Care for older people in Dutch general practice: Results from the FIT study

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Chapter 1

General introduction
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_Aging population and multimorbidity_

Have you heard of Henk Schueler? In 2012, at the age of 89 years he was training to skate his eighth ‘Eleven cities tour’. Of course not all Dutch people are born as talented ice-skaters. But growing old raises an important question for many people: living your old days, will it be in good health, without disabilities, or will it be in ill health and in dependence on other people?

Increased life expectancy is one of the most remarkable achievements of health care of the 20th century. Between 1950 and 2014 life expectancy increased ten years, and is expected to further increase with another seven years in 2060 in the Netherlands. This will coincide with a further increase in the number of people aged 65 years and over from 2.9 million in 2014 to 4.7 million in 2060. In parallel, over the last two decades, the prevalence of diseases and chronic conditions in older people has increased. Earlier diagnosis and better treatment possibilities may partly account for this effect and result in longer periods of life with known morbidity, but with improved functional status. Multimorbidity is associated with many adverse conditions such as disability, poorer quality of life, increased use of healthcare resources, institutionalization, and increased mortality.

In general, clinical guidelines are disease-specific. Applying clinical guidelines to people with multimorbidity may result in care that is impractical or even harmful, since treatments potentially counteract. In 2008, the Health Council of the Netherlands [HC] concluded that the current Dutch primary healthcare system was not sufficiently equipped to deal with older people with multifactorial diseases and care needs and provided reactive and fragmented care. The HC suggested further research on proactive and integrated care for older people with multifactorial care needs.

_New disabilities in older people_

With the ageing population, the increase of multimorbidity, and growing strain on limited resources, the need to preserve physical functioning and prevent new disabilities in later life has become ever more urgent. 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. The occurrence of new disabilities is often called functional decline.
Depending on the applied definition 20%-30% of the community-living older people report disabilities in ADL or IADL. Functional decline is associated with loss of quality of life,\textsuperscript{11} loss of independence,\textsuperscript{12} need for hospital and nursing home care,\textsuperscript{13} and strains on social and economic resources.\textsuperscript{14} Older people consider prevention of new disabilities as an important priority because this is essential for maintaining independence.\textsuperscript{15}

The development of disabilities can be described by several conceptual models.\textsuperscript{16} The International Classification of Functioning, Disability and Health (ICF), developed by the World Health Organization is a widespread used model of disability. This bio-psycho-social model conceptualizes functioning as a ‘dynamic interaction between a person’s health condition, environmental and personal factors’. In the ICF model, a disease may cause functional impairment, which in turn, leads to disability and restricted social participation.\textsuperscript{17}

\begin{figure}[h]
\centering
\includegraphics[width=0.8\textwidth]{icf_diagram.png}
\caption{Framework of International Classification of Functioning, Disability and Health by the World Health Organization in 2001}
\end{figure}

\textbf{Identifying older persons at increased risk for functional decline}

When designing interventions to prevent or postpone new disabilities, identifying the appropriate target population that will benefit the most of an intervention is an important first step. Screening older people for those at increased risk of functional decline (i.e. >75 years) may identify people who may benefit most from a preventive intervention.\textsuperscript{9,18} Over the last decades, considerable effort has been put into the
identification of frail older people.\textsuperscript{19,20} Different strategies consist of self-assessment instruments,\textsuperscript{21-23} the judgment of the general practitioner (GP),\textsuperscript{24} or on the routine healthcare data from the GPs’ electronic medical records (EMR).\textsuperscript{25} At the start of this study, no results were available on the predictive accuracy of the GP’s estimation of functional decline, or of self-assessment instruments to predict functional decline over time.\textsuperscript{21-23} Furthermore, some well-known instruments such as the Sherbrooke Postal Questionnaire,\textsuperscript{26} or Vulnerable Elders Survey,\textsuperscript{27} required external validation in a Dutch population.

To identify older people at increased risk of functional decline a self-reporting, generic, easy-to-apply, and validated instrument is needed. The Identification of Seniors at Risk (ISAR) questionnaire is a self-report screening instrument that identifies older people at increased risk of functional decline in the emergency department (ED) and is validated in a Dutch population.\textsuperscript{28,29} Because the original ISAR contains risk factors that are associated with functional decline in community-living older people,\textsuperscript{13,30} we hypothesized that the ISAR could also be usable in a primary healthcare setting. Therefore, we aim to (1) assess the predictive performance of the original ISAR questionnaire to detect older persons at increased risk of functional decline and further improve or modify the instrument where possible, (2) test a modified ISAR questionnaire in a validation cohort, and (3) compare the performance of the modified ISAR with risk stratification by age alone, since several nationwide prevention programs for older people only use age as a selection criterion.

\textit{Nurse-led multifactorial care (FIT care model)}

The growing interest in multifactorial interventions to prevent or postpone new disabilities and maintain independence in community-living older people is evident.\textsuperscript{31} Despite controversies over their effects, annual multidimensional assessments or preventive home visit programs for frail and non-frail older people are already part of national policies in several Western countries, including the United Kingdom and Denmark.\textsuperscript{31-35} Previous meta-analyses and reviews demonstrated that interventions with beneficial effects on overall functioning include a comprehensive geriatric assessment (CGA), multifactorial interventions, and multiple follow-up visits.\textsuperscript{34,36,37}

Over the last two decades, in the Netherlands, there has been an increasing task delegation towards registered nurses (RN) working in general practice, especially for chronic conditions.\textsuperscript{38} In 2008, the Dutch government launched the National Care for
the Elderly Programme (NCEP) stimulating innovative healthcare projects focusing on older people with multifactorial care needs to promote physical, mental and social health and well-being. The NCEP stimulated nurse-led care coordination for older people.\textsuperscript{39}

We designed an intervention (Functiebehoud in Transitie (FIT care model)) combining CGA, multifactorial interventions, and multiple follow-up visits with individualized care and nurse-led care coordination, with the aim to prevent or postpone new disabilities. The FIT care model consist of the following steps:

- Identification of community-living people at increased risk of functional decline using the modified version of Identification of Seniors at Risk questionnaire for primary care (ISAR-PC).
- A comprehensive geriatric assessment consisting of multidimensional items for the 24 most prevalent geriatric conditions encountered in primary care.
- An individually tailored care treatment plan (CTP) consisting of multifactorial interventions, and nurse-led care coordination with multiple follow-up visits.

The CGA focuses on somatic, psychological, functional and social domains, representing conditions such as urinary incontinence, memory problems, fall risk, and loneliness.\textsuperscript{40} After conducting the CGA, the RN and the participant discuss the yield of the CGA, and the participant’s priorities and goals, resulting in an individually tailored CTP. However, standardized evidence-based protocols for people with multimorbidity are not yet available. Therefore, a multidisciplinary expert panel developed a toolkit containing evidence-based protocols to create uniformity in further diagnostic assessments and interventions. The nurse-led care coordination consists of elements of disease and case management, self-management and caregiver support, which are derived from several chronic care models.\textsuperscript{41-43} In a cluster randomized trial, we aim to evaluate the effects of the FIT care model compared to care as usual on the prevention or postponement of new disabilities in community-living older people at increased risk of functional decline. We conduct a 1-year intervention with a two-year follow-up period in twenty-four general practices in the North-West of the Netherlands. Secondary outcomes are the participants’ change in health-related quality of life, emotional wellbeing, healthcare utilization, number of falls at all follow-up moments, and all-cause mortality. For better understanding of the results of the trial, we study the yield of the CGA and CTPs, and the recognition of identified geriatric conditions by participants.
Economic evaluation

Identification of cost-effective interventions to prevent or postpone new disabilities may help health services to efficiently allocate healthcare resources to those older people who may benefit most.\textsuperscript{44} It has been suggested that multifactorial interventions for community-living older people with complex care needs may postpone new disabilities, support independent living, and curtail health and social costs by preventing, delaying, or reducing hospitalizations and nursing home admissions.\textsuperscript{45,46} A cost-effectiveness analysis compares the relative costs and outcomes of two or more conditions. Currently the evidence on the (cost-)effectiveness of multifactorial interventions to prevent or postpone new disabilities is conflicting.\textsuperscript{44,47-51} We therefore aim to evaluate the cost-effectiveness of the FIT care model.

Self-reported data and healthcare utilization

Self-reported data on healthcare utilization are often used for estimates of healthcare utilization in cost-effectiveness studies.\textsuperscript{52,53} Self-report is mostly a quick and effective mode of data collection compared to data extraction from medical records or administrative claims data. However, while people at older age and with more disabilities under-report their healthcare utilization,\textsuperscript{54,55} research on community-living older people heavily relies on data solely gathered through self-reported questionnaires,\textsuperscript{56} which may result in underestimation of health-care cost among older people.

The accuracy of self-reported data compared to administrative data on healthcare utilization among older people has been studied in several cross-sectional studies,\textsuperscript{55,57} but results from longitudinal studies are scarce. In longitudinal studies on frail older people, those who are lost to follow-up are generally older,\textsuperscript{58} have more functional impairments,\textsuperscript{58} and are more inaccurate in self-reporting costs compared to respondents.\textsuperscript{59} However, more research is needed to investigate the relationship between loss to follow-up and healthcare utilization, to study the potential bias in self-reported healthcare utilization data in studies with a longitudinal design.

Minimal important change

The Katz-activities of daily living (ADL) index score and the Lawton instrumental activities of daily living (IADL) scale are frequently used self-reporting instruments to assess ADL and IADL in community-living older people, both in research and in clinical
The interpretability of measurements is an important concept and refers to the clinical meaning of (changes in) scores and includes two measures: the minimal important change (MIC) and the minimal detectable change (MDC). 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. The minimal detectable change (MDC) refers to the smallest change that can be detected by the instrument, beyond measurement error. With scarcity of research on the MIC of (I)ADL scales, interpreting the clinical relevance of treatment effects measured by the scales remains challenging. We therefore aim to estimate the MIC and the MDC of the Katz-ADL index score and the Lawton IADL scale in community-living older people.

**Aims and outline of this thesis**

The main aim of this thesis was to develop an instrument to identify community-living older persons at increased risk of functional decline, a multifactorial intervention for the most prevalent geriatric conditions based on all available evidence in primary care, to prevent or postpone new disabilities in older community-living people, and to evaluate the (cost-)effectiveness of nurse-led multifactorial care (FIT care model). In Chapter 2, we present the modification, validation, and performance of a simple validated questionnaire: Identification of Seniors at Risk - Primary Care (ISAR-PC) with the aim to identify community-living older people at risk of functional decline. In Chapter 3, we describe the FIT study protocol on a cluster randomized trial in which we investigate the effects of nurse-led multifactorial care to prevent or postpone new disabilities compared with care as usual in community-living older people. It addresses the rationale and methods, as well as organizational challenges that are expected. Subsequently in Chapter 4, we present the effects of nurse-led multifactorial care to prevent or postpone new disabilities compared with care as usual in community-living older people. For a better understanding of the results, in Chapter 5, we describe the yield of the comprehensive geriatric assessment and the recognition of geriatric conditions by older people. In Chapter 6, the cost-effectiveness of the nurse-led multifactorial care to prevent or postpone new disabilities in community-living older people is described. Because self-report data of healthcare utilization are often used in (cost-) effectiveness studies, Chapter 7 provides the results of self-report of healthcare
utilization compared to data obtained from the general practitioners’ (GP) electronic medical record (EMR). Finally, to explore which decline in ADL or IADL is meaningful to older people, we assessed the minimal important change and minimal detectable change of the Katz-activities of daily living (ADL) index score and the Lawton instrumental activities of daily living (IADL) scale in community-living older people in Chapter 8. In Chapter 9, we discuss the main findings of the studies presented in this thesis. We reflect on the methodological issues and the interpretation of study findings, and provide recommendations for use in clinical practice and further research.
General introduction

References


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