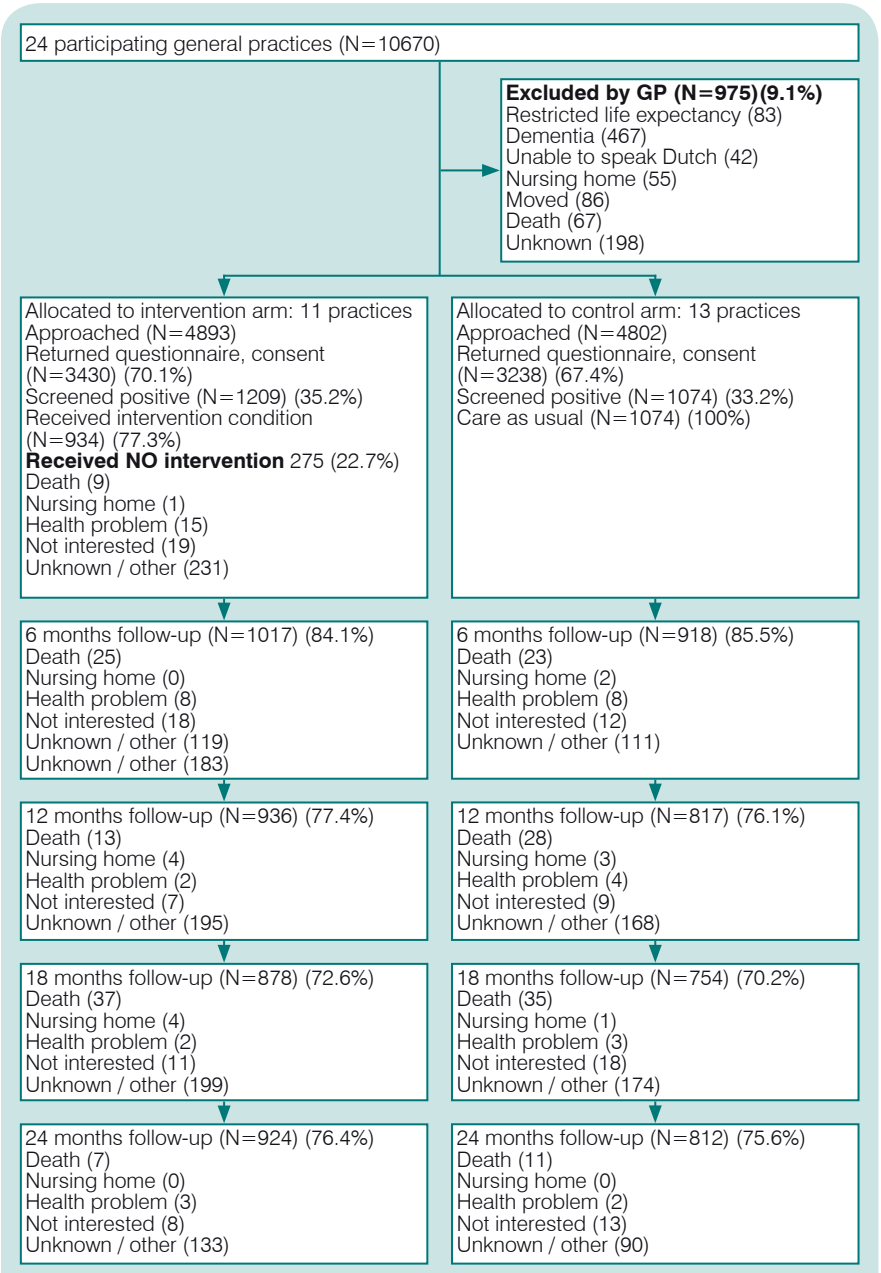

Figure 1. Flow of practices and participants through the trial
Numbers do not add up because persons who did not return a questionnaire at 6 months (N=119) could return a questionnaire at 12, 18 and/or 24 months.

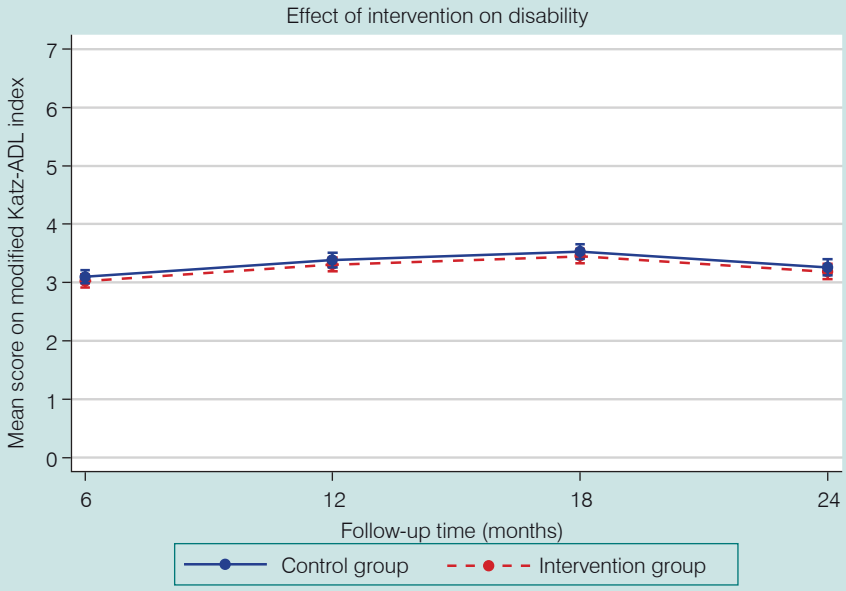

Figure 2. Effect of the intervention on disability (modified Katz-ADL index score)
The effect of the intervention was equal (-0.07) and very small across all follow-up times; The scale on the y-axis only ranges from 0 to 7.0 points on the modified Katz-ADL index score, which is a 15-point scale.

Table 1 Baseline variables of participants, and Table A-1 and Table A-2. The participants' baseline characteristics were balanced between both study groups except that the intervention group showed a higher percentage of people with a high SES level (Table 1). The median age of the participants was almost 83 years in both groups. The median modified Katz-ADL index score was 2 (IQR 1–5) points in the intervention group and 3 (IQR 1–5) points in the control group. The participants who declined the comprehensive geriatric assessment (n = 275) were older, had more (I)ADL disabilities, and more often lived in a home for the elderly (Table A-3).

The prevalence of geriatric conditions identified by the CGA is shown in Table A-4. The mean number of problems identified in the CGA was 6.4 (SD 2.8). The median number of geriatric conditions that were recognised as a problem was 1 (IQR 0–2). Geriatric conditions that were mostly recognised as a problem were pain, depressive symptoms, hearing impairment and loneliness. The median number initiation of interventions was 1 (IQR 0–2). Most interventions were initiated for pain, incontinence, mobility, fall risk and loneliness. Reasons for no intervention are shown in Table A-5.

Eleven practices were randomised to the intervention group and 13 practices were randomised to the control group. In both groups around 35% of the

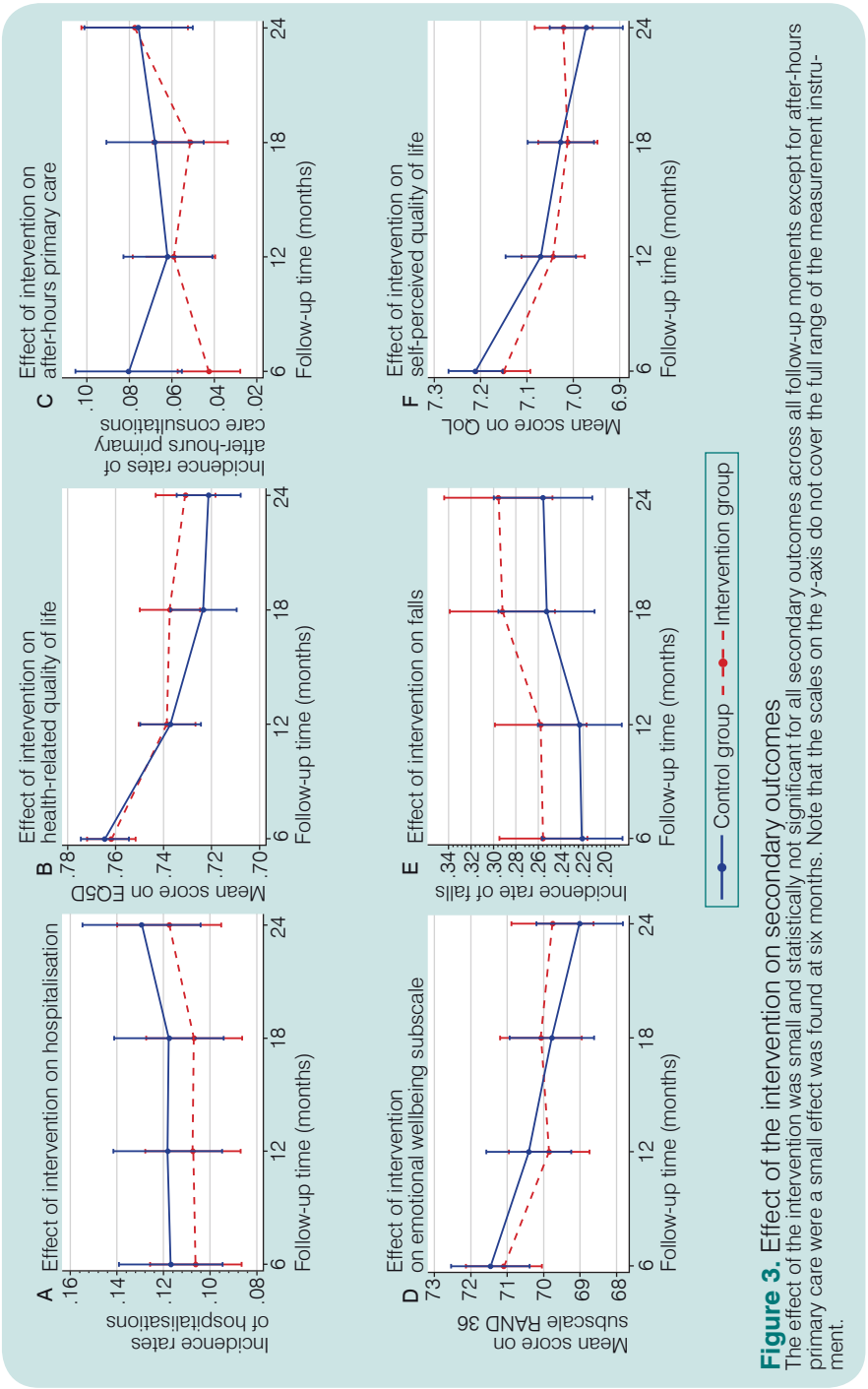

Figure 3. Effect of the intervention on secondary outcomes
The effect of the intervention was small and statistically not significant for all secondary outcomes across all follow-up moments except for after-hours primary care were a small effect was found at six months. Note that the scales on the y-axis do not cover the full range of the measurement instrument.

Table 2. Primary results of trial: Mean scores and difference between intervention and control group at 6, 12, 18 and 24 months

Outcome	Baseline		6 months		12 months		18 months		24 months		6, 12, 18, 24 months		
	Mean score (95% CI)		Mean score (95% CI)		Mean score (95% CI)		Mean score (95% CI)		Mean score (95% CI)		Mean difference (95% CI)	p-value	ICC (SE)
	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Intervention	Control	Time × intervention ($p_{interaction}$=0.68)		
Modified Katz-ADL index (0-15)	3.13 (2.97-3.29)	3.34 (3.15-3.52)	3.02 (2.92-3.12)	3.09 (2.98-3.21)	3.31 (3.20-3.42)	3.39 (3.26-3.51)	3.46 (3.33-3.58)	3.53 (3.40-3.66)	3.19 (3.05-3.32)	3.27 (3.12-3.41)	-0.07 (-0.22-0.07)	0.33	0.47 (0.01)*

Estimated mean scores and mean differences between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline Katz- ADL score
ICC = intracluster coefficient participant level.
* based on random-intercept (participants) model . On a two-level model (general practice, participant) the ICC was 0.003.

invited persons were at increased risk of functional decline and participated in the study. In both groups the follow-up rates were around 77% and 76% after one and two years respectively.

Adherence to the protocol

Among all participants, older people 77.0% (934/1209) received a CGA and 76.6% (926/1209) received a CTP (Figure 1 Flow chart). The CCRN discussed 61.6% (575/934) of the CGAs with the general practitioner. The CGAs that were not discussed with the GP (38.4%; 359/934) involved participants declining care or with no unmet care needs. After one year, 77.4% (698/898) of the CTPs were evaluated with the participants (Table A-5). During the intervention, the mean number of home visits was 3.2 (SD 1.5). A more detailed description of the adherence to the protocol will be described in the process evaluation of the study and will be published separately.

Primary outcome

One year after the start, the mean modified Katz-ADL index score had increased in both groups, indicating an increase in disability. The effect of the intervention after one year, adjusted for baseline modified Katz-ADL score, age, sex, SES and level of education, was -0.07 (95% confidence interval (CI) -0.22 to 0.07) (Figure 2 Effect of the intervention on disability, Table 2 Primary results of trial). The results of the unadjusted and adjusted analyses are presented in Table A-6. The sensitivity analyses accounting for missing data gave similar results (Table A-7).

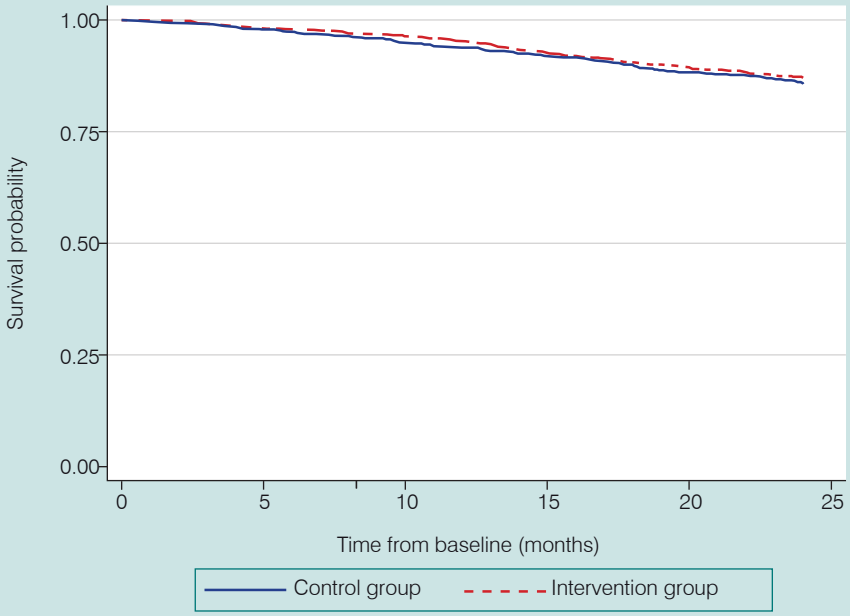

Figure 4. Kaplan Meier all-cause mortality for persons at increased risk for functional decline
No difference was found in overall mortality between both study arms; Log rank test = 0.84; P = 0.36.

Secondary outcomes

At each follow-up moment, we found neither clinically nor statistically significant intervention effects for health-related quality of life (EQ5D), emotional wellbeing, self-perceived quality of life, or number of hospitalisations or falls (Figure 3 Effect of intervention on secondary outcome and Table A-8, Table A-9 and Table A-10). At six months, the incidence rate ratio for after-hours use of primary care was 0.53 (95% CI 0.36 to 0.77). This effect had disappeared at one year. Unadjusted and adjusted analyses for the secondary outcomes are presented in S8 Table, S9 Table and S10 Table. We found no intervention effect on all-cause mortality (Figure 4 Kaplan Meier all cause mortality).

Post-hoc analyses

No interactions were found between treatment group and level of education, level of socio-economic status, baseline level of disability or baseline level of age in the post-hoc analyses (Table A-11). Furthermore, we explored the variation between CCRNs (all in the intervention group) with regard to the primary outcome. Overall, the mean changes in disability score were similar across the 13 CCRNs. We also explored the existence of "dose-response" effects by the number of home visits and interventions in the CTP but found

none (Figure A-1, Figure A-2 and Figure A-3).

Discussion

In this cluster randomised trial, we found no evidence that a one-year individualised multifactorial intervention program with nurse-led care coordination was better than current primary care in community-living older people at increased risk of functional decline in The Netherlands. Additionally, the intervention was not more effective than current primary care for all other outcomes assessed.

Strengths and limitations of this study

A major strength of the study is that, given that we avoided major bias, it robustly excluded clinically relevant effects of the intervention on the primary outcome. Specifically, the 95% confidence interval around the mean difference between the two treatment groups (-0.07; 95% CI, −0.22 to 0.07) excluded the predefined functional decline of -0.5 points by a wide margin. Thus, although the study was not designed as a non-inferiority trial, we found evidence of no effect. The sensitivity analyses accounting for missing data confirmed the robustness of the main analyses. To prevent bias in the outcome assessment, outcome assessors and participants were blinded using a postponed informed consent procedure. Another strength is the patient-centered approach comprising recognition and prioritisation of identified problems for care and treatment. Addressing problems that older persons consider important may increase adherence to the intervention and facilitate implementation. Other strengths of the study include the active involvement of older people in the design and evaluation of the study, the high participation rate, the high adherence rate to the structured study protocol, and the evidence-based toolkit.

The study also has some limitations. First, the CCRNs and the GPs could not be blinded for the purpose of the study because they were part of the intervention. Second, despite computerised randomisation the study showed some imbalance in baseline disability and SES. To overcome this, we adjusted the analyses for SES and baseline value of the outcome measure. Third, in the intervention group 23% of the participants declined to take part in the CGA. Although we collected reasons for non-participation/declining (Figure 1 Flow chart), a large number did not fill in the reason for decline (n = 150 unknown), or could not be contacted (n = 81 other reasons). Overall, the participants who declined CGA were older, had more (I)ADL disabilities, and more often lived in a home for the elderly compared to the participants who received the CGA (Table A-3). These non-respondents may have caused underestimation of the overall effect, as analyses were intention to treat. Fourth, not all parts of the intervention were implemented as planned. According to the nurses' registration, not all CGAs were discussed with the GPs. These CGAs involved

participants declining care or without unmet care needs. This may have caused underestimation of the adherence to the intervention, and thus of the overall effect. A detailed more qualitative process evaluation is therefore needed to gain more insight in the motivation and morale towards adherence to the protocol.

Comparison with other studies

Two recent meta-analyses on multifactorial interventions [12, 41], and one meta-analysis on preventive home visits[24] have demonstrated small effects on functional decline. However, these results should be interpreted with caution due to heterogeneity in the target population, the large variability of possible interventions and the variation in outcome measurements of ADL and IADL [12, 24, 41]. One meta-analysis demonstrated that studies that were conducted before the year 1993 showed increased risk reduction on physical function [12]. This implicates that healthcare systems probably improved since then, adapting principles of effective elderly care in usual care [12]. Studies performed in the United States also demonstrated increased risk reduction on functional decline, because primary care for older people is less developed in the US compared to most European countries [41].

Recent studies in the United Kingdom, Canada, and The Netherlands found neutral effects of multifactorial preventive interventions to prevent disability or functional decline [15-18, 20, 21], except for one study who described a small effect of nurse-led personalised care on postponing functional decline among highly educated participants [42]. The window of opportunity for multifactorial interventions to prevent functional decline may therefore be larger in countries without a well-developed primary healthcare, such as the US [43].

Explanation of the finding and implications for future research

There are several possible explanations why we did not find an effect of a one-year nurse-led multifactorial intervention. First, the intervention lasted one year and measured its potential effects over a two-year period, which may have been too short to see effects emerge. Targeting a pre-frail population, which focuses on the prevention of future incidents, such as disability or mortality, a longer intervention and follow-up period has demonstrated beneficial effects [44-47]. Furthermore, although experienced CCRNs were trained before and during the intervention, we observed that nurses needed time to build a steady collaboration with the GPs with focus on the new way of working with the GP and to focus on geriatric conditions. A detailed process evaluation is needed to learn how both professionals interacted together and which components of the intervention were or were not regarded useful to implement.

Second, insufficient contrast between the study groups could explain the lack of effect that was observed. The majority of the participants in the control group contacted their GP on a regular basis and received home

care nursing (Table A-12). The Netherlands has a very easy assessable healthcare system [48], and the quality of regular GP care is considered to be of high standard; evidence-based guidelines for the management of chronic conditions managed in the GP practice are available and the adherence to these protocols is good [49]. Problem-based, goal-oriented approaches might already have been incorporated in usual care and additional improvement seems difficult [43].

Third, although the modified Katz-ADL index is able to validly and reliably measure unfavourable health outcomes [50], more insight is needed in its ability to detect clinical relevant change in disability over time. Besides, the separate components of the interventions were developed to provide treatment and care for geriatric conditions, such as pain, incontinence, hypertension, and loneliness, but this may not have been sufficiently associated with daily functioning as such. To enhance the effect of the intervention, more emphasis should be put on interventions that can directly postpone new disabilities, such as physical activity [44, 51]. Using other measures with a closer relation to the individual outcome, such as goal-attainment scaling (GAS) might suit a patient-centered approach better [52]. GAS, is a clinimetric tool that describes goal achievement for individual patients. GAS has demonstrated to detect clinically important change in the evaluation of complex interventions in frail elderly patients [52].

Fourth, the intensity of the intervention may have been too low to see effects emerge. However, we found no "dose-response" effects by the number of home visits and interventions in the CTP.

Fifth, although many geriatric conditions were identified in the CGA, only one condition per participant was recognised as a problem and only one intervention was initiated. This could indicate that the CGA detected many conditions without unmet needs. Older persons may simply accept certain conditions as a normal part of ageing, or perhaps they were already addressed. Furthermore, prioritizing geriatric conditions may have resulted in a selection of interventions, while unfavorable conditions where left untreated. However, recognition and prioritizing may be useful in developing a person-centred approach to care, potentially facilitating shared decision-making and overall efficiency.

Finally, although we found a small and transient effect of the intervention for after-hours GP care use, we think that this should be interpreted with caution because of the relatively large number of outcome measures assessed.

Conclusions

In this cluster randomised trial, we found no evidence that a one-year multifactorial nurse-led care program was better than current primary care in community-living older people at increased risk of functional decline in The Netherlands. Nevertheless, the implementation of preventive programs in general practice is ongoing in many healthcare systems throughout the

Western world. We may learn from process evaluations why Dutch general practitioners want to implement preventive interventions despite the apparent ineffectiveness of a one-year intervention on functional decline over and above current primary care. In consideration of the ageing of Western societies, increasing task delegation from GPs to nurses warrants further non-inferiority analyses on both quality and costs, and warrants evaluation from a societal perspective to explore whether such programs may still deliver valuable services at acceptable costs and efforts.

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Appendix

Contents

Text A-1. Identification of Senior At Risk- Primary Care (ISAR-PC) screening instrument

Identification of Senior At Risk- Primary Care (ISAR-PC) is a validated screening instrument, developed to identify older community-dwelling persons (≥ 70 year) at increased risk of functional decline. The instrument is short and easy to apply. ISAR-PC consists of three questions:

ISAR-PC

1. Did you need assistance on a regular basis in the last month (e.g. preparing meals, shopping, housekeeping)?	No Yes	0.0 2.5
2. Do you regularly have memory problems?	No Yes	0.0 2.0
3. Your age is:	74 years or younger Between 75 and 84 years 85 years and older	0.0 1.5 3.0
Total score		.....

Maximum score:	7.5 points
Total score 0 or 1:	Not at risk of functional decline
Total score 2 or higher:	At risk of functional decline

The range of scores varies from 0 to 7.5 points. A score of ≥ 2 points indicates increased risk of functional decline over a one-year period. In the development cohort (n= 790) at a cut-off ≥ 2 points the AUC of the ISAR-PC ranged from 0.67 to 0.70 and the positive and negative predictive values were 48.3 and 80.5%. In the validation cohort (n= 2573) the AUC ranged from 0.63 to 0.64 and the positive and negative predictive values were 45.1 and 74.7% [1]. Participants with a score of ≥ 2 points were eligible to participate in the FIT trial.

Text A-2. Training of nurses involved in the trial

In total, 15 experienced community-care registered nurses participated in the intervention. They followed a 10-day training with specific focus on geriatric care in the community. The training was developed together with the School of Nursing from InHolland University of Applied Sciences, in collaboration with the Academic Medical Center and the Regional Council of General Practitioners, all based in Amsterdam. The training comprised of two sections of three days and one section of 4 days; 1) introduction into research and frail older persons; 2) somatic and functional geriatric conditions; and 3) psychological and social conditions. To obtain a training certificate the nurses had to fulfil a practical assignment for each section.

Section 1: Introduction to research focused on methodological and ethical aspects of research, participating in a randomised clinical trial, and the study protocol. Introduction to frail older persons concerned background information on ageing, care models, frailty and physical functioning, and comprehensive geriatric assessment (CGA). Subsequently, nurses were trained in conducting the CGA, drafting a care- and treatment plan (CTP) and how to formulate goals of care with patients.

Section 2: Somatic and functional geriatric conditions were provided by geriatric experts (e.g. general practitioners, geriatricians, pharmacist, and clinical nurse specialist) and included polypharmacy, pain management, malnutrition, fall prevention, incontinence, sleep disorder, and ADL and IADL impairments.

Section 3: The training in psychological and social conditions was also provided by content experts and consisted of caregiver burden, cognitive impairment, depression, financial problems, and elder abuse.

Across the three modules the training focused on how to apply evidence-based interventions, how to provide patient-centred care and empower the older person.

Every six weeks, the nurses attended a refresher course on adherence to the study protocol, conducting the CGA, making a care- and treatment plan, formulating goals of care with patients, patient-centred care and empowerment of the older person. Two additional afternoons were spent on communication training provided by an expert, applying principles of motivational interviewing and complex situations (e.g. the informal caregiver has other wishes than the patient).

Text A-3. Evidence-based protocols used in the trial

To create uniformity in diagnostic assessments and interventions, a multidisciplinary expert panel developed a toolkit that underpins the individually tailored care and treatment plan (CTP). The toolkit was constructed based on previous experience from the DEFENCE study. The toolkit consisted of standardised protocols for the 24 most prevalent geriatric conditions in the CGA following international guidelines and were based on evidence or on current best practice [2]. The protocols are available on a website: https://www.acute-ouderenzorg.nl/toolkit/ [in Dutch] The nurses could apply the evidence-based protocols after the initial CGA. If the older person recognised the geriatric conditions, that resulted from the CGA, and identified these conditions as a priority, the evidence-based protocols were subsequently used.

The protocols were a practical translation of existing guidelines. They consisted of further diagnostic assessments, a stepwise overview of risk factors, and evidence-based interventions that the older person him/herself, the nurse, the GP or other healthcare professionals could perform. For example, if a person had previously fallen, risk factors for falling, such as visual impairment or medication side-effects, were assessed, and the nurses were guided to make an overview to address the most important diagnostic or prognostic factors. Subsequently, they were guided to propose interventions to the GP or the geriatrician such as physiotherapy, evaluation of visual impairment or evaluation of medication. Furthermore, for each geriatric condition also background and additional in-depth information was available, such as prevalence, risk factors, screening, diagnostic assessment and interventions.

Text A-4. Care as usual in the Dutch healthcare system

In the Dutch healthcare system, the general practitioner (GP) plays a central role; as the gatekeeper of the healthcare system, s/he is the first and only freely accessible medical professional, and people are used to visiting their GP first if they have a health problem [3]. In the last two decades, there has been an increasing task delegation from GP to registered nurses working in GP practice. Evidence-based protocols for care provided by GPs are available for the management of chronic conditions such as diabetes mellitus, cardiovascular disease, COPD, and obesity. In 2001, the average adherence rate to these protocols was 67% with a large variation [4]. In 2010, the healthcare insurer started to reimburse preventive primary care for community-dwelling frail older people and GPs began to employ qualified nurses specialised in providing such preventive care. In the control group, we offered practices a temporary reimbursement to postpone this nurse-led care for older people until study termination. Throughout the study, we monitored all participants' healthcare and home care utilisation (Table 1).

Table A-1. Characteristics of participants and general practices in the intervention group

General practice	Intervention group										
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Participants (N)	131	143	74	89	99	46	228	177	31	113	78
Age, in years, median (IQR)	83.5 (78.3-87.3)	82.5 (76.5-87.2)	83.1 (77.1-87.1)	85.4 (79.8-90.0)	82.6 (76.4-87.1)	78.5 (73.9-84.9)	82.1 (76.2-86.8)	83.3 (78.9-86.9)	84.0 (76.7-88.1)	82.6 (76.9-88.0)	84.1 (75.9-87.9)
female sex	68.7	59.4	62.2	69.7	65.7	63.0	64.5	68.4	61.3	65.5	62.8
Socio-economic status											
low (≤1SD)	1.5	-	1.4	1.1	1.0	-	-	-	-	22.1	35.9
intermediate	97.7	100	98.6	98.9	97.0	95.7	51.8	55.9	100	51.3	62.8
high ≥1SD)	0.8	-	-	-	2.0	4.3	48.2	44.1	-	26.5	1.3
Katz-ADL (range 0-6), median (IQR)	1 (0-1)	1 (0-1)	0 (0 -1)	1 (0-2)	1 (0-2)	1 (0-1)	0 (0-1)	1 (0-1)	1 (1-2)	1 (0-1)	1 (0 -1)
IADL scale (range 0-7), median (IQR)	1 (1-3)	1 (0-3)	1 (0-2)	2 (1-4)	2 (0-3)	1 (1-3)	1 (0-2)	2 (1-3)	2.0 (1-4)	2 (0-3)	1 (0-3)

Values are numbers (percentages) unless stated otherwise; IQR=interquartile range; SD=standard deviation; Katz-activities of daily living; IADL=instrumental activities of daily living

Table A-2. Characteristics of participants and general practices in the control group

General practice	Control group												
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**
Participants (N)	102	38	60	70	84	188	151	69	19	85	59	83	66
Age, in years, median (IQR)	84.6 (79.5-88.0)	81.6 (76.8-86.5)	80.4 (74.7-85.7)	82.6 (75.6-86.5)	83.9 (77.2-87.4)	82.6 (77.7-86.5)	83.0 (76.8-87.8)	81.0 (75.0-86.6)	77.5 (74.1-82.9)	81.3 (75.9-86.6)	81.9 (76.6-85.3)	83.2 (77.2-86.8)	80.7 (74.9-86.8)
Female sex	56.9	73.7	61.7	62.9	63.1	64.4	57.6	60.9	73.7	62.4	66.1	63.9	66.7
Socio-economic status													
low (≤1SD)	-	2.6	-	-	1.2	-	10.6	-	-	-	47.5	27.7	13.6
intermediate	99.0	97.4	100	77.1	36.9	98.9	86.1	91.3	63.2	98.8	49.2	69.9	74.2
high ≥1SD)	1.0	-	-	22.9	61.9	1.1	3.3	8.7	36.8	1.2	3.4	2.4	12.1
Katz-ADL (range 0-6), median (IQR)	0 (0-1)	1 (0-2)	1 (0-1)	1 (0-1)	0 (0-1)	1 (0-2)	1 (0-2)	0 (0-1)	1 (0-1)	0 (0-1)	1 (0-1)	1 (0-1)	1 (0-1)
IADL scale (range 0-7), median (IQR)	1 (0-3)	2 (0-3)	1 (0-3)	1 (1-3)	1 (0-3)	2 (1-4)	2 (1-4)	1 (0-3)	2 (1-3)	1 (0-0)	2 (1-3)	2 (0-4)	1 (0-3)

Values are numbers (percentages) unless stated otherwise; IQR=interquartile range; SD=standard deviation; Katz-activities of daily living; IADL=instrumental activities of daily living

Table A-3. Characteristics of participants in the intervention group who received or declined the comprehensive geriatric assessment

Characteristics	Intervention group received CGA N=934	Intervention group declined CGA N=275
	N(%)	%
Age, in years, median (IQR)	82.7 (76.8-87.1)	84.0* (78.2.6-88.1)
Female sex	65.4	64.2
Level of education		
primary school or less	20.3	24.7
secondary education	64.0	62.5
college or university	15.7	12.7
Socio-economic status		
low (≥1SD)	4.3	6.5
intermediate	77.4	74.2
high (≤1SD)	18.3	19.4
Married/living together	47.1	45.5
Living situation		
independent, alone	46.2	36.7***
independent, together	44.6	41.0
home for elderly	8.2	22.3
Multimorbidity (≥2)	83.4	82.3
Polypharmacy (≥3)	69.0	71.0
Memory problems (self report)	33.3	38.7
Modified Katz-ADL index (range 0-15), median (IQR)	2.0 (1-4)	3.0*** (1-6)
Katz-ADL (range 0-6), median (IQR)	1.0 (0-1)	1.0*** (0-1)
IADL scale (range 0-7), median (IQR)	1.0 (0-3)	2.0*** (1-4)
EuroQol-5D (range -0.33 to 1.0), mean (SD)	0.76 (0.20)	0.70*** (0.25)
Emotional wellbeing (RAND36), (range 4-100), mean (SD)	72.2 (16.9)	68.5** (18.5)
Quality of Life mark (range 0-10), mean (SD)	7.3 (1.2)	6.9*** (1.5)
Falls (≥1) in past 12 months	34.6	36.0

Values are numbers (percentages) unless stated otherwise; IQR=interquartile range; SD=standard deviation; Katz-activities of daily living; IADL=instrumental activities of daily living.
Student's t-test for continuous variables; Mann-Whitney U test for continuous nonparametric variables; Chi-square test for categorical variables.
*p<0.05; **p<0.01; ***p<0.001

Table A-4. Prevalence of geriatric conditions in CGA

Geriatric condition	Description	%
Mobility problems	Use of walking aid	47.2
Polypharmacy (≥5)	Use ≥5 different medications	45.5
Blood pressure	Systolic blood pressure ≥ 160 mmHg	43.4
Sleeping disorder	Problems with sleeping or use of sleeping medication	39.6
Physical inactivity	Physical activity < once a month	26.1
Falls	At least one fall (in past 12 months)	38.4
Depression	Geriatric depression scale (one of two questions)	38.1
Pain	Score ≥ 4 on visual analogue scale	37.7
Urine incontinence	Involuntary loss of urine	37.1
Cognitive impairment	Self-report memory problem	35.3
Loneliness	Score ≥ 3 on Jong Gierveld loneliness scale	32.7
Osteoporosis risk	Score ≥ 4 on osteoporosis risk factors	28.1
Hearing impairment	Self-report hearing impairment	27.3
Alcohol use	Score: ≥ 4 units/week women; ≥ 5 units/week men	24.2
Medication use	Problems with compliance or side-effects	22.0
Obesity	BMI[1] > 30 kg/m2	18.6
Visual impairment	Self-report visual impairment	18.3
Dizziness	Problems of dizziness in the last month	13.2
Anxiety	Feelings of anxiety (in the last month)	10.4
Oral hygiene	Problems or pain of mouth in last month	9.2
Living situation	inadequate living situation	7.8
Constipation	Stool < 3 times a week	5.5
MMSE[2]	Score ≤ 23 mini mental state examination	4.4
Malnutrition	SNAQ[3] 65+	3.1

[1] BMI = Body Mass Index;
[2] MMSE = Mini Mental State Examination;
[3] SNAQ = Short Nutritional Assessment Questionnaire.

Table A-5. Adherence to the trial protocol

Participants in intervention n = 1209	**% (n/N)**
Comprehensive geriatric assessment	77.0 (934/1209)
Care and treatment plan (CTP)	76.6 (926 /1209)
CTP discussed with General Practitioner	61.6 (575/934)
Evaluation of CTP after one year	77.4 (698/898*)
Decline CTP: participants declining care	16.9(158/936)
Decline CTP: problems already being addressed	14.2 (133/936)
Decline CTP: participants not recognizing the identified problem	7.3 (68/936)

Values are numbers (percentages) unless stated otherwise
*after one year 38 persons died.

Table A-6. Primary results of trial: Mean scores and difference between intervention and control group at 6, 12, 18 and 24 months

Outcome	6 months		12 months		18 months		24 months		6, 12, 18, 24 months	
	Mean score (95% CI)		Mean score (95% CI)		Mean score (95% CI)		Mean score (95% CI)		Mean difference (95% CI)	p-value
	Int.	Cont.	Int.	Cont.	Int.	Cont.	Int.	Cont.	Time X treatment ($p_{interaction}$=0.68)	
Modified Katz-ADL index (0-15) *	3.11 (2.94-3.28)	3.32 (3.13-3.50)	3.38 (3.20-3.56)	3.59 (3.39-3.78)	3.53 (3.34-3.71)	3.74 (3.54-3.93)	3.27 (3.09-3.45)	3.48 (3.28-3.67)	-0.21 (-0.46-0.04)	0.10
Modified Katz-ADL index (0-15) **	3.05 (2.94-3.15)	3.10 (2.98-3.21)	3.33 (3.21-3.44)	3.38 (3.25-3.51)	3.47 (3.35-3.59)	3.52 (3.39-3.65)	3.20 (3.07-3.34)	3.26 (3.11-3.40)	-0.05 (-0.20-0.10)	0.49
Modified Katz-ADL index (0-15) ***	3.02 (2.92-3.12)	3.09 (2.98-3.21)	3.31 (3.20-3.42)	3.39 (3.26-3.51)	3.46 (3.33-3.58)	3.53 (3.40-3.66)	3.19 (3.05-3.32)	3.27 (3.12-3.41)	-0.07 (-0.22-0.07)	0.33

* Estimated mean scores and mean differences between intervention and control group (unadjusted)
**Estimated mean scores and mean differences between intervention and control group adjusted for baseline Katz score
***Estimated mean scores and mean differences between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline Katz-score
CI = confidence interval. The mean difference was the same at all follow-up moments.

Table A-7. Primary results of trial: Mean difference between intervention and control group at 12 months after accounting for missing values

Outcome	No of participants in MLA	Mean difference (95% CI)	p-value
Modified Katz-ADL index ***	2249	-0.05 (-0.20-0.10)	0.52

***Estimated mean scores and mean differences between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline Katz-score; CI = confidence interval, MLA = multilevel analyses
Data were based on 10 imputed datasets

Table A-8. Mean scores and differences between intervention and control group at 6, 12, 18 and 24 months for secondary outcomes health related quality of life and psychological health status

Outcome	6 months			12 months		
	Mean score (95% CI)		Mean difference (95% CI), p-value	Mean score (95% CI)		Mean difference (95% CI), p-value
	Int.	Cont.		Int.	Cont.	
EQ5D*	0.76 (0.75-0.77)	0.75 (0.73-0.76)	0.01 (-0.01-0.03), 0.20	0.74 (0.72-0.75)	0.72 (0.71-0.74)	0.01 (-0.01-0.03), 0.17
EQ5D**	0.76 (0.75-0.77)	0.76 (0.75-0.77)	-0.003 (-0.02-0.01), 0.70	0.74 (0.73-0.75)	0.74 (0.72-0.75)	0.00 (-0.02-0.02), 0.97
EQ5D***	0.76 (0.75-0.77)	0.76 (0.75-0.77)	0.00 (-0.02-0.01), 0.72	0.74 (0.73-0.75)	0.74 (0.72-0.75)	0.00 (-0.01-0.02), 0.84
RAND-36 *	70.25 (70.20-72.29)	70.39 (70.31-72.48)	-0.15 (-1.65-1.36), 0.85	70.08 (68.98-71.19)	70.33 (69.16-71.50)	-0.25 (-1.86-1.36), 0.77
RAND-36 **	71.25 (70.21-72.29)	71.39 (70.30-72.47)	-0.14 (-1.64-1.37), 0.86	70.09 (68.98-71.19)	70.32 (69.15-71.49)	-0.24 (-1.84-1.37), 0.77
Rand-36 ***	70.12 (70.07-72.16)	71.50 (70.42-72.59)	-0.39 (-1.91-1.13), 0.62	69.90 (68.79-71.01)	70.43 (69.26-71.60)	-0.53 (-2.16-1.09), 0.52
QOL*	7.12 (7.05-7.19)	7.17 (7.09-7.24)	-0.05 (-0.15-0.06), 0.39	7.01 (6.93-7.10)	7.02 (6.94-7.11)	-0.01 (-0.13-0.11), 0.87
QOL**	7.14 (7.08-7.20)	7.21 (7.16-7.27)	-0.07 (-0.15-0.01), 0.08	7.04 (6.97-7.11)	7.07 (6.99-7.15)	-0.03 (-0.13-0.08), 0.62
QOL***	7.15 (7.09-7.21)	7.21 (7.15-7.27)	-0.06 (-0.14-0.02), 0.14	7.05 (6.98-7.11)	7.07 (7.00-7.15)	-0.03 (-0.13-0.08), 0.61

* Estimated mean scores and mean differences between intervention and control group
**Estimated mean scores and mean differences between intervention and control group adjusted for baseline outcome score
***Estimated mean scores and mean differences between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline outcome score

Table A-8. Continued

18 months			24 months			Outcome
Mean score (95% CI)		Mean difference (95% CI), p-value	Mean score (95% CI)		Mean difference (95% CI), p-value	
Int.	Cont.		Int.	Cont.		
0.75 (0.72-0.76)	0.71 (0.69-0.73)	0.03 (0.01-0.05), 0.01	0.73 (0.71-0.74)	0.71 (0.69-0.72)	0.02 (0.00-0.04), 0.03	EQ5D*
0.74 (0.73-0.75)	0.72 (0.71-0.74)	0.01 (0.00-0.03), 0.11	0.73 (0.72-0.74)	0.72 (0.71-0.73)	0.01 (-0.01-0.03), 0.33	EQ5D**
0.74 (0.73-0.75)	0.72 (0.71-0.74)	0.01 (0.00-0.03), 0.12	0.73 (0.72-0.74)	0.72 (0.71-0.73)	0.01 (-0.01-0.03), 0.29	EQ5D***
70.24 (69.12-71.35)	69.94 (68.49-70.80)	0.59 (-1.01-2.20), 0.47	69.80 (68.67-70.92)	68.90 (67.71-70.09)	0.89 (-0.74-2.53), 0.28	RAND-36 *
70.24 (69.13-71.35)	69.63 (68.48-70.79)	0.61 (-0.99-2.21), 0.46	69.80 (68.68-70.93)	68.89 (67.70-70.08)	0.90 (-0.73-2.55), 0.28	RAND-36 **
70.14 (69.01-71.26)	69.80 (68.64-70.96)	0.34 (-1.29-1.97), 0.69	69.76 (68.63-70.90)	69.06 (67.87-70.25)	0.70 (-0.95-2.36), 0.40	Rand-36 ***
6.98 (6.91-7.06)	6.97 (6.89-7.05)	0.01 (-0.10-0.13), 0.81	6.98 (6.91-7.06)	6.92 (6.83-7.01)	0.07 (-0.05-0.18), 0.27	QOL*
7.01 (6.94-7.07)	7.02 (6.95-7.10)	-0.02 (-0.11-0.08), 0.73	7.01 (6.95-7.07)	6.98 (6.90-7.06)	0.03 (-0.07-0.13), 0.52	QOL**
7.01 (6.95 -7.08)	7.03 (6.96 -7.10)	-0.02 (-0.11-0.09), 0.75	7.02 (6.96 -7.08)	6.98 (6.90-7.06)	0.04 (-0.06-0.15), 0.40	QOL***

EQ5D ranges from -0.33 to 1.0 and higher scores indicate better health related quality of life. Rand-36 = Psychological health status ranges from 4 to 100 and higher scores indicate better psychological wellbeing. Quality of life mark ranges from 1 to 10 and higher scores indicate better quality of life. CI = confidence interval, QOL = Quality of life

Table A-9. Incidence rates and rate ratio's for intervention and control group at 6, 12, 18 and 24 months for secondary outcomes hospitalisation and falls

Outcome	6 months		12 months		18 months		24 months		No of participants in MLA	6, 12, 18, 24 months	
	Incidence rate (95% CI)		Incidence rate (95% CI)		Incidence rate (95% CI)		Incidence rate (95% CI)			Incidence rate ratio (95% CI)	p-value
	Int.	Cont.	Int.	Cont.	Int.	Cont.	Int.	Cont.			
Hospitalisation *	0.10 (0.08-0.11)	0.11 (0.09-0.13)	0.10 (0.08-0.12)	0.11 (0.09-0.13)	0.09 (0.08-0.11)	0.10 (0.08-0.12)	0.10 (0.08-0.12)	0.11 (0.09-0.14)	2013	0.92 (0.77-1.09)	0.33
Hospitalisation **	0.10 (0.08-0.12)	0.11 (0.09-0.14)	0.11 (0.09-0.13)	0.12 (0.10-0.14)	0.10 (0.08-0.12)	0.12 (0.09-0.14)	0.11 (0.09-0.13)	0.13 (0.10-0.15)	1949	0.88 (0.74-1.05)	0.17
Hospitalisation ***	0.11 (0.09-0.13)	0.12 (0.10-0.14)	0.11 (0.09-0.13)	0.12 (0.10-0.14)	0.11 (0.09-0.13)	0.12 (0.10-0.14)	0.12 (0.09-0.14)	0.13 (0.10-0.15)	1924	0.90 (0.76-1.07)	0.25
Falls*	0.20 (0.17-0.23)	0.17 (0.14-0.20)	0.20 (0.17-0.23)	0.17 (0.14-0.19)	0.21 (0.18-0.25)	0.18 (0.15-0.21)	0.21 (0.18-0.25)	0.18 (0.15-0.21)	2003	1.17 (0.99-1.38)	0.06
Falls **	0.25 (0.21-0.29)	0.22 (0.18-0.26)	0.25 (0.21-0.29)	0.22 (0.19-0.26)	0.29 (0.24-0.33)	0.25 (0.21-0.29)	0.28 (0.24-0.33)	0.25 (0.21-0.29)	1941	1.14 (0.98-1.32)	0.10
Falls***	0.25 (0.21-0.29)	0.22 (0.18-0.26)	0.26 (0.21-0.30)	0.22 (0.19-0.26)	0.29 (0.24-0.34)	0.25 (0.21-0.30)	0.29 (0.24-0.34)	0.25 (0.21-0.30)	1916	1.15 (0.98-1.34)	0.08

*Estimated incidence rates and incidence rate ratio between intervention and control group
**Estimated incidence rates and incidence rate ratio between intervention and control group adjusted for baseline score of outcome
***Estimated incidence rates and incidence rate ratio between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline score of outcome
Incidence rate ratios below 1 indicate a protective effect of the intervention. CI = confidence interval. The incidence rate ratios at 12 months were the same at all follow-up moments.

Table A-10. Incidence rates and rate ratio's for intervention and control group at 6, 12, 18 and 24 months for secondary outcome after-hours primary care

Outcome	6 months			12 months			18 months			24 months		
	Incidence rate (95% CI)		Incidence rate ratio (95% CI), p-value	Incidence rate (95% CI)		Incidence rate ratio (95% CI), p-value	Incidence rate (95% CI)		Incidence rate ratio (95% CI), p-value	Incidence rate (95% CI)		Incidence rate ratio (95% CI), p-value
	Int.	Cont.		Int.	Cont.		Int.	Cont.		Int.	Cont.	
After-hours GP care *	0.04 (0.03-0.05)	0.07 (0.05-0.09)	0.54 (0.38-0.79), <0.001	0.05 (0.03-0.06)	0.06 (0.04-0.08)	0.84 (0.57-1.22), 0.35	0.04 (0.03-0.06)	0.06 (0.04-0.08)	0.73 (0.49-1.08), 0.12	0.06 (0.04-0.08)	0.06 (0.04-0.08)	0.98 (0.67-1.45), 0.94
After-hours GP care **	0.04 (0.03-0.05)	0.08 (0.05-0.10)	0.51 (0.35-0.74), <0.00	0.06 (0.04-0.08)	0.06 (0.04-0.09)	0.87 (-0.60-1.28), 0.49	0.05 (0.03-0.06)	0.07 (0.04-0.09)	0.72 (-0.48-1.08), 0.11	0.07 (0.05-0.10)	0.07 (0.05-0.10)	0.97 (0.66-1.43), 0.89
After-hours GP care ***	0.04 (0.03-0.06)	0.08 (0.06-0.11)	0.53 (0.36-0.77), <0.00	0.06 (0.04-0.08)	0.06 (0.04-0.08)	0.95 (0.65-1.41), 0.83	0.05 (0.03-0.07)	0.07 (0.05-0.09)	0.76 (0.50-1.14), 0.18	0.08 (0.05-0.10)	0.08 (0.05-0.10)	1.02 (0.69-1.51), 0.90

*Estimated incidence rates and incidence rate ratio between intervention and control group
**Estimated incidence rates and incidence rate ratio between intervention and control group adjusted for baseline score of outcome
***Estimated incidence rates and incidence rate ratio between intervention and control group adjusted for age, sex, socio-economic status, level of education, and baseline score of outcome
Incidence rate ratios below 1 indicate a protective effect of the intervention. CI = confidence interval.

Table A-11. Interaction terms of different levels of education, socio-economic status, baseline disability, and age

	Significance level interaction term	**Significance level interaction term**	**Significance level interaction term**	**Significance level interaction term**
Level of education	intermediate p=0.94	high p=0.39		
level of socio-economic status	low p=0.99	intermediate p=0.79		
Baseline level of disability (Katz score)	2-4 p=0.41	5-7 p=0.24	8-15 p=0.34	
Baseline level of age (years)	75-79 p=0.19	80-84 p=0.59	85-89 p=0.40	≥90 p=0.41

Interaction terms for treatment × levels of education (high and intermediate), treatment × socio-economic status (low and intermediate), treatment × levels of age (quartiles), and treatment × baseline disability (tertiles)

Table A-12. In hours general practice care during follow-up for older persons at increased risk of functional decline (ISAR-PC≥2).

	Intervention group (%)	Control group (%)	Intervention group mean (SD)	Control group mean (SD)
Follow-up (6 months intervals)		**GP consultation (≥1)**		
6	59.0	61.0	1.2 (1.5)	1.4 (1.8)
12	57.1	55.8	1.3 (1.6)	1.3 (1.8)
18	57.8	59.4	1.3 (1.7)	1.3 (1.5)
24	56.2	57.5	1.2 (1.6)	1.3 (1.6)
Follow-up (6 months intervals)		**GP visit (≥1)**		
6	24.8	24.2	0.6 (1.4)	0.5 (1.3)
12	24.3	23.2	0.6 (1.7)	0.5 (1.2)
18	25.3	25.6	0.5 (1.2)	0.5 (1.2)
24	24.5	22.9	0.5 (1.1)	0.5 (1.2)

Values are numbers (percentages) unless stated otherwise.
GP = general practitioner; sd = standard deviation

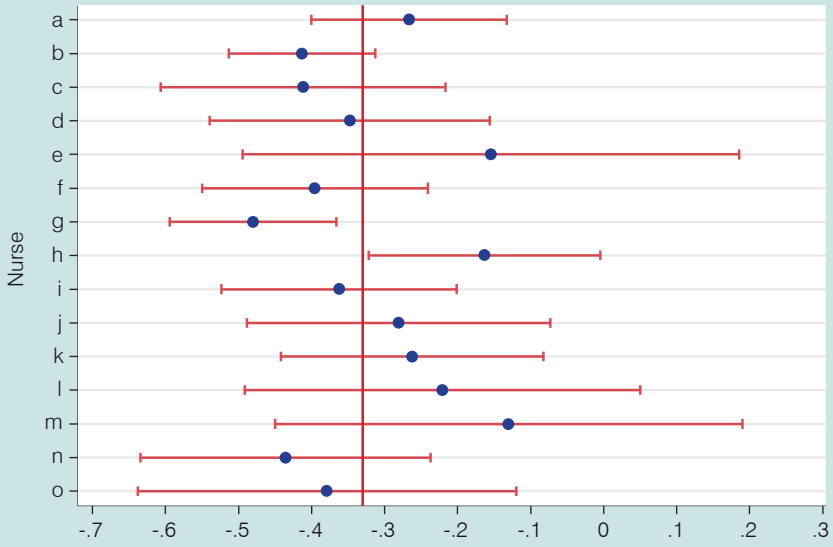

Figure A-1. Mean changes in modified Katz-ADL index scores among nurses
Adjusted for age, sex, socio-economic status, level of education, baseline score on modified Katz-ADL index and multimorbidity
The vertical line represents the mean change in the modified Katz-ADL index score for all nurses

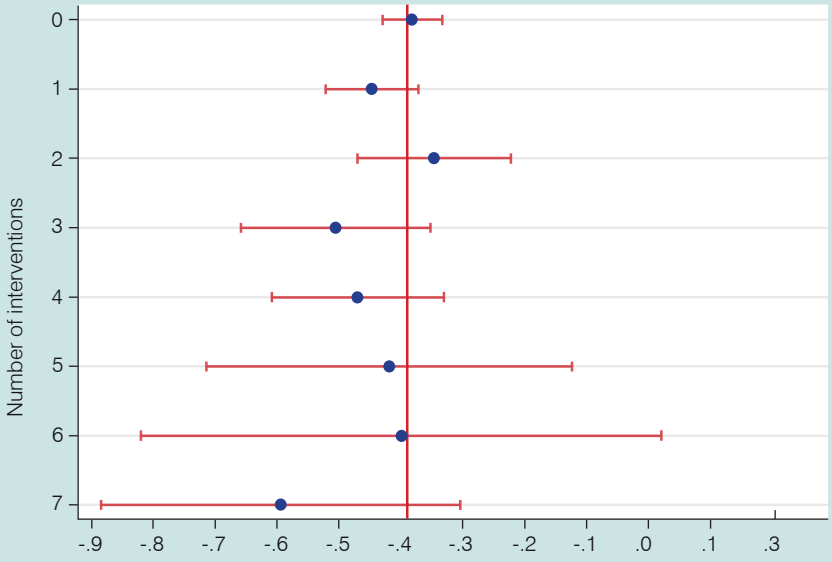

Figure A-2. Mean changes in modified Katz-ADL index scores by increasing number of interventions performed
Adjusted for age, sex, socio-economic status, level of education, baseline score on modified Katz-ADL index and multimorbidity
The vertical line represents the mean change in the modified Katz-ADL index score for the overall number of interventions

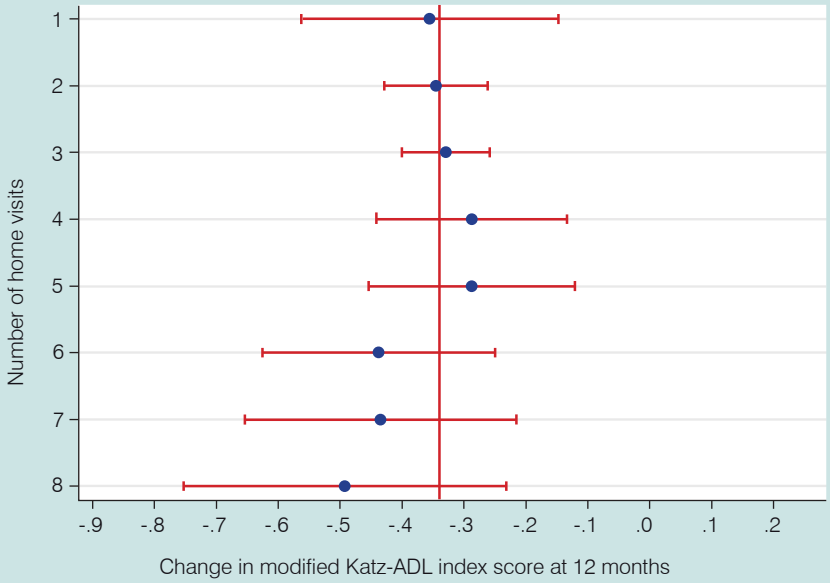

Figure A-3. Mean changes in modified Katz-ADL scores for increasing number of home visits
Adjusted for age, sex, socio-economic status, level of education, baseline score on modified Katz-ADL index and multimorbidity
The vertical line represents the mean change in the modified Katz-ADL index score for the overall number of home visits

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Chapter

3

Do multiple chronic conditions influence personal views on the ageing process? A qualitative analysis

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Abstract

Background: For older people with multiple chronic conditions (MCC) insight into what they perceive as important in their lives is essential when discussing preferences in the shared decision making process. The aims of this study were to 1) investigate the personal views on the ageing process communicated by older people and 2) compare the personal views of older people with and without MCC.

Methods: Using structured interviews, 547 community-dwelling older people aged 70 years and above were asked five questions about what they perceived as important in terms of ageing, worries, their future, healthy ageing and quality of life. Two independent researchers coded the data and performed content analyses. A stratified content analysis was performed to explore whether persons with and without MCC expressed different personal views with regard to the ageing process.

Results: The mean (SD) age was 78.9 (5.9) years, and 60.3% were female. MCC were present in 72% of the study sample. There were no significant differences in demographic characteristics between older people with and without MCC. However older people with MCC more often had polypharmacy (43% vs 24%; $p<0.001$), more difficulties with (instrumental) activities of daily living (mean number of impairments 2.4 vs 0.8; $p< 0.001$) and reported more falls (35% vs 23% $p = 0.01$) than those without MCC. The qualitative analysis identified the following main themes: ageing was associated with acceptance of ageing, (further) deterioration and worries about limitations and family. A healthy lifestyle, keeping busy, maintaining social contacts and a positive attitude were considered prerequisites to healthy ageing. In 24 out of 28 sub-themes no significant differences were found between participants with and without MCC. Persons with MCC more often expressed that ageing for them meant having to cope with deterioration and limitations, they had more worries and feared more deteriorations compared to those without MCC. Also older people with MCC less often considered a positive attitude to life a prerequisite to healthy ageing.

Conclusions: Acceptance of ageing, (further) deterioration and worries about limitations and family were important themes on the ageing process communicated by older people. Overall, we found no major differences between persons with and without MCC. The results of this study may help raising awareness amongst healthcare professionals that eliciting and understanding an older persons' views on the ageing process is an important first step in making health decisions that support older persons' personal goals and expectations.

Introduction

Older people with multiple chronic conditions (MCC) face many health-related decisions, including those related to diagnostic procedures, medication use and invasive treatments [1, 2]. For professionals caring for older people with MCC is challenging due to the limitations of single-disease-focused guidelines, which do not take into account the complexity of MCC and are sometimes contradictory [3]. Moreover, having MCC often leads to problems in the functional, social or psychological domains [2, 4]. The presence of MCC in older people influences their goals and expectations of medical treatment; for older people with MCC maintaining independence and quality of life becomes more important than survival [5]. Therefore, in literature it is hypothesised that especially for older people with MCC it is necessary to elicit their personal values and views before starting medical treatment [2, 6-10] in order to assure that diagnostic procedures and treatment are in line with the outcomes that are important to an older person.

Eliciting a person's values and views [11] is an important step in the shared decision making (SDM) process, guiding the subsequent steps of 'choice talk' (we have options), 'option talk' (what options do we have) and 'decision talk' (what option do we choose?) [12]. This is also described in the Guiding Principles for the care of older adults with MCC by the American Geriatrics Society [2] and in the dynamic model for shared decision-making in frail older patients [13]. Clarification of personal values and views facilitates the decision talk in which preferences must be articulated about the various options. The best option always depends on the person's individual preferences regarding the preferred outcome, such as quality of life or survival [10, 14]. Identifying a person's values, which is a prerequisite for SDM, is not yet a regular component of healthcare conversations [8, 10, 15]. Healthcare professionals often lack routine practices in eliciting older peoples' preferences, and older people often lack the confidence to express them [10, 15-17].

Exploring the personal views of older people with and without MCC could raise awareness among healthcare professionals regarding the topics that are important to older people and might be a first step in making health decisions that support an older persons' personal goals and expectations. The aim of this study was to 1) investigate which personal views on the ageing process older people hold and 2) compare the views of older people with and without MCC.

Methods

Design and setting

Data from a prospective cohort study and from a cluster randomised clinical trial (C-RCT) on the prevention of functional decline in community-

dwelling elderly were combined for this study. Eight general practices (GPs) in Amsterdam, the Netherlands, which were participating in the prospective cohort study and two GPs in IJmuiden, the Netherlands, participating in the intervention arm of the C-RCT, were included in our study. Both studies were conducted between December 2010 and 2014. Details on the prospective cohort study [18] and the C-RCT [19] have been published elsewhere.

Participants and recruitment

All community-dwelling persons who were 70 years and older and registered with one of the participating GPs were selected from the electronic medical records by their GP. Persons were excluded if they were terminally ill, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad or lived in a nursing home. Eligible persons received a letter with information on the study from their GP, together with a written informed consent form, a self-reporting questionnaire and a stamped envelope [19]. The study was approved by the Medical Ethics Committee of the Academic Medical Centre, University of Amsterdam (protocol ID MEC10/182).

Data collection and outcomes

The self-reported questionnaire included questions on multimorbidity, polypharmacy, activities of (instrumental) daily living (KATZ Activities of Daily Living), cognition (Mini Mental State Examination), quality of life (EQ-6D), healthcare utilisation, psychological status (Rand 36) and falls [20]. MCC was defined as having two or more chronic conditions [1] and based on a questionnaire to record MCC. This questionnaire consists of 17 pre-defined chronic conditions (e.g. diabetes, asthma, cancer) and is widely used in the Netherlands [21]. Participants were asked whether they experienced the pre-defined morbidities in the last twelve months. All participants were seen by a Community Care Registered Nurse (CCRN), who performed a comprehensive geriatric assessment (CGA) [19] during a home visit. The CGA started with five questions on personal views on the ageing process and included 1) What does it mean for you to get older? 2) Do you worry about things? 3) What do you think the future will be like? 4) What, in your opinion, is needed for healthy ageing? and 5) What does quality of life mean to you?

Statistical analyses

Two researchers (RP, PV) independently analysed all answers to the five questions by means of an inductive content analysis [22]. In the first step, the categories were derived from key words in the data in an inductive content analysis based on a random and representative sample of the answers of 200 participants (with and without MCC). Subsequently, each answer was classified into one of the defined categories. When persons addressed more than one category within one answer, the first two categories were noted. Only very few people addressed more than two categories. If the categories

contained less than 5% of the total number of answers in both groups, they were included in the category 'other'. Descriptive statistics were used to characterize the participants with and without MCC. To compare the groups at baseline we used chi square tests and independent sample t-tests as appropriate. The same procedure was followed to compare the personal views on the ageing process in older people with and without MCC. We used SPSS (version 21.0) for the statistical analyses.

Results

Participants

Table 1 shows the characteristics of the 547 participants in this study. In total, 396 participants (72%) had MCC. There were no statistically significant differences in the demographic characteristics between persons with and without MCC. However, persons with MCC compared to those without MCC more often had polypharmacy (43% vs 24%; $p<0.001$), experienced more difficulties with (instrumental) activities of daily living (mean number of impairments 2.4 vs 0.8; $p< 0.001$) and a lower health-related quality of life (20% vs 10%; $p <0.001$). Furthermore, their psychological health status was lower (19% vs 16%; $p = 0.01$), and they reported to have had more falls (35% vs 23% $p = 0.01$).

Personal views on the ageing process

Table 2 shows the categories and themes that the participants addressed answering the five questions with regard to personal views on the ageing process. We described the emerging themes for each question and provided an example for each theme.

What does it mean for you to get older?

"Getting older is not so bad; it's the limitations that become a nuisance"

In answering the question 'What does it mean for you to get older?', the respondents addressed the following themes: 'having to manage decline and limitations' (17.6%), 'a positive experience' (14.2%), 'a negative experience' (14.4%), 'acceptance' (15.4%), 'no difficulties' (9.6%), 'no specific meaning' (7.8%) and 'fine, if my condition remains as it is' (8.5%).

Do you worry about things?

"I worry about my husband and that I can't provide care for him anymore"

In response to the question 'Do you worry about things?', 24.2% of the persons expressed worries. Of those who expressed worries, the concerns were focused on 'deterioration' (37.0%) and 'family' (29.0%). The other respondents (34.0%) did not specify the nature of their worries.

Table 1. Baseline Participant Characteristics

Characteristics	Persons with MCC* N=396 (72%)	Persons without MCC* N=151 (28%)	P-value	Total N=547 (100%)
Demographics				
Age, in years (mean, SD)	79.3 (5.9)	77.7 (5.7)	0.23	78.9 (5.9)
Female sex (n, %)	248 (62.6)	82 (54.3)	0.08	330 (60.3)
Level of education				
Primary school or less (n, %)	85 (21.5)	27 (17.9)	0.65	112 (20.5)
Secondary education (n, %)	269 (67.9)	104 (68.9)		373 (68.2)
College or university (n, %)	37 (9.3)	16 (10.6)		53 (9.7)
Socioeconomic status				
Low (%)	267 (67.4)	121 (80.1)	0.01	388 (70.9)
Intermediate (%)	97 (24.5)	26 (17.2)		123 (22.5)
High (%)	31 (7.8)	4 (2.6)		35 (6.4)
Married/living together (n, %)	168 (42.4)	81 (53.6)	0.06	249 (45.5)
Living situation				
Independent, alone (n, %)	213 (53.8)	69 (45.7)	0.08	282 (51.6)
Home for the elderly (n, %)	182 (45.0)	80 (53.0)		262 (47.9)
Clinical characteristics				
Polypharmacy [a] (≥5) (n, %)	216 (43.4)	36 (23.8)	<0.001	252 (46.1)
Modified Katz-ADL index [b] (mean, SD)	2.4 (2.3)	0.8 (1.3)	<0.001	1.9 (2.2)
ADL impairment (mean, SD)	0.7 (0.9)	0.2 (0.4)	<0.001	0.6 (0.8)
IADL impairment (7 items) (mean, SD)	1.3 (1.6)	0.4 (1.0)	<0.001	1.1 (1.5)
Cognitive functioning [c] (mean, SD)	27.9 (3.3)	28.0 (2.6)	0.09	27.9 (2,4)
Health-related quality of life [d] (mean, SD)	0.8 (0.2)	0.9 (0.1)	<0.001	0.8 (0.2)
Psychological health status [e] (mean, SD)	70.2 (18.7)	79.2 (15.8)	0.01	72.7 (18.3)
Quality of Life [f] (mean, SD)	7.5 (1.0)	7.8 (0.9)	0.03	7.5 (1.0)
Falls (≥1) in past 12 months [g] (n, %)	139 (35.1)	34 (22.5)	0.01	173 (31.6)

* MCC (multiple chronic conditions) is defined as having ≥ 2 chronic conditions.
[a] Polypharmacy: use of ≥5 different medications
[b] Modified Katz-ADL, Katz-ADL and Katz-IADL scale indicate ADL and IADL dependency; higher scores indicate more impairment (range 0-15)
[c] Mini Mental State Examination: lower score indicates lower cognitive functioning (range 0 -30)
[d] EQ-5D: utility weights can be attached to the EQ-5D health state. Utility views range from 1 (best possible health) to -0.59 (worse than death)
[e] Rand-36: higher score indicates better psychological and social functioning (range 0-100)
[f] "Could you provide a rating for your quality of life (0: very bad – 10: very good)?"
[g] "Have you experienced one or more falls in the past 12 months?"

What do you think the future will be like?

"If it continues the way it is going now, great"

Persons addressed the following themes for the question 'What do you think the future will be like?': 'hoping or expecting the situation to remain as is' (19.0%), 'having an overall negative view on the future' (17.5%) and 'don't know' (16.9%). Other themes that were addressed by the respondents were as follows: 'it cannot be influenced, just have to wait and see' (13.8%), 'fearing more limitations' (8.6%), 'having an overall positive view on the future' (9.2%) and 'maybe a change in living conditions' (6.0%).

What, in your opinion, is needed for healthy ageing?

"Go to bed on time, eat well and exercise"

In answering the question 'What, in your opinion, is needed for healthy ageing?', the majority of the respondents answered 'a healthy lifestyle, balance between activity and rest' (52.4%). A smaller proportion of persons addressed the following themes: 'keeping busy and interested' (13.1%), maintaining social contacts, family' (7.5%) and 'having a positive attitude to life' (7.5%).

What does quality of life mean to you?

"That I can wake up healthy every day"

In response to the question 'What does quality of life mean to you?', the persons addressed the following themes: 'health (both physical and mental)' (18.1%), 'being able to do what you want to do' (17.6%), 'having social contacts, family and friends around you' (14.2%), 'that you are able to enjoy things' (11.2%) and 'remaining independent' (8.4%). Some persons did not define quality of life but expressed their feeling about it: 'I am positive about my quality of life' (15.8%).

Differences between older people with and without MCC

For four of the 28 sub-themes statistically significant differences were found between participants with MCC compared to participants without MCC. With regard to the question 'What does it mean for you to get older?' persons with MCC more often mentioned 'having to address deterioration and limitations' compared to persons without MCC (19.4% vs 12.9%, $p=0.03$). Persons with MCC less frequently reported for the question 'Do you worry about things?' that they had no worries compared to those without MCC (51.9% vs 63.7%, $p=0.01$). With regard to the question 'What do you think the future will be like?' persons with MCC expressed 'dreading more limitations' more often compared to persons without MCC (10.6% vs 3.3%, $p=0.02$). Finally, regarding the question 'What, in your opinion, is needed for healthy ageing?' persons with MCC said 'having a positive attitude to life' less often compared to persons without MCC (6.2% vs 10.6%, $p=0.03$).

Table 2. Personal views on the ageing process

		Persons with MCC*	Persons without MCC*	Total
Question: What does it mean for you to get older?		**N **= 477**	**N **= 171**	**N **= 648**
Emerging themes	**Example**	**% (n)**	**% (n)**	**% (n)**
Having to address decline and limitations	"Getting older is not so bad; it's the limitations that are a nuisance"	19.3 (92)	12.9 (22)	17.6 (114)
A positive experience	"After a studying and working phase, I'm now in the phase of 'enjoying life"	14.9 (71)	12.2 (21)	14.2 (92)
A negative experience	"I don't like it; I'm only going 'down'"	14.9 (71)	12.9 (22)	14.4 (93)
Acceptance	"Yes, one gets older; little can be changed about that"	14.1 (67)	19.3 (33)	15.4 (100)
No difficulties	"I've experienced no problems"	8.8 (42)	11.7 (20)	9.6 (62)
It has no specific meaning	"It just happens; it doesn't bother me"	7.8 (37)	8.2 (14)	7.8 (51)
Fine, if my condition remains as it is	"I don't mind getting older, as long as I don't experience physical discomfort"	7.3 (35)	11.7 (20)	8.5 (55)
Other		13.0 (62)	11.1 (19)	12.5 (81)
Question: Do you worry about things?				
No Worries	"No"	51.9 (237)	63.7 (109)	55.1 (346)
Worries	"Yes" (no further explanation)	21.9 (119)	19.3 (33)	24.2 (152)
Worries about deterioration	"Yes, I worry about having ailments that add up"	8.4 (38)	5.9 (10)	7.6 (48)
Worries about family	"Yes, I worry about my husband and that I won't be able to provide care for him anymore"	6.1 (28)	5.9 (10)	6.1 (38)
Other		7.7 (35)	5.3 (9)	7.0(44)
Question: What do you think the future will be like?				
Hoping or expecting the situation to remains as is	"If it continues the way it is going now, great"	18.1 (75)	20.3 (31)	19.0 (106)
Having an overall negative vision of the future	"It will probably all get worse slowly; I feel pessimistic about it"	17.9 (74)	16.3 (25)	17.5 (99)
Don't know	"I cannot foresee the future"	16.2 (67)	19.0 (29)	16.9 (96)

Table 2. continued

It cannot be influenced, just have to wait and see	"The future will present itself"	13.5 (56)	14.4 (22)	13.8 (78)
Dreading more limitations	"I think it will get worse because of the discomforts".	10.6 (44)	3.3 (5)	8.6 (49)
Having an overall positive vision of the future	"If things continue like this, I'll make it to 95".	7.7 (32)	13.1 (20)	9.2 (52)
Maybe a change in living conditions	"I live in a house, but I want to move to a flat because there will be no stairs".	6.0 (25)	5.9 (9)	6.0 (34)
Other		9.9 (41)	7.9 (12)	9.4 (53)
Question: What, in your opinion, is needed for healthy ageing?				
A healthy lifestyle, balance between activity and rest	"Go to bed on time, eat well and exercise"	51.5 (225)	54.4 (98)	52.4 (323)
Keeping busy and interested	"To do a lot, have hobbies, leave the house a lot"	12.4 (54)	15.0 (27)	13.1 (81)
Social contacts, family	"To keep being among other people and to not grow lonely"	7.1 (31)	8.3 (15)	7.5 (46)
Having a positive attitude toward life	"Being cheerful is very important to me to be happy"	6.2 (27)	10.6 (19)	7.5 (46)
Other		22.9 (100)	11.7 (21)	19.6 (121)
Question: What does quality of life mean to you?				
Being able to do what you want to do	"To have a normal life, to do what you are used to doing"	16.7 (74)	20.0 (35)	17.6 (109)
Health (both physical and mental)	"That I can wake up healthy every day"	16.7 (74)	21.7 (38)	18.1 (112)
I am positive about my quality of life	"I still enjoy every day of life!"	16.4 (73)	14.3 (25)	15.8 (98)
Social contacts, family and friends around you	"As long as I can socialize, for example with my family"	15.8 (70)	10.3 (18)	14.2 (88)
That you are able to enjoy things	"To live pleasurably, to have a broad interest in all things"	9.9 (44)	14.3 (25)	11.2 (69)
Staying independent	"To stay independent as long as possible"	8.3 (37)	8.6 (15)	8.4 (52)
Other		16.2 (72)	10.9 (19)	14.7 (91)
Emerging themes	**Example**	**Persons with MCC***	**Persons without MCC***	**Total**

*MCC is defined as having > 2 chronic conditions.
** As persons could address multiple themes in one question, N represents the number of answers and not the number of persons.

Discussion

In this study, we explored which personal views older people have regarding the ageing process and if there were differences in personal views between older people with and without MCC . The personal views that were communicated most often were the association of ageing with (further) deterioration, acceptance of ageing and worries about limitations and family. Healthy lifestyles, staying active, keeping social contacts and a positive attitude were considered prerequisites to healthy ageing. The ability to do what one wants to do, good health and social contacts contributes to quality of life. Older people with MCC experienced more impairments in activities of daily living and had a lower health-related quality of life and a lower psychological health status compared to those without MCC. Older people with and without MCC addressed many of the same topics regarding the ageing process but an important difference was that persons with MCC had more worries, had a more negative view on the future and especially feared further physical deteriorations and limitations.

The 28 sub-themes we identified regarding the personal views on the ageing process are consistent with studies that focus on successful ageing [23-25]. In studies that focus on the factors that define successful ageing [23], participants highlighted that being able to do what you want to do, good health and social contacts are prerequisites for healthy ageing and quality of life and not solely the absence of physical limitations. This is in line with our results and the new definition of health, presented by Huber et al [26]. Huber et al describe health as 'the ability to adapt and self-manage' within the context of challenges in all domains of life; cognitive functioning, emotional state, self- respect, experience of being in charge, self-management and resilience. Moreover, many participants in studies focussing on successful ageing mentioned the importance of a positive attitude to cope with the decline in health many of the participants experienced. This is a key feature of the resilience literature that is a further development of the successful ageing movement [24, 25]. Resilience focuses on a person's lifelong search to find a balance between limitations and opportunities, also encompassing a social view on health. Many factors addressed by older people in our study focused on this social view on health, such as maintaining social contacts and being able to do what they wanted to do.

In our study participants identified the preservation of physical function as an important factor contributing to quality of life. Around one third of the participants had negative views on the ageing process. Fear of deteriorations and the inability to take care of family members because of deteriorations were topics that participants worried most about. The deteriorations that were feared are associated with the inability to perform those activities that were indicated by our participants as important to quality of life: interaction with family members, good health, and being able to do what you want to do.

The importance of preservation of physical function has also been found in previous studies on outcomes that are important to older people with MCC. For example, the study of Fried et al [27] emphasises the importance of functional outcomes for patients when they consider a treatment. Although we did not find many differences between older people with and without MCC, those with MCC had more worries and specifically about further deteriorations. At the start of the study they already had more impairment in ADLs. Therefore, this group is at higher risk to develop new disabilities because of their chronic conditions and more frequent hospitalisations [1]. It indicates that for older people with MCC the prevention of functional decline becomes more important.

We expected to find more differences between persons with and without MCC but the differences in personal views were limited. A first explanation might be that the five questions were not asked in the context of a treatment decision. Maybe personal views change when facing an actual treatment decision and differences between patients with and without MCC might become visible. Another explanation could be that the nature and duration of the existing comorbidities influence personal views. According to Gijsen et al [1] the consequences of specific disease combinations vary and depend on many factors. It is possible that specific combinations of coexisting morbidities do influence a person's view on the ageing process, but we were not able to study this in our study.

The Guiding Principles for the care of older adults with MCC by the American Geriatrics Society [2] emphasize that clinicians need an individualised approach for these patients that 'reflects an older person's own preferences and goals in the context of his or her own combination of diseases and conditions'. Our results indicate that these principles might also be followed for patients without MCC, as there were not many differences in personal views on the ageing process. Exploring what defines quality of life for an older person and exploring the views on ageing and the worries people have, might reveal views that can be useful in the decision making process.

Interestingly, fear of deterioration was almost exclusively defined as a decline in physical function and very rarely as a decline in mental health. This outcome warrants further study. A possible explanation might be that it is hard to imagine that cognitive decline will actually happen to you, when you still are in good mental health, whereas many older people already encounter a decline in physical function.

The strength of this study is that we were able to assess personal views in more than 500 older participants, and were able to confirm that many older people have the same personal views on the ageing process and what is needed for healthy ageing and quality of life. However, this study has some limitations. First the inclusion of the five questions used to gain insight into aspects that matter to older people was recommended by CCRN and has no theoretical basis. Furthermore, the answers were written interpretations

recorded concisely by the CCRN, which may have caused some bias . Future in-depth interviews on the answers could provide more insight into the underlying views of persons and the influence of these views on health decisions.

In conclusion, the results of this study show that older people with and without MCC perceive a broad range of personal views as important in their stage of life. Those views can influence the health-related decisions that need to be made regarding diagnostics, treatment and care. For older people with MCC fear of deterioration is a relevant topic to discuss because of the impact on quality of life: interaction with family members, good physical and mental health and being able to do what you want to do. When eliciting a patients views in the context of a treatment decision, MCC must be taken into account because of their influence on functional outcomes and the impact of that on quality of life. The results of this study may help raise awareness amongst healthcare professionals that questioning and understanding individuals' views can contribute to making health decisions that support an individual's personal goals and expectations.

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Chapter

4

Comprehensive geriatric assessment: recognition of identified geriatric conditions by community-dwelling older persons

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Age Ageing. 2016; 45 (6)

Abstract

Objectives: To study (i) the prevalence of geriatric conditions in community-dwelling older persons at increased risk of functional decline and (ii) the extent to which older persons recognise comprehensive geriatric assessment (CGA)-identified conditions as relevant problems.

Methods: Trained registered nurses conducted a CGA in 934 out of 1209 older persons at increased risk of functional decline participating in the intervention arm of a randomised trial in the Netherlands. After screening for 32 geriatric conditions, participants were asked which of the identified geriatric conditions they recognised as relevant problems.

Results: At baseline, the median age of participants was 82.9 years (interquartile range (IQR) 77.3–87.3 years). The median number of identified geriatric conditions per participant was 8 (IQR 6–11). The median number of geriatric conditions that were recognised was 1 (IQR 0–2). Functional dependency and (increased risk of) alcohol and drug dependency were the most commonly identified conditions. Pain was the most widely recognised problem.

Conclusion: CGA identified many geriatric conditions, of which few were recognised as a problem by the person involved. Further study is needed to better understand how older persons interact with identified geriatric conditions, in terms of perceived relevance. This may yield a more efficient CGA and further improve a patient-centred approach.

Introduction

Comprehensive geriatric assessment (CGA) for older persons is increasingly being implemented in community settings [1, 2]. CGA is a multidisciplinary, systematic procedure addressing the physical, psychological, functional and social conditions of older persons to create a tailored care and treatment plan (CTP) [3, 4]. CGA in combination with interventional actions aim to prevent functional decline, nursing home or hospital admission and mortality [3]. However, research on the effectiveness of CGA in community care setting in countries with high primary care standards, such as the Netherlands and UK, remain inconclusive [5–9]. From a patient-centred perspective, a CGA should include an individual's needs, goals and preferences [10, 11]. Shared decision making enhances a patient-centred approach and focuses on outcomes that matter to the persons involved [12, 13]. Some authors investigated CGA-identified care needs and interventions initiated after a CGA [14–16]. However, little is known about the extent to which geriatric conditions are recognised as relevant problems in community-dwelling frail older persons. Here, we report on the prevalence of geriatric conditions in community-dwelling older persons at increased risk of functional decline and the extent to which the older persons recognise CGA-identified conditions as relevant problems.

Methods

Design and setting

We carried out a randomised controlled trial to investigate the effects of a home visiting programme. In this paper, we focus on the intervention group, describing the process evaluation of the programme. Participants were community-dwelling older persons aged 70 years and older from 13 general practices in the Netherlands who took part in the intervention arm of a cluster randomised trial (RCT). The trial involved CGA and nurse-led care coordination with multiple follow-up visits to prevent disability. This RCT was conducted between December 2010 and 2014. Details of the study have been published elsewhere [17].

Study population

The eligibility of older persons was determined through a self-report questionnaire, including the risk of functional decline as assessed by the Identification of Seniors At Risk-Primary Care (ISAR-PC) screening questionnaire [18]. The general practitioner (GP) excluded persons whom s/he expected to have a life expectancy of less than 3 months, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad or lived in a nursing home. All participants received a baseline questionnaire assessing demographics and comorbidities.

Comprehensive geriatric assessment

A trained community care registered nurse (CCRN) conducted the CGA to screen for the presence of 32 geriatric conditions. The CGA covered physical, psychological, functional and social domains. Further diagnostic assessments and interventions were drawn from a toolkit containing evidence-based protocols for these geriatric conditions [17].

Recognition of geriatric conditions

After the CGA, participating older persons were asked the following questions for all identified conditions: do you recognise {identified condition} as a problem and if yes, do you want an intervention for {identified condition}? Subsequently, the CCRN discussed the yield of the CGA and further diagnostic assessments with the participant's GP and a tailored CTP was made. The CCRN evaluated the CTP during one or more follow-up visits. At each visit, the CCRN completed a logbook in which interventions and reasons for no intervention were documented.

Statistical analysis

Recognition was calculated as the proportion of geriatric conditions identified in the CGA that was recognised as a problem by the participants. Three reviewers (M.v.R., W.B. and E.H.) screened the logbooks to assess which interventions a participant had received. Descriptive statistics were used to summarise quantitative data, using SPSS for Windows, version 23.0.

Results

Thirteen practices with 3,430 community-dwelling people aged 70 years and older were randomised to the intervention arm of the cluster RCT. Of these, 1,209 participants were identified as being at increased risk of functional decline and were eligible to participate in the intervention.

At baseline, the median age of the participants was 82.9 years (interquartile range (IQR) 77.3–87.3) and 65.1% were women (Table 1). Fourteen nurses conducted CGAs on 934 participants (77.5%). Participants who declined the CGA (n = 275) were older, more often lived in a residential home and reported a lower quality of life (Table 1).

Geriatric conditions identified

The CGA resulted in a median of 8 (IQR 6–11) identified geriatric conditions per participant. Table 2 shows the prevalence of geriatric conditions. The most prevalent geriatric conditions were polypharmacy (47.5%), (an increased risk of) alcohol and drug dependency (68.9%), limitations in daily functioning (85.0%) and loneliness (32.4%) in the physical, psychological, functional, and social domains, respectively.

Table 1. Characteristics of participants in the intervention group who had an ISAR-PC score ≥ 2

Characteristics	Total intervention group, invited for CGA N= 1209	Intervention group receiving CGA N= 934	Intervention group declining CGA N= 275
	N (%)	N(%)	N (%)
Age, in years, median (IQR)	82.9 (77.3-87.3)	82.7 (76.8-87.1)	84.4 (78.2.6-88.1)*
Female sex	787 (65.1)	614 (65.7)	173 (62.9)
Born in the Netherlands	1138 (94.1)	879 (94.1)	259 (94.2)
Level of education			
primary school or less	254 (21.0)	184 (19.7)	70 (25.5)
secondary education	758 (62.7)	592 (63.4)	166 (60.4)
college or university	179 (14.8)	146 (15.6)	33 (12.0)
Socio-economic status			
low (≤1SD)	57 (4.8)	39 (4.2)	19 (6.9)
intermediate	927 (76.7)	726 (77.7)	201 (73.1)
high (≥1SD)	224 (18.5)	169 (18.1)	55 (20.0)
Married/living together	561 (46.4)	436 (46.7)	125 (45.5)
Living situation			***
independent, alone	528 (43.7)	431 (46.1)	97 (35.3)
independent, together	535 (44.3)	420 (45.0)	115 (41.8)
residential home	138 (11.4)	77 (8.2)	61 (22.2)
Multimorbidity (≥2)	997 (83.2)	769 (82.3)	227 (82.5)
Psychological health status (Rand-36) (range 4-100), mean (SD)[a]	71.3 (17.4)	72.2 (16.9)	68.5 (18.5)**
Quality of Life (range 0-10), mean (SD)	7.2 (1.3)	7.3 (1.2)	6.9 (1.5)***
Identification of seniors at risk-primary care (range 0-7.5), median (IQR)[b]	4 (3-5)	4 (3-5)	4 (3-5)

Values are numbers (percentages) unless stated otherwise; IQR=interquartile range; SD=-standard deviation. Student's t-test for continuous variables; Mann-Whitney U test for continuous nonparametric variables; Chi-square test for categorical variables.*p<0.05; **p<0.01; ***p<0.001

[a] Higher scores represent a better psychological health status

[b] Higher scores represent an increased risk of functional decline

Recognition of geriatric conditions as a problem

The median number of geriatric conditions that were recognised as a problem was 1 (IQR 0–2). The most prevalent geriatric conditions (as a proportion of geriatric conditions identified) recognised by respondents as a problem were pain (41.2%), depressive symptoms (20.3%), hearing impairment (27.4%) and loneliness (19.1%) in the physical, psychological, functional and social domains, respectively.

Initiated interventions

Table A-1, shows the rate and all types of interventions that were initiated for the identified geriatric conditions. The median number of initiations of

Table 2. Identification and recognition of geriatric conditions (by decreasing numbers identified within 4 domains)

Geriatric condition	Identified % (N) N=934*	Recognition % (N)*
Physical		
Polypharmacy[a]	47.5 (444)	22.5 (100)
Incontinence[b]	42.3 (396)	30.6 (121)
Pain[c]	38.3 (359)	41.2 (148)
Hypertension[d]	34.7 (325)	9.5 (31)
Osteoporosis risk[e]	30.6 (287)	16.7 (48)
Dizziness[f]	29.6 (276)	37.7 (104)
Obesity[g]	22.3 (209)	13.9 (29)
Medication safety and side effects[h]	21.1 (197)	23.4 (46)
Heart rate[i]	17.9 (168)	3.0 (5)
Oral hygiene[j]	9.3 (87)	19.5 (17)
Medication adherence[k]	9.2 (86)	7.0 (6)
Swallowing disturbance[l]	8.0 (75)	28.0 (21)
Constipation[m]	7.7 (72)	38.9 (28)
Malnutrition[n]	4.9 (46)	26.1 (12)
Deydration[o]	1.5 (14)	35.7 (5)
Indwelling urinary catheter use[p]	1.5 (14)	7.1 (1)
Pressure ulcer[q]	1.5 (14)	35.7 (5)

*All 934 were asked for the presence of 32 geriatric conditions by a nurse. If a geriatric condition was present/identified, the participant was asked whether he/she recognised the identified problem. For example: 934 (number of patients in intervention arm, overall denominator) were asked whether they use 5 or more different medications (defined as polypharmacy). 444 participants answered this question with 'yes' (CGA positive). Those 444 participants were asked whether they recognised the use of 5 or more different medications as a problem. 100 (out of 444) participants recognised polypharmacy as a problem.

a 'Do you use 5 or more different medications?'
b 'Did you experience incontinence of urine or stool in the past month?'
c Visual analogue scale for pain, range 0-10, score ≥4
d Blood pressure SBD >160 mmHg
e Osteoporosis and fracture risk, score ≥ 4
f 'Did you experience dizziness in the past month?'
g Body Mass Index (kg/m2)
h 'Do you experience difficulties or side effects with medication use?'
i Beats/min
j 'Did you have pain in your mouth in the past month?'
k 'Do you know when and how you should take your medication?'
l 'Did you experience difficulties with swallowing in the past month?'
m 'Do you have stool less than three times per week?'
n Short Nutritional Assessment Questionnaire 65+ (SNAQ 65+)
o 'Have you been admitted to a hospital because of dehydration in the past year?'
p 'Do you have an indwelling urinary catheter?'
q 'Do you have pressure ulcer(s)?'

Table 2. Continued

Geriatric condition	Identified % (N) N=934*	Recognition % (N)*
Psychological		
Alcohol/drug abuse[r]	68.9 (646)	2.8 (18)
Depressive symptoms[s]	38.4 (360)	20.3 (73)
Memory problems[t]	38.1 (357)	11.8 (42)
Anxiety[u]	10.7 (100)	20.0 (20)
Delirium[v]	6.8 (64)	9.4 (6)
Functional		
Functional dependency[w]	85.0 (796)	7.0 (56)
Walking aid[x]	52.7 (494)	13.6 (67)
Falls[y]	44.3 (415)	17.6 (73)
Exhaustion[z]	40.3 (378)	21.7 (82)
Sleeping disorder[aa]	39.9 (374)	19.5 (73)
Hearing impairment[bb]	30.7 (288)	27.4 (79)
Vision impairment[cc]	21.3 (200)	36.0 (72)
Social		
Loneliness[dd]	32.4 (304)	19.1 (58)
Living situation[ee]	9.3 (87)	16.1 (14)
Finance[ff]	4.5 (42)	4.8 (2)

r 1)'Do you smoke?' 2) Screening test for problem drinking: AUDIT-C 3) 'Do you use benzodiazepines?'
s 1)'During the past month, have you often been bothered by feeling down, depressed, or hopeless?' 2)'During the past month, have you often been bothered by little interest or pleasure in doing things? Both questions displayed'
t 1)'Do you have memory problems?' 2) Mini Mental State Examination (MMSE), range 0-30, cognitively impaired if ≤ 23;
u 'Did you feel anxious in the past month?'
v 'Have you ever experienced delirium?'
w Katz-ADL index
x 'Are you using a walking aid?'
y 'Did you experience a fall during the last six months?'
z 1) 'I felt that everything I did was an effort' 2) 'I could not get going'
aa 'Do you experience problems with sleeping?' 'Do you use sleeping medication?'
bb 'Do you have a hearing impairment, regardless the use of a hearing device?'
cc 'Do you have a visual impairment, regardless the use of glasses?'
dd 'Jong Gierveld-questionnaire, score ≥3'
ee 'Do experience problems with your living situation?'
ff 'Can you manage financially?'

treatment was 1 (IQR 0–2). Most interventions were initiated for pain (n = 114), depressive symptoms (n = 65), mobility (n=82) and loneliness (n =65), in the physical, psychological, functional and social domains, respectively. The reasons for lack of intervention were often unknown. These results include non-recognition and refusal of intervention(s) (Table A-2).

Discussion

This study demonstrates that CGA in community-dwelling older persons with an increased risk of functional decline detects many geriatric conditions, yet results in low recognition rates of these geriatric conditions. Out of 32 geriatric conditions, functional dependency was the most commonly identified. Pain was the most widely recognised problem.

Comparison with other literature

Previous studies on CGA in community-dwelling older persons focused on the prevalence of identified geriatric conditions [16, 19–26]. However, comparing the results of these studies is difficult because of differences in the inclusion criteria for participants and geriatric conditions evaluated.

To our knowledge, ours is one of the first studies assessing how often older persons recognised that the geriatric conditions are being evaluated. We found a recognition rate of one geriatric condition out of a median of eight identified geriatric conditions. Pain and incontinence were recognised most. Other problems such as hypertension, constipation and alcohol or substance misuse were infrequently recognised as a problem. This could indicate that the CGA detected many conditions with no apparent clinical relevance. For example, older persons may simply accept certain conditions as a part of normal ageing, problems were perhaps already treated or were not perceived as appropriate problems to discuss with the GP. Nevertheless, asking older persons which of the identified geriatric conditions they recognise may be useful in facilitating shared decision making and overall efficiency [27].

Most studies evaluating the prevalence of geriatric conditions also report on the initiation of interventions; however, the intervention rates reported in these studies are higher compared to our results [16, 25, 26]. This could be the result of the older persons' prioritisations, but could also be due to already high standards of care as usual in the Dutch GP practice.

Strengths and limitations

Strengths of this study include the large sample of community-dwelling older persons at increased risk of functional decline. The CGA was based on a comprehensive review of all available evidence for the detection and treatment of the 32 most prevalent geriatric conditions or problems and was validated by a multidisciplinary team [17].

There were several limitations. First, despite a detailed nurse protocol and

training in motivational interviewing and patient empowerment, we have no exact data how nurses inquired about the recognition of detected conditions and perceived problems. Second, we were unable to determine whether identified geriatric conditions were newly detected or conditions previously identified and already known to (and acted upon by) GPs. Third, prevalence of geriatric conditions, recognition and initiation of intervention were not pre-specified as an outcome in our randomised trial protocol [17].

Implication for further research The findings of this study indicate that future research should first investigate current care and treatment of the individual being assessed, and then investigate the potential unmet needs. More insight in priorities, goals and potential behaviour change in care and treatment of geriatric conditions and unmet needs may avoid detecting conditions that are not perceived as relevant for further treatment and can contribute to a cost-effective and affordable CGA. Identifying geriatric conditions that are more often perceived as relevant for treatment may further improve an efficient and patient-centred approach.

Conclusion

In a setting with high-quality primary care, a carefully designed CGA identified many geriatric conditions, of which few were recognised as problems by older persons at risk of functional decline. Further study is needed to better understand how older persons interact with identified geriatric conditions, in terms of perceived relevance. This may yield a more efficient CGA and further improve a patient-centred approach.

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Table A-1. Type of interventions per geriatric condition

	Number of persons that received an intervention	Total interventions*	Advice	Aid(s)	Medication (adaptation)	Follow-up by CCRN	Referral to paramedic	Referral to GP	Referral to specialist	Volunteer/ social intervention	Referral to dementia team	Self-management	Other
Physical													
Polypharmacy	58	90	20	18	24	4	1	14	2	0	0	2	5
Incontinence	107	172	49	47	10	2	23	31	8	0	0	2	0
Pain	114	192	33	7	35	1	32	52	27	0	0	2	3
Hypertension	79	96	4	0	11	11	2	57	4	0	0	4	3
Osteoporosis risk	32	47	11	0	17	1	0	6	8	0	0	2	2
Dizziness (past month)	43	67	12	5	3	6	3	21	5	0	0	4	8
Obesity	28	46	19	2	1	1	10	3	0	0	0	5	5
Medication safety and side effects	20	26	4	0	14	1	0	6	0	0	0	1	0
Heart rate	13	10	1	1	3	1	0	4	0	0	0	0	0
Oral hygiene	6	5	1	1	0	0	1	1	0	0	0	1	0
Medication adherence	16	20	11	5	1	0	1	0	0	0	0	1	1
Swallowing disturbance	10	13	0	0	0	0	3	6	2	0	0	0	2
Constipation	26	38	22	0	9	0	2	3	2	0	0	0	0
Malnutrition	21	25	13	2	0	1	3	2	0	0	1	1	2
Dehydration	8	9	8	1	0	0	0	0	0	0	0	0	0
Indwelling urinary catheter use	2	4	0	0	1	0	1	2	0	0	0	0	0
Pressure ulcer	1	4	1	1	0	1	1	0	0	0	0	0	0

Table A-1. Continued

	Number of persons that received an intervention	Total interventions*	Advice	Aid(s)	Medication (adaptation)	Follow-up by CCRN	Referral to paramedic	Referral to GP	Referral to specialist	Volunteer/ social intervention	Referral to dementia team	Self-management	Other
Psychological													
Alcohol/drug abuse	57	70	61	1	2	3	1	0	0	0	0	0	2
Depressive symptoms	65	107	25	0	10	26	10	12	3	3	0	4	14
Memory problems	41	60	5	0	0	11	1	13	5	1	22	0	2
Anxiety	10	14	2	0	1	2	2	2	0	0	0	2	3
Delirium	1	2	0	0	0	1	0	1	0	0	0	0	0
Functional													
Functional dependency	60	91	17	14	0	2	51	0	1	0	0	1	5
Mobility	82	129	18	56	3	2	21	6	3	0	0	2	18
Falls	79	125	32	37	2	2	31	5	3	0	0	2	11
Exhaustion	25	39	11	1	5	0	2	10	6	0	0	0	4
Sleeping disorder	55	80	40	2	15	1	3	9	1	1	0	6	2
Hearing impairment	40	78	5	16	0	0	30	7	12	0	0	8	0
Vision impairment	38	72	5	18	0	15	3	17	9	0	0	5	0
Social													
Loneliness	65	90	24	6	0	17	12	1	0	11	3	5	11
Living situation	23	33	5	7	0	1	4	0	0	1	1	2	12
Finance	2	2	2	0	0	0	0	0	0	0	0	0	0

Results are presented as number.
*A person may have received more than one intervention per problem. The numbers presented here are a total of the initiated interventions and can represent different types of interventions

Table A-2. Reasons why treatment or care was not initiated

Geriatric condition		No treatment (no recognition included)*					
	Identified	Treatment already in place		Declined treatment		Reason for no treatment unknown	
	N	N (%)		N (%)		N (%)	
Physical							
Polypharmacy	444	41	9.2	20	4.5	325	73.2
Incontinence	396	22	5.6	31	7.8	236	59.6
Pain	359	37	10.3	19	5.3	189	52.6
Hypertension	325	16	4.9	3	0.9	227	69.9
Osteoporosis risk	287	11	3.8	6	2.1	238	83.0
Dizziness (past month)	276	20	7.2	11	4.0	202	73.2
Obesity	209	6	2.9	10	4.8	165	78.9
Medication safety and side effects	197	4	2.0	3	1.5	170	86.3
Heart rate	168	6	3.6	2	1.2	147	87.5
Oral hygiene	87	9	10.3	2	2.3	70	80.5
Medication adherence	86	2	2.3	1	1.2	67	77.9
Swallowing disturbance	75	3	4.0	1	1.3	61	81.4
Constipation	72	5	6.9	0	0.0	41	57.0
Malnutrition	46	5	10.9	4	8.7	16	34.7
Dehydration	14	0	0.0	0	0.0	6	42.9
Indwelling urinary catheter use	14	3	21.4	0	0.0	9	64.3
Pressure ulcer	14	2	14.3	0	0.0	11	78.6
Psychological							
Alcohol/drugs abuse	646	0	0	13	2.0	576	89.2
Depressive symptoms	360	11	3.1	27	7.5	257	71.3
Memory problems	357	22	6.2	13	3.6	281	78.7
Anxiety	100	1	1.0	7	7.0	82	82.0
Delirium	64	1	1.6	0	0.0	62	96.8
Functional							
Functional dependency	796	47	5.9	9	1.1	680	85.5
Mobility	494	17	3.4	20	4.0	375	76.0
Falls	415	10	2.4	17	4.1	309	74.5
Exhaustion	378	12	3.2	6	1.6	335	88.6
Sleeping disorder	374	6	1.6	17	4.5	296	79.2
Hearing impairment	288	16	5.6	18	6.3	214	74.2
Vision impairment	200	31	15.5	4	2.0	127	63.5
Social							
Loneliness	304	7	2.3	25	8.2	207	68.1
Living situation	87	4	4.6	5	5.7	55	63.3
Finance	42	0	0.0	1	2.4	39	92.8

* The last three columns represent reasons why treatment or care was not initiated. These three columns also include participants who did not recgonise the geriatric condition as a problem.

Chapter

5

Community-dwelling older peoples' experiences with nurse-led comprehensive geriatric assessment and care coordination

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Abstract

Background: A qualitative analysis can help to explore the appropriateness of complex care interventions for community-dwelling older people. Therefore, the aim of this qualitative study is to explore community-dwelling older peoples' experiences and views on nurse-led comprehensive geriatric assessment and care coordination.

Methods: We conducted semi-structured interviews with fifteen participants from the intervention group of a cluster-randomised trial with multifactorial interventions and nurse-led care coordination to prevent functional decline. All interviews were audio recorded, transcribed, and analysed independently by two researchers using a thematic analyses approach.

Results: Participants appreciated nurse-led comprehensive geriatric assessment and care coordination because of the feeling to be looked after. The attention to their psychosocial needs and well-being strengthened their relation with the general practice and routine check-ups contributed to the feeling of reassurance. However, for specific medical problems they indicated there was little room for substitution by the nurse.

Conclusion: Community-dwelling older people valued nurses paying attention to their psychosocial functioning and checking their general health. However, they felt that surveillance of all medical care should remain in the hands of the GP and can not be delegated to nurses.

Introduction

Over the past decades, complex healthcare interventions including comprehensive geriatric assessment (CGA), multifactorial interventions and nurse-led care coordination for community-dwelling older people to prevent or postpone functional disability have been widely implemented in primary care settings [1]. A CGA in primary care is a multidisciplinary approach often conducted by a community care registered nurse (CCRN) during a visit at the home of the older person and is followed by multiple home visits to create, discuss and evaluate an individually tailored care and treatment plan based on multifactorial interventions [2, 3]. It has been suggested that a proactive, integrated care provision for community-dwelling older people might help to enable independent living, improve quality of life and address needs and preferences of community-dwelling older people [4, 5]. Earlier meta-analyses and reviews demonstrated that complex healthcare interventions had beneficial effects on overall functioning [3, 6]. Nevertheless, more recent primary care studies on prevention or postponement of functional disability showed neutral findings [7-12]. Qualitative analyses on the experiences of community-dwelling older people can help to explore the appropriateness of complex care interventions for community-dwelling older people [13]. Therefore, we performed a qualitative sub-study among Dutch community-dwelling older people in a recent cluster RCT, to explore community-dwelling older peoples' experiences and views on task delegation of comprehensive geriatric assessment and care coordination toward the CCRN.

Methods

Participants

Participants were community-dwelling older people aged 70 years and over, taking part in the intervention arm of a cluster randomised trial. Details of the study have been published elsewhere [2, 9].

Participants were eligible for the present study if they met all three following criteria: 1) an increased risk on functional decline (based on the Identification of Seniors at Risk – Primary Care Screening Questionnaire (ISAR PC)) [14]; 2) received at least one home visit and 3) one or more interventions according to their care and treatment plan (CTP) (n= 926). Participants were purposively selected to reflect the health and education spectrum of the studied population. We aimed for variation in gender, age, living situation, level of education, multimorbidity, polypharmacy, number of home-visits, GPs and CCRNs (Table 1). Prior to the interview, participants were contacted by phone by the researcher (NH or MvR) to determine eligibility. They were asked whether they remembered the home-visits and if they consented to participate in an interview.

Interviews and data collection

We conducted semi-structured interviews with 15 participants at their homes that lasted approximately 40 to 90 minutes. A topic list was developed prior to the interviews and focused on participants' experiences with the home visits, including nurse-led comprehensive geriatric assessment (CGA), multifactorial interventions and care coordination. The interviews started with a short introduction on the study aim, followed by the open question 'What were your experiences with the home-visits by the nurse?' or 'What do you remember of the home-visits?'. After this question the interview was semi-structured, based on the topic list and the intention was to let the participants elaborate on their experiences and the potential role nurses may play in care for older people.

Analysis

All interviews were audio recorded and transcribed verbatim to written text. We analysed the data according to the thematic analysis approach of Braun and Clarke following six phases[15]. First, to get familiar with the data two authors (NH and MvR) interviewed participants and read and re-read the transcripts (1). Then NH and MvR independently generated codes (2) and searched for the main themes (3). The identified codes were grouped into themes based on similarities, and connections were made between the different codes and themes derived through open coding. After every interview, the independent code lists were compared, discrepant interpretations discussed and it was decided whether the identified themes had enough data to support them and which of the themes had to be removed (4). After twelve interviews, data saturation was reached as no new themes or issues emerged during the code process of the remaining three interviews. Then, a final thematic and coding structure was developed (5). Finally, illustrative quotes were selected and data were reported relating the final analysis to the research question and existing literature (6).

Results

Fifteen participants aged 76-97 years were interviewed from eight different general practices (Table 1). The overarching theme was 'the appreciation to be looked after' and consisted of four subthemes: 1) lowering the threshold to the GP practice, 2) attention for psychosocial functioning, 3) reassurance through check-ups and 4) professional care and task delegation between nurse and GP.

Appreciation to be looked after

The interviewees appreciated to be looked after. They wanted to be taken seriously, talk with someone they could trust and feel that someone was listening and paying attention to them.

Table 1. Characteristics of interviewees

	Interviewees N=15
Age, Y, median (range)	85 (76-97)
Female, N (%)	10 (67)
Born in the Netherlands, N (%)	13 (87)
Level of education, N (%)	
Primary school or less	3 (20)
Secondary school or vocational education	8 (53)
College or university	4 (27)
Married or living together, N (%)	6 (40)
Comorbidities, median (range)	5 (2-9)

> *'Yes, because I like the idea that there is someone who pops by occasionally to see how things are going, because then I know whenever there is something the matter, they'll keep an eye on you.' (P1, female, 91 years)*

Nevertheless, most interviewees experienced that the GP often did not have enough time for them. They said that during GP consultations they narrowed the conversation down to medical questions because of perceived time constraints by the GP.

> *'Well, I understand the GPs. They have become so busy with other things. They have other patients who need them much more I think [...] So then it is a waste of time of the GP, I think. No it is not necessary. And we are quite satisfied. That uh, if I need him, than he will come.' (P10, female, 91 years)*

Lower the threshold to the GP practice

Interviewees felt that talking to the nurse lowered the threshold to discuss matters for which they would not easily contact the GP. They valued the additional service advice from the nurse. Overall, the participants found it important to build a trusting relationship with the nurse, with sufficient continuity over time. The nurse was perceived as a safety net around potential future problems. Some interviewees indicated that they would first contact the nurse in case of a new medical problem to discuss whether a GP consultation would be warranted.

> *'Yes, because you always need someone to stay in touch with, someone you can trust. Because that's another thing ... (...) Contact and uh .. if there is something wrong, she will immediately contact the doctor, she shares the conversation and all the difficulties with the doctor, so then I don't have to go there. Indeed, then I don't have to go there at all. Ah, what problems do I have anyway? I only have minor things for which I ask myself: 'Do I have to see the GP for that?'. Honestly, I don't see a doctor very often.' (P6, female, 89 years)*

Attention for psychosocial functioning

Generally, the interviewees thought the home visits had been especially useful with respect to their psychosocial functioning, because this was something they often missed from their GP. They stated that attention for the psychosocial context is essential in a good patient-professional relationship.

> *'I was just happy that I could pour my heart out, tell her what was bothering me. And yes, you also talk about your illnesses for a brief moment. And just about problems. Yes, she asked about our problems.' (P3, female, 88 years)*

> *'The loss of loved ones and friends, that should always be addressed. Since the loss of loved ones and friends is a major life event. It is important that we talk about everything that is important. There are a lot of taboos, such as loneliness. If you're not looking for loneliness, then you will not find it.' (P8, male, 97 years)*

Reassurance from check-ups

Interviewees often liked to know whether they were doing well with regard to their physical and mental health or their health status in general. It gave them a sense of security to know that they scored well on physical and mental health parameters, such as blood pressure, walking speed and mini-mental state examination. Interviewees generally felt reassured by the check-ups that the nurses performed.

> *'They checked my physical and mental state, or actually it was a check-up. It was kind of a reassurance, they check me, if everything was still OK. They looked at my well-being, which I found pleasant, because today you're still here and you don't know what tomorrow will bring.' (P1, female, 91 years)*

Professional care and task delegation between nurse and GP

Interviewees stated that the professional and medical background was a crucial prerequisite for the nurse to be a liaison between them and their GP. When compared to a visit of a volunteer, interviewees preferred a nurse, because of her knowledge with all kinds of medically oriented issues.

> *'I think such a nurse has experience with all kinds of things and stuff. Well, and then you have this or that or a small wound. Well, then I also sometimes ask, will you take a look? I think it is nice that a nurse visits me, instead of a volunteer for example. Yes, she knows more than simply a volunteer.' (P10, female, 91 years)*

However, for more complex medical issues the interviewees would prefer to see the GP.

> *'I think I ask the nurse more than the doctor, or there must be something serious. Things about medication for example, I prefer to ask the GP for that.' (P14, female, 85 years)*

The interviewees thought that the visits of a nurse could, in part, substitute for some roles of the GP in the care for older people, especially with regard to psychosocial problems, more general issues on well-being, and some elements of a regular check-up (including anthropometric measurements and blood pressure). Most interviewees welcomed the visits of the nurse, they appreciated that someone was interested in their thoughts and needs and spent time with them. Often they thought the nurse was a nice and friendly person, who listens and gives attention.

> *'The physician focuses on the disease and the nurse focuses on the person who has the disease.' (P8, male, 97 years)*

Discussion

Community-dwelling older people participating in a cluster RCT on complex interventions to prevent functional decline appreciated nurse-led comprehensive geriatric assessment and care coordination because of the feeling to be looked after. The attention to their psychosocial needs and well-being strengthened their relation with the general practice and routine check-ups contributed to feeling of reassurance. Although participants thought that nurses could take over some primary care tasks, they felt that the surveillance of their medical care should remain in the hands of the GP.

Strength and limitations

This qualitative study addresses the experiences of community-dwelling older participants in a recent cluster RCT on comprehensive geriatric assessment (CGA), multifactorial interventions and nurse-led care coordination. Most interviews took part several weeks to months after the last home visit. This could have introduced recall bias. To overcome this limitation the final five interviews took place among older people still receiving home visits according to the original study protocol [2]. Furthermore, as the aim of our study was to explore experiences with nurse led geriatric care and treatment coordination, we selected participants who had, according to our administrative data, received a care and treatment plan. Therefore we did not interview participants who declined a CGA and/or care and treatment plan and therefore may have missed less favorable experiences or opinions.

Comparison with existing literature

The appreciation to be looked after, is a theme that was previously described [16-19]. Bayliss et al, reported 'being heard' as main theme in a study on

processes of care in older people with multimorbidity [16]. Older people preferred health-care professionals who would listen to and acknowledge their needs, appreciate that these needs were unique and fluctuating, and have a caring attitude [16]. Vass et al. stated that preventive home visits conveyed the message to them, that they were 'not forgotten' [19]. Behm et al. found that very old participants felt that preventive home visits made them more visible and emphasised their human value [17]. In accordance with our findings, older people in similar studies were satisfied with the home-visits [18, 20-23].

Interviewees regarded the nurse as a liaison with the general practice. Bindels et al. found that older people see the nurse as someone who could help them to get access to other professionals and services [24]. Van der Pol et al. stated that older people felt that the participation of nurses in primary care could improve accessibility to care [25].

Van Kempen et al. also found that most older people preferred home visits focusing on the psychosocial context [26]. Van der Pol stated that GPs and nurses adhere to their professional perspective and are more medically oriented, while, for most patients the perspectives of their well-being and mutual understanding of personalised communication are more important than their actual medical condition [25].

In our study, the check-ups during the home visits gave the interviewees a sense of security to know they scored well on physical and mental health parameters. The sense of safety by being 'checked up on' was also found by Ligthart et al [27]. More studies described an increased feeling of safety as an important benefit of preventive home visits for older people [18, 20, 28].

Finally, van Kempen et al. also reported that, according to older people, nurses could do the home-visits instead of the GP, provided that these nurses have the professional expertise to treat older patients. However, they also expressed the desire to be able to discuss their problems directly with their GP, without nurse involvement. This is consistent with our findings on medical problems, for example medication related issues. In a similar studies, many patients held the traditional view of the nurse's role as an assistant to the GP [29, 30].

Implications for research and practice

Although recent studies on complex healthcare interventions to prevent functional decline in community-dwelling older people found neutral or very small effects [(7-12)], nurse-led comprehensive geriatric assessment and care coordination appears to be generally appreciated by community-dwelling older people. Community-dwelling older people valued nurses paying attention to their psychosocial functioning and checking their general health. However, they felt that surveillance of all medical care should remain in the hands of the GP and can not be shifted towards nurses. Further research is needed on the role of CCRNs in primary care for older people; in particular on preferences of older people regarding the role of GPs and CCRNs.

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Chapter

6

Minimal important change and minimal detectable change in activities of daily living in community-living older people

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The Journal of Nutrition, Health & Aging. 2017;21(2)

Abstract

Objective: To estimate the minimal important change (MIC) and the minimal detectable change (MDC) of the Katz-activities of daily living (ADL) index score and the Lawton instrumental activities of daily living (IADL) scale.

Design: Data from a cluster-randomised clinical trial and a cohort study.

Setting: General practices in the Netherlands.

Participants: 3184 trial participants and 51 participants of the cohort study with a mean age of 80.1 (SD 6.4) years. Measurements: At baseline and after 6 months, the Katz-ADL index score (0-6 points), the Lawton IADL scale (0-7 points), and self-perceived decline in (I)ADL were assessed using a selfreporting questionnaire. MIC was assessed using anchor-based methods: the (relative) mean change score; and using distributional methods: the effect size (ES), the standard error of measurement (SEM), and 0.5 SD. The MDC was estimated using SEM, based on a test-retest study (2-week interval) and on the anchor-based method.

Results: Anchor-based MICs of the Katz-ADL index score were 0.47 points, while distributional MICs ranged from 0.18 to 0.47 points. Similarly, anchor-based MICs of the Lawton IADL scale were between 0.31 and 0.54 points and distributional MICs ranged from 0.31 to 0.77 points. The MDC varies by sample size. For the MIC to exceed the MDC at least 482 patients are needed.

Conclusion: The MIC of both the Katz-ADL index and the Lawton IADL scale lie around half a point. The certainty of this conclusion is reduced by the variation across calculational methods.

Introduction

With an ageing society, the increase of multimorbidity and growing strain on limited resources, the prevention of disability in older people has received considerable attention over the last decades. Disability is often defined as difficulty of or dependence in activities of daily living (ADL) such as bathing and dressing, or instrumental activities of daily living (IADL) such as shopping and traveling [1]. Older people consider prevention of disability as a patient-relevant outcome [2]. Accurate assessment of ADL and IADL is critical for the development and evaluation of interventions designed to prevent disability [3]. The Katz-ADL index score and Lawton IADL scale are frequently used to assess changes in ADL and IADL in community-living older people, both in research and in clinical practice [4]. Developed as patient-reported outcomes measures (PROM), they are convenient to administer, easy to apply and cheap. Apart from validity and reliability, interpretability of measurements is an important concept and refers to the clinical meaning of (changes in) scores. Interpretability includes two measures, the minimal important change (MIC) and the minimal detectable change (MDC) [5].

The minimal important change (MIC) is defined as the smallest change in score in the outcome of interest that patients or informed proxies perceive as important, either beneficial or harmful, which would lead the patient or clinician to consider a change in their behavior or in management [5-7].

However, with scarcity of research on the MIC of (I)ADL scales, interpreting the clinical relevance of treatment effects measured by the scales remains challenging [7, 8]. The minimal detectable change (MDC) refers to the smallest change that can be detected by the instrument, beyond measurement error [9]. So, if an instrument's MDC exceeds the MIC, the change might be important but cannot be distinguished from measurement error [5]. The aim of this study is to estimate the MIC and the MDC of the Katz-ADL index score and the Lawton IADL scale in community-living older people.

Methods

Design and setting

Data from two different studies were used [10, 11]. We used data of the intervention and control group of a clusterrandomised trial on the effect of multifactorial interventions to prevent the onset of new disability in community-living older people [10]. This study was conducted in 24 general practices in the northern region of the Netherlands between December 2010 and 2014. We also used data from two general practices from a prospective cohort study in the central region of the Netherlands. In total, 51 participants were included in the test-retest study. Measurements began in April 2012 and the cohort was followed up for 12 months. Both studies have been approved by the Medical Ethics

Committee of the Academic Medical Center, University of Amsterdam, in the Netherlands (protocol ID MEC10/182).

Study population

In both studies all community-living people aged 70 years and over were eligible for inclusion. The GP excluded people expected to have a life expectancy less than three months, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad, or lived in a nursing home. Participants signed informed consent before inclusion. Participant recruitment was described in detail elsewhere [10]. For the present study, we included participants with one or more disabilities in ADL or IADL at baseline (3184 out of 6668 participants in the trial and 51 out of 86 participants in the test-retest study) thus obtaining data with normally distributed changes in (I)ADL functioning.

Measurements

In both studies baseline assessment consisted of a selfreport questionnaire containing demographics, comorbidities, the Katz-ADL index score, the Lawton IADL scale) [12,13], self-perceived change in (I)ADL, health-related quality of life (EQ-5D) [14], psychological and social health status (RAND-36) [15], and variables that were associated with decline in (I)ADL such as polypharmacy and impaired memory. Baseline measures were described in detail elsewhere [10]. In both studies, the same self-report questionnaire was conducted at six months follow-up. Persons of general practices who participated in the test-retest study received the same questionnaire along with an information letter after two weeks. For the analyses of the MIC, baseline and 6-month data of the trial were used. For the analyses of the MDC, baseline and 6-month data of the trial and baseline and 2-week data of the cohort study were used.

ADL and IADL functioning

ADL functioning was measured using the Katz-ADL index score, which consists of six dichotomous questions on bathing, dressing, toileting, transfer, incontinence and eating. Scores range from zero to six points and a higher score indicates more dependence [12]. IADL disability was measured using the Lawton IADL scale, which consists of seven dichotomous questions on housekeeping, meal preparation, shopping, telephone use, transportation, medications use, and budgeting. Scores range of zero to seven points and a higher score indicates more dependence [13]. To calculate change at six months, the (I)ADL scores at six months were subtracted from the baseline (I)ADL scores.

Self-perceived decline in (I)ADL used as an external anchor

An anchor is an external criterion (often a patient-based judgment) to determine which change people consider as important deterioration or improvement [16].

We assessed selfperceived decline in (I)ADL with four dichotomous questions at six-months of follow-up:
1. In the past six months, has there been a decline in activities to take care of yourself, for example: taking a shower, dressing, or going to the toilet? If yes, did this decline cause limitations?
2. In the past six months, has there been a decline in daily activities, for example: shopping, preparing a meal, or housekeeping? If yes, did this decline cause limitations?
Participants were classified into three groups based on their answers; 1. No self-perceived decline in (I)ADL; 2. Selfperceived decline in (I)ADL without limitations; 3. Selfperceived decline in (I)ADL with limitations. We defined selfperceived decline in (I)ADL without limitations [2] as minimal important change [17].

Statistical analysis

At baseline, 1.1% of data relevant for our analysis was missing. After six months 15.9% (358/2257) of the participants with baseline ADL disability and 17.4% (415/2353) of the participants with IADL disability were lost to follow-up for the primary outcome.
Descriptive statistics (e.g., mean and SD) were used to describe demographics, the Katz-ADL index score, and the Lawton IADL scale at baseline.
MIC can be calculated based on anchor-based and distributional methods [17, 18]. Anchor-based methods are based on a predefined external anchor, and assess which change on the measurement instrument corresponds with the MIC defined on the anchor [5]. Distributional methods are based on statistical and psychometric properties of a measure in a population. There is no consensus on the best method to determine MIC. Because anchor-based and distributional methods have limitations, applying both is often recommended in the literature to create interpretive guidelines that are not field-specific or method-bound, and are therefore a more accurate reflection of minimal important change [17-19].

Anchor-based calculation of the MIC

Since self-perceived decline in (I)ADL was similar in both trial groups ($p=0.49$ for ADL decline and $p=0.31$ for IADL decline), data from both groups was used in all analyses. The agreement between self-perceived decline in (I) ADL and change on the Katz-ADL-index score and the Lawton IADL scale was described using a Spearman correlation coefficient. The strength of the correlation can be interpreted as: >0.5 large; 0.5-0.3 moderate; 0.3-0.1 small; and less than 0.1 trivial [20]. A correlation threshold of at least 0.30 between an anchor and a PRO change score has been recommended to calculate the MIC [17].
We used the mean change score to calculate the anchorbased MIC [6]. The mean change score was defined as the difference between the mean change

in the group who perceived minimal important change and the mean change in the group who experienced no change on the anchor; MIC = mean change (minimal important change) – mean change (no self-perceived change) [6]. The MIC can be affected by baseline values. That is, people with severe baseline disability might require a smaller change to perceive it as important as people with less severe baseline disability. We therefore also calculated MIC using mean relative changes in identical fashion as above, but now using relative change, defined as (I)ADL score at follow-up (T1) subtracted from the baseline (I)ADL score (T0) divided by baseline (I)ADL disability [((T0-T1)/T0) x 100].

Distributional calculation of the MIC

We used three distributional methods who have been shown to yield good estimations of MIC: the effect size (ES) [20], the standard error of the measurement (SEM) [21], and 0.5 SD [22]. The ES evaluates individual change in relation to the baseline variation of the sample [18]. It was calculated as the difference of the mean scores (μ) at baseline (T0) and follow-up (T1) divided by the standard deviation (SD) at baseline; ES= (μT0 - μ(T1))/SD(T0) [20]. For the interpretation of the effect size values of 0.20, 0.50 and 0.80 represent a small, moderate and large change, respectively [20]. An effect size of 0.20 is considered (by some) the minimum value for important change [23]. By reworking this formula, mean change in (I)ADL corresponding with minimal important change is obtained as 0.2 x SD(T0) [24]. The SEM is a measure of the precision of a test instrument [18]. It was calculated by multiplying the SD of the (I)ADL scores at baseline measurement by the square root of the difference of 1 minus the intraclass coefficient of the measure; SEM= SD(T0) x $\sqrt{}$ (1-ICC) [21]. 0.5 SD is defined as 0.5 times the SD of the baseline measurement 0.5 SD =0.5 x SD(T0) [22].

To assess the impact of missing data, we repeated all analyses after multiple imputation of missing values using ten imputation sets. Demographics, comorbidities, (I)ADL functioning, self-perceived change in (I)ADL, health-related quality of life (EQ-5D), psychological and social health status (RAND-36), were used as predictors [25].

Anchor-based calculation of the minimal detectable change

The MDC reflects the smallest change in a person that can be interpreted as real change above measurement error [26]. The MDC was assessed using the SEM of unchanged participants according to the external anchor in the RCT, assuming that people who had perceived no decline after six months had not declined. MDC was calculated as 1.96 x $\sqrt{}$2 x SEM [26].

Distributional calculation of the MDC

Assuming that people did not decline within a two-week interval, MDC was based on the test-retest data from the cohort study. The MDC was calculated

using the same formula as described above.
In contrast to individual measurements, calculating MDC based on group average reduces measurement error, depending on group size. In particular, MDC is reduced by the factor √n, when a group of n participants is studied [5].

Sample size calculation

Using the MDC and MIC values found in this study, we estimated the minimal number of participants required in new studies to ensure sufficient precision to measure changes beyond measurement error. We used the mean (I)ADL score (SD), the MIC-value, a two-sided alpha of 0.05 and power of 80%. All statistical analyses were performed using SPSS version 20.

Table 1. Baseline characteristics of participants with ADL and/or IADL disability at baseline

Characteristics	Trial N=3184	Cohort N=51
	N(%)	N(%)
Age, in years, mean (SD)	80.1 (6.4)	79.7 (6.5)
Female sex	2358 (73.3)	36 (70.6)
Caucasian	3057 (96.1)	40 (78.4)
Level of education		
primary school or less	697 (22.0)	12 (24.0)
secondary education	2106 (66.5)	35 (70.0)
college or university	366 (11.5)	3 (6.0)
Socio-economic status		
low (≤1SD)	193 (6.0)	
intermediate	2564 (79.7)	
high (≥1SD)	461 (14.3)	
Married/living together	1558 (48.7)	13 (25.5)
Living situation		
independent, alone	1408 (44.1)	29 (58.0)
independent, together	1488 (46.6)	15 (30.0)
home for elderly	299 (9.4)	6 (12.0)
Multimorbidity (≥2)	2516 (78.8)	46 (90.2)
Number of comorbities, mean (SD)	3.2 (2.0)	4.1 (2.1)
Polypharmacy (≥3 drugs)	2105 (66.1)	38 (81.3)
Katz-ADL (6 items), mean (SD)	1.0 (1.0)	1.1 (1.0)
IADL scale (7 items), mean (SD)	1.7 (1.7)	1.7 (1.7)
EQ-5D, mean (SD)	0.8 (0.2)	0.7 (0.2)
Psychological health status (RAND-36), mean (SD)	71.5 (17.2)	71.3 (16.9)
Quality of Life, mean (SD)	7.3 (1.2)	7.1 (1.4)

Values are numbers (percentages) unless stated otherwise; SD=standard deviation; Katz-activities of daily living (range 0-6); IADL=instrumental activities of daily living (range 0-7); EQ-5D =EuroQol-5D health-related quality of life (range -0.33 to 1.0); Psychological health status (RAND-36) (range 4-100); Quality of Life mark (range 1-10);

Results

In total, 3184 participants of whom 2257 (70.9%) with one or more disability in ADL, and 2353 with one or more disability in IADL were included in the analyses. At baseline the participants had a mean age of 80.1 (SD 6.4), a mean Katz-ADL score of 1.0 (SD 1.0), and a mean Lawton IADL score of 2.3 (SD 1.7) (Table 1). Participants who were lost to followup for the primary outcome were older and had more (I)ADL disabilities at baseline. After six months 15.9% (197/1899) of the participants with baseline disability in ADL had declined on the Katz-ADL index score and 17.5% (340/1938) of the participants with baseline disability in IADL had declined on the Lawton IADL scale.

The correlation coefficient between self-perceived decline in (I)ADL and change was -0.23 for both instruments (Table 2). The misclassification in change in (I)ADL functioning for each category of self-perceived decline in (I)ADL is presented in Table 3; 39.4% (74/188) of the participants with self-perceived decline in ADL with limitations had declined on the Katz-ADL index score and 34.9% (185/530) of the people with selfperceived decline in IADL with limitations had declined on the Lawton IADL scale. Change and relative change on the Katz-ADL index score and the Lawton IADL scale for each category of self-perceived (I)ADL decline are described in Table 4. People with no selfperceived change showed a small average improvement in (I) ADL functioning on both the Katz-ADL index score and the Lawton IADL scale.

MIC calculations

The MIC of the Katz-ADL index score estimate was 0.47 points for both the mean change and the mean relative change method. The MIC of the Katz-ADL index score estimate was 0.18 points based on the ES, 0.47 points using the SEM method, and 0.44 points based on 0.5SD. The MIC of the Lawton IADL scale estimate was 0.54 points based on the mean change method, and 0.31 points based on the mean relative change method. The MIC of the Lawton-IADL scale estimate was 0.31 points based on the ES, 0.69 points using the SEM method, and 0.77 points based on 0.5SD (Table 2).

Using imputed datasets the MIC of the Katz-ADL index score and the Lawton IADL scale estimate were 0.38 points and 0.44 points respectively based on the mean change method. Distributional MIC values of the imputed datasets were similar to the original dataset (Table A-1).

Anchor-based MDC

Within the anchor-based analysis, there was no selfperceived decline on ADL in 1233 (64.9%) participants and on IADL in 248 (12.8%) participants. The ICC was 0.45 for the Katz-ADL index score and 0.80 for the Lawton IADL scale. The MDC of the Katz-ADL index score and the Lawton IADL scale were 1.99 and 1.81 respectively (Table 2).

Distributional MDC

In the test-retest study, 86 persons were invited to fill in the questionnaire, 51 of whom had one or more baseline (I) ADL disabilities. These participants had a mean age of 79.7 (SD 6.5) years and 36 participants (70.7%) were female. In total 40 (78.4%) with one or more disabilities in ADL and 42 (82.3%) with one or more disabilities in IADL were included in the analyses to calculate the MDC. Baseline characteristics of participants in the cohort study were similar to the participants in the randomised trial (Table 1). The ICC was 0.81

Table 2. Characteristics and scores of Katz-Activities of Daily Living index score and Lawton Instrumental Activities of Daily Living scale for persons with ≥ 1 (I)ADL baseline disability

	Katz-ADL	Sample size (N)	Lawton IADL	Sample size (N)
Mean score, baseline (SD)	1.42 (0.89) (N=2257)	-	2.33 (1.55) (N=2353)	-
Mean score, follow-up (SD)	1.23 (1.03) (N=1899)	-	2.04 (1.77) (N=1939)	-
Change score (baseline minus follow-up) (SD)	0.14 (0.87) (N=1899)	-	0.20 (1.34) (N=1939)	-
Correlation anchor - baseline	0.35 (N=1866)	-	0.29 (N=1906)	-
Correlation anchor - follow-up	0.43 (N=1850)	-	0.39 (N=1887)	-
Correlation anchor - change	-0.23 (N=1850)	-	-0.23 (N=1887)	-
MIC Anchor (mean change)	0.47 (0.11-0.83) (N=34)	41	0.54 (0.29-0.79) (N=124)	121
MIC Anchor (mean relative change)	0.47 (0.18-0.76) (N=34)	41	0.31 (0.17-0.45) (N=124)	356
MIC ES (0.2)	0.18 (0.14-0.22) (N=2257)	463	0.31 (0.25-0.37) (N=2353)	482
MIC SEM	0.47 (0.43-0.51) (N=2257)	74	0.69 (0.63-0.75) (N=2353)	102
MIC 0.5 SD	0.44 (0.40-0.48) (N=2257)	84	0.77 (0.71-0.83) (N=2353)	82
$MDC_{(individual)}$ Anchor	1.99 (N=284)	-	1.81 (N=1233)	-
$MDC_{(individual)}$ Test-retest	1.18 (N=40)	-	2.81 (N=42)	-

Katz-activities of daily living (range 0-6); IADL=instrumental activities of daily living (range 0-7); SD = Standard deviation; Change score baseline-follow-up: positive scores indicate improvement in (I)ADL. MIC = minimal important change. ES = Effect size; SEM = Standard error of the measure; MDC = minimal detectable change. Sample-size = participants per group. For the analyses of the MIC, baseline and 6-month data of the trial were used. For the analyses of the MDC, baseline and 6-month data of the trial and baseline and 2-week data of the cohort study were used.

Table 3. Misclassification between self-perceived (I)ADL decline and change on the Katz-ADL index score and Lawton IADL scale

	Change on Katz-ADL (T0-T1)			
	Decline N (%)	**No change N (%)**	**Improvement N (%)**	**Total**
No self-perceived ADL decline	106 (6.5)	1101 (67.7)	420 (25.8)	1627
Self-perceived ADL decline without limitations	10 (29.4)	17 (50.0)	7 (20.6)	34
Self-perceived ADL decline with limitations	74 (39.4)	86 (45.7)	28 (14.9)	188
	Change on Lawton-IADL (T0-T1)			
No self-perceived IADL decline	192 (15.7)	491 (40.1)	542 (44.2)	1225
Self-perceived IADL decline without limitations	39 (31.5)	49 (39.5)	36 (29.0)	124
Self-perceived IADL decline with limitations	185 (34.9)	218 (41.1)	127 (24.0)	530

The misclassification between self-perceived decline on the external anchor and change on the Katz-ADL index score and Lawton IADL scale is in grey.

Table 4. Change and relative change on Katz-ADL index score and Lawton IADL scale between baseline and follow-up for three different categories of self-perceived (I)ADL decline

	Change in Katz-ADL (SD)	**Relative change in Katz-ADL (SD)**	**Change on IADL scale (SD)**	**Relative change on IADL scale (SD)**
No self-perceived (I)ADL decline	0.23 (0.74) N=1627	0.15 (0.53) N=1627	0.39 (1.23) N=1225	0.18 (0.75) N=1225
Self-perceived (I)ADL decline without limitations	-0.24 (1.07) N=34	-0.32 (0.88) N=34	-0.15 (1.41) N=124	-0.13 (0.76) N=124
Self-perceived (I)ADL decline with limitations	-0.58 (1.35) N=188	-0.47 (1.05) N=188	-0.22 (1.40) N=530	-0.22 (0.80) N=530

To calculate change on the Katz-ADL index score and the Lawton IADL scale we subtracted follow-up (T_1) scores from baseline scores(T_0). Negative scores indicate functional decline. To calculate relative change we subtracted follow-up scores (T_1) from the baseline (I)ADL scores (T_0) in relation to baseline (I)ADL disability [$((T_0-T_1)/T_0) \times 100$].

for the Katz-ADL index score and 0.68 for the Lawton IADL scale. The MDC of the Katz-ADL index score and the Lawton IADL scale were 1.18 and 2.82 respectively (Table 2).

Sample size calculation

The sample size varies with the estimated MICs. To find a MDC smaller than the smallest MIC at least 463 participants for the Katz-ADL index score and

482 participants for the Lawton IADL scale should becluded in the study. In Table 2 presents the sample size for each estimated MIC of both instruments.

Discussion

In this study we calculated both the minimal important change (MIC) and the minimal detectable change (MDC) of the Katz-ADL index score and the Lawton IADL scale using both anchor-based and distributional methods for community-living older people with one or more disabilities in (I)ADL. The MIC of both the Katz-ADL index and the Lawton IADL scale lie around half a point. The MDC was far above one point on both instruments. There was substantial variation across methods for both the MIC and the MDC. To measure a change beyond measurement error on both instruments' sample-sizes depend on the used method to calculate the MIC and lie between at least 463-482 participants.

Strengths and limitations of this study

To our knowledge, this is the first study on minimal important change and minimal detectable change of selfreported (I)ADL in community-living older people using both anchor-based, and distributional methods. Another strength of the current study is that the study population is representative for the Dutch population [10]. The interpretability of patient reported outcomes is important since it allows us to weigh the clinical relevance of interventions and it can be used for sample size calculations. In addition, better interpretability may induce clinicians to adopt PROMs more easily and accept that traditional outcome measures, such as mortality, may not always be the most relevant ones for older persons. ADL and IADL are highly valued and frequently used patient reported outcomes [4].

The study also has limitations. First, we found selective loss to follow-up at six months. Using imputed data anchor based-MIC values were slightly lower and distributional MIC values were similar to non-imputed data (Supplementary Table 1). Second, the three-point scale of our anchor question is relative crude. Applying a five, or seven-point global rating scale could possibly reflect the perceived decline more precise. However, there is no consensus whether the best cut-off on the anchor to determine the MIC yields a difference of one or two levels on the anchor. Of course, this decision influences the MIC value [16]. Third, our external anchor needs further validation. The lack of validity of the external anchor may partially account for the low correlations between the external anchor and the two measurement instruments (Table 2). Fourth, we observed considerable misclassification between self-perceived (I)ADL and change on the measurement instruments (Table 3). This misclassification might have been caused by recall bias or response shift, since retrospective self-reports are known to be affected by these phenomena [5, 17]. This

misclassification could partly explain the low correlation between the external anchor and the two measurement instruments. Although low correlations do not necessarily affect the MIC value, they may result in more misclassification at the individual level [16]. Therefore, our anchor-based MIC of (I)ADL should be interpreted with caution. Using other anchor questions such as change in health-related quality of life (EQ-5D) or change in emotional wellbeing (RAND-36) did not improve the correlation between the change on the external anchor and change in (I)ADL disability (data not shown).

Comparison to literature

In the literature, the MIC of performance-based measures of physical function in older people has been assessed for various instruments and is used to interpret treatment effects [24, 27, 28]. Distributional methods of meaningful change of self-report measures were described for the Late-Life Function and Disability Instrument Functional Component (LLFDIFC) [29] and the minimal detectable change was described for the Functional Autonomy Measurement System (SMAF) [30]. On the LLFDI-FC scales (scale 0-100) the absolute ES ranged from 0.54 to 0.64 and the SEM ranged from 1.59 to 2.71. The MDC of the LLDI-FC was 3.69 points (3.7%). The MDC of the SMAF was 5 points (4.4%) on a 87 point scale. In this study, the lowest MDC of the Katz-ADL index scale was 1.18 (19.7%) on a six point scale and the lowest MDC of the Lawton IADL scale 1.81 points (25.9%) on a seven point scale. We did not use other methods to estimate anchor-based MIC such as ROC analysis [31] or the predictive modeling approach [32] because these methods obtain the change that is optimally discriminating between importantly changed and notimportantly changed. These methods reflect important change whereas we were interested in minimal important change.

Explaining the findings

The estimated MIC and MDC values of both instruments showed a substantial range across the anchor-based and distributional methods. For IADL we found a lower MIC based on mean relative change compared to the mean change method. This can be explained because people with severe baseline IADL disability might easily unbalance and therefore a smaller change is perceived as important change. We found no difference in MIC values between mean change or mean relative change for ADL functioning. Additionally, both instruments have a narrow score-range, which might have influenced the estimated MIC and MDC values. Furthermore, the wide confidence intervals around the anchor-based MIC values reflect the large variability among participants. It has been suggested that research should focus on the individual wishes rather than the group consensus for example using goal attainment scores, which take into account the individual minimal important change [33, 34]. Although the Katz-ADL index score and the Lawton IADL scale are frequently used in both clinical practice and research [4], both

scales were developed to study results of (clinical) treatment in older persons and chronically ill, but were not designed to measure change. The estimated MIC of both instruments are therefore especially useful for clinical research, while they may not be for clinical practice.

Conclusion

The MIC of both the Katz-ADL index and the Lawton IADL scale lie around half a point. The certainty of this conclusion is reduced by the variation across calculational methods. The MDC was far above one point on both instruments. There was substantial variation across methods for both the MIC and the MDC. To measure a change beyond measurement error on both instruments sample sizes depend on the used method to calculate the MIC.

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Table A-1. Characteristics and scores of Katz-Activities of Daily Living index score and Lawton Instrumental Activities of Daily Living scale for persons with ≥ 1 (I)ADL baseline disability in an imputed dataset

	Katz-ADL	**Lawton IADL**
	Imputed data	Imputed data
Mean score, baseline (SD)	1.39 (0.89)	2.28 (1.55)
Mean score, follow-up (SD)	1.23 (1.01)	2.07 (1.73)
Change score (baseline minus follow-up) (SD)	0.16 (0.84)	0.21 (1.28)
Correlation anchor - baseline	0.28	0.29
Correlation anchor - follow-up	0.37	0.40
Correlation anchor - change	-0.20	-0.22
MIC Anchor (mean change)	0.38 (0.11-0.65)	0.44 (0.23-0.65)
MIC Anchor (mean relative change)	0.37 (0.14-0.60)	0.29 (0.18-0.40)
MIC ES (0.2)	0.18 (0.14-0.22)	0.31 (0.25-0.37)
MIC SEM	0.45 (0.41-0.49)	0.66 (0.60-0.72)
MIC 0.5 SD	0.44 (0.40-0.48)	0.77 (0.71-0.83)

Katz-activities of daily living (range 0-6); IADL=instrumental activities of daily living (range 0-7); SD = Standard deviation; MIC = minimal important change. Change score baseline-follow-up: positive scores indicate improvement in (I)ADL. Data were based on 10 imputation sets.

Chapter

7

Transitions in functional disability and associated healthcare costs in community-dwelling older people

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Abstract

Aim: The aims of this study are to 1) assess healthcare utilisation and its association with four functional disability categories over a period of one year in community-dwelling older people, 2) determine excess healthcare costs per person for transitions in functional disability relative to older people without limitations and 3) determine the healthcare costs per point change in functional disability.

Methods: Data from a cluster-randomised clinical trial were used for this study. Participants (n=6664) were community-dwelling older people registered at 24 participating general practices (GP) practices in the Netherlands. Based on the difference in the modified Katz-ADL index scores between baseline and 12-month follow-up, four functional disability categories were created: 1) stable without limitations, 2) stable with limitation(s), 3) functional improvement, and 4) functional decline. Data on GP care, hospitalisation, home care and nursing home care were used to calculate healthcare costs using multivariable linear models.

Results: At baseline, the mean age was 77.5 (SD 5.8) years, and 55.7% were female. Mean total excess healthcare costs per person relative to 1) those without limitations were 2) EUR 3071 (SE 919) for participants in the stable with limitation(s) category, 3) EUR 5036 (SE 1092) for those with functional improvement, and 4) EUR 9416 (SE 1373) for participants with functional decline. In all categories, hospitalisation accounted for most of the excess cost, and GP care contributed the least to the total excess costs.

Conclusion: During one-year follow-up, community-dwelling older people with changes in daily functioning had high mean excess healthcare costs per person relative to those who remained stable without limitations.

Introduction

The ageing of the population is a major challenge for the healthcare sector [1]. Ageing is associated with an increase in the prevalence of chronic diseases [2]. In the last years of life, these chronic diseases are often accompanied by impairments in (instrumental) activities of daily living (I)ADL, which is referred to as functional disability [3]. Functional disability is a dynamic process [4]. Short-term disability among community-dwelling older people can have a long-term, deleterious effect on functioning, and recovery from disability is often short-term [5]. Some older people regain independence in function, but those who recover from functional disability are at high risk for recurrent disability [6]. Functional disability in community-dwelling older people is associated with the loss of independence, hospitalisation, and admission to a nursing home and is therefore an important driver of healthcare costs [7, 8]. In a 2001 study by Fried and colleagues of 843 persons, older people with stable functional dependence and those who developed functional dependence cost an additional 10,000 dollars over two years compared to those who were stable without limitations and those who improved [9]. This study was performed more than 15 years ago. Since then, no studies relating to the cost of disability in older people have been published. However, due to the growth of the population aged 70 years and over and rising related healthcare costs, a common policy response to the consequences of population ageing has been to encourage older people to live in their own homes, a process known as ageing in place. Ageing in place is generally expected to result in cost savings because home care is less expensive than long-term care [10]. By determining the healthcare utilisation and cost effects of transitions in functional disability in community-dwelling older people, we might be able to improve the efficiency and quality of care provided by existing care programs for community-dwelling older people. Therefore, the aims of this study are to 1) assess healthcare utilisation for four functional disability categories over a period of one year in community-dwelling older people in the Netherlands, to 2) determine the excess healthcare costs per person of transitions in functional disability relative to older people without limitations and to 3) determine the healthcare costs per point change in functional disability.

Methods

Design and setting

We conducted a cluster-randomised trial (RCT) in 24 general practices in the Netherlands that aimed to evaluate the effects of nurse-led multifactorial care to prevent disability in community-dwelling older people. Since the overall effects of this study were neutral, all participants in the intervention and control groups were included in the analysis. We also included participants

without an increased risk of functional decline based on the increased risk of functional decline screening questionnaire (ISAR PC) [11]. The study was conducted between December 2010 and December 2014. All participants were asked to provide written informed consent for data collection and to participate in the study. The study was approved by the Medical Ethics Committee of the Academic Medical Center, University of Amsterdam, the Netherlands (protocol ID MEC10/182). The details of the study have been described elsewhere [12].

Dutch healthcare system

In the Dutch healthcare system, a general practitioner (GP) is accessible to all citizens and acts as a gatekeeper for secondary healthcare. Only in the case of an emergency can a patient go directly to the emergency department of a hospital without a GP referral. Physical home care for people with various types of disabilities is provided by community care registered nurses (CCRN) and healthcare assistants. The CCRN works in close collaboration with the GP. Through obligatory healthcare insurance, health coverage for all inhabitants is guaranteed. There is a deductible of 350 euros, which patient meet by paying fees for hospital or emergency department visits and for drugs. GP care is excluded from this deductible. Patients pay an income-dependent deductible for home care.

Study population

Participants were community-dwelling older people, aged 70 and older, who were registered at the participating GP practices. Older people were ineligible if, according to their GP, they were terminally ill, suffered from dementia, did not understand Dutch, planned to move or spend a long time abroad, or lived in a nursing home.

Data collection
Measurements

Data were collected at baseline and after twelve months and consisted of a self-reported questionnaire containing items on demographics, comorbidities, modified Katz-ADL index, health-related quality of life (EQ-5D), and psychological health status (RAND-36) [12, 13].

Functional disability states

(I)ADL functioning was measured using the modified Katz-ADL index, which consists of six dichotomous questions on ADL, bathing, dressing, toileting, transfer, incontinence and eating, and nine dichotomous questions on IADL, housekeeping, meal preparation, shopping, combing hair, telephone use, transportation, medication use, budgeting and walking. Scores range from zero to fifteen points, and a higher score indicates higher dependence [14]. To a calculate change in disability at twelve months, the (I)ADL scores at twelve

months were subtracted from the (I)ADL scores at baseline. Transitions in disability at one-year follow-up were defined as follows: 1) stable without limitations – participants without limitations at baseline or at follow-up; 2) stable with limitation(s) – participants with the same number of limitations at baseline and follow-up; 3) functional improvement – participants with fewer limitations at follow-up than at baseline; and 4) functional decline – participants with more limitations at follow-up than at baseline.

Healthcare utilisation and costs

Healthcare utilisation was measured by means of self-reported questionnaires assessing the total volume of healthcare services used divided into the following areas: 1) GP care (GP consultations during and after hours) and GP home visits; 2) hospital care and emergency department (ED) visits and admissions; and 3) long-term care (nonmedical and medical home care), admissions to a home for the elderly or a nursing home, and the use of day care. Using the Manual for Cost Studies [15], the standard cost of a single healthcare service unit were obtained for the year 2010. To calculate total healthcare costs per patient, healthcare utilisation rates were multiplied by the standard cost for a specific healthcare item.

Statistical analysis

Baseline characteristics were described for the four functional disability categories using the number (percentage) for categorical variables and the mean (SD) for continuous variables. Dummy variables were created with stable independent older people as the reference group. To calculate healthcare utilisation for the four functional disability categories, healthcare utilisation was dichotomised into yes (use of a particular healthcare service in the past 12 months) and no (no use of particular healthcare service in the past 12 months). Linear regression analyses were used to calculate the healthcare costs of transitions in disability. Furthermore, costs were calculated per point change (no change, decline and improvement) in the modified Katz-ADL index score. Change (decline and improvement) was defined as a difference of one, two or three or more points on the continuous modified Katz-ADL scale at follow-up compared to baseline. Additionally, unadjusted and adjusted odds ratios of healthcare utilisation by older people in a specific functional status category were obtained from multivariable logistic models. Covariates included age and multimorbidity.

Missing data on disability and healthcare utilisation were multiple imputed using MICE (multivariate imputation by chained equations) [16] using predictive mean matching. Ten completed imputation datasets were created. The results of the ten imputed datasets were pooled using Rubin's rules [17]. For 1421 participants, we were able to verify data from the hospital electronic medical record of one regional non-teaching hospital. The length of hospital stay in this hospital was used to impute the length of stay for admission in

other hospitals in the region (including one teaching hospital). All analyses were carried out using SPSS software for Windows 23.0.

Results

The 6664 participants had a mean age of 77.5 (SD 5.8) years, and most were born in the Netherlands (95.0%), female (55.7%) and married or living together (61.4%). Based on the difference in the modified Katz-ADL scores at baseline and at 12-month follow-up, participants were assigned to one of four functional disability states: 1) stable without limitations (n= 2580), 2) stable with limitation(s) (n=1258), 3) functional improvement (n=1127), 4) functional decline (n= 1699). Compared to the stable without limitations category, participants in the stable with limitations, functional improvement

Table 1. Baseline characteristics of participants in total cohort and in the different functional disability categories. Functional disability categories were distinguished at one year follow-up

	Total	Stable without limitations	Stable with limitations	Functional improvement	Functional decline
N (%)	6664	2580 (39)	1258 (19)	1127 (17)	1699 (25)
Mean age (SD)	77.5 (5.8)	75.2 (4.3)	78.4 (5.8)	79.2 (6.1)	79.4 (6.2)
Sex (female), n(%)	3714 (55.7)	935 (36.2)	944 (75.0)	726 (64.4)	1109 (65.3)
Born in the Netherlands, n(%)	6332 (95.0)	2455 (95.2)	1192 (94.8)	1077 (95.6)	1608 (94.6)
Educational level, n(%)					
Primary school or less	1072 (16.1)	233 (9.0)	246 (19.6)	240 (21.3)	353 (20.8)
Secondary school	4461 (66.9)	1771 (68.6)	873 (69.4)	745 (66.1)	1114 (65.6)
College or university	1036 (15.5)	549 (21.3)	158 (12.6)	124 (11.0)	203 (11.9)
Socio-economic status, n(%)					
Low (≤1SD)	184 (2.8)	63 (2.4)	38 (3.0)	34 (3.0)	49 (2.9)
Intermediate	4351 (65.5)	1629 (63.1)	830 (66.0)	760 (67.4)	1127 (66.3)
High (≥1SD)	2111 (31.8)	882 (34.2)	384 (30.5)	327 (29.0)	517 (30.4)
Married/living together, n(%)	4097 (61.4)	1934 (75.0)	638 (50.7)	589 (52.3)	934 (55.0)
Living situation, n(%)					
Independent, alone	2312 (34.7)	642 (24.9)	568 (45.2)	448 (39.8)	655 (38.6)
Independent w. others	3994 (59.9)	1922 (74.5)	614 (48.8)	561 (49.8)	897 (52.8)
Home for elderly	324 (4.9)	8 (0.3)	70 (5.6)	109 (9.7)	138 (8.1)
Multimorbidity (≥2), n(%)	4112 (42.0)	1064 (41.2)	923 (73.4)	859 (76.2)	1262 (74.3)
Fall in past year (yes), n(%)	1385 (20.8)	264 (10.2)	306 (24.3)	351 (31.1)	465 (27.4)
Hospitalisation in past year, n(%)	1267 (19.5)	361 (14.3)	231 (18.9)	291 (26.8)	382 (23.1)
Quality of life (range 0-10), mean (SD)[a]	7.7 (1.1)	8.1 (0.9)	7.5 (1.1)	7.2 (1.3)	7.4 (1.1)
Psychological health status (Rand-36) (range 0-100), mean (SD)[b]	75.0 (14.3)	81.4 (10.9)	72.3 (14.3)	69.0 (15.5)	70.9 (14.3)

[a] Higher scores represent a better quality of life

[b] Higher scores represent a better psychological health status

and functional decline categories were older, had lower quality of life and lower psychological health status. Most participants in the functional improvement category were hospitalised once or more the past year (26.8%) (Table 1). Within 12 months of follow-up, 145 participants were deceased. Furthermore, participants who were lost to follow-up at 12 months were older and more often women, living alone, more dependent in (I)ADL, had more comorbidities and reported more falls in the past year (Table A-1).

Healthcare utilisation

Table 2 presents the healthcare utilisation, dichotomised into yes (any use) and no (no contact with health professionals) over one year. Participants within the functional decline category contributed most to healthcare utilisation. Most participants in the functional decline category were hospitalised once or more during the year (32.8%).

The association between healthcare services and functional disability is presented in Table A-2. After adjustment for age and multimorbidity; individuals with stable functional dependence, functional decline and functional improvement were significantly more likely to use GP care, hospitalisation, home care and nursing home services compared to those with stable functional independence. The strongest associations were found between functional decline and home care (OR 9.68 (95% CI 7.57 - 12.37)) and functional decline and nursing home admission (OR 9.58 (95% CI 4.31 - 21.30)) compared to the stable independent category.

Healthcare costs

Linear regression analysis showed that mean total excess healthcare costs per person relative to those without limitations were highest in older people

Table 2. Healthcare utilisation during one year

	Total N= 6664	Stable without limitations N= 2580	Stable with limitations N= 1258	Functional improvement N= 1127	Functional decline N= 1699
GP care					
Consult during hours	4713 (70.7)	1756 (68.1)	950 (75.5)	791 (70.2)	1216 (71.6)
Visit at home	1223 (18.4)	137 (5.3)	251 (20.0)	289 (25.6)	546 (32.1)
After hours	751 (11.3)	209 (8.1)	135 (10.7)	128 (11.4)	278 (16.4)
Hospital care					
Emergency Department	877 (13.2)	240 (9.3)	151(12.0)	146 (13.0)	341 (20.1)
Hospitalisation	1451 (21.8)	372 (14.4)	266 (21.1)	256 (22.7)	558 (32.8)
Long-term care					
Domestic homecare	1815 (27.2)	128 (5.0)	477 (37.9)	462 (41.0)	748 (44.0)
Physical homecare	486 (7.3)	17 (0.7)	98 (7.8)	116 (10.3)	256 (15.1)
Home for elderly	134 (2.0)	9 (0.4)	22 (1.8)	24 (2.1)	78 (4.6)
Nursing home	57 (0.9)	2 (0.1)	6 (0.5)	5 (0.4)	44 (2.6)
Day care	127 (1.9)	4 (0.2)	22 (1.8)	32 (2.8)	69 (4.1)

Numbers (%) represent healthcare utilisation, 1 or more time(s) during one year. Healthcare utilisation was dichotomised into yes (use of particular healthcare service in the past 12 months) and no (zero use of particular healthcare service in the past 12 months).

Table 3. Mean excess healthcare costs per person for functional disability states relative to stable without limitations

	Stable without limitations N=2580 M (SE)	Stable with limitations N=1258 M (SE)	Functional improvement N=1127 M (SE)	Functional decline N= 699 M (SE)
GP care				
Consult during hours	Ref	32 (16)	3 (17)	13 (15)
Visit at home	Ref	12 (3)	18 (3)	33 (3)
After hours	Ref	7 (8)	8 (10)	41 (8)
Hospital care				
Emergency Department	Ref	4 (6)	4 (8)	42 (6)
Hospitalisation	Ref	1898 (632)	2759 (861)	6977 (1214)
Long-term care				
Domestic homecare	Ref	430 (28)	443 (35)	479 (28)
Physical homecare	Ref	589 (247)	417 (262)	956 (243)
Home for the elderly / nursing home	Ref	41 (558)	1285 (654)	677 (527)
Day care	Ref	57 (38)	99 (38)	198 (38)
Total cost	Ref	3071 (919)	5036 (1092)	9416 (1373)

Mean (SE) excess healthcare costs per person are measured in € and functional transition categories are measured from baseline to the one year study period. Linear regression is performed, with stable without limitations as the reference group and costs of the other groups are displayed as additional costs. Results are adjusted for age and multimorbidity.

with functional decline (EUR 9416 (standard error (SE): 1373)) (table 3). Mean total excess healthcare costs per person with functional improvement were EUR 5036 (SE 1092), and mean total excess healthcare costs per person with stable limitations were EUR 3071 (SE 919). The highest excess healthcare costs were found for hospitalisation in older people with functional decline (EUR 6977 (SE 1214) and older people with functional improvement EUR 2758 (SE 861). Furthermore, admission to a care facility (assisted living or nursing home) contributes to high excess healthcare costs in older people with functional improvement EUR 1285 (SE 654).

Healthcare cost per point change on the modified Katz-ADL index scale

The costs per point change on the modified Katz-ADL index scale are presented in Figure 1. Participants in the stable independent group, without any form of disability over one year have mean total healthcare costs of EUR 5509. The mean cost for a one-point decline is EUR 10414; for a two-point decline, EUR 13633; and for a decline of three or more points, EUR 23947. The mean total cost for participants with a one-point improvement is EUR 7482; for a two-point improvement, EUR 10240; and for improvement of three or more points, EUR 12267. In all groups, hospitalisation costs accounted for the majority of total costs, and GP care cost contributed the least to total healthcare costs.

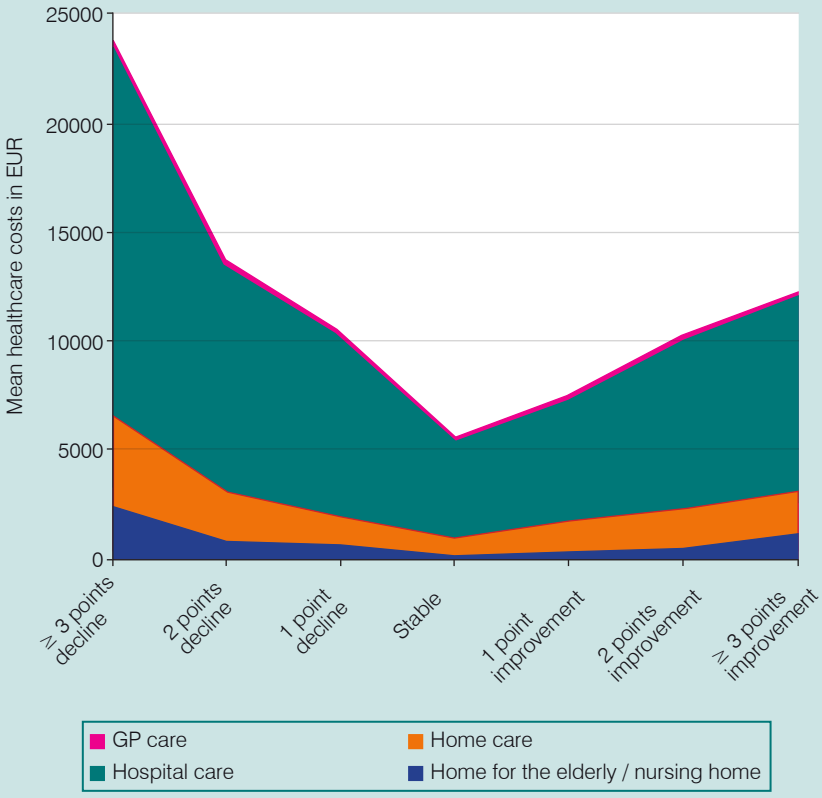

Figure 1. Mean healthcare costs of improvement or decline on the modified Katz-ADL index scale
Mean costs are measured in € and functional status categories are measured from baseline to one year follow-up during the one year study period.

Discussion

The results of this study demonstrate that different functional disability categories have different healthcare costs in older people during 12 months of follow-up. Participants who experienced functional decline over a one-year period had the highest mean excess healthcare costs, and this group consisted of 25% of the total population. Hospitalisations were the most important contributors to overall healthcare costs in all groups, especially among participants with functional decline. Additionally, we observed an increase in mean total healthcare costs per point decline and improvement on the modified Katz-ADL index.

Comparison with the literature

This study confirms the findings of earlier studies that evaluated the association between functional decline and healthcare costs. Fried et al previously showed that stable dependence in community-dwelling older people was predominantly associated with long-term care expenditures and that functional decline was associated with both short- and long-term healthcare expenditures [9]. These results are comparable to those of this study, which also showed that participants with stable limitations had high healthcare costs, especially long-term care costs. This can be explained by the already poor functional status and greater multimorbidity of these participants at baseline. We assessed both (I)ADL and ADL disability in our study, whereas Fried et al only assessed ADL disability. However, cost comparisons are difficult because of different calculation methods, operationalisations of functional status and length of the follow-up period. Furthermore, we found that mean excess total healthcare costs in the group of participants who improved were higher relative to participants who were stable without limitations. This probably reflects the costs related to rehabilitation from hospitalisation-associated disability, which is quite common after hospitalisation [18]. This group needs healthcare services in order to improve or maintain their daily functioning.

Strengths and limitations

The strength of our study is that we included a large sample of community-dwelling older people in the Netherlands recruited from 24 general practices that were prospectively followed for one year. However, this study has some limitations. First, the data are self-reported. Self-reported data carries a risk of recall bias, and as people age and become more functionally impaired, misreporting becomes more common [19]. To increase the precision of the healthcare cost estimates, we used data from hospital EMRs to calculate the cost of the hospital length of stay, which was the largest contributor to total healthcare costs in our study. Second, we observed some missing data. Based on a missing value analysis, we concluded that drop-outs had more (I)ADL-related disabilities and worse covariates at baseline compared to the participants. We tried to overcome this limitation by imputing data for missing participants using multiple imputation. Furthermore, the cost data in this study were skewed, and nonparametric bootstrap methods are normally advised to calculate confidence intervals for the mean healthcare costs. Multiple imputation eliminates the need to make assumptions about the shape of the distribution, such as normality [20]. In this study, we based our analysis on the central limit theorem (CLT) because we have such a large cohort of participants, and the cost data will thus be approximately normally distributed. A comparison between CLT and non-parametric bootstrapping indicated that both methods are appropriate [21].

Implications of the findings

Since hospitalisation is, by far, the largest cost driver, the prevention of hospitalisation could lead to more cost-effective care. Ambulatory care– or primary care–sensitive conditions (ACSCs) are conditions for which acute hospitalisation might be partly preventable by primary care interventions [22]. Continuity of care through a GP [23] and hospital-at-home concepts [24] are interventions with evidence of positive effect. Access to rapid response nursing and social care at home, intermediate care and acute nursing home beds were identified by an expert panel of health professionals as interventions key to reducing acute hospitalisation [25]. The availability of more suitable alternatives to acute hospitalisation might reduce acute hospitalisations and their associated functional decline. Therefore, future research should focus on the cost-effectiveness of these concepts in reducing both the number of acute hospitalisations and the negative impact of hospitalisations.

Conclusion

Older people with functional decline or improvement during one-year follow-up have the highest total healthcare costs compared to those with stable limitations and those without limitations. Hospitalisation was the major cost driver in both groups. Future research is needed to investigate whether interventions focused on the prevention of acute hospitalisation in community-dwelling older people result in more cost-effective care.

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Table A-1. Comparison of baseline characteristics of participants who were lost to follow-up at 12 months

	Missing data	CCA
N (%)	1162	5509
Mean age (SD)	79.7 (6.4)	77.1 (5.5)
Sex (female), n(%)	682 (58.7)	3035 (55.1)
Born in the Netherlands, n(%)	1089 (95.6)	5241 (95.9)
Educational level, n(%)		
Primary school or less	259 (22.3)	813 (14.8)
Secondary school	732 (63.0)	3729 (67.7)
College or university	140 (3.3)	896 (16.3)
Socio-economic status, n(%)		
Low (≤1SD)	37 (3.2)	147 (2.7)
Intermediate	762 (65.8)	3590 (65.4)
High (≥1SD)	359 (31.0)	1752 (31.9)
Married/living together, n(%)	603 (51.9)	3494 (63.4)
Living situation, n(%)		
Independent, alone	456 (39.6)	1860 (33.9)
Independent w. others	566 (49.2)	3431 (62.5)
Home for elderly	129 (11.2)	195 (3.6)
Multimorbidity (≥2), n(%)	794 (68.3)	3318 (60.2)
Fall in past year (yes), n(%)	329 (28.3)	1056 (19.2)
Hospitalisation in past year, n(%)	105 (17.1)	1004 (18.3)
Quality of life (range 0-10), mean (SD)	7.3 (1.3)	7.7 (1.1)
Psychological health status (Rand-36) (range 0-100), mean (SD)	69.4 (16.3)	76.1 (13.6)
KATZ-ADL	2.7 (3.1)	1.3 (2.1)
Mortality within 12 months of follow up	145 (12.5)	-

CCA = Complete Case Analysis

Table A-2. Association between functional status categories and use of healthcare services

a. Unadjusted

	Stable without limitations	Stable with limitations	Functional improvement	Functional decline
GP care				
Consult during hours	Ref	1.45 (1.39 - 1.52)	1.10 (1.05 - 1.16)	1.18 (1.13 - 1.23)
Visit at home	Ref	4.42 (4.13 - 4.72)	6.12 (5.73 - 6.54)	8.44 (7.95 - 8.97)
After hours	Ref	1.36 (1.27 - 1.46)	1.45 (1.35 - 1.56)	2.21 (2.09 - 2.34)
Hospital care				
Emergency Department visit	Ref	1.32 (1.23 - 1.41)	1.43 (1.34 - 1.53)	2.43 (2.31 - 2.57)
Hospitalisation	Ref	1.58 (1.50 - 1.67)	1.73 (1.64 - 1.82)	2.89 (2.76 – 3.02)
Long-term care				
Home care	Ref	11.32 (10.64 - 12.05)	13.37 (12.55 - 14.24)	15.60 (14.70 - 16.56)
Home for the elderly / nursing home	Ref	4.78 (3.85 - 5.93)	5.76 (4.65 - 7.13)	14.01 (11.59 - 16.94)

Healthcare utilisation was dichotomised into yes (use of particular healthcare service in the past 12 months) and no (zero use of particular healthcare service in the past 12 months).

b. Adjusted*

	Stable without limitations	Stable with limitations	Functional improvement	Functional decline
GP care				
Consult during hours	Ref	1.36 (1.10 - 1.67)	1.03 (0.81 - 1.04)	1.15 (0.92 - 1.44)
Visit at home	Ref	2.93 (2.29 - 3.74)	3.85 (3.00 - 4.93)	5.28 (4.20 - 6.64)
After hours	Ref	1.17 (0.91 - 1.51)	1.22 (0.90 - 1.66)	1.90 (1.52 - 2.39)
Hospital care				
Emergency Department visit	Ref	1.18 (0.93 - 1.50)	1.27 (0.92 - 1.75)	2.15 (1.71 - 2.69)
Hospitalisation	Ref	1.46 (1.18 - 1.80)	1.59 (1.29 - 1.96)	2.66 (2.12 – 3.24)
Long-term care				
Home care	Ref	7.53 (5.93 - 9.56)	8.23 (6.22 - 10.90)	9.68 (7.57 - 12.37)
Home for the elderly / nursing home	Ref	3.46 (1.50 - 7.97)	3.97 (1.70 - 9.24)	9.58 (4.31 - 21.30)

Healthcare utilisation was dichotomised into yes (use of particular healthcare service in the past 12 months) and no (zero use of particular healthcare service in the past 12 months).
*Results were adjusted for age and multimorbidity.

Chapter

8

Changes in the in-hospital mortality and 30-day post-discharge mortality in acutely admitted older patients: retrospective observational study

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Age Ageing. 2016;45(1)

Abstract

Objectives: To compare changes over time in the in-hospital mortality and the mortality from discharge to 30 days post-discharge for six highly prevalent discharge diagnoses in acutely admitted older patients as well as to assess the effect of separately analysing the in-hospital mortality and the mortality from discharge to 30 days post-discharge.

Study design and setting: Retrospective analysis of Dutch hospital and mortality data collected between 2000 and 2010.

Subjects: The participants included 263,746 people, aged 65 years and above, who were acutely admitted for acute myocardial infarction (AMI), heart failure (HF), stroke, chronic obstructive pulmonary disease, pneumonia or hip fracture.

Methods: We compared changes in the in-hospital mortality and mortality from discharge to 30 days post-discharge in the Netherlands using a logistic- and a multinomial regression model.

Results: For all six diagnoses, the mortality from admission to 30 days post-discharge declined between 2000 and 2009. The decline ranged from a relative risk ratio (RRR) of 0.41 (95% confidence interval (CI) 0.38–0.45) for AMI to 0.77 (0.73–0.82) for HF. In separate analyses, the in-hospital mortality decreased for all six diagnoses. The mortality from discharge to 30 days post-discharge in 2009 compared to 2000 depended on the diagnosis, and either declined, remained unchanged or increased.

Conclusions: The decline in hospital mortality in acutely admitted older patients was largely attributable to the lower in-hospital mortality, while the change in the mortality from discharge to 30 days post-discharge depended on the diagnosis. Separately reporting the two rate estimates might be more informative than providing an overall hospital mortality rate.

Introduction

Since the implementation of the hospitalised standardised mortality ratio (HSMR) in the Netherlands, hospitals report their mortality rates on an annual basis as an indicator for the quality and safety of their patient care [1]. The HSMR is currently focused on the inpatient period, but this scope might be too limited. In recent decades, several studies have focused on broadening the hospital mortality ratios to 30-day post-discharge mortality ratios [2, 3]. Most researchers conclude that the hospital mortality rates should not be focused on the in-hospital period alone because these may be affected by differences in the discharge policies [4]. Hospitals with a shorter length of stay (LOS) might have better results for the hospital mortality ratios, whereas hospitals with a palliative care unit perform worse [5].

In addition to discharge policies, different patient groups affect the mortality rates. For example, acutely hospitalised older patients have in-hospital mortality rates ranging from 7 to 25% [6–8]. Increased age, functional disabilities upon admission, multimorbidity and pre-existing cognitive impairment are associated with both higher in-hospital and post-discharge mortality rates [9].

In the past two decades, hospitals in the Netherlands have implemented improved treatment strategies. System-wide interventions to identify older patients who are at risk for functional decline and medication reconciliation have contributed to a decline in the in-hospital mortality of older patients [10–12]. At the same time, the mean LOS decreased from weeks to days. Nordström et al. [13] concluded that a shorter LOS for patients with a hip fracture is associated with an increased post-discharge mortality rate among patients with a LOS of 10 days or less. However, the influence of improved treatment strategies and new patient safety procedures on the in-hospital and 30-day post-discharge mortality for the most common acute diagnoses in older patients is unknown. Therefore, the aims of this study are (i) to separately compare the changes over time in the in-hospital mortality and mortality from discharge to 30 days post-discharge for acute myocardial infarction, heart failure, stroke, chronic obstructive pulmonary disease, pneumonia and hip fracture in acutely admitted older patients and (ii) to assess the effect of separately analysing the in-hospital mortality and the mortality from discharge to 30 days post-discharge.

Methods

Data

Data on hospital admissions were retrieved from the Dutch Hospital Discharge Register (LMR) [14]. The LMR has a national coverage with missing values of less than 5% before 2006, 10.5% in 2006 and 12.7% in 2009 respectively. Data on the type of hospital, hospital admission dates, main (discharge) diagnoses

and secondary diagnoses, acute and elective admissions, discharge dates, length of hospital stay, sex, age and mortality are stored in this database.
Statistics Netherlands linked records from the LMR to the Dutch population register. The Dutch population register contains personal characteristics of all persons registered in the Netherlands. More than 85% of all hospital discharges in the LMR were successfully linked, at the patient level, to the population register [15].
To retrieve the date of death, we linked the LMR to the Causes of Death Registry (CDR). The CDR is maintained by the Statistics Netherlands and collects data on all Dutch deceased patients as well as documents the patients' places of death, primary causes of death, and up to three secondary causes of death.

Population

The study population included acutely admitted patients, aged 65 years or older, with a first index hospitalisation in the years 2000, 2003, 2006 or 2009. Eligible patients had an acute hospitalisation for either acute myocardial infarction (AMI), heart failure (HF), stroke, chronic obstructive pulmonary disease (COPD), pneumonia or hip fracture based on their discharge diagnoses. The LMR uses the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9 CM) to register the discharge diagnosis [16]. Table 1 shows the codes of the selected discharge diagnoses [17]. If a person was acutely admitted more than once during the single index year, the first acute hospitalisation was included (Fig A-1.), although a new first index admission was selected every index year; therefore, an individual patient could have been included more than once in the complete dataset.

Outcome measures and covariates

To compute the mortality from discharge to 30 days post-discharge, the time of discharge was subtracted from the time of death. Covariates in our final model were, where possible, according to previous literature on standardised hospital mortality ratios [1, 18]. Age, sex, LOS in days, type of hospital (academic versus non-academic), socioeconomic status score and Charlson comorbidities were included as covariates in our final model.
The socioeconomic status scores (SES) were calculated by the Netherlands Institute for Social Research and include the average income in a district, the percentage of people with low incomes, the percentage of people with low education level and the percentage of people not working. Through factor analysis, these variables are summarised into one variable [19].
At discharge, the main (primary) diagnosis of the admission and up to 10 secondary diagnoses can be registered. From the primary and the secondary diagnoses a comorbidity score was derived by converting all diagnosis codes into the 17 clinical conditions that are used in the Charlson comorbidity index [20].

Table 1. Characteristics of patients acutely admitted according to discharge diagnoses and year of discharge

Diagnosis	ICD-9 CM Code	Year	N	Sex (F)	Age (mean, SD)	Length of stay
Myocardial infarction	410	2000	11,083	4,615 (41.6)	75.6 (6.8)	9 (6–12)
		2003	10,538	4,524 (42.9)	76.3 (7.1)	8 (5–12)
		2006	8,125	3,503 (43.1)	76.8 (7.4)	7 (4–11)
		2009	8,468	3,482 (41.1)	76.7 (7.5)	5 (5–9)
Heart failure	428	2000	13,216	6,908 (52.3)	78.9 (7.2)	9 (6–15)
		2003	13,208	6,990 (52.9)	79.3 (7.2)	9 (5–15)
		2006	12,721	6,873 (54.0)	80.2 (7.4)	9 (5–14)
		2009	13,893	7,519 (54.1)	80.6 (7.4)	8 (4–12)
Stroke	430–434, 436–438	2000	12,836	6,895 (53.7)	77.4 (7.1)	14 (7–30)
		2003	14,080	7,588 (53.9)	77.8 (7.1)	12 (6–22)
		2006	13,798	7,259 (52.6)	78.4 (7.3)	10 (5–17)
		2009	13,895	7,484 (53.9)	78.6 (7.4)	8 (4–14)
Chronic obstructive pulmonary disease	490–492, 493, 494, 496	2000	7,858	3,094 (39.4)	75.6 (6.5)	12 (8–17)
		2003	7,524	3,046 (40.5)	75.8 (6.4)	11 (7–15)
		2006	6,961	3,054 (43.9)	76.3 (6.6)	10 (7–14)
		2009	7,280	3,269 (44.9)	76.6 (6.8)	8 (6–12)
Pneumonia	480–486	2000	7,457	3,016 (40.4)	78.0 (7.4)	12 (8–18)
		2003	9,209	3,729 (40.5)	78.0 (7.4)	11 (7–16)
		2006	10,689	4,437 (41.5)	78.5 (7.6)	10 (7–15)
		2009	13,040	5,535 (42.4)	78.8 (7.7)	9 (6–13)
Hip fracture	820, 821	2000	11,692	9,064 (77.5)	81.6 (7.5)	16 (10–27)
		2003	12,511	9,570 (76.5)	81.9 (7.4)	14 (9–23)
		2006	11,429	8,610 (75.3)	82.4 (7.5)	12 (8–19)
		2009	12,235	9,068 (74.1)	82.3 (7.6)	10 (7–15)

Statistical analysis

Descriptive analyses were performed for each year to characterise the population. Separate analyses were performed for AMI, HF, stroke, COPD, pneumonia and hip fracture. We calculated the unadjusted percentages of observed in-hospital mortality and mortality from discharge to 30 days post-discharge at 3-year time intervals between 2000 and 2009. Logistic regression analyses were performed to compare the probabilities of dying from the start of an acute hospitalisation to 30-days post-discharge in 2009 compared to 2000.

To compare the time-trends in the in-hospital mortality and mortality from discharge to 30 days post-discharge, multinomial regression analyses were performed, and those patients who were alive at 30-days post-discharge were included in the reference category. We included age, sex, LOS type of hospital, SES and Charlson comorbidities in our final adjusted model. A P-value of <0.05 was used as threshold for statistical significance. All analyses were performed with SPSS 20 software (SPSS Inc., Chicago, IL, USA).

Results

A total of 263,746 patients were included. Table 1 reports the socio-demographic characteristics of the patients who were acutely admitted in 2000, 2003, 2006 and 2009. The most prevalent acute discharge diagnoses were stroke (2009: n = 13,895) and HF (2009: n = 13,893). From 2000 to 2009, the absolute number of hospitalisations for patients with a discharge diagnosis of AMI decreased by 24%, whereas an increase of 75% was observed for a discharge diagnosis of pneumonia. Between 2000 and 2009, we observed an overall increase in the patients' mean age at admission. Older patients with HF had the largest mean difference in age between 2000 and 2009 (+1.7 years). For all diagnoses, the LOS decreased. The largest reductions in the LOS were found for stroke; there was a mean difference between 2000 and 2009 of −14.2 days. The lowest decline was found for AMI (−3.2 days).

Unadjusted percentages in the in-hospital mortality and mortality from discharge to 30 days post-discharge

The unadjusted percentages of in-hospital mortality and mortality from discharge to 30 days post-discharge for each diagnosis group are shown in Figure 1. A decline in the in-hospital mortality between 2000 and 2009 was observed for all diagnoses. The largest decline was observed for stroke; in 2000, 29% (n = 3,701) of older patients who were acutely admitted for AMI died in the hospital, whereas in 2009, 17% (n = 2,373) died in the hospital. Minimal differences were found in the unadjusted percentages of the 30-day post-discharge mortality between 2000 and 2009; the largest difference was found for stroke, and the percentages for stroke changed from 3% (n = 448)

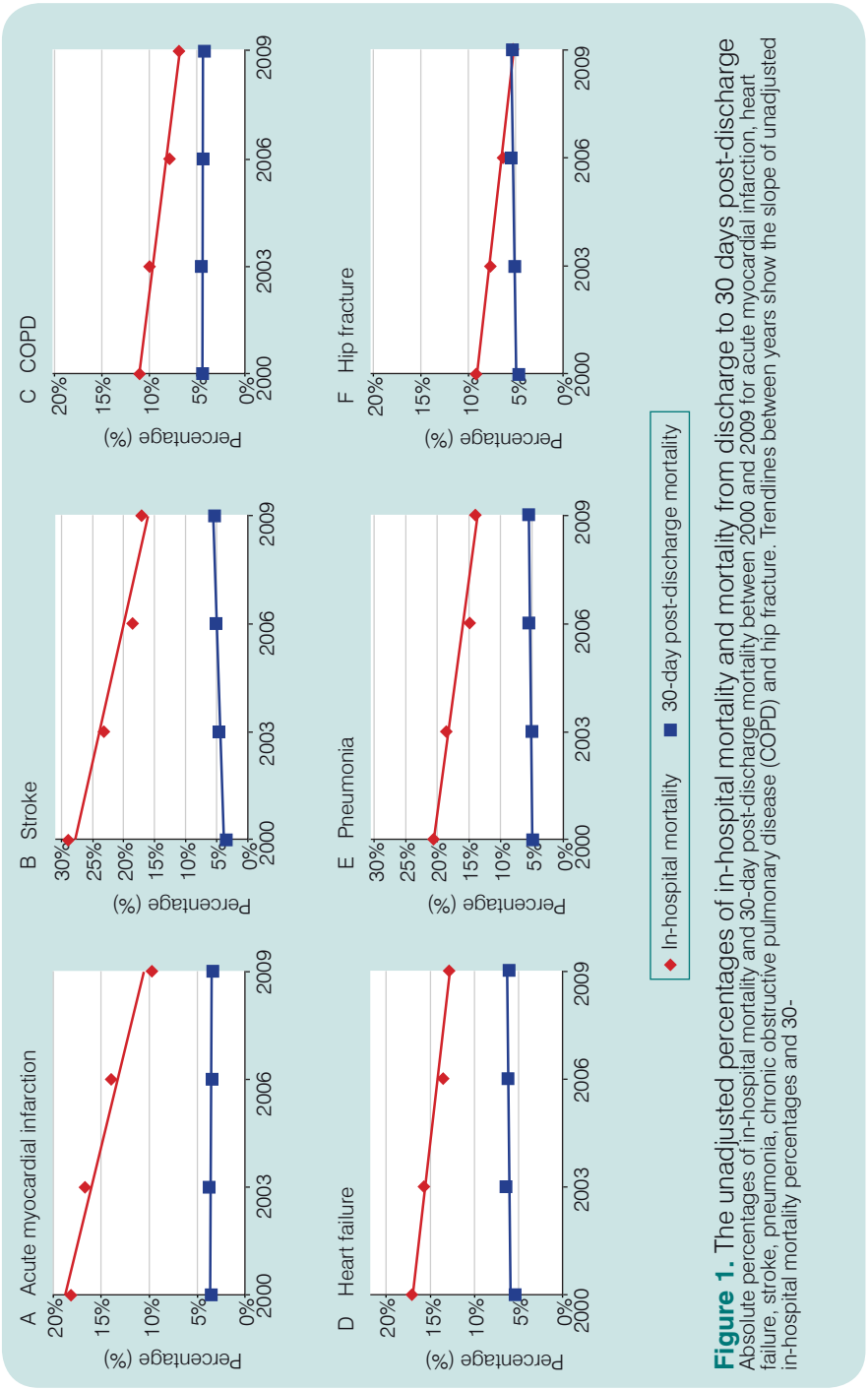

Figure 1. The unadjusted percentages of in-hospital mortality and mortality from discharge to 30 days post-discharge
Absolute percentages of in-hospital mortality and 30-day post-discharge mortality between 2000 and 2009 for acute myocardial infarction, heart failure, stroke, pneumonia, chronic obstructive pulmonary disease (COPD) and hip fracture. Trendlines between years show the slope of unadjusted in-hospital mortality percentages and 30-

Table 2. Multinomial regression for in-hospital mortality, mortality from discharge to 30 days post-discharge, and survival

	Year	In-hospital mortality (versus survival)				30-day post-discharge mortality (versus survival)			
		Unadjusted		Adjusted*		Unadjusted		Adjusted*	
		Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P
Acute myocardial infarction	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.902 (0.841–0.968)	0.004	0.799 (0.741–0.861)	≤0.001	1.045 (0.908–1.203)	0.540	0.968 (0.839–1.117)	0.664
	2006	0.729 (0.673–0.789)	≤0.001	0.572 (0.525–0.624)	≤0.001	0.915 (0.784–1.068)	0.261	0.828 (0.706–0.972)	0.020
	2009	0.486 (0.445–0.530)	≤0.001	0.339 (0.308–0.373)	≤0.001	0.859 (0.736–1.001)	0.051	0.754 (0.640–0.889)	≤0.001
Heart failure	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.916 (0.858–0.978)	0.008	0.900 (0.841–0.962)	0.002	1.178 (1.063–1.305)	0.002	1.211 (1.091–1.344)	≤0.001
	2006	0.771 (0.720–0.826)	≤0.001	0.745 (0.695–0.800)	≤0.001	1.108 (0.998–1.229)	0.054	1.149 (1.032–1.279)	0.011
	2009	0.722 (0.675–0.773)	≤0.001	0.665 (0.619–0.714)	≤0.001	1.076 (0.972–1.192)	0.159	1.116 (1.002–1.243)	0.045
Stroke	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.754 (0.713–0.797)	≤0.001	0.626 (0.591–0.663)	≤0.001	1.272 (1.125–1.439)	≤0.001	1.330 (1.171–1.521)	≤0.001
	2006	0.572 (0.540–0.606)	≤0.001	0.416 (0.391–0.443)	≤0.001	1.326 (1.174–1.497)	≤0.001	1.370 (1.204–1.560)	≤0.001
	2009	0.517 (0.488–0.548)	≤0.001	0.347 (0.325–0.370)	≤0.001	1.354 (1.200–1.527)	≤0.001	1.356 (1.189–1.547)	≤0.001
COPD	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.892 (0.805–0.990)	0.023	0.884 (0.796–0.983)	0.019	1.015 (0.872–1.182)	0.847	1.051 (0.900–1.227)	0.531
	2006	0.688 (0.615–0.770)	≤0.001	0.685 (0.610–0.769)	≤0.001	0.952 (0.813–1.113)	0.535	0.995 (0.846–1.170)	0.948
	2009	0.594 (0.530–0.667)	≤0.001	0.575 (0.509–0.649)	≤0.001	0.913 (0.781–1.067)	0.253	0.959 (0.813–1.131)	0.619
Pneumonia	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.884 (0.818–0.955)	≤0.001	0.857 (0.791–0.928)	≤0.001	1.003 (0.871–1.155)	0.965	1.047 (0.907–1.209)	0.527
	2006	0.676 (0.625–0.730)	≤0.001	0.649 (0.599–0.704)	≤0.001	1.050 (0.918–1.201)	0.477	1.131(0.984–1.299)	0.082
	2009	0.631 (0.586–0.681)	≤0.001	0.596 (0.525–0.617)	≤0.001	1.046 (0.919–1.191)	0.493	1.088 (0.949–1.248)	0.226

Table 2. Continued

	Year	In-hospital mortality (versus survival)				30-day post-discharge mortality (versus survival)			
		Unadjusted		Adjusted*		Unadjusted		Adjusted*	
		Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P	Relative risk ratio (95% CI)	P
Hip fracture	2000	Ref (-)		Ref (-)		Ref (-)		Ref (-)	
	2003	0.820 (0.749–0.898)	≤0.001	0.781 (0.709–0.860)	≤0.001	1.067 (0.949–1.199)	0.279	1.033 (0.917–1.164)	0.591
	2006	0.669 (0.606–0.738)	≤0.001	0.666 (0.599–0.739)	≤0.001	1.145 (1.018–1.287)	0.024	1.109 (0.982–1.253)	0.097
	2009	0.550 (0.497–0.608)	≤0.001	0.521 (0.466–0.581)	≤0.001	1.084 - (0.965–1.218)	0.175	1.025 (0.905–1.160)	0.701

*Final adjusted models were adjusted for age, sex, LOS in days, type of hospital, socioeconomic status score and Charlson comorbidities. A P-value of <0.05 was used as threshold for statistical significance.

in 2000 to 5% (n = 752) in 2009.

Trends over time in the mortality from admission to 30 days post-discharge

Between 2000 and 2009, the adjusted relative risk ratios (RRR) for mortality from admission to 30 days post-discharge decreased for all discharge diagnoses. For all discharge diagnoses, mortality from admission to 30 days post-discharge was lower in 2009 than in 2000. The adjusted RRRs in 2009 were 0.41 (95% CI 0.38–0.45) for AMI, 0.77 (95% CI 0.73–0.82) for HF, 0.44 (95% CI 0.42–0.47) for stroke, 0.68 (95% CI 0.62–0.76) for COPD, 0.67 (95% CI 0.62–0.72) for pneumonia and 0.70 (95% CI 0.64–0.76) for hip fracture. The results of logistic regression analysis are shown in Supplementary data, Appendix 2, available in Age and Ageing online.

Trends over time in the in-hospital mortality

Unadjusted and adjusted multinomial logistic regression models are shown in Table 2. In 2009, patients were less likely than in 2000 to die in-hospital. The RRRs in 2009 were 0.34 (95% CI 0.31–0.37) for AMI, 0.67 (95% CI 0.62–0.71) for HF, 0.35 (95% CI 0.33–0.37) for stroke, 0.58 (95% CI 0.51–0.65) for COPD, 0.60 (95% CI 0.53–0.62) for pneumonia and 0.52 (95% CI 0.47–0.58) for hip fracture.

Trends over time in the mortality from discharge to 30 days post-discharge

Older patients with a discharge diagnosis of HF or stroke were more likely to die from discharge to 30 days post-discharge in 2009 than in 2000. The RRRs were 1.12 (95% CI 1.00–1.24) for HF and 1.36 (95% CI 1.19–1.55) for stroke. We found no

significant changes in the RRR for the mortality from discharge to 30 days post-discharge for COPD, pneumonia and hip fracture in 2009 compared to 2000. The RRRs were 0.96 (95% CI 0.81–1.13) for COPD, 1.09 (95% CI 0.95–1.25) for pneumonia and 1.03 (95% CI 0.91–1.16) for hip fracture. Older patients with AMI were less likely to die from discharge to 30 days post-discharge in 2009 than in 2000 with a RRR of 0.75 (95% CI 0.64–0.89) (see Table 2).

Discussion

In this large nationwide study, older patients had lower probabilities of dying from admission to 30 days post-discharge in 2009 compared to 2000. However, the decline was largely due to the lower in-hospital mortality rates over time. The in-hospital mortality in older patients decreased between 2009 and 2000, while the results for mortality from discharge to 30 days post-discharge in older patients depended on the diagnosis and either declined, remained unchanged or increased. No significant changes in the RRR for the mortality from discharge to 30 days post-discharge between 2000 and 2009 were found for COPD, pneumonia and hip fracture. In 2009, older patients with a discharge diagnosis of HF or stroke were more likely to die from discharge to 30 days post-discharge than those in the year 2000. Only for AMI did we find a declining RRR between 2000 and 2009 for dying from discharge to 30 days post-discharge.

Strengths and limitations of the study

The strength of this study is a national sample of mortality in 263,746 older patients who were acutely admitted for one out of six common discharge diagnoses over a 10-year period. However, the administrative databases containing the data used for this study have some limitations. Approximately 10% of the admissions could not be linked to the population registry and were excluded. Nevertheless, Statistics Netherlands considers this number of linkable admissions reliable for performing statistical analysis [15]. Furthermore, detailed information on the precise location of death outside the hospital and the care patients received after discharge was not available. Therefore, we could not evaluate the impact of discharge care on the mortality rates.

Comparison with other studies

Our results of declining in-hospital mortality rates are in accordance with previous studies [3, 21, 22]. However, most of these studies focused on all patients who were admitted to the hospital instead of specifically on acutely hospitalised older patients. Acutely hospitalised older patients are characterised by high mortality ratios. In this study, we detected a mean overall mortality rate at 30 days (both in-hospital and out of hospital) of 19% for the 2000–2009 period, whereas Pouw et al. [2] reported a mean overall mortality rate of 7.2%.

A possible explanation for this difference may be the inclusion of a highly vulnerable population of acutely hospitalised older patients in our study. A mean 30-day post-discharge mortality ratio of 5% was observed in our study. A study with a comparable vulnerable population, by Drye et al. [5], found similar 30-day mortality ratios in older patients who were admitted for HF, AMI and pneumonia. Bueno et al. [21] previously observed reductions in the in-hospital mortality and less marked reductions in the 30-day mortality in patients admitted for HF.

Implications of findings

Many of the efforts in the past decades have focused on improving the treatment strategies for a variety of diagnoses, reducing the LOS and improving care for older persons during hospitalisation [23]. This could have contributed to the lower in-hospital mortality rates. After the manifest 'to err is human', many countries have implemented system-wide patient safety interventions, such as medication reconciliation [24], improved handovers [25] and malnutrition prevention programmes [26].

There is increasing awareness that older hospital patients are especially vulnerable shortly after hospital discharge [27]. Due to the presence of geriatric conditions that are often not resolved after hospital discharge [28] and the presence of cognitive impairments that continue after hospital discharge, this patient population is at a higher risk for adverse events. Forster et al. already demonstrated that adverse events shortly after discharge are common, such as adverse drug events, inadequate follow-up and hospital-acquired airway and/or urinary tract infections, resulting in higher readmission and mortality rates [29]. As the ageing population across the world increases we would expect hospital mortality ratios to increase as this population is known to be at higher mortality risk than younger adults. In order to improve evaluations on mortality ratios across the world, we advise to keep the two mortality ratios separate.

Our results highlight the need for the development of new interventions that address the needs of older persons in the post-discharge period to further reduce post-discharge mortality. Transitional care interventions, extended collaboration with pharmacists, and better handovers to the practice or district nurse may help to reduce this post-discharge mortality [30].

Mortality from discharge to 30 days post-discharge may also be affected by factors outside of the hospital, such as the quality of primary care and long-term care. If mortality from discharge to 30 days post-discharge becomes a more important quality indicator, hospitals might invest more in developing optimal handover and post-discharge care. The mortality ratios from discharge to 30 days post-discharge are less vulnerable to discharge bias than the in-hospital mortality ratios.

Conclusion

In this large, nationwide study, a decline was observed in six highly prevalent discharge diagnoses in terms of the in-hospital mortality, while the change in mortality from discharge to 30 days post-discharge depended on the diagnosis, and it either declined, remained unchanged or increased. Because the decline was largely from the lower in-hospital mortality rates over time, separately reporting both rate estimates might be more informative than providing an overall hospital mortality rate from admission to 30 days post-discharge. We need more detailed insight into the causes and consequences of changes in the in-hospital mortality and mortality from discharge to 30 days post-discharge to optimise hospital and post-discharge care.

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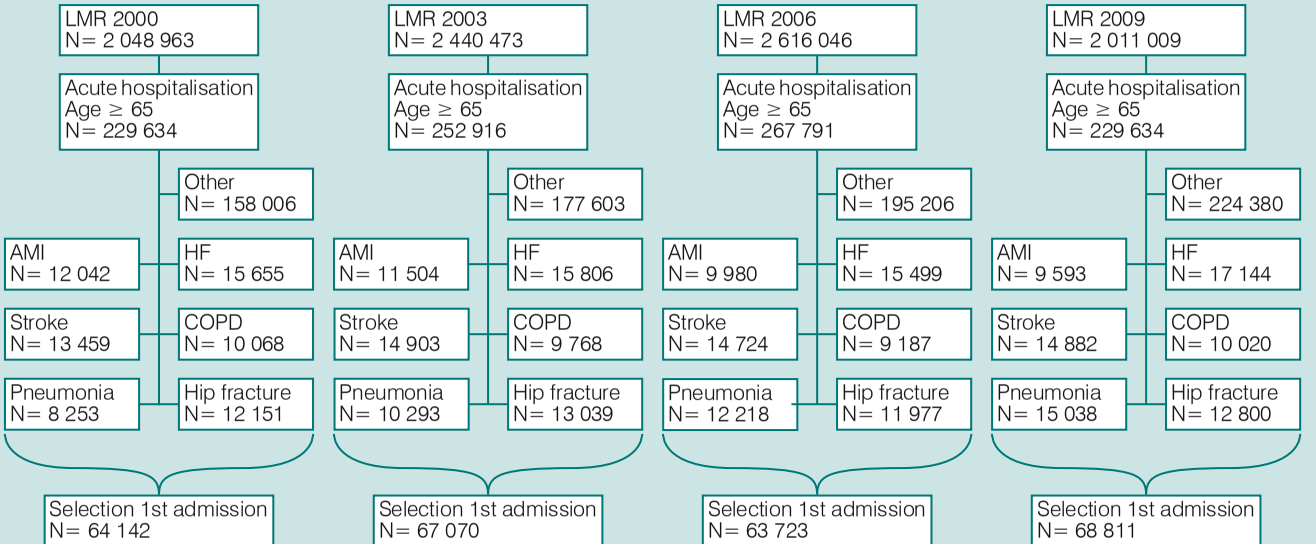

Dataset

Discharge → / Diagnosis ↓ year	AMI	Heartfailure	Stroke	COPD	Pneumonia	Hip fracture
2000	11 083	13 216	12 836	7 858	7 457	11 692
2003	10 538	13 208	14 080	7 524	9 209	12 511
2006	8 125	12 721	13 798	6 961	10 689	11 429
2009	8 468	13 893	13 895	7 280	13 040	12 235

Figure A-1. Flow chart of selection of acutely hospitalised older patients from the Dutch Hospital Discharge Register

Chapter

9

General discussion

The overall aim of this thesis was to improve primary care for community-dwelling older people in the Netherlands. First, by improving the general health and daily functioning of community-dwelling older people; second, by exploring the values, health priorities and experiences of older people with nurse-led multifactorial care; and third by the assessing per capita healthcare costs. In this chapter, the results of these three aims will be summarised and possible explanations for the findings will be discussed. Furthermore, potential implications for clinical practice, education and research will be addressed.

The general health and daily functioning of community-dwelling older people (chapter 2)

As part of the National Care for the Elderly Programme [1], we evaluated the effects of nurse-led multifactorial care in a cluster randomised controlled trial (RCT). The primary outcome of the intervention, a three-step patient-centered approach (the FIT (Functiebehoud In Transitie) care model), was the onset of new disabilities in community-dwelling older people. We found no evidence that a one-year individualised multifactorial intervention programme with nurse-led care coordination resulted in prevention or postponement of new disabilities in community-dwelling older people at increased risk of functional decline. Additionally, the intervention was not more effective than current primary care in The Netherlands for health-related quality of life, emotional wellbeing, self-perceived quality of life, falls, number of hospitalisations, mortality.

We carefully followed the steps of the Medical Research Council (MRC) framework to develop, pilot, evaluate and implement our trial to study the effectiveness of nurse-led multifactorial care [2]. As a first step, we studied all available evidence, developed a screening instrument to identify older people at increased risk for functional decline (ISAR-PC), and performed a pilot study to assess the feasibility of the intervention (step 2). In the third step we evaluated the effectiveness of the intervention. The results of the evaluation study robustly excluded clinically relevant effects of the intervention on the primary outcome. Specifically, the 95% confidence interval around the mean difference between the two treatment groups (-0.07; 95% CI, −0.22 to 0.07) excluded the predefined functional decline of -0.5 points by a wide margin. Yet, there are several possible explanations why the FIT study did not reveal an effect of a one-year nurse-led multifactorial intervention on the primary and secondary outcomes: 1) insufficient alignment between intervention and outcomes, 2) the potential for improvement of proactive primary care for older people in the Netherlands and 3) the adaptation time of new interventions. These possible explanations will be further elaborated.

Insufficient alignment between intervention and outcomes

Disability is a broad concept [3]. The primary outcome of the FIT study was the onset of new disabilities, measured with the modified Katz-ADL index score [4]. The modified Katz-ADL index score includes a wide range of possible impairments and therefore a sum score may be difficult to interpret or compare across older people [5]. Part of the intervention was a comprehensive geriatric assessment (CGA). This CGA covered physical, psychological, functional and social domains. Participants received interventions for geriatric conditions within these domains, such as pain, incontinence, mobility, depressive symptoms, and loneliness. However, these interventions may not sufficiently affect the onset of new disabilities, number of hospitalisations or mortality to yield an effect during this one-year intervention.

The potential for improvement of proactive primary care for older people in the Netherlands

The quality of primary care provision for older people in the Netherlands is considered to be high [6]. Free and easy accessibility, multidisciplinary collaboration with other primary care professionals and secondary care contributes to this high-quality primary healthcare delivery for older people in the Netherlands. Our RCT on the effects of nurse-led multifactorial care resulted in neutral effects on the prevention or postponement of new disabilities. Other studies in the Netherlands and countries with high primary care standards also yielded neutral findings [7-12]. Nevertheless, there may still be room for improvement in the provision of care for older people, since, overall, much of the care is delivered on demand (reactive) rather than within a more prevention approach (proactive), which may harbour additional benefit towards preservation of daily functioning.

The adaptation of new interventions takes time

The nurse-led intervention lasted one year. The combination of implementing a new intervention and the possibility to find an effect on daily functioning within one year might not be possible. The intervention required a transition from reactive to proactive care that GP's, nurses and older people may need to adapt to. Those changes in practice may take longer than one year. CCRNs were not used to proactively assess geriatric conditions. The process of decision making based on recognition and prioritisation by the older person was also new to nurses. Therefore our educational strategy was based on the pyramid of Miller [13]. Miller's pyramid traditionally has four stages; 1) knows, 2) knows how, 3) shows and 4) does. We started with a 10 day training [14], with the first two steps from the pyramid of Miller; 1) knows and 2) knows how. The first home visits with attending coaches were aimed to 3) show and 4) do, according to the pyramid of Miller. After the 10 day training, regular intervision sessions were arranged to reflect on situations in daily practice. Despite this training and follow-up sessions, it may have taken several months to apply

and even longer to expect results on the care and treatment plans that were developed. The questions on recognition and prioritizing used in the FIT study also represented a new approach to older people that was part of this 'culture change', asking for additional time to adopt for older people and might therefore have longer time needed to learn a new way of being patient. For instance, older people came to realize that some geriatric conditions are risk factors for the onset of new disabilities and that preventive measures, on top of regular treatment, could have the potential of decelerating their functional decline.

Community dwelling older peoples' values, health priorities and experiences with nurse-led multifactorial care (chapter 3-6)

If we further focus on how older people value what is important for them, the recognition of geriatric conditions, the experiences with the intervention, and the minimal important change in daily function, we may develop a better understanding of the mechanisms that contributed to the neutral trial results and to find new approaches to improve patient-centered care in daily practice.

Personal views of community-dwelling older people with and without multiple chronic conditions

The CGA started with five questions on personal views on ageing and included 1) What does it mean for you to get older? 2) Do you worry about things? 3) What do you think the future will be like? 4) What, in your opinion, is needed for healthy ageing? and 5) What does quality of life mean to you? Frequent responses included 1) the association of ageing with functional disabilities and deterioration, 2) the acceptance of ageing as an inevitable and unalterable reality and 3) worries about functional disabilities and family. Healthy lifestyles, staying active, keeping social contacts and a positive attitude were considered prerequisites to healthy ageing. Older people with multiple chronic conditions (MCC) mostly addressed the same personal views as older people without MCC. An important difference was that older people with MCC had more worries, had a more negative view on the future and especially feared further functional decline. Many factors addressed by older people focus on the social perspective on health, such as maintaining social contacts and being able to do what one wants to do. Embedding the personal views of older people in a CGA is also incorporated in the model of shared decision making in older people [15]. According to this model it is important to prepare, to perform and to interpret a CGA, regarding recognition and prioritisation of geriatric conditions, resulting in relevant values for older people. These values are relevant when formulating goals [16] .

Recognition of identified geriatric conditions

CGA in community-dwelling older people with an increased risk of functional

decline detected many geriatric conditions, yet resulted in low recognition rates of these geriatric conditions. The median number of identified geriatric conditions per participant was 8 (IQR 6–11) and the median number of geriatric conditions that were recognised was 1 (IQR 0–2). Out of 32 geriatric conditions, functional dependency was the most commonly identified geriatric condition. Pain was the most widely recognised condition. Other conditions such as hypertension, constipation and alcohol or substance misuse were rarely recognised as a problem by older people. Maintaining overall functioning was regarded as key value in the context of ageing and impending functional decline (chapter 3). However, we observed that while functional disabilities were most often identified, only few older persons recognised this as a problem. These results are in line with the new definition of health, presented by Huber et al., in which not solely the absence of physical limitations are important, but rather the ability to adapt and self-manage in the face of social, physical, and emotional challenges [17]. Low recognition rates might also be related to the acceptance of ageing, which was often mentioned by older people (chapter 4). Adaption to functional limitations is also mentioned in the concept of successful ageing and resilience [18, 19]. These concepts focus on a person's lifelong search to find a balance between limitations and opportunities, also encompassing a more psychosocial view on health. The personal views of older people and the recognition rates from the outcomes of the CGA reflect the importance and need of attention to psychosocial wellbeing of community-dwelling older people by the CCRN or GP. Psychosocial functioning might therefore deserve to be more strongly embedded in the CGA.

Community-dwelling older peoples' experiences with nurse-led comprehensive geriatric assessment and care coordination

In-depth interviews with older people on the experience with nurse-led comprehensive geriatric assessment and care coordination yielded an overarching theme 'appreciation to be looked after' by their own GP practice. This main theme branched out into four subthemes: 1) lowering the threshold to the GP practice, 2) attention for psychosocial functioning, 3) reassurance through check-ups and 4) professional care and task delegation between nurse and GP. Participants appreciated nurse-led care coordination because of the feeling of being looked after. Community-dwelling older people valued nurses paying attention to their psychosocial functioning and checking their general health. However, they felt that surveillance of all medical care should remain in the hands of the GP and can not be shifted towards nurses.

Minimal important change and minimal detectable change

To improve our understanding of what constituted relevant functional decline for older people, we calculated both the minimal important change (MIC) and the minimal detectable change (MDC) of the Katz-ADL index score and the

Lawton IADL scale, using both anchor-based and distributional methods for community-dwelling older people with at least one (I)ADL disability. The MIC of both the Katz-ADL index and the Lawton IADL scale were around half a point. The MDC was, however, well above one point on both instruments. There was substantial variation across methods for both the MIC and the MDC. Both instruments have a narrow score-range, which might have influenced the estimated MIC and MDC values. Although the Katz-ADL index score and the Lawton IADL scale are frequently used in both clinical practice and research, both scales were developed to study results of (clinical) treatment in older people on group level, and were not designed to measure change and responsiveness at an individual level. Therefore, the use of different outcome measurements, such as walking speed and hand grip strength for disability might reflect a more individually relevant estimate of overall functioning.

Assessment of per capita healthcare costs of older people (chapter 7-8)

Nurse-led multifactorial care in primary care may enable reductions in healthcare utilisation as it has the potential to prevent hospitalisation and early admission to a nursing home, which are important drivers of healthcare costs and are associated with changes in ADL and IADL functioning. Therefore, we explored the economic impact of disability in older people. Furthermore, due to interventions for acutely admitted older patients, length of hospital stay (LOS) in the Netherlands has declined. Therefore we explored changes in the in-hospital mortality and 30-day post-discharge mortality. These results may contribute to the improvement of transitional care between hospital and home and prevention of acute hospitalisation.

Transitions in functional disability and healthcare costs among community-dwelling older people

We defined four transitions in disability at 12-months of follow-up: 1) stable without limitations – participants without limitations at baseline or at follow-up; 2) stable with limitation(s) – participants with the same number of limitations at baseline and follow-up; 3) functional improvement – participants with fewer limitations at follow-up than at baseline; and 4) functional decline – participants with more limitations at follow-up than at baseline. During 12 months of follow-up, older people in different categories of functional disability have different healthcare costs. Participants who experienced functional decline had the highest mean excess healthcare costs and this group consisted of 25% of the total population. Hospitalisation costs were the most important contributor to the overall healthcare costs in all groups, especially for participants with the largest functional decline. Hence, prevention of hospitalisation could lead to reduction in overall healthcare costs.

Changes in the in-hospital mortality and 30-day post-discharge-mortality

Older people acutely admitted to a hospital in the Netherlands had lower probabilities of dying between admission and 30 days post-discharge in 2009 compared to 2000. This decline was largely due to the lower in-hospital mortality rates over time, while up to 30 days post-discharge mortality rates depended on the diagnosis and either declined, remained unchanged or increased. In the past decades, a multitude of measures and innovations have contributed to lower in-hospital mortality rates, reducing the LOS and improving care for older people during hospitalisation. Examples include system-wide patient safety interventions that have been implemented, such as medication reconciliation, improved handovers and malnutrition prevention programs [20, 21]. However, there is increasing awareness that older hospital patients are especially vulnerable during the transition from hospital to home [22, 23]. Geriatric conditions, such as malnutrition and functional dependence, are often not addressed and/or resolved after hospital discharge, leading to an increased risk for readmission and mortality [24].

The results of chapter 7 and 8 highlight the need for the development of interventions that address the needs of older people in the post-discharge period to further reduce post-discharge mortality and functional decline. This points towards further integration into proactive primary care for older people. Transitional care interventions, extended collaboration with pharmacists, and better handovers to the GP or CCRN may help to reduce this post-discharge mortality and promote recovery [25]. If daily functioning and mortality from discharge to 30 days post-discharge become a more important quality indicator and a shared responsibility of primary and secondary care, primary care organisations and hospitals might invest more in developing optimal handover and care during the transition from hospital to home.

Methodological considerations

Performing an RCT in a changing landscape of primary care for older people

The active involvement of older people in the design and evaluation of the study is a strength of our cluster randomised trial. Other strengths are the high participation rate, the high adherence rate to the structured study protocol, and the evidence-based toolkit we developed for nurses. However, we designed our complex healthcare intervention in a time of a changing landscape of primary care for older people in the Netherlands. Overall, care for older people (also in the control group) probably improved during the intervention period, because principles of effective care for older people became already incorporated in daily practice, such as a focus on proactive care [26]. Furthermore, due to the growth of the older population and rising

related healthcare costs, a common policy response to the consequences of an ageing population has been to encourage older people to live in their own homes, a process known as ageing in place [27]. Ageing in place, in which admittance to residential care is postponed as long as possible, is generally expected to result in cost savings because home care is less expensive than residential care [28]. Since 2013, current government policies aim for an accelerated reduction of residential care facilities [29]. One of the consequences of the ageing-in place concept in The Netherlands is that older people with multiple chronic conditions and functional disabilities are now living at home instead of in a residential care facility. For GPs, this meant an increase in the number of complex older patients [30]. This could have contributed to a relatively large group of older people at increased risk of functional decline with limited potential on preventive interventions on preservation of daily functioning. On the other hand the effect of a relatively large group of older people at increased risk of functional decline might be limited by the participation of a slightly less frail population, 'the worried well', relatively healthy older people who participate to be reassured. Those older people may be more likely to participate in preventive primary care interventions compared to older people at high risk for adverse outcomes [31].

Finding the optimal target population

From the literature, it appeared that exclusively focusing on frail older people may not be efficient, because older people without or only mild disabilities who are at increased risk of functional decline are the most likely to benefit from preventive interventions [32]. Therefore, we focused on a population at increased risk for functional decline, including a somewhat younger population (70-74 years) [32, 33]. However, some included older people were really fit. They, nor their CCRN or GP, did see the need of prevention of geriatric conditions as there were no real needs or recognised problems. Focusing on a better targeted population may result in more efficient care and treatment. For example by focusing on older age and/or a life event, such as the death of spouse, fall and acute hospital admission. Intensive coaching after such a life event may result in prevention of crisis, acute hospital (re)admission or mortality [25, 34].

Outcome assessment

The main aim of the FIT study was to prevent or postpone new disabilities. The intervention focused on a patient-centered individualised care plan. The CGA contained 32 possible geriatric conditions. Recognition and personal prioritisation should contribute to the individualised care plan with higher chance of success. Addressing geriatric conditions that older people consider important may increase adherence to the intervention and facilitate implementation. However this patient-centered individualised focus may not have affected the onset of new disabilities. From the in-depth interviews

(chapter 5) it appears that older people were not aware of the purpose of the home visits. If a more patient-centered approach is desired, then other evaluation methods should probably be used. Using other measures with a closer relation to the individual outcome, such as goal-attainment scaling (GAS) might better suit a patient-centered approach [35]. GAS, is a clinimetric tool that describes goal achievement for individual patients. GAS has demonstrated to detect clinically important change in the evaluation of complex interventions in older people [36].

Implications

The results of this thesis have several implications for clinical practice, education and future research.

Clinical practice

Older people live longer at home with more complex healthcare needs and functional limitations. This development, called 'ageing in place', might have consequences for the wellbeing of older people with complex care needs at home. Those older people are at higher risk to experience loneliness and decreased quality of life because of their limitations. Therefore, attention for their psychological wellbeing is needed. GPs experience an increased burden of older people with complex care needs [30]. This increased complex care for older people increased the need for nurse-led care coordination, as the workload for solely a GP does seem too large to be able to handle the demand of care for older people in primary care. Therefore, GPs and CCRNs will become more and more part of a network of patients, informal care and healthcare professionals, both in primary and secondary care, who exchange knowledge and skills and collaborate in order to continually improve the quality of care for older people [37]. Those networks of extended collaboration between patients, informal care, CCRNs, GP's, nursing home physicians, pharmacists and hospitals may lead to improved quality of care, reduced acute hospitalisation and lower functional decline, which might have impact on wellbeing and quality of life of older people.

Education

In our trial we observed that CCRNs needed time to adapt to their new roles (chapter 2). The CCRNs were expected to work proactively, following the principles of shared decision making, focus on geriatric conditions and build a steady collaboration with the GPs. In order to have well-prepared nurses in the future, it is recommended to start with training on these themes during the bachelor phase of nursing students [38]. To have the competences to build a steady collaboration with other (primary) care professionals, interprofessional education strategies might contribute to more knowledge and improved collaboration between GP's, CCRNs and other network related professionals

[39]. Interprofessional education and team based learning strategies in both undergraduate and postgraduate education might have the potential to improve quality of care for older people [40]. Finally, the growing amount of older people living longer in the community with more complex healthcare needs urges the need for higher educated CCRNs. However, it has been showed that undergraduate nursing students do not want to work with older people in community care [41]. Therefore, there is an urgent need for role models and early practice experiences in care for older people to give a realistic impression of working with older people in community care.

Research

Maybe it is not possible to emerge an effect of a complex healthcare intervention with one fixed outcome measure. Therefore, outcome measures in future research should incorporate outcomes relevant to the individual older person. Furthermore, the potential of task delegation from GPs to nurses warrants further investigation. According to the perspective of older people; there are possibilities in task delegation. The balance between the experience of older people to be looked after (by a nurse and/or GP) on the one hand and the importance of reducing costs on the other hand is a challenge for further research. With the adoption of nurse-led care coordination for older people in the Netherlands, a study of this kind will not be easy to carry out again in the Netherlands. Therefore, it might be recommended to replicate this study in a setting or country where nurse-led care coordination for community-dwelling older people is not yet common practice. Then, to enhance the effect of the intervention, more emphasis should be put on preventive interventions that can directly or indirectly postpone new disabilities, such as promoting physical activity [42]. Furthermore, the intervention should have a long follow-up period, because many preventative interventions (eg, fall prevention or blood pressure reduction) usually require many years to reveal any outcomes [43, 12]. Crucial is the target group, because too little or too much frailty in older people in the intervention group will result in too little effect. Finally, the use of qualitative methods should be incorporated in quantitative analyses of complex interventions as qualitative methods contribute to the acceptability of nurse-led multifactorial care.

Final conclusion

In this thesis we focused on three aims: improving the general health and daily functioning of community-dwelling older people, exploring the experiences of older people with nurse-led multifactorial care, and assessing per capita healthcare costs of older people. First, nurse-led multifactorial care in community-dwelling older people did not result in the prevention of functional decline, reduction of mortality, improved quality of life and healthcare utilisation. Second, CGA detected many geriatric conditions, yet resulted in low recognition rates of these geriatric conditions by older people.

Nevertheless, older people appreciated the home visits, especially because of the feeling of being looked after. Third, hospitalisation costs were the most important contributor to the overall healthcare costs, especially for participants with most functional decline. Furthermore, the in-hospital mortality in older patients decreased between 2000 and 2009, while the results for mortality from discharge to 30 days post-discharge in older patients depended on the diagnosis and either declined, remained unchanged or increased. Despite our tailor-made multifactorial intervention programme with nurse-led care coordination was not more effective than current primary care in the Netherlands for the onset of new disabilities, our study results reveal that shared decision making and collaboration with older people has the potential to improve overall quality of care and to change clinical practice, education and research in the near future.

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Summary

Chapter 1 describes the context in which this thesis was written. In 2008, the Health Council of the Netherlands stated that the current healthcare provision for older people was inadequate, fragmented and not designed to meet the needs of older people with multiple chronic conditions. Hence, in 2008 the Dutch Government launched the National Care for the Elderly Programme. In 2009, a new report from the Health Council focused on daily functioning. Prevention or postponement of disability in daily functioning might contribute to living independent in the community for as long as possible with preservation of quality of life and reduced per capita healthcare costs. A more preventive approach in primary care (proactive care), compared to the demand driven care for older people (reactive care) might help to maintain daily functioning and timely identified values, needs and preferences of community-dwelling older people. The aim of this thesis is to improve primary care for community-dwelling older people in the Netherlands. First, by improving the general health and daily functioning of community-dwelling older people; second, by exploring the experiences of older people with nurse-led multifactorial care; and third by assessing per capita healthcare costs of older people.

Therefore we developed a three-step FIT care model. The first step was the selection of the target population. We modified and validated the Identification of Seniors At Risk (ISAR) screening questionnaire to identify older people at increased risk of functional decline in primary care. This resulted in the ISAR-Primary Care (ISAR-PC) screening instrument. The second step in the FIT care model was a comprehensive geriatric assessment (CGA), including recognition and prioritisation of geriatric conditions by older people. The third step was to make an individually tailored care plan including multifactorial interventions coordinated by a trained community-care registered nurse (CCRN).

In **chapter 2** the effects of nurse-led multifactorial care (the FIT care model) on the onset of new disabilities in community-dwelling older people are presented. Eleven general practices (n=1,209 participants) were randomised to the intervention group, and thirteen general practices (n=1,074 participants) were randomised to the control group. Participants aged ≥ 70 years were at increased risk of functional decline based on a score ≥ 2 points on the ISAR-PC. Participants in the intervention group received a CGA, and individually tailored multifactorial interventions coordinated by a trained CCRN with multiple follow-up home visits. At baseline, the median age of the participants was 82.7 years (IQR 77.0–87.1). The adjusted intervention effect on disability was -0.07 (95% confidence interval -0.22 to 0.07; p=0.33). No intervention effects were found for the secondary outcomes: health-related quality of life, hospitalisation, and mortality.

Chapter 3 describes how multiple chronic conditions (MCC) affect personal views and the process of shared decision making in community-dwelling older people. Using the CGA, 547 community-dwelling older people were asked five questions about what they perceived important in terms of ageing, worries, their future, healthy ageing and quality of life. The personal views that were communicated most often were the association of ageing with (further) functional decline, acceptance of ageing and worries about limitations and family. A healthy lifestyle, staying active, maintaining social contacts and a positive attitude were considered prerequisites to healthy ageing. The ability to do what one wants to do, good health and social contacts contribute to quality of life. Older people with and without MCC addressed many of the same topics regarding the ageing process but an important difference was that persons with MCC had more worries, had a more negative view on the future and especially feared further physical deteriorations and limitations.

Chapter 4 reports on a qualitative study exploring community-dwelling older peoples' experiences and views on nurse-led comprehensive geriatric assessment and care coordination. We conducted semi-structured interviews with fifteen participants from the intervention group of our cluster-randomised clinical trial (RCT). A thematic analysis was used. Participants appreciated nurse-led comprehensive geriatric assessment and care coordination because of the feeling to be looked after. The attention to their psychosocial needs and well-being strengthened their relation with the general practice and routine check-ups contributed to feeling of reassurance. Although participants thought that nurses could take over some primary care tasks, they felt that the surveillance of their medical care should remain in the hands of the GP.

Chapter 5 presents the prevalence of geriatric conditions identified in the CGA and the recognition by community-dwelling older people with an increased risk of functional decline (n=934). Out of 32 geriatric conditions, the median number of identified geriatric conditions per participant was 8 (IQR 6-11) and the median number of geriatric conditions that were recognised was 1 (IQR 0-2). Functional dependency was the most commonly identified geriatric condition. Pain was the most widely recognised condition. Other conditions such as hypertension, constipation and alcohol substance misuse were infrequently recognised as a problem by older people themselves.

Chapter 6 focusses on the accuracy and clinical meaning of changes in daily functioning in community-dwelling older people measured with the Katz-ADL index score and Lawton IADL scale. Therefore we estimated the minimal important change (MIC) and the minimal detectable change (MDC) of the Katz-ADL index score and Lawton IADL scale, using different calculation methods (anchor-based and distributional methods). We included 3184

participants out of our RCT and 51 participants of a cohort study. Anchor-based MICs of the Katz-ADL index score were 0.47 points, while distributional MICs ranged from 0.18 to 0.47 points. Similarly, anchor-based MICs of the Lawton IADL scale were between 0.31 and 0.54 points and distributional MICs ranged from 0.31 to 0.77 points. The MIC of both the Katz-ADL index and the Lawton IADL scale lie around half a point.

Chapter 7 presents the costs associated with transitions in disability in a population of community-dwelling older people. Data from our RCT were used for this study. In addition to the RCT we also included participants without an increased risk of functional decline based on the ISAR-PC and defined four transitions in disability at 12 months of follow-up: 1) stable without limitations (n= 2580); 2) stable with limitation(s) (n=1258); 3) functional improvement (n=1127); and 4) functional decline (n= 1699). Mean total excess healthcare costs per person relative to 1) those without limitations were 2) EUR 3071 (SE 919) for participants in the stable with limitation(s) category, 3) EUR 5036 (SE 1092) for those with functional improvement, and 4) EUR 9416 (SE 1373) for participants with functional decline. In all categories, hospitalisation accounted for most of the excess costs. We concluded that during 12 months follow-up, community-dwelling older people with changes in daily functioning had high mean excess healthcare costs per person relative to those who remained stable without limitations.

Chapter 8 provides an overview of changes in hospital mortality and 30-day post-discharge mortality between 2000 and 2009 in acutely admitted older patients in the Netherlands. The participants included 263,746 older people, who were acutely admitted for acute myocardial infarction (AMI), heart failure (HF), stroke, chronic obstructive pulmonary disease, pneumonia or hip fracture. For all six diagnoses, the mortality from admission to 30 days post-discharge declined between 2000 and 2009. The decline ranged from a relative risk ratio of 0.41 (95% confidence interval 0.38–0.45) for AMI to 0.77 (0.73–0.82) for HF. Hospital mortality decreased for all six diagnoses. Compared to 2000, the decline in hospital mortality in acutely admitted older patients was largely attributable to the lower in-hospital mortality, while the change in the mortality from discharge to 30 days post-discharge depended on the diagnosis.

Chapter 9 presents a general discussion of the main findings. The general discussion includes a reflection on three main explanations why the FIT study did not reveal an effect of a one-year nurse-led multifactorial intervention on the primary and secondary outcomes: 1) insufficient alignment between intervention and outcomes, 2) the potential for improvement of proactive and nurse-led multifactorial primary care for older people in the Netherlands and 3) the adaptation time of new interventions. The methodological considerations

include a reflection on 1) performing an RCT in a changing landscape of primary care for older people, 2) finding the optimal target population and 3) outcome assessment. The main explanations and the methodological reflections are followed by potential implications for clinical practice, education and research.

Samenvatting

Hoofdstuk 1 beschrijft de context waarin dit proefschrift is geschreven. In 2008 stelde de Nederlandse Gezondheidsraad dat de zorg voor ouderen inadequaat en gefragmenteerd was en niet voldeed aan de behoeftes van ouderen met meerdere chronische ziektes. Daarom lanceerde de Nederlandse overheid in 2008 het Nationaal Programma Ouderenzorg. In 2009 volgde een nieuw rapport van de Gezondheidsraad met een focus op dagelijks functioneren. Preventie of het uitstellen van beperkingen in het dagelijks functioneren draagt mogelijk bij aan het zo lang mogelijk zelfstandig wonen van thuiswonende ouderen waarbij kwaliteit van leven behouden blijft en per capita kosten gereduceerd kunnen worden. Een meer preventieve aanpak in de eerste lijn (proactieve zorg), vergeleken met vraaggestuurde zorg (reactieve zorg) helpt mogelijk bij het behoud van dagelijks functioneren en het tijdig identificeren van waarden, behoeften en voorkeuren van thuiswonende ouderen. Het doel van dit proefschrift is het verbeteren van eerstelijnszorg voor thuiswonende ouderen in Nederland. Ten eerste door het verbeteren van de algehele gezondheid en het dagelijks functioneren bij thuiswonende ouderen; ten tweede door het exploreren van de ervaringen van thuiswonende ouderen met multifactoriële zorg, gecoördineerd door een verpleegkundige; en ten derde, door het in kaart brengen van de per capita kosten in de gezondheidszorg voor ouderen.

Om deze reden hebben we het drie-staps FIT (Functiebehoud In Transitie) zorgmodel ontwikkeld. De eerste stap was de selectie van de doelgroep. We modificeerden en valideerden het screeningsinstrument genaamd 'Identification of Seniors At Risk' (ISAR) om ouderen met een verhoogd risico op functieverlies in de eerste lijn te kunnen identificeren. Dit resulteerde in de ISAR-PC (ISAR-Primary Care). De tweede stap in het FIT zorgmodel was het compleet geriatrisch assessment (CGA), inclusief de herkenning en prioritering van geriatrische condities door ouderen zelf. De derde stap was het opstellen van een individueel zorgplan op maat met multifactoriële interventies, gecoördineerd door een geschoolde en geregistreerde verpleegkundige in de eerste lijn.

In **hoofdstuk 2** worden de effecten gepresenteerd van multifactoriële zorg, gecoördineerd door een verpleegkundige (het FIT zorgmodel) op het ontwikkelen van nieuwe beperkingen bij thuiswonende ouderen. Elf huisartsenpraktijken (n=1209 deelnemers) werden na randomisatie toegewezen aan de interventiegroep en dertien huisartsenpraktijken (n=1074 deelnemers) werden na randomisatie toegewezen aan de controlegroep. Deelnemers met een leeftijd van 70 jaar of ouder hadden een verhoogd risico op functieverlies op basis van een score van 2 of meer punten op de ISAR-PC. Deelnemers in de interventiegroep kregen een CGA en een individueel

zorgplan op maat met multifactoriële interventies en meerdere huisbezoeken, gecoördineerd door een daartoe geschoolde verpleegkundige. Aan het begin van de studie was de mediaan leeftijd van de deelnemers 82.7 jaar (IQR 77.0-87.1). Het gecorrigeerde effect van de interventie op beperkingen was -0.07 (95% betrouwbaarheidsinterval -0.22 tot 0.07; p= 0.33). Er werd ook geen verschil in effect gevonden op de secundaire uitkomsten: gezondheid gerelateerde kwaliteit van leven, ziekenhuisopname en sterfte.

Hoofdstuk 3 beschrijft hoe de aanwezigheid van meerdere chronische condities (MCC) een invloed kan hebben op persoonlijke waarden en het proces van gedeelde besluitvorming. Door middel van het CGA werden vijf vragen gesteld aan 547 thuiswonende ouderen. Deze vragen gingen over wat zij belangrijk vinden als het gaat om ouder worden, hun zorgen, de toekomst, gezond ouder worden en kwaliteit van leven. De persoonlijke waarden die het meest werden gecommuniceerd waren de associatie van ouder worden met (verder) functieverlies, acceptatie van het ouder worden en zorgen over beperkingen en over familie. Een gezonde leefstijl, bezig blijven, het behoud van sociale contacten en een positieve houding werden gezien als voorwaarden om gezond ouder te kunnen worden. De mogelijkheid om te kunnen doen wat je wilt doen, een goede gezondheid en sociale contacten dragen bij aan kwaliteit van leven. Ouderen met en ouderen zonder MCC adresseerden veelal dezelfde onderwerpen als het gaat om het proces van ouder worden, maar een belangrijk verschil was dat ouderen met MCC zich meer zorgen maakten, meer negatief naar de toekomst keken en vooral bang waren voor verdere fysieke achteruitgang en beperkingen.

Hoofdstuk 4 rapporteert een kwalitatieve studie waarin de ervaringen van thuiswonende ouderen met het CGA en zorg gecoördineerd door een verpleegkundige worden geëxploreerd. We hielden semigestructureerde interviews met vijftien deelnemers uit de interventiegroep van ons ons cluster gerandomiseerde onderzoek (RCT). Een thematische analyse methode werd gebruikt. Deelnemers waardeerden de verpleegkundige geriatrische zorg vanwege het gevoel in de gaten te worden gehouden. De aandacht voor hun psychosociale behoeften en welzijn versterkte de relatie met de huisartsenpraktijk en routine controles droegen bij aan een gevoel van geruststelling. Hoewel deelnemers vonden dat de verpleegkundige bepaalde taken kan overnemen van de huisarts, moet, volgens de deelnemers, de surveillance en medische zorg in handen blijven van de huisarts.

Hoofdstuk 5 presenteert de prevalentie en herkenning van geriatrische condities geïdentificeerd met het CGA bij thuiswonende ouderen met een verhoogd risico op functieverlies (n=934). Gebaseerd op 32 geriatrische condities, was de mediaan van het aantal geïdentificeerde geriatrische condities per deelnemer 8 (IQR 6-11) en de mediaan van het aantal geriatrische

condities dat werd herkend door de oudere 1 (IQR 0-2). Functionele beperkingen werden het meest geïdentificeerd als geriatrische conditie door de verpleegkundige. Pijn werd het meest herkend als probleem door ouderen zelf. Andere condities, zoals hypertensie, constipatie en alcohol en middelen misbruik werden het minst herkend als een probleem door ouderen zelf.

Hoofdstuk 6 focust op de accuraatheid en klinische relevantie van veranderingen in dagelijks functioneren bij thuiswonende ouderen gemeten met de Katz-ADL index en de Lawton IADL schaal. Daarvoor hebben we een schatting gemaakt van de minimaal relevante verandering (minimal imporant change; MIC) en de minimaal meetbare verandering (minimal detectable change; MDC). Hiervoor gebruikten we verschillende methoden. We includeerden 3184 deelnemers uit onze RCT en 51 deelnemers uit onze cohort studie. Op een anker gebaseerde MIC's van de Katz-ADL waren 0.47 punten, terwijl de op distributie gebaseerde methoden varieerden van 0.18 tot 0.47 punten. Op anker gebaseerde MIC's van de Lawton IADL schaal lagen tussen de 0.31 en 0.54 punten en op distributie gebaseerde MIC's varieerden van 0.31 tot 0.77 punten. De MIC van zowel de Katz-ADL index score en de Lawton IADL schaal liggen rond een half punt. De MDC blijkt afhankelijk te zijn van de grootte van de studiepopulatie.

Hoofdstuk 7 presenteert de kosten die geassocieerd zijn met transities in functioneren bij thuiswonende ouderen. Data van onze RCT werden gebruikt voor deze studie. In aanvulling op de RCT includeerden we voor deze studie ook deelnemers zonder een verhoogd risico op functieverlies gebaseerd op de ISAR-PC en we definieerden vier mogelijke transities in functioneren na 12 maanden follow-up: 1) stabiel zonder beperkingen (n=2580); 2) stabiel met beperking(en) (n=1258); 3) verbetering in functioneren (n=1127); en 4) functieverlies (n=1699). De gemiddelde totale extra kosten per persoon vergeleken met 1) ouderen zonder beperkingen waren 2) EUR 3071 (SE 919) voor deelnemers in de categorie stabiel met beperkingen, 3) EUR 5036 (SE 1092) voor deelnemers die verbeterden in functioneren en 4) EUR 9416 (SE 1373) voor deelnemers met functieverlies. In alle categorieën droeg ziekenhuisopname het meest bij aan de totale extra kosten. We concludeerden dat gedurende 12 maanden follow-up, thuiswonende ouderen met veranderingen in dagelijks functioneren hoge gemiddelde kosten hadden vergeleken met deelnemers die stabiel bleven zonder beperkingen.

Hoofdstuk 8 geeft een overzicht van veranderingen in ziekenhuissterfte en sterfte binnen 30 dagen na ontslag uit het ziekenhuis tussen 2000 en 2009 bij acuut opgenomen ouderen patiënten in Nederland. Deelnemers waren 263.746 ouderen die acuut waren opgenomen met een acuut myocardinfarct, hartfalen, beroerte, COPD, pneumonie of heupfractuur. Voor alle zes opnamediagnoses nam sterfte vanaf opname tot 30 dagen na ontslag af

tussen 2000 en 2009. De afname varieerde van een relatief risico van 0.41 (95% betrouwbaarheidsinterval (BI) 0.38-0.45) voor acuut myocardinfarct, tot 0.77 (95% BI 0.73-0.82) voor hartfalen. Sterfte tijdens ziekenhuisopname nam af voor alle zes de diagnoses. Vergeleken met 2000, werd de afname in ziekenhuissterfte bij acuut opgenomen oudere patiënten grotendeels bepaald door de afgenomen sterfte tijdens ziekenhuisopname, terwijl de verandering in sterfte van ontslag tot 30 dagen na ontslag afhankelijk was van de diagnose.

Hoofdstuk 9 presenteert de algemene discussie van de belangrijkste bevindingen van dit proefschrift. De algemene discussie bevat een reflectie op de drie belangrijkste verklaringen waarom de FIT studie geen effect heeft aan kunnen tonen op een 12 maanden durende multifactoriële interventie, gecoördineerd door een verpleegkundige, op de primaire en secundaire uitkomsten: 1) onvoldoende afstemming tussen de interventie en de uitkomsten, 2) de potentie voor verbetering van proactieve zorg en multifactoriële zorg voor ouderen gecoördineerd door een verpleegkundige in Nederland en 3) de adaptatie van nieuwe interventies die tijd kost. De methodologische overwegingen bevatten een reflectie op 1) het uitvoeren van een RCT in een veranderend landschap van eerstelijns zorg voor ouderen, 2) het vinden van de optimale doelgroep en 3) het meten van uitkomsten. De belangrijkste verklaringen en methodologische reflecties worden gevolgd door potentiële implicaties voor de dagelijkse praktijk, onderwijs en onderzoek.

PhD Portfolio

Name:	Marjon van Rijn
PhD period:	2010 - 2017
PhD supervisor:	Prof. dr. S.E.J.A. De Rooij
PhD co-supervisors:	Prof. dr. B.M. Buurman Dr. E.P. Moll van Charante

PhD training	Year	Workload ECTS
Courses		
• Medical Literature: Searching for a Systematic Review	2013	0.1
• Practical Biostatistics	2013	1.1
• Qualitative Health Research	2013	1.9
• Basiscursus Regelgeving en Organisatie voor Klinisch onderzoekers (BROK)	2014	1
• Clinical Epidemiology	2014	0.6
• Computing in R	2014	0.4
• Medical Literature: EndNote	2014	0.1
• Scientific Writing in English for Publication	2014	1.5
• Basiskwalificatie Didactische Bevoegdheid	2015	10
• Oral Presentation in English	2016	0.8
Seminars, workshops and master classes		
• Masterclass Bekostiging	2011	0.2
• Masterclass Ouderenparticipatie	2011	0.2
• Masterclass Research methods in frail older subjects by prof.dr. Stephanie Studenski	2011	0.2
• Masterclass Multimorbiditiy by dr. Cynthia Boyd	2013	0.2
• Masterclass Transitional care by prof. dr. Mary Naylor	2017	0.2
• Monthly Geriatric research meeting	2010 - present	4
Oral presentations (selection)		
• Een toolkit voor zorgprofessionals in de ouderenzorg, Geriatriedagen, Den Bosch	2012	0.5

PhD training (continued)	Year	Workload ECTS
• De prevalentie en prioritering van geriatrische problemen in de huisartsenpraktijk, Geriatriedagen, Den Bosch	2013	0.5
• Samen sterker in de ouderenzorg: onderwijs als verbindende schakel, workshop in samenwerking Hogeschool Utrecht en Radboudumc, NPO Congres, Den Bosch	2013	0.5
• Shared decision making in general practice. What do older people really want? Anna Reynvaan expert meeting, Amsterdam (invited speaker)	2014	0.5
• Workshop cocreatie – onderzoek, verpleegkundige en patiënt. Tussen weten en doen netwerkbijeenkomst, Rotterdam	2015	0.5
• Transitions in functional disability and associated healthcare costs in community-living older people, EUGMS, Lisboa	2016	0.5
• Zorg voor kwetsbare ouderen in de huisartsenpraktijk, Alkmaarse specialiteiten, Alkmaar	2016	0.5
Poster presentations		
• (I)ADL functieverlies in relatie tot zorggebruik en zorgkosten, Geriatriedagen, Den Bosch	2012	0.5
• Prevalence of geriatric conditions, priorities and tailor-made care plans in community-dwelling older persons EUGMS, Venice	2013	0.5
• Two say more than one: in-hospital mortality and 30-day post-discharge mortality in acutely admitted older patients between 2000 and 2009 in the Netherlands, EUGMS, Rotterdam	2014	0.5
• Ervaringen van thuiswonende ouderen met preventieve huisbezoeken gecoördineerd door een verpleegkundige: een kwalitatieve studie Geriatriedagen, Den Bosch	2016	0.5
• Preventive home-visits and nurse-led care coordination: a qualitative study on the experiences of community-living older people, EUGMS, Lisboa	2016	0.5

Teaching	Year	Workload ECTS
Lecturing		
InHolland Academy		
Ouderenzorg eerste lijn		
• Methodisch werken	2010 - present	1
Amsterdam School of Health Professions		
School of Nursing		
• Evidence Based Practice 4	2015 - present	1
Minor Intensief klinische zorg		
• Klinisch redeneren - Geriatrie	2014 - present	1
Supervising		
• Anouska Kruithof , Master thesis	2013	1
• Marjolein Schimmel, Master thesis	2015	1
• Nienke Hoogteijling, Master thesis	2015	1
• Eline Evelo, Master thesis	2017	1
Tutoring		
Amsterdam School of Health Professions		
School of Nursing		
• Supervise and examine graduation	2014 - present	1
Minor Intensief klinische zorg		
• Project Kwetsbare ouderen	2014 - present	1
• Project Transitie in Zorg	2014 - present	1
Mentoring		
• Mentor 3th /4th -year undergraduate nursing students	2014 - present	1
Media		
Co-development and administrator of websites:		
• http://effectieveouderenzorg.nl	2010	
• http://acute-ouderenzorg.nl	2017	
News coverage:		
• http://nos.nl/nieuwsuur/artikel/2139646-studenten-verpleegkunde-werken-liever-niet-in-verpleeghuis.html	2016	

Teaching (continued)	Year	Workload ECTS
Other		
• Course coordination of 'Ouderenzorg in de eerste lijn'	2010 - 2013	1
• Advisory commitee 'Ouderenzorg eerste lijn'	2014 - present	0.5

Parameters of esteem

Grants	Year
• VIMP, Transmurale Zorgbrug Ouderen	2015
Awards and Prizes	
• Nomination Anna Reynvaan Praktijkprijs	2012
• Nomination best poster presentation EUGMS	2014
• 3th Price Codde & Van Beresteyn Gerontologieprijs	2016

Publication list

1. **van Rijn M**, Hoogteijling N, Pols J, Suijker JJ, Moll van Charante EP. Community-dwelling older peoples' experiences with nurse-led comprehensive geriatric assessment and care coordination (submitted)
2. **van Rijn M**, Bosmans JE, Suijker JJ, Kruithof A, Moll van Charante EP, de Rooij SE, Buurman BM. Transitions in functional disability and associated healthcare costs in community-dwelling older people (submitted)
3. Pel-Littel R, **van Rijn M**, Vermunt PW, van Weert JC, Minkman MM, ter Riet G, Scholte op Reimer WJ, Buurman BM. Does multimorbidity influence personal views on the ageing process: a qualitative analysis (submitted)
4. Suijker JJ, MacNeil Vroomen JL, **van Rijn M**, Buurman BM, de Rooij SE, Moll van Charante EP, Bosmans JE. Cost-effectiveness of nurse-led multifactorial care to prevent or postpone new disabilities in community-living older people: Results of a cluster randomized trial. PLoS One. 2017 Apr 17;12(4):e0175272.
5. Suijker, JJ, **van Rijn M**, ter Riet G, Moll van Charante EP, de Rooij SE, Buurman BM. Minimal important change and minimal detectable change in activities of daily living in community-living older people J Nutr Health Aging. 2017;21(2):165-172
6. **van Rijn M**, Suijker JJ, Bol W, Hoff E, ter Riet G, de Rooij SE, Moll van Charante EP, Buurman BM. Comprehensive geriatric assessment: recognition of identified geriatric conditions by community-dwelling older persons. Age Ageing. 2016; 45 (6)
7. **van Rijn M** / Suijker JJ, Buurman BM, ter Riet G, Moll van Charante EP, de Rooij SE. Effects of Nurse-Led Multifactorial Care to Prevent Disability in Community-Living Older People: Cluster Randomized Trial. PLoS One. 2016;11(7):e0158714.
8. **van Rijn M**, Buurman BM, MacNeil Vroomen JL, Suijker JJ, ter Riet G, Moll van Charante EP, de Rooij SE. Changes in the in-hospital mortality and 30-day post-discharge mortality in acutely admitted older patients: retrospective observational study. Age Ageing. 2016;45(1):41-7.
9. Askari M, Eslami S, **van Rijn M**, Medlock S, Moll van Charante EP, van der Velde N, de Rooij SE, Abu-Hanna A. Assessment of the quality of fall detection and management in primary care in the Netherlands based on the ACOVE quality indicators. Osteoporos Int. 2016;27(2):569-76.
10. Jansen S, Schoe J, **van Rijn M**, Abu-Hanna A, Moll van Charante EP, van der Velde N, de Rooij SE. Factors associated with recognition and prioritization for falling, and the effect on fall incidence in community dwelling older adults. BMC Geriatr. 2015;15:169.
11. MacNeil Vroomen JL, Bosmans JE, Holman R, **van Rijn M**, Buurman BM, van Hout HP, de Rooij SE. Place of Death with Dementia-Dutch People Rarely Die in the Hospital. J Am Geriatr Soc. 2015;63(9):1961-2.

12. Suijker JJ, Buurman BM, **van Rijn M**, van Dalen MT, ter Riet G, van Geloven N, de Haan RJ, Moll van Charante EP, de Rooij SE. Een gevalideerd screeningsinstrument voorspelt functieverlies bij thuiswonende ouderen: de Identification of Seniors at Risk – Primary Care (ISAR-PC). Tijdschr Gerontol Geriatr. 2015 Apr;46(2):113-21
13. Suijker JJ, Buurman BM, **van Rijn M**, van Dalen MT, ter Riet G, van Geloven N, de Haan RJ, Moll van Charante EP, de Rooij SE. A simple validated questionnaire predicted functional decline in community-dwelling older persons: prospective cohort studies. J Clin Epidemiol. 2014;67(10):1121-30.
14. van Dalen MT, Suijker JJ, MacNeil Vroomen JL, **van Rijn M**, Moll van Charante EP, de Rooij SE, Buurman BM. Self-report of healthcare utilization among community-dwelling older persons: a prospective cohort study. PLoS One. 2014 Apr 7;9(4):e93372
15. Suijker JJ, Buurman BM, ter Riet G, **van Rijn M**, de Haan RJ, de Rooij SE, Moll van Charante EP. Comprehensive geriatric assessment, multifactorial interventions and nurse-led care coordination to prevent functional decline in community-dwelling older persons: protocol of a cluster randomized trial. BMC Health Serv Res. 2012;12:85.
16. **van Rijn M**, Beijers-Ebbelaar S, de Koning JL, Brouwer JP, Buurman BM. Systematisch opsporen en behandelen van urine-incontinentie. Nederlands Tijdschrift voor Evidence Based Practice 5-2011.

Dankwoord

In de afgelopen jaren heb ik ontzettend veel mensen leren kennen. Velen hebben mij geholpen, op wat voor manier dan ook. Op deze plek wil ik iedereen met wie ik heb samengewerkt en die op enige wijze heeft bijdragen aan het tot stand komen van dit proefschrift hartelijk bedanken. Iedereen bij naam noemen en bedanken lijkt onmogelijk. Toch wil ik een aantal van jullie in het bijzonder bedanken:

Mijn promotor, prof. dr. Sophia de Rooij. Ik kan me ons eerste gesprek nog goed herinneren. Wat was het fijn om te zien dat er nog iemand zo enthousiast kon zijn over ouderenzorg. Aan promoveren wilde ik toen nog niet denken, er moest zoveel gebeuren als ik jouw ambitieuze ideeën aanhoorde. Dankjewel voor al je inspiratie, betrokkenheid en kritische blik.

Mijn copromotor, prof.(!) dr. Bianca Buurman. Je hebt me begeleid van onderzoeksverpleegkundige naar promovenda en nu uiteindelijk doctor. Het is ontzettend fijn dat het contact zo laagdrempelig is. Je bent een inspiratiebron voor me. Dankjewel voor het vertrouwen en voor alle mogelijkheden die je me hebt geboden. Ik kijk er naar uit om ook in de toekomst samen te blijven werken.

Mijn copromotor, dr. Eric Moll van Charante. Met jouw kennis, rust, vriendelijkheid en humor weet jij ieder overleg tot leerzame feestjes te maken. Je grote betrokkenheid bij alle artikelen door middel van kritische vragen en uitgebreide feedback heb ik enorm gewaardeerd.

Dr. Jacqueline Suijker. Wat was het fijn een partner in crime te hebben tijdens dit mega project. Dat hebben we toch maar ‘even’ mooi neergezet. Ik heb bewondering voor hoe je de afgelopen jaren een promotie, een huisartsopleiding en een gezin kon combineren.

José de Koning. Herinner jij je ook nog de geweldige tijden op kamer F4-108? Tussen alle dozen, brieven, enveloppen, Excel-bestanden en studenten hebben we het mede dankzij jou voor elkaar gekregen om de hele studie te organiseren en coördineren.

Alle ouderen en hun mantelzorgers in de regio Noord-Kennemerland, IJmuiden, Amsterdam-Noord, Amsterdam-Zuidoost en Almere: hartelijk dank voor uw moeite om steeds maar weer de enorme vragenlijsten in te vullen en de verpleegkundigen thuis te ontvangen voor allerlei vragen en testjes (de looptest en handknijpkracht vond u stiekem het leukst). Zoals velen van u zelf ook aangaven, u deed eigenlijk niet mee voor uzelf, maar vooral voor uw huisarts of voor andere ouderen, ter verbetering van de ouderenzorg in

Nederland. Dank dat u daar een bijdrage aan heeft willen leveren.

Zonder betrokkenheid en hulp van Huisartsenorganisatie Noord-Kennemerland had dit onderzoek niet mogelijk geweest. Paul Witteman en Jacco Rempe, dank jullie wel voor jullie bereidheid om dit onderzoek mede mogelijk te maken. Melinda van Moorst, jouw hulp bij de organisatie en uitvoer van dit onderzoek was onmisbaar. Vanuit de deelnemende huisartsenpraktijken hebben we in totaal meer dan tienduizend ouderen mogen benaderen. Graag wil ik daarom de huisartsen van de volgende praktijken bedanken voor hun bereidheid om deel te nemen aan dit onderzoek: De Bergense Huisartsen, Huisartsenpraktijk Bok en Grapendaal, Huisartsenpraktijk Rietveld, Huisartsenpraktijk Gianotten, Huisartsenpraktijk Duif, Huisartsenpraktijk den Engelsen, Huisartsenpraktijk Hoog en Laag, Huisartsenpraktijk Egmond aan Zee, Huisartsenpraktijk Noordhof, Huisartsenpraktijk Sonnenberg, Huisartsenpraktijk Walvis, Huisartsenpraktijk Braak, Praktijk de Watertoren, Huisartsen Faber en Falke, Huisartsen het Baken, Huisartsenpraktijk Nederhof, Huisartsenpraktijk Duindoornplein, Huisartsenpraktijk Bruce, Huisartsenpraktijk Jonker en Koetsier, Huisartsenpraktijk Amsterdam Noord, Huisartsenpraktijk Heimansweg, Huisartsenpraktijk Franken, Medisch Centrum Spelderholt, Gezondheidscentra Amsterdam Zuid-Oost, en Zorggroep-Almere. Wat goed om te zien dat er ook echt wat gebeurt met de resultaten van het onderzoek.

Wijkverpleegkundigen en praktijkondersteuners. Voor dit onderzoek bezochten jullie ruim vijftienhonderd ouderen meerdere malen thuis. Annaleen, Iris, Ilona, Maaike, Geralda, Anne-Marie, Tamara, Danielle, Annemieke, Emmarike, Lida, Jeroen, Irene, Janna, Marijke, Anja, Ger, Isaura, Francien, Francisca, Mieke, Ida, Welmoed, Odette en Saboohi, jullie zorgden ervoor dat de interventie daadwerkelijk werd uitgevoerd en daarmee zijn jullie één van de belangrijkste elementen van de hele interventie. Hartelijk dank voor het enthousiasme waarmee jullie nieuwe ontwikkelingen binnen de ouderenzorg aanpakken. Jullie zijn een onmisbare brug tussen wetenschap en praktijk.

Ouderenmonitors; mw A. Cornelis, dhr W. van Lint, mw D. van Lint, mw R. van Delden, mw J. van Diepen, mw H. Herpers, mw K. Bergmans, dhr J. van der Vis, mw S. Boerlage, mw G. de Vries, dhr W. Schuijlenburg en wijlen mw W. Keman, bijna iedere maand zagen we elkaar. Wat is uw input waardevol voor onze projecten. De stem van de ouderen laten horen in het onderzoek en bij de implementatie, dat is zeker gelukt! (maar het kan altijd beter, hoor ik u nu al zeggen).

Mede auteurs, in het bijzonder Gerben ter Riet, Judith Bosmans, Jeannette Pols, Ruth Pel-Littel en Janet MacNeil Vroomen, dank jullie wel voor de samenwerking, inspiratie en deskundigheid. Ook wil ik graag Anouska Kruithof, Nienke Hoogteijling, Eva Hoff en Wietske Bol bedanken voor de

inhoudelijke bijdrage aan dit proefschrift.

De overige leden van de promotiecommissie prof. dr. W. Scholte op Reimer, prof. dr. D. Willems, prof. dr. J. van Weert, prof. dr. C. Hertogh, dr. N. van der Velde en dr. N. Bleijenberg wil ik hartelijk danken voor het beoordelen van mijn proefschrift en het opponeren.

Collega's en oud-collega's van de afdeling ouderengeneeskunde, zonder jullie had ik het nooit zo lang volgehouden. Lucienne, Rosanne, Isabelle, Marije, Lotta, Marlies, Marlien, Özgül, José H, Jacqueline K, Astrid, Juliette, Hanna, Marieke, Remco, Rosa, Marjolein P, Liesbeth, Suzanne, Renate, Sofie, Kim, Rikie, Annemarie, Alice, Jeroen, Limke, Nancy, Annemarieke, Barbara, Erja, Marjolein vd Z, Rita, Josephine en alle anderen, dank jullie wel voor jullie hulp, steun, adviezen en gezelligheid.

Studenten van de afdeling ouderengeneeskunde, in het bijzonder Saskia, Nicole, Annika, Paulien, Anna, Judith, Francien, Femke, Floor, Arjen, Sanne en Wendy. Jullie hulp is van grote waarde geweest. Zonder jullie waren we nu nog bezig geweest met het verzendklaar maken van de tienduizenden vragenlijsten, het invoeren van alle data, het controleren, het bellen en de huisbezoeken. Wat hebben we jullie toch allemaal aangedaan met het saaie invoerwerk en de zware tassen die jullie op een ov-fiets meenamen naar een huisbezoek in een dorp waar geen treinstation te vinden is? Bedankt voor jullie inzet!

Collega's en studenten van de opleiding Verpleegkunde aan de Hogeschool van Amsterdam. Ik wil jullie bedanken voor jullie interesse in mijn onderzoek. Speciale dank ben ik verschuldigd aan mijn kamergenoten (voordat er flexplekken waren; hoewel het voor de indeling niet veel uitmaakt); Anna, Inke, Ype, Gerdien, Marjolein en Yvonne, van jullie kreeg ik de mentale ondersteuning die zelfs ik soms nodig had. Ook wil ik graag mijn eigen team jaar 3-4 bedanken, met Sanne als teamcoördinator (dank voor de eerste versie van mijn proefschrift in surprise vorm). Het management, Corine, Judith en Jolanda, dank jullie wel voor de mogelijkheden om mij verder te ontwikkelen. Ook wil ik Margriet van Iersel bedanken, jij begeleidde mij bij de eerste stappen in onderwijsland. En wat is samen schrijven met jou toch fijn!

Patricia Jepma, je begon als één van de studenten bij de FIT studie en nu ben je collega docent en promovenda. Samen krijgen we echt heel veel gedaan. En wat is het fijn om de goede en minder goede momenten te kunnen delen als het even nodig is. Dankjewel dat je altijd voor me klaarstaat, ook nu weer als paranimf tijdens mijn promotie. Nu op naar je eigen promotie!

Lieve familie, vrienden en vriendinnen. Ook jullie verdienen een klein plekje in dit dankwoord. Dank jullie wel voor jullie interesse in mijn onderzoek, de afleiding en het gevoel van thuiskomen in het Westland (ja, ook Dalfsen voelt een beetje als thuiskomen in het Westland).

Lieve Richard, je bent als grote broer altijd een voorbeeld voor me geweest. Een paar jaar geleden mocht ik jou bijstaan als paranimf bij jouw promotie en wat fijn dat je nu ook bij mij paranimf wilt zijn.

Lieve pap en mam, dank jullie wel voor alle mogelijkheden en kansen die ik van jullie heb gekregen. Jullie hebben mij altijd gestimuleerd en gaven mij de ruimte om mezelf te blijven ontwikkelen. Zie hier het resultaat!

Lieve Jasper, het is gelukt! (ook al wist jij natuurlijk al lang dat het zou gaan lukken). Jouw vertrouwen, liefde en geduld is van onschatbare waarde. Samen met jou letterlijke en figuurlijke hoogte en dieptepunten kunnen delen is ontzettend fijn. Zichtbaar en onzichtbaar heb je veel bijgedragen aan dit proefschrift, waarvoor heel veel dank.

Dit mooie avontuur is nu ten einde gekomen, het is tijd om nieuwe avonturen te laten beginnen!

Curriculum Vitae

Marjon van Rijn werd op 11 januari 1986 geboren in Maasdijk. Na het behalen van haar VWO-diploma aan de Interconfessionele Scholengemeenschap het Westland in Naaldwijk, is zij in 2004 begonnen aan de HBO-V aan de Hogeschool Rotterdam. Tijdens stages in een verpleeghuis, de thuiszorg en in het ziekenhuis ontwikkelde zij haar enthousiasme voor ouderenzorg. In 2008 rondde zij de HBO-V af en begon aan de (pre)master gezondheidswetenschappen aan de Vrije Universiteit in Amsterdam. Ondertussen bleef zij als verpleegkundige werken op de afdeling interne geneeskunde van het Reinier de Graaf Gasthuis in Delft. Na het behalen van haar master gezondheidswetenschappen in 2010 startte zij als onderzoeksverpleegkundige op de afdeling geriatrie/ouderengeneeskunde van het Academisch Medisch Centrum in Amsterdam. In deze functie coördineerde Marjon de opzet en uitvoer van de FIT studie. Dit resulteerde uiteindelijk in een promotietraject. Vanaf 2014 combineerde Marjon haar promotieonderzoek met de functie van docent verpleegkunde aan de Hogeschool van Amsterdam. Marjon heeft de ambitie om in de toekomst onderzoek, onderwijs en praktijk te (blijven) combineren.