HIP FRACTURES AND DAILY FUNCTIONING IN OLD AGE

When does the decline start and how can it be measured?

Willeke Ravensbergen

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Hip fractures and daily functioning in old age – When does the decline start and how can it be measured?

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ITHAKA

Als je de tocht aanvaardt naar Ithaka
wens dat de weg dan lang mag zijn,
vol avonturen, vol ervaringen.
De Kyklopen en de Laistrygonen,
de woedende Poseidon behoef je niet te vrezen,
hen zul je niet ontmoeten op je weg
wanneer je denken hoog blijft, en verfijnd
de emotie die je hart en lijf beroert.

(...)

Houd Ithaka wel altijd in gedachten.
Daar aan te komen is je doel.
Maar overhaast je reis in geen geval.

(...)

Ithaka gaf je de mooie reis.
Was het er niet, dan was je nooit vertrokken,
verder heeft het je niets te bieden meer.

- K.P. Kavafis -
(vertaling door Hans Warren en Mario Molengraaf,
Gedichten, Amsterdam 1991, p.25)

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Chapter

1

General introduction

Worldwide, the number of older people is expected to increase from 771 million in 2022 to 1.6 billion in 2050, which is a change in proportion of the worldwide population from 10 to 16 percent.[1, 2] In the Netherlands, the number of persons aged 65 years and over is expected to increase from 3.1 million in 2015 to 4.8 million in 2040.[3] The fastest growing group within the population are the oldest old (those aged 80 years and over), with an expected three-fold increase in the coming thirty years.[1-3] With the rapid expansion of the older population, the number of older people with chronic diseases and multimorbidity (i.e. the presence of two or more long-term conditions) also increases. More than half of those aged 75 years and over have multimorbidity.[4] Accumulation of chronic diseases and other age-related problems, such as incontinence, decreased mobility or loneliness, results in complex problems with corresponding complex healthcare needs.[5, 6] This will have vast consequences for the healthcare sector and for society in general. However, it is not evident what the increase in the number of older people and the incidence of complex health problems will precisely mean for future trends in for example daily functioning, self-rated health and healthcare use. Studies on expected trends that are available show mixed results. Some studies reported increased dependency in daily functioning and healthcare use, while other studies reported an improvement of independence.[7, 8]

To make reliable predictions about future health trends on a population level, detailed information on the individual influencing factors, for example the impact of a certain disease, is needed. Apart from the fact that not all influencing factors are known or can be captured, for known factors the exact impact is often unknown. One of the reasons for this is that impact of a disease is often expressed in terms of healthcare use, which is largely dependent on policy and political choices. Preferably, impact would be expressed with measures that are less dependent on policy, for example daily functioning or self-rated health. In this thesis, the impact of hip fractures, as one of the important factors that influence health and daily functioning at old age, is further studied to eventually better inform future research on health trends and predictions.

THE OLDER HIP FRACTURE PATIENT

Just like the overall older population, the hip fracture population is changing, both in numbers and in complexity of (health) problems. Worldwide there were an estimated 1.6 million hip fractures in the population of 50 years and older in 2000, but the incidence rate greatly varied between countries and regions.[9-12] In the Netherlands, the age-adjusted incidence rate in those aged 65 years and

over was 627/100,000 in 2008, which comes down to 17,500 patients annually, and this incidence rate increased with age.[13-16] Besides the variation in incidence rate between countries, a secular trend in incidence rates has been observed. In the last two decades, many European countries had stabilising or even decreasing incidence rates, after previously increasing rates.[9, 13] In addition, several studies showed differences in hip fracture incidence rates between birth cohorts. For example, age-adjusted incidence rates were higher in the 1901-1910 cohort compared to those in the 1887-1900 cohort, but decreased again in later birth cohorts.[9, 17]

In terms of complexity of health problems the hip fracture population also seems to be changing. This population typically had a male/female ratio of about 1 to 3, age at fracture around 80 years, and about 70% had comorbidities at presentation.[13, 18-21] However, compared to patients who presented two decades ago, current hip fracture patients are older and have more comorbidities at presentation.[19, 20]

IMPACT OF HIP FRACTURES

The socioeconomic impact and disease burden of hip fractures in the older population remain high, with a substantial number of disability-adjusted life years (DALYs) lost and increased healthcare use and costs worldwide annually.[12, 18, 22-26] Despite advances in hospital and rehabilitation care, mortality rates at one year after the hip fracture are about 25% and seem to have remained stable over the last decades. However, when adjusting for comorbidity level the mortality rate after a hip fracture did decline over the last decades.[19, 20, 27] Of those who are still alive after one year, about one in five of the previously community-dwelling patients are permanently institutionalised, approximately half recover to their pre-fracture walking ability, and many do not regain their pre-fracture quality of life.[28, 29]

Impact on daily functioning

An even more important outcome measure for older people is daily functioning.[30] Daily functioning is about functioning of the whole person in its (social) context. It includes body functions, performance of activities (i.e. execution of a task by an individual) and participation in different areas of life. It is the result of interactions between health conditions, such as diseases, and contextual factors, such as living environment and coping styles.[31] When people grow older, they experience an age-related loss of function in the performance of activities (e.g. self-care or shopping) and in the participation in different areas of life. These limitations are often expressed in terms of activities of daily living (ADL) and instrumental activities

of daily living (IADL). The age-related loss of daily functioning follows a certain pattern, in which abilities are lost in a particular order, if not disturbed by other causes such as diseases or acute events like a hip fracture. In other words, even in the absence of disease or acute events, daily functioning declines with age.[32] However, daily functioning, expressed as ADL and IADL, declines even more rapidly after a hip fracture. Of those who are still alive after one year, only up to 70% recovered to their, retrospectively self-reported, pre-fracture ADL and 30-50% recovered to their pre-fracture IADL.[28, 33] Furthermore, older persons who had a hip fracture showed a worse daily functioning with a faster decline up to two years after the hip fracture compared to age-related peers without a hip fracture.[28, 33, 34] Nevertheless, there is significant variation in recovery of functioning between hip fracture patients. Some patients, often those who had good daily functioning before the hip fracture, recover quickly in the first six months after the hip fracture and have a stable level of functioning afterwards. Others have a bit slower recovery but do achieve a high, but lower than pre-fracture, level of daily functioning after six months, which gradually declines again after one year. A small group of patients show only a modest recovery at six months post-fracture, and a substantial decline afterwards. [35-37] Overall, about a quarter of the loss of ADL at one year after the hip fracture can be attributed to the hip fracture.[34, 38]

Despite the heterogeneity in recovery of function, hip fractures are generally seen as the beginning of functional decline at old age. However, considering the advanced age and high levels of multimorbidity of hip fracture patients, one might wonder whether the hip fracture truly is the cause of this decline, or just one of the contributing factors in a pathway of decline that already started earlier, before the hip fracture. Few studies described daily functioning before a hip fracture. These studies showed that just before their hip fracture older persons have worse daily functioning compared to age-related peers.[39] Furthermore, disability increases on a group level ten months before a hip fracture.[40] The level of functioning just before the hip fracture is associated with functioning after the hip fracture.[35, 37, 41-43] However, functioning in these studies was often retrospectively reported and/or measured cross-sectionally. How functioning develops before a hip fracture, whether there is a trajectory of decline already ongoing and how this relates to post-fracture decline in functioning is unknown. Better insight in the relation between pre-fracture and post-fracture daily functioning could help to understand the role of a hip fracture in the changing daily functioning at old age. On an individual level this is essential to set reliable treatment goals; on a population level this will help to improve predictions on future health and healthcare use.

MEASURING FUNCTIONING

Daily functioning has a central role in research and clinical practice in the older population, and correct measurement of this outcome measure is therefore important. In the current healthcare system and in research, the concept of value-based healthcare is getting more important. Value-based means providing healthcare that brings the most value for the patient. This 'value' should be defined in terms of what matters to the patient.[44] For patients themselves, the most relevant outcome parameters are not necessarily healthcare use or mortality, but institutionalisation, mobility, quality of life and daily functioning.[30] As said before, daily functioning is often operationalised in research and clinical practice using ADL and IADL scales. There is a wide variety of (I)ADL instruments, from short versions that focus on a few essential (I)ADL abilities (e.g. Katz ADL questionnaire) to questionnaires that include a broad range of (I)ADL abilities, from transfers to doing intensive sports activities (e.g. PROMIS Physical Function).[45-47] However, for most of the ADL and IADL instruments it is unknown whether they truly measure what matters to the older person. Most instruments were developed without involving the older (complex) patients themselves and no studies evaluated the concordance between self-perceived functioning and outcomes of (I)ADL instruments.

Another trend in research is the gradual shift towards using routine care data for research instead of solely using data collected for study purposes only. The use of the current (I)ADL instruments is time and labour intensive, which hinders collecting these data on a large scale for research. Routine care data might be an interesting source to collect information on daily functioning on a larger scale. Currently, outcome measures such as mortality and institutionalisation can be retrieved relatively well from routine care data.[48, 49] However, these outcome measures alone are not enough for research studies; patient-related outcome measures such as daily functioning are also needed to measure effect and value. There are no studies on how to retrieve the parameter (daily) functioning from routine care data yet. However, there are attempts to retrieve frailty from routine care data. Frailty and functioning are two measures that show a lot of overlap and often used frailty instruments measure several aspects of functioning.[5, 6] Frailty instruments that use routine care data could therefore help to retrieve information on daily functioning from routine care data.

AIM AND OUTLINE OF THIS THESIS

The overall aim of this thesis is to describe the relation between daily functioning and hip fractures in older people, and to explore different aspects of the measurement of daily functioning.

Part 1 gives a general impression of expected developments in future healthcare use of the older population. The increase in the number of older people and the incidence of complex health problems will influence future healthcare use, but how it will do so is not evident. **Chapter 2** describes the expected effect of further ageing of the population in combination with current societal changes on future healthcare use. In a qualitative Delphi study, experts in the field of ageing were asked how they expect predicted trends in health, healthcare and the social domain to affect healthcare use of the older population in the future. This study was part of the four-year Public Health Foresight Study (VTV) of the National Institute for Public Health and the Environment (RIVM), which provides insight into the most important societal challenges for public health and healthcare in the Netherlands, and serves as a guide for policy makers.

The second part of this thesis zooms in on the impact of hip fractures, as information on the impact of single diseases is needed to reliably predict future trends in health and healthcare. In particular, the relation between daily functioning and hip fractures is explored. The overall aim is to assess whether a hip fracture is a cause of decline or a modifying factor in a pre-existing pathway of decline in daily functioning in older people. **Chapter 3** zooms in on the current healthcare use of older persons who obtained a hip fracture. The changing incidence rates and declining mortality rate adjusted for comorbidity level suggest that the hip fracture population is changing, just like the older population in general. In this chapter we provide a more recent description of the patient characteristics of the current community-dwelling hip fracture population and their healthcare use before a hip fracture. For this study, data from the Extramural LUMC Academic Network (ELAN) data warehouse, which includes routine care data from Dutch general practitioners in the region of The Hague and Leiden, and data from Statistics Netherlands (CBS) was used. **Chapter 4** explores whether there is a change (presumably decline) in daily functioning in the year before a hip fracture. C**hapter 5** assesses whether there is a relation between the change in daily functioning in the year before the hip fracture and the change after the hip fracture. Chapters 4 and 5 both present results from individual patient data meta-analyses conducted in four longitudinal

cohorts of people aged eighty years and older from the Netherlands, the United Kingdom, and New Zealand (Māori and non-Māori).

The third part of this thesis explores different aspects of how to measure daily functioning in clinical practice and research. **Chapter 6** describes a cohort study which evaluated whether an electronic frailty index (approach) based on routine (primary) care data could be used as a measure for daily functioning in research among community-dwelling older people. Both routine primary care data and data collected for study purposes from the ISCOPE (Integrated Systemic Care for Older People) trial were used. **Chapter 7** assesses whether we always measure what we aim or should aim to measure. Results of a qualitative interview study that was part of the HIP CARE (Hip fractures: Inventarisation of Prognostic factors and Their Contribution towards Rehabilitation in older pErsons) prospective cohort study are presented. The aim of the interview study was to explore what daily functioning is according to older persons who had had a hip fracture, and how this corresponds with what the (I)ADL questionnaires, which are often used to measure this daily functioning, measure.

The main findings of this thesis are summarised and discussed in **Chapter 8**.

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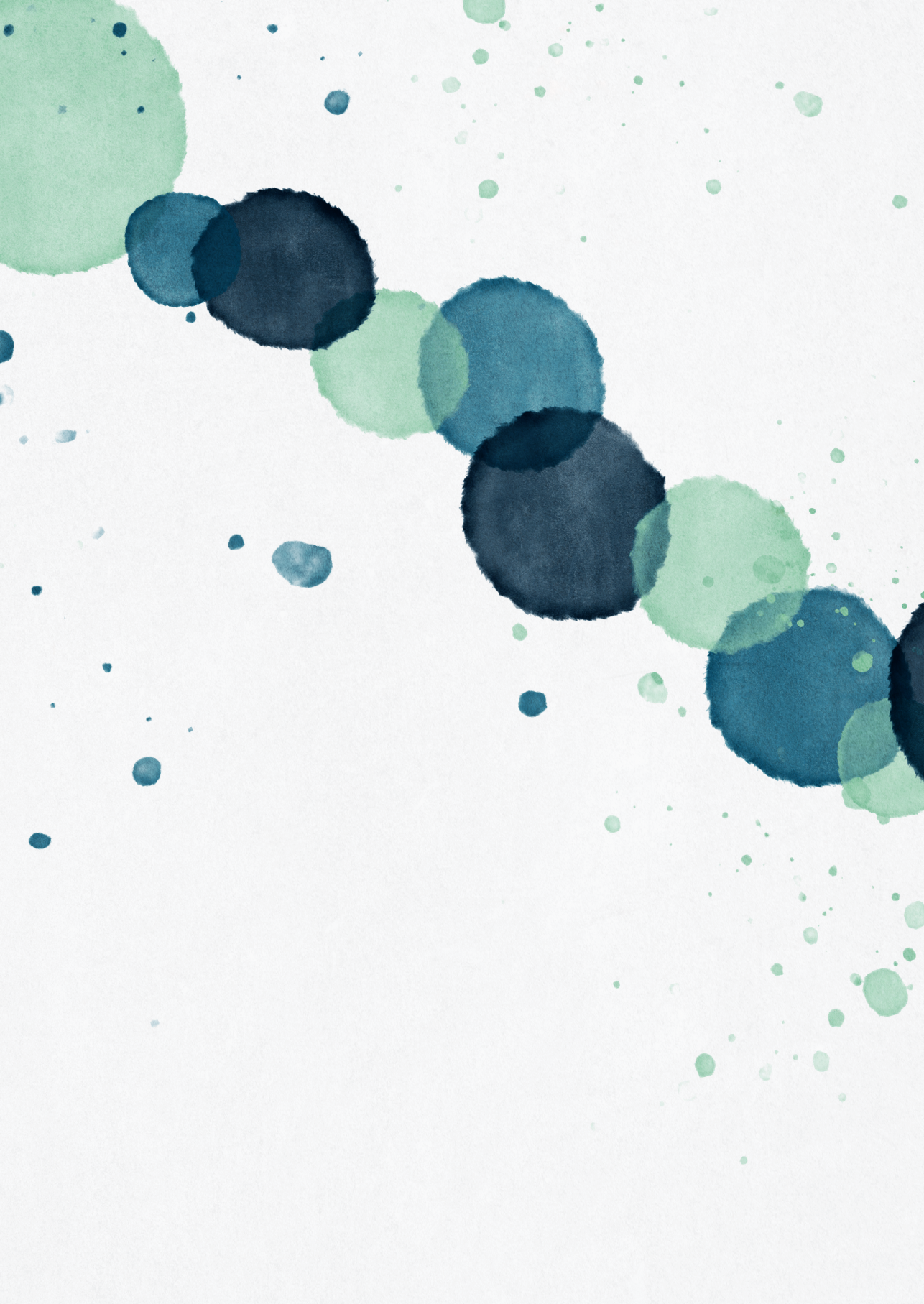

Part I

Healthcare use of the older population

Chapter

2

Combined impact of future trends on healthcare utilisation of older people: a Delphi study

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ABSTRACT

Purpose

To explore the combined effect of trends in older people on their future healthcare utilisation.

Methods

A Delphi study consisting of two rounds was conducted. The heterogeneous expert panel (n=16) in the field of elderly care rated the effect of combinations of trends in the Netherlands on the use of seven healthcare services: i.e. informal, home, general practitioner, acute, specialist, nursing home and mental health care. The percentage and direction of the overall consensus, for the different health services, and for three main trends were analysed.

Results

Experts reached consensus in 57 of 92 ratings (62%). Taking into account the interaction between trends, they expected an extra increase for informal, home, and general practitioner care, but no additional effect of interaction for specialist and acute care. Combinations that included trends leading to less support were expected to lead to an extra increase in utilisation.

Conclusions

Experts expect that interaction between trends will lead to an extra increase in the use of general practitioner, home, and informal care. This increase is mainly the result of interaction with trends leading to less support for older persons. The present results show the need to take the effect of interaction into account when designing new health policy and in research on future healthcare utilisation.

Keywords

Public health trends, healthcare planning, ageing society, population health foresight, Delphi method

KEY POINTS

- Previous studies on future healthcare utilisation only consider the effect of single trends.
- This work explores the effect of interaction between trends on healthcare utilisation.
- The expected extra increase of healthcare use by older people emphasises the need to include interaction in foresight studies.

INTRODUCTION

Governments need information on the current health status of a population and how it will develop in order to design and evaluate policy options and interventions.[1-4] The health status of a population depends on various factors, including population characteristics, individual health behaviour, the healthcare system, the external environment, and health outcomes.[5] Population health foresight studies aim to describe the development of these factors in the future, their underlying determinants, and their expected effects on future healthcare need, demand, use and supply. However, future developments always encompass a certain level of uncertainty due to limitations of the available evidence on the effect of trends and limited knowledge on how trends will evolve.[6-8]

Population ageing is expected to lead to increased healthcare utilisation.[9, 10] This is not a linear relationship, as the future older population will differ from the current older population in, for example, lifestyle, (e)health literacy skills, and social network.[9-11] The effects of single trends on future healthcare utilisation by older people have been examined.[12-16] However, because multiple trends apply to older persons, these trends influence each other's effect on the total healthcare utilisation of a population. Although most studies (at local and international level) acknowledge that multiple factors and the interaction between them play a role, they generally only take the individual effects of trends into account when reporting on future healthcare utilisation.[11, 15-18]

This preference for individual trends is not surprising. Interaction between and effects of multiple and often heterogeneous trends in public health and healthcare (i.e. health, disease, environmental and socio-economic trends) are notoriously hard to adequately quantify.[19, 20] Methods that facilitate exchange of expert opinions, feedback of results, brainstorming and discussions, such as 'deliberative dialogues' or Group Decision Rooms (GDRs), were demonstrated to be useful to tackle this issue.[6, 21-23]

Therefore, this study aims to explore the relevance of combined effect of trends in older people on their future healthcare utilisation using a similar interactive method: the Delphi study. While it does not offer the possibility of *real time* exchange, it does offer a platform for expert exchange of opinions, feedback of results, brainstorming and discussions, which are necessary to gain insight in the complex interaction of heterogeneous trends. Furthermore, the Delphi method can be used when evidence on a topic is limited and complex interdependencies

play a role.[8] It uses an expert consensus procedure to identify the main effects and needs for further research. The results of this study will give an indication of the relevance, direction and effect of interacting trends in terms of healthcare utilisation that could not be adequately quantified. By doing so, this study can provide input for strategic discussions on complex public health issues, like population ageing.

METHODS

Delphi method

The Delphi method is a validated technique used to collect the opinions of a group of experts on a complex topic on which there is limited evidence. The goal of the Delphi method is to reach consensus within an expert panel on the topics under discussion. However, the absence of consensus also provides information, as it indicates the topics for which there are knowledge gaps or disagreements. The expert panel usually consists of fifteen to twenty respondents.[24-30]

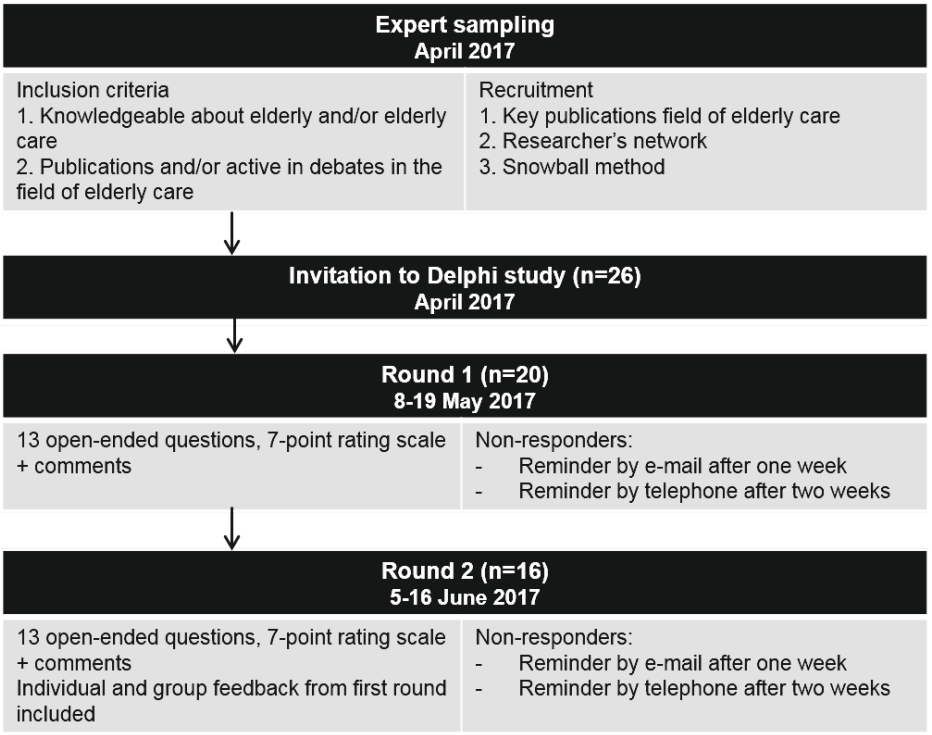
The present study used a Delphi consensus procedure consisting of two rounds of questionnaires distributed via e-mail. The topic investigated was: the combined effect of medical and social trends on healthcare utilisation by the older population in 2040 in the Netherlands. The responses to the first questionnaire were fed back anonymously to the expert panel. This feedback enabled participants to reflect on the different views and modify their own view in the second round, when they again filled out the same questionnaire.[24-28] All experts were asked to participate in both rounds of the study; they could only participate in the second round if they had completed the first one. Each round lasted two weeks. In case of non-response, e-mail and telephone reminders were sent after one and two weeks, respectively. The Delphi study was conducted between April 2017 and June 2017. Figure 1 gives an overview of the study procedure. No ethical approval was required for this study.

Expert panel and patient involvement

A total of 26 experts in the field of elderly care in the Netherlands were invited by e-mail to participate in this Delphi study. Experts were those who 1) were knowledgeable about older people and/or elderly care in the Netherlands, and 2) had published and/or were active in debates in the field of elderly care. Recruitment of experts was guided by the researchers' network, key publications in the field, and the snowball method. During the selection and inclusion process, the representativeness of the panel for the whole scope of elderly care in the Netherlands was kept in mind. The future old (65-80 years) and oldest old (80+

years) were involved in the study as part of the Delphi expert panel, by inviting representatives of the elderly board region South-Holland North to participate. Further details on the expert panel are provided in the Results section.

Figure 1. Flowchart study procedure and expert participation



Questionnaire design

The questionnaire (S1 Appendix) for both rounds consisted of combinations of (mostly) quantitative trends in the determinants of healthcare utilisation of older people. These trends were extracted from the Dutch Public Health Foresight Study (*Volksgezondheid Toekomst Verkenning*-2018; VTV-2018) Trend Scenario.[9, 10] This report describes future trends in the (public) health status of the Dutch population until the year 2040. To be included in this study, trends also had to be a proven determinant of healthcare utilisation according to the literature.[13, 31-36] The trends (S2 Appendix) included demographic changes, socioeconomic changes, trends in lifestyle and health, and recent developments in health policy.

With regard to demographic changes, various aspects of population ageing were incorporated in the questionnaire. These include an increase in the number of

oldest old (80+ years), an increase in the number of older people that will live independently, and a decrease in the parent support ratio (i.e. the ratio of the 50 to 64-year-olds to those aged ≥ 85 years). This latter trend gives an indication of the future decrease in 'potential informal caregivers'.[37-39] With regard to (population) health, trends in the number of people with multiple chronic diseases, in self-rated health and in loneliness were included.[40] Other population characteristics that were included concerned tangible and less tangible trends in the level of education, income and expectations about healthcare.[10, 14, 41-43] Lastly, several contemporary trends in health policy were incorporated in the questionnaire. These include i) the ambition of the Dutch government to enable older people to live independently for as long as possible, ii) the gradual increase of the retirement age, and iii) the ambition to stimulate the use of eHealth-solutions in healthcare.[44, 45]

The researchers incorporated combinations of trends that (according to the literature) contrasted in terms of consequences for future healthcare utilisation by older people in thirteen questions using a seven-point rating scale. Most questions focussed on either the old (65-80 years) or the oldest old (80+ years), as these are different groups and the VTV-2018 trend descriptions often only described one of them. For each question, the experts were asked to score on a scale of 1-7 (1 = very great decrease; 7 = very great increase) what they thought would be the combined effect of the trends on healthcare utilisation by older people.[46] This was asked for seven different types of health services: informal care, home care, general practitioner (GP) care, hospital/specialist care, nursing home care, mental healthcare and acute care. One question, which was about income and the parent support ratio (i.e. the ratio of the 50 to 64-year-olds to those aged ≥ 85 years), also covered private care as a type of health service. The experts had the opportunity to comment on their scoring in a free-text field. In the first round, they were asked to always add a comment if they scored the highest or lowest score on the rating scale, or if they were uncertain about their answer. In the second round, the experts were asked to always comment on their scoring if it strongly deviated from what most experts had scored in the first round, or if they were uncertain about their answer. In the questionnaire of the second round, the responses to the first round were presented per question as the number of experts scoring each rating category. Moreover, all comments of the first round were anonymised and presented per question in the second round. The questionnaire was tested on one elderly care expert and one future older person; these persons were not included in the Delphi study.

Data analysis

In the analysis, the scoring categories one and two were categorised into the cluster 'great decrease' and the scorings six and seven into the cluster 'great increase'. The other scoring categories (3=decrease, 4=no effect, 5=increase) were analysed separately. If an expert filled in two scores instead of one for a question (n=2), the score closest to the category 'no effect' was chosen. Consensus was defined as a certain percentage of agreement. In the literature, different percentages are applied, depending on, amongst others, the design of the study (e.g. number of rounds and rating scale used).[30] In this study, two levels of consensus were used because of the limited number of rounds. 'Full consensus' was defined as ≥ 75% agreement on the strength of the effect expected for a type of healthcare service. More than or equal to 62.5% agreement was also considered relevant and was described as 'intermediate consensus'. The criteria for consensus were determined before the start of the study. Finally, the results were also analysed on consensus on the direction of the effect: decrease (score 1-3), no effect (score 4), increase (score 5-7) (percentage of agreement: ≥ 62.5%). In the sub analyses (i.e. health services, overarching trends, and age groups), the three types of consensus are described together under the term 'consensus'.

SPSS Statistics version 24.0 (IBM Corp., Armonk, NY, USA) was used for the quantitative analysis. For each question, the scoring frequency per rating category and the median (with its interquartile range) was calculated per type of health service. Afterwards, the percentage and direction of consensus was calculated i) for overall, ii) for the seven types of health services, and iii) for questions with similar trends. The percentage of consensus was calculated as the number of items with consensus divided by the total number of items in that category. Finally, the comments accompanying each question were categorised according to the theme and expected effect (e.g. extra decrease, no effect, or extra increase). These categories were analysed regarding the extent to which they supported and explained the scoring of the expert panel.

RESULTS

Expert panel

Of the 26 invited experts, 20 responded to the first questionnaire (response rate 77%) and 16 experts responded to the second questionnaire (response rate 80%, n=20). Reasons for dropout were time constraints and not feeling comfortable with filling in the questionnaire. The final expert panel was heterogeneous and comprised five 'experience experts' (representatives from the current 45+-, 65+-

and 80+-cohorts) and eleven experts in the field of demography (n=2), social networks (n=1), cultural perception of older people (n=1), health beliefs (n=1), organisation of healthcare (n=3), elderly care (n=2) and informal care (n=1). This panel was considered to reflect different perspectives regarding older people and elderly care in the Netherlands (Table 1).

Table 1. Characteristics Delphi expert panel

Expert	Gender	Professional background	Field of expertise	Completed 2nd round (yes/no)
1	M	Business administration and economics	Organisation of healthcare	Y
2	M	Economics	Demography	Y
3	M	Medical doctor / researcher	Demography	Y
4	F	Social and cultural anthropology	Cultural perception of older people	Y
5	F	Manager in healthcare and social welfare	Informal care	Y
6	M	Geriatrician / researcher	Health beliefs	Y
7	F	Sociology	Social networks	Y
8	M	Health economics	Organisation of healthcare	Y
9	F	GP / researcher	Elderly care	Y
10	M	Specialist internal medicine / researcher	Elderly care	Y
11	F	Econometrics	Organisation of healthcare	Y
12	F	Clinical nurse / researcher	Representative future old	Y
13	M	Elderly board	Representative older people	Y
14	F	Elderly board	Representative older people	Y
15	M	Elderly board	Representative older people	Y
16	M	Elderly board	Representative older people	Y
17	F	Elderly board	Representative older people	N
18	F	GP / researcher	Elderly care	N
19	F	Public health sciences	Health literacy	N
20	F	Health sciences	Patients with chronic diseases and quality of life	N

Overall consensus throughout the rounds

In both rounds, the expert panel scored thirteen questions on seven (and once on eight) types of health services (total n=92). The level of overall consensus within the expert panel increased throughout the rounds. After the first questionnaire, experts agreed on the direction of change in 38% (35/92) of the cases; the experts

also agreed on the strength of the effect in 8% of the cases (7/92). These latter agreements all represent an 'intermediate' level of consensus as described in the methods section.

In the second round, experts agreed on the direction of change in 57 of 92 ratings (62%). The experts also agreed on the strength of the change in 45% of the ratings (41/92), of which 18% was full consensus and 27% intermediate consensus. In all cases where consensus was reached (n=57), the panel expected either no effect on healthcare (42%, 24/57) or an extra increase of healthcare utilisation (58%, 33/57) due to interaction between the presented trends. At no time did the panel expect an *extra decrease* of healthcare utilisation. In all questions, the overall scoring centred around 'increase' to 'no effect' (Table 2).

Health services

The experts did not expect an effect of interaction between trends on the use of specialist and acute care (for both: 10 of 13 ratings consensus, 80% (8/10) no effect). In contrast, the experts expected an extra increase in the use of informal care (8 of 13 ratings consensus, 75% (6/8) extra increase), home care (7 of 13 ratings consensus, 86% (6/7) extra increase), and GP care (9 of 13 ratings consensus, 100% (9/9) extra increase). The expected increase was explained by one of the experts as follows: "*Much of the healthcare demand – either acute or not – will end up with GPs; that is the aim of government policy after all*". This quote illustrates the way the Dutch healthcare system is currently organised. In the Netherlands, GPs are the first medical professionals to contact in case of health problems for all community-dwelling persons. They serve as a gatekeeper for more specialised healthcare services (i.e. hospital care and mental healthcare). The quote also illustrates the effect of recent government policy, which aims for substitution of hospital/specialist care with primary care and for older people to live independently for as long as possible.[47-49]

Besides the direction of the expected effect, the percentage of consensus reached also differed between the types of health services. The health services specialist and acute care had a high percentage of consensus (both 77% of 13 ratings), while the percentage of consensus reached for informal, home and GP care was lower with 62%, 54% and 69%, respectively (all 13 ratings). The percentage of consensus for nursing home care and mental healthcare was low (46% and 38%, respectively, both 13 ratings); equally often, the experts expected both 'no effect' as well as 'an extra increase' in the use of these two services because of the interacting trends. These ambiguous expectations were formulated by one expert

as follows: "*I do expect a slight increase in the need of nursing home care, but no increase in the effective demand – as the health system discourages this…*". This quote illustrates the tension between demographic trends in the population and current healthcare policies. Demographic trends such as an increase of the number of older people living alone and a decrease of the parent support ratio tend to increase the use of institutionalised care.[50] On the other hand, current policies intend to increase independent living (i.e. reduce institutionalisation and the use of long-term care) and to give people more responsibility to organise their own care. [47-49] For private care, assessed with one question, the panellists reached consensus on the direction of the effect (i.e. extra increase).

Overarching trends

Three overarching trends can be identified in the questions presented to the experts: eHealth, less support, and change in health status. Experts rarely reached consensus on questions that included eHealth (consensus on 6 of 21 ratings, 29%) and they never expected an effect on healthcare utilisation. An expert formulated his doubts as follows: "*… it goes beyond my imagination, on the one hand because future developments in the field of eHealth are hard to visualise, and on the other hand because the differences in the competence to use these new care forms will probably increase*". In this quote the expert formulates two uncertainties, the first being the rapid developments in the field of eHealth, which are often unexpected and therefore unpredictable. The uncertainty as formulated in second part of the quote refers to the, already existing, differences in health and eHealth literacy, which are shown to influence healthcare use.[51, 52] In contrast to the questions on eHealth, a high percentage of consensus was reached on questions that included trends that will lead to less support (consensus on 26 of 35 ratings, 74%). Such trends include a decrease in the parent support ratio (i.e. the ratio of the 50 to 64-year-olds to those aged ≥ 85 years) and an increase in older people living independently. Questions including these trends were mainly expected to lead to an extra increase in healthcare utilisation (81% of all consensus, 21/26) and, in particular, in informal, home and GP care. This increase was motivated as follows: "*Because of less possibilities in informal care, the need for home care will increase considerably, just like the need for GPs, as they are a trusted advisor within someone's social network."* Combinations of trends that included a change in health status reached a percentage of consensus of 65% (23 of 35 ratings) and were equally often expected to have no effect (57% of all consensus, 13/23) or to lead to an extra increase (43% of all consensus, 10/23) in healthcare utilisation. The expected extra increase was mainly in GP and specialist care (70% of all expected increase, 7/10).

Table 2. Scoring results Delphi round 2

	Informal care	Home care	GP care	Specialist / hospital care	Acute care	Nursing home care	Mental healthcare
eHealth							
Increase oldest old + eHealth (oldest old)							
Increase loneliness + eHealth (oldest old)							
Increase education level + eHealth (old)							
Less support							
Decrease parent support ratio + increase alone living older persons + increase low feeling control (oldest old)							
High proportion older persons rural areas + low service level (oldest old)							
Increase alone living men (vs alone living women) (oldest old, not explicit)							
Decrease income + decrease parent support ratio (old)							
Transition care + increase alone living older persons + decrease parent support ratio (both)							
Change in health status							
Higher expectations + no change age physical limitations (oldest old)							
Decrease smokers + increase overweight and obesity (old)							
Longer working + increase chronic conditions (old)							
Increase chronic conditions + increase proportion feeling healthy (old)							
Increase education level + increase migration background (both)							

Table 2 legend: *GP, general practitioner*

Consensus ≥75% *Consensus 62.5-75%* *Consensus <62.5%*

Green – Extra increase expected *Purple – No effect expected* *Orange – Extra decrease expected*

Old and oldest old

The percentage of consensus reached was almost equal for the old and oldest old [60% (21/35) and 54% (23/42), respectively]. However, an extra increase of healthcare utilisation due to interaction between trends was expected slightly more often for the oldest old (65%, 15/23) than for the old (43%, 9/21). This difference is based on small dissimilarities in expectations regarding GP, home and informal care (i.e. extra increase expected: old 7/15; oldest old 10/18), and by differences in expectations regarding nursing home care and mental healthcare. In cases where consensus was reached on nursing home care and mental healthcare, there was never an effect of interaction expected for the old (no effect 4/10; increase 0/10), while for the oldest old an extra increase was sometimes expected (no effect 2/12; increase 3/12). This difference is in line with current policies that aim to reserve institutional care (i.e. nursing home care and mental healthcare) exclusively for the most frail, which are often the oldest old.

DISCUSSION

This study aimed to explore the effect of interaction between trends in older people on their future healthcare utilisation with the help of a Delphi study. Our study shows that interaction between trends will lead to an extra increase in the use of healthcare. In other words, the experts expect a greater increase in healthcare utilisation than the already expected increase based on the extrapolation of single trends. However, there were clear differences between types of healthcare services and trends regarding the expected effect and the extent to which the experts agreed on this. The experts rarely agreed on the effect of interaction on nursing home care and mental healthcare. On the other hand, an extra increase in use due to interaction was expected for GP, home and informal care, while mostly no effect of interaction was expected for specialist and acute care. The most important trends that contribute to the expected extra increase in healthcare use due to interaction are those that lead to less support for older people (e.g. decrease of parent support ratio, increase in the number of older people living independently). The effect of interaction between demographic trends and eHealth, which plays an important role in current health policy, was rarely agreed on by the experts.

Difference between healthcare services

Based on this study, two explanations could be given regarding both the difference between health services on the expected effect of interaction and the difference in the extent to which the experts agreed on this. First of all, the difference between

the healthcare services might be explained by a difference in focus between these services. For example, GP, home and informal care are healthcare services that provide a more integrated type of care, which is focussed on both disease and social circumstances. Interaction between trends is expected to cause an extra increase in the use of these latter services. On the other hand, the use of specialist and acute care is expected to be unaffected by interaction between trends; because the care provided by these services is more directly related to a disease, social circumstances affect the use of these services to a lesser extent. Even though the trends included in this study cover both changes in disease and/or physical health, as well as changes in social circumstances, the extra utilisation is mainly expected for healthcare services that focus on both disease and social circumstances. Thus, interaction between trends has a stronger influence on healthcare services that provide both disease-related and social-focussed care than on services that provide more disease-related care alone.

A second explanation for the differences between health services could be the interplay between trends and their interactions with current trends in health policy. As apparent from the experts' comments, interaction between demographic trends, such as an increase in the number of older people, might increase the need of care. However, the eventual use of healthcare services is not only the effect of trends in a population, but also of current trends in health policy. Current policies, for example, aim to dampen the use of long-term and institutionalised care, to stimulate the substitution of hospital/specialist care with primary care, and to increase self-reliance of all citizens, including that of older persons. As a result, a future rise in the need of care will not necessarily lead to a rise in the use of care. Our findings of an expected effect of interaction on GP, home and informal care, and no effect on specialist and acute care is, for example, in line with the contemporary policy focus on substitution of hospital/specialist care with primary care. Also, the lack of agreement and uncertainty expressed by the experts concerning nursing home care and mental healthcare seem to be a consequence of developments in health policy.

Both services were recently subjected to major policy changes in the Netherlands and are therefore still rapidly evolving. Although the experts stated in their comments that they expect an effect of interaction between demographic trends on healthcare need, they did not reach agreement on what the effect on healthcare use would be because of policy trends that aim to redirect these needs. Finally, no conclusions can be drawn from this study regarding the effect of interaction on private care, as this type of health service was covered by only one question.

Decreasing support and eHealth

The expected extra increase in the use of health services (especially GP, home and informal care) can mainly be attributed to trends that lead to less formal and informal support for older people. This observation is in line with the conclusion above: services with a focus on both disease and social circumstances are affected by the interaction of health and social trends to a larger extent than the disease-related health services. These findings also show that, although self-reliance is an important focus of current health policies, interaction between trends that lead to less support is expected to lead to an increase in the use of care anyway. However, the experts expect that this increase in healthcare utilisation will be redirected from institutions and hospital to primary care. In contrast to the trends that lead to less support, the expert panel rarely agreed on the effect of interaction of trends with eHealth on healthcare utilisation. As is apparent from the experts' comments, this low consensus is mainly the result of both rapid developments in the field of eHealth, which makes it hard to visualise the future, and scepticism about the actual positive effects of eHealth, especially in an older population. Despite these existing uncertainties, current healthcare policy (i.e. to stimulate independent living, and self-reliance) does rely on the expected advancement of eHealth.[45, 51, 52] The expert panel in this study seems to have more restrained expectations on the potential of eHealth for both cure and care.

Considering interaction between trends: the added value of a Delphi Study

To our knowledge, this study is the first to assess the effect of interaction between trends on future healthcare utilisation and therefore cannot be compared to previous reports. However, the results of this study are in line with previous research on determinants of healthcare utilisation. In these latter studies, multivariable models were often used to identify factors that influenced care utilisation in a retrospective cohort. The effect of some factors (e.g. age and living alone) was consistent across studies, but the estimated effect of most factors (e.g. gender and income) varied widely between the studies. However, all these studies on determinants of healthcare utilisation showed that healthcare utilisation is the result of an interplay between different factors.[53-58] To our knowledge, the present study is the first to attempt to translate this knowledge to research on future healthcare utilisation. Therefore, it gives a more accurate impression of future healthcare utilisation based on quantitative trends than previous studies; more importantly, it emphasises the need to include interaction in research and reports on future healthcare utilisation. A reason for not having done this before, might be the scarcity of (quantitative) data and evidence on the combined effect of trends, which complicates extrapolation of interaction and quantitative modelling.

However, interaction could be included in research on future healthcare utilisation by means of the Delphi method. The interpretation of trends by multiple experts can yield different estimations of future healthcare utilisation than expected when based on the analysis of single trends and, thereby, provide a more comprehensive impression of future healthcare utilisation.[24, 29]

Strengths and limitations

One of the strengths of this study is the diversity and size of the expert panel. As the results from a Delphi study are highly dependent on the included experts, an expert panel needs to cover the whole field under study.[30] In the present study, the perspectives of experts from multiple areas of expertise were combined, including those of future older people themselves. Therefore, the results include perspectives from the entire scope of elderly care in the Netherlands, which strengthens the validity of the results. Another strength of this study is the inclusion of both disease-related and social trends in the questionnaire. Previous research often only included single trends that were either disease-related or social, while healthcare utilisation is influenced by both. In the present study, the inclusion and combination of both groups of trends brings the results closer to reality.

A limitation of this study is the complexity of the topic. One of the experts remarked: "*...the combined effect is difficult to interpret*", and several experts reported to have difficulty filling out the questionnaire. This complexity might have led to the large dropout in the study; however, this was also the reason for selecting the Delphi method for this study. By asking a group of experts with diverse backgrounds to share their opinion and reflect on it, various inputs and perspectives can be combined into a more comprehensive overall conclusion.[24] It might also be seen as a limitation that this study does not report on the expected total future healthcare utilisation of older people in the Netherlands, or that of subgroups within this group. However, it was not the aim of this study to estimate future healthcare utilisation, but to study the *relevance* of interaction for future utilisation and the expected direction of the effect of interaction.

Finally, it could be seen as a limitation that this study only included Dutch experts and trends. However, we do expect that our findings are valid outside the Netherlands. Most trends included in this study are also seen in other countries (e.g. ageing of the population, decreasing (informal) support for older people). This study assessed the combined effect of these (universal) trends in the Dutch context and showed that interaction between such trends does have an influence on healthcare utilisation. Although the exact effect of interaction depends on the

cultural and health system context, we expect that the presence of an effect of interaction on healthcare utilisation does not. Furthermore, we expect that the presence of the influence of policy on the effect of interaction, as observed in this study, is generalisable to other healthcare settings. Therefore, the conclusions of this study that interaction between trends has an effect on healthcare utilisation and that health policy influences this effect are expected to be applicable to other international contexts. Finally, trends in health policy that are seen in the Netherlands, such as an increased focus on self-reliance and stimulation of independent living outside institutions, are answers to the challenges of an ageing society. As countries throughout the world face similar challenges because of an ageing society, similar patterns of the effect of trends on the use of care due to interaction can be expected in other countries.

Conclusions

To conclude, our Delphi-study shows that experts expect that interaction between future trends will lead to an extra increase in the use of GP, home and informal care by older people on top of the expected increase due to population ageing. The main trends behind this extra increase are those that lead to less support for older people (i.e. decrease parent support ratio, increase older people living alone, high proportion older people living in rural areas). Although the exact effect of interaction on healthcare utilisation is dependent on the national healthcare system, national health policy and cultural differences, the presence of an effect of interaction between trends, as shown in this study, is likely to also be there in other international contexts. Therefore, the results of this study emphasise the importance of taking into account the interaction between trends when studying future healthcare utilisation.

In this study we used the Delphi method as a first exploration of the effect of interaction between trends as expected by experts. As a next step in future healthcare research, interaction could be included in and studied in more detail by means of simulation modelling. Furthermore, the effect of interaction between trends in a population should be taken into consideration when designing new health policy. Future healthcare use was already expected to increase because of population ageing, but this study shows that this increase is expected to be even higher because of interaction between trends. In addition, policy makers should keep in mind that contemporary trends in health policy are also expected to influence the effect of interaction between other trends on healthcare utilisation. Therefore, the consequences of (new) health policy on the interaction between trends and the resulting healthcare use should be taken into account when designing new health policies.

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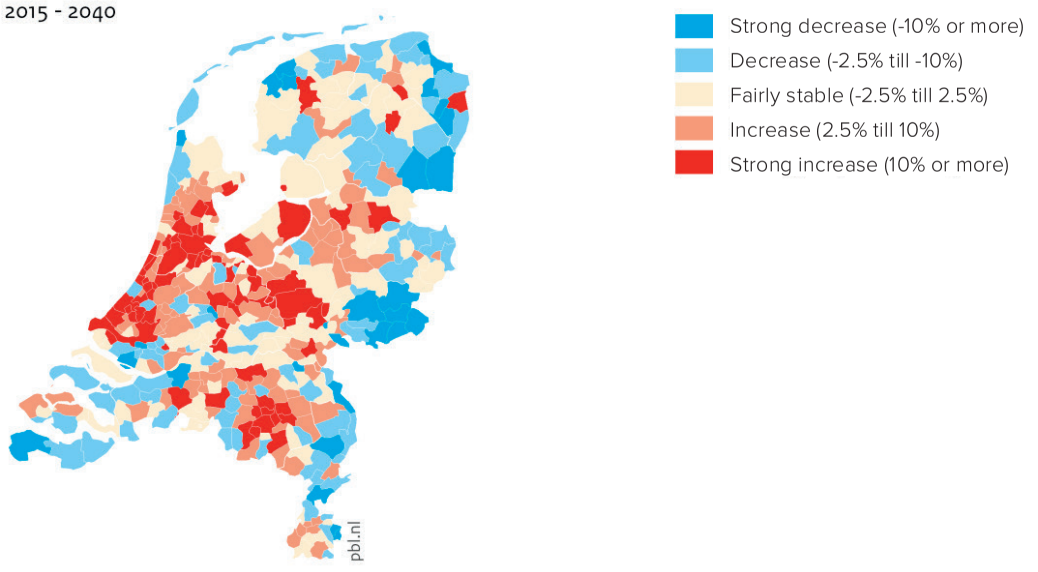
SUPPLEMENTARY DATA

S1 Appendix. Copy of questionnaire used in the Delphi procedure

Change in population size per municipality



Source: PBL/CBS regional population- and household prognosis 2015-2040

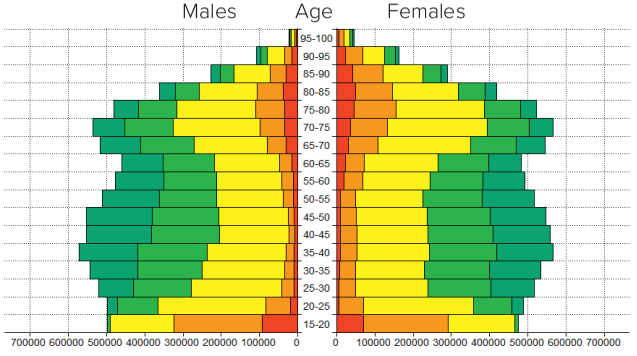
1. In several regions there is a decline in population size, which is partly the result of migration of young people out of these regions. In these so-called 'shrinking regions' the ratio of old to young people is therefore relatively high and the level of facilities is low. What is the effect of interaction between these trends on the future healthcare utilisation of the oldest old in these regions according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

2. The future old (the current 40+) will smoke less in 2040 compared to the current old (17% of the old in 2015, 10% of the old in 2040). On the other hand, a higher percentage of old will be overweight or obese in 2040 (of the old in 2015 47% overweight and 17% obese, of the old in 2040 51% overweight and 24% obese). What is the effect of interaction between these trends on the future healthcare utilisation of the old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

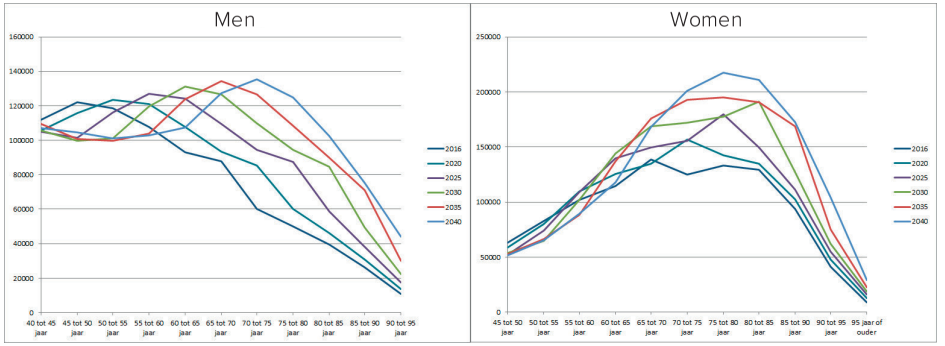
Population sorted on level of education - 2040



Legend red = no education; orange = only lower education; yellow = secondary education; light green = higher education; dark green = university Source: RIVM

3. Language proficiency of a patient plays an important role in diagnostics and treatment within mental healthcare, as sufficient proficiency is needed for adequate communication. The level of education of the older population will increase till the year 2040. At the same time, the percentage of older persons with a migration background will also increase. What is the effect of interaction between these trends on the future utilisation of mental healthcare, and as a result of that on utilisation of other healthcare services, according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	



Number of older persons (65+) living alone

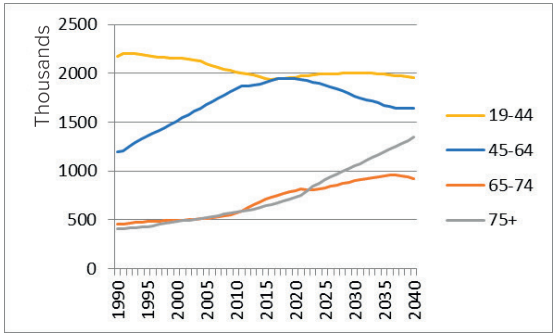
Source: RIVM

4. The number of older men living alone will strongly increase till the year 2040. This group differs from the group of older women living alone, for example in terms of lifestyle and social network. In contrast to that of older women, the healthcare needs of the group of older men living alone is relatively unknown. What do you expect in terms of future healthcare utilisation of this group compared to the group of older women living alone?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

5. The number of oldest old will increase (number of 80+ from 0.74mln in 2015 to 1.6mln in 2040). At the same time, the possibilities and the use of eHealth increase. What is the effect of interaction between these trends on the future healthcare utilisation of the oldest old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	



y-axis: number feeling lonely (x 1.000)

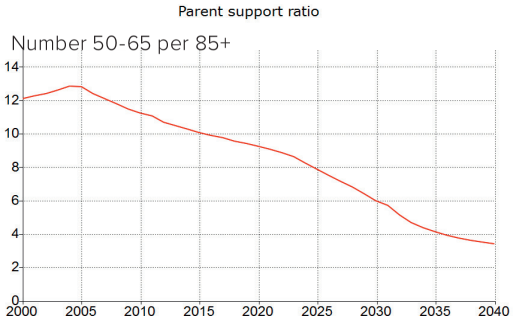
Source: RIVM

6. There will be an absolute increase in loneliness (moderate and severe) amongst older persons till the year 2040, and particularly loneliness amongst the oldest old (from 0.6mln in 2015 to 1.3mln in 2040). Loneliness negatively influences physical and mental health. At the same time, the possibilities and the use of eHealth increase. What is the effect of interaction between these trends on the future healthcare utilisation of the oldest old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

7. The future old, the current 40+, are more used to technology in everyday life than the current old. Furthermore, the level of education of the future old will be higher. At the same time, the possibilities and the use of eHealth increase. What is the effect of interaction between these trends on the future healthcare utilisation of the old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	



Source: RIVM

8. The ratio of 50 to 64-year-olds over those aged 85 years and over (parent support ratio) is a measure of informal caregiver availability. This ratio will decrease from 10 in 2015 to 4 informal caregivers for each person aged 85 years and over in 2040. At the same time, the number of older persons living alone will increase with 0.8 million. In general, older persons experience a lower feeling of control over their own health than people from other age groups, which is reflected in an absolute increase in the number of people that experiences a low feeling of control over their own health. What is the effect of interaction between these trends on the future healthcare utilisation of the oldest old according to you?

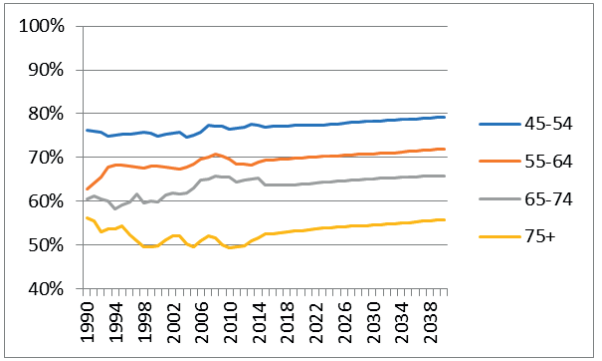
Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

9. More and more healthcare tasks shift from secondary to primary care and/or are delivered at the patient's home. The number of older persons living alone increases between 2015 and 2040. At the same time, the informal caregiver availability decreases (see previous question). What is the effect of interaction between these trends on the future healthcare utilisation of the old and oldest old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

10. The State Pension age will increase alongside the increase in life expectancy. At the same time, there is an increase in the proportion of old with chronic conditions and multimorbidity. What is the effect of interaction between these trends on the future healthcare utilisation of the old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

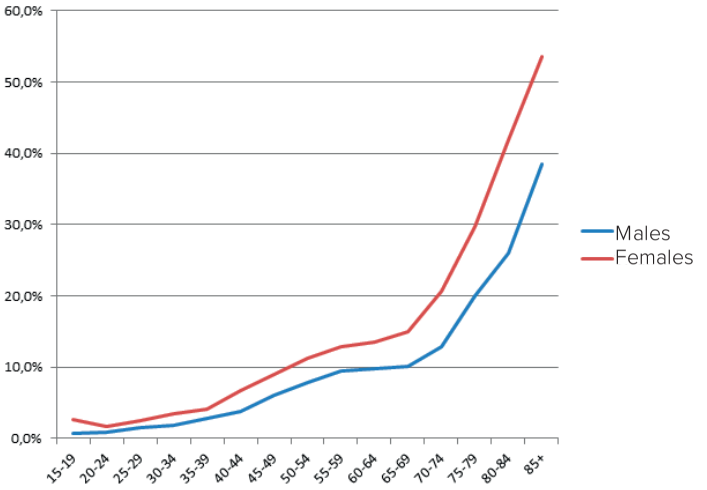


y-axis: percentage with perceived (very) good health

Source: CBS, RIVM

11. The proportion of chronically ill at relatively young age increases, which can in part be attributed to earlier diagnosis. As a result, there is an increase in multimorbidity at a younger age. At the same time, an increasing proportion of the older population is feeling healthy, despite having chronic conditions. What is the effect of interaction between these trends on the future healthcare utilisation of the old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	



Y –axis: Percentage with a chronic condition who feel unhealthy and limited

Source: CBS, RIVM.

12. The future oldest old (currently aged 65 years and over) have higher expectations of old age than the current oldest old. They want to age well and dignified, stay "young" as long as possible and be able to choose for themselves which care they receive. However, physical health of this group is also expected to worsen when they get 75 years and older, and they will then also feel more and more unhealthy and limited. What is the effect of interaction between these trends on the future healthcare utilisation of the oldest old according to you?

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	

13. The average income of the current old per household is higher than twenty years ago but is expected to be lower for the future old. A lower income leads to more use of cheaper forms of healthcare, such as informal care. At the same time, the informal caregiver availability will also decrease (see previous questions). What is the effect of interaction between these trends on the future healthcare utilisation of the old according to you?
Note: An extra healthcare service is added to this question
Source: CBS

Use of:	Very great decrease (1)	Great decrease (2)	Decrease (3)	No effect (4)	Increase (5)	Great increase (6)	Very great increase (7)	Please add a **comment** if you score the lowest (1) or highest (7) category. Also add a comment if you have doubts about your scoring. This space can also be used for additional remarks.
Informal care	☐	☐	☐	☐	☐	☐	☐	
Home care	☐	☐	☐	☐	☐	☐	☐	
GP care	☐	☐	☐	☐	☐	☐	☐	
Specialist care	☐	☐	☐	☐	☐	☐	☐	
Nursing home care	☐	☐	☐	☐	☐	☐	☐	
Mental healthcare	☐	☐	☐	☐	☐	☐	☐	
Acute care	☐	☐	☐	☐	☐	☐	☐	
Informal care	☐	☐	☐	☐	☐	☐	☐	

GP; general practitioner

S2 Appendix. Trends in the older population included in the Delphi questionnaires[1, 2, 3, 5-10, 20-25]

Increase in utilisation	Decrease in utilisation
Trend increases	Trend increases
Number of old (4.1 to 4.8 million)	Proportion of older persons feeling healthy
Number of oldest old (0.74 to 1.6 million)	Education level
Number of older persons living alone (+0.8 million)	Number of working older persons (due to rise in retirement age)
Percentage of older persons with a migration background	eHealth potential and availability
Number of overweight (47% to 51%) and obese (17% to 24%) older persons	
Number of lonely, oldest old (0.6 to 1.3 million)	
Number of older persons with chronic conditions	
Expectations of quality of life and care	
Trend decreases	Trend decreases
Parent-support ratio (10 to 4 informal caregivers/oldest old)	Number of smokers (17% to 10%)
Proportion older persons in urban regions compared to proportion in rural regions	Income and resources
Trend unchanged	
Low feeling of control amongst older persons	
Low service level in rural regions	
Transition of care from secondary to primary care	
Average age at which physical limitations occur	

Explanation of the trends

With regard to demographic changes, various aspects of population ageing were included. According to the VTV-2018, people will not only live longer in 2040, but the share of people aged 65 and older in the total population will have increased as well. This increase will be especially visible among the oldest old. The number of people aged eighty years and over (oldest old) will more than double, from 740 thousand in 2015 to 1.6 million in 2040.[26] There are, however, important regional differences with regard to the impact of population ageing. In rural areas, the share of old and oldest old in the total population is (much) larger than in the more urbanised parts of the Netherlands.[11] The number of people with a non-Western migration background aged 65 years and over will increase as well, from roughly 110 thousand in 2015 to 456 thousand in 2040.[12] Furthermore, the VTV-2018 shows that the number of older people (both men and women) that will live independently in the future will increase with approximately 800 thousand people. At the same time, the parent support ratio (i.e. the ratio of 50 to 64-year-olds to those aged ≥

85 years) will decrease between 2015 and 2040 from ten to four. This latter trend gives an indication of the future decrease in 'potential informal caregivers'.[13, 27]

With regard to (population) health, trends in the number of people with multiple chronic diseases, in self-rated health and in loneliness were included. The VTV-2018 report shows an increase in the percentage of patients with two or more chronic diseases as registered with their GP, mainly as a result of population ageing. This will increase from almost twenty-five percent (4.3 million) in 2015 to thirty percent (5.5 million) in 2040.[28] However, this increase does not seem to affect the trend in self-rated health. According to the VTV-2018, people aged 75 years and over will feel slightly healthier in 2040 than people of that age currently do. In 2015, 52 percent of people aged 75 years and over felt that they were in (very) good health; in 2050 this will increase to 56 percent. The number of lonely people will increase as well, from 5.2 million in 2015 to almost 5.9 million in 2040 (i.e. 41% of all adults). Although loneliness is a problem that affects all age categories, its prevalence tends to increase with age.[14, 29] With regard to lifestyle, trends in smoking and obesity were selected. The VTV-2018 shows a continuation of the decrease in smoking patterns in the Dutch population, but an increase in obesity. In 2040, roughly fourteen percent of the Dutch population smokes versus 25% in 2015. Yet, 62% of the population will be overweight in 2040, while this was still 49% in 2015.[30]

Other population characteristics that were included concerned tangible and less tangible trends in the level of education, income and expectations about healthcare. In 2040, the old and oldest old will in general have a higher level of education compared to the same group today.[26] The trends in income are uncertain. Even though the current group of older people is more affluent than ever before, it is not a given this trend will continue in the future.[17] Similarly, changes in popular expectations about what healthcare can and cannot do are hard to pin down in numbers. In general, it is well established that people often have high expectations of the benefits of healthcare. The current stress on 'successful ageing' might lead to even higher expectations, which in turn might affect their demand.[4, 15, 16]

Lastly, several contemporary trends in health policy were incorporated in the questionnaire. These include i) the ambition of the Dutch government to enable older people to live independently for as long as possible, ii) the gradual increase of the retirement age, and iii) the ambition to stimulate the use of eHealth-solutions in healthcare.[18, 19]

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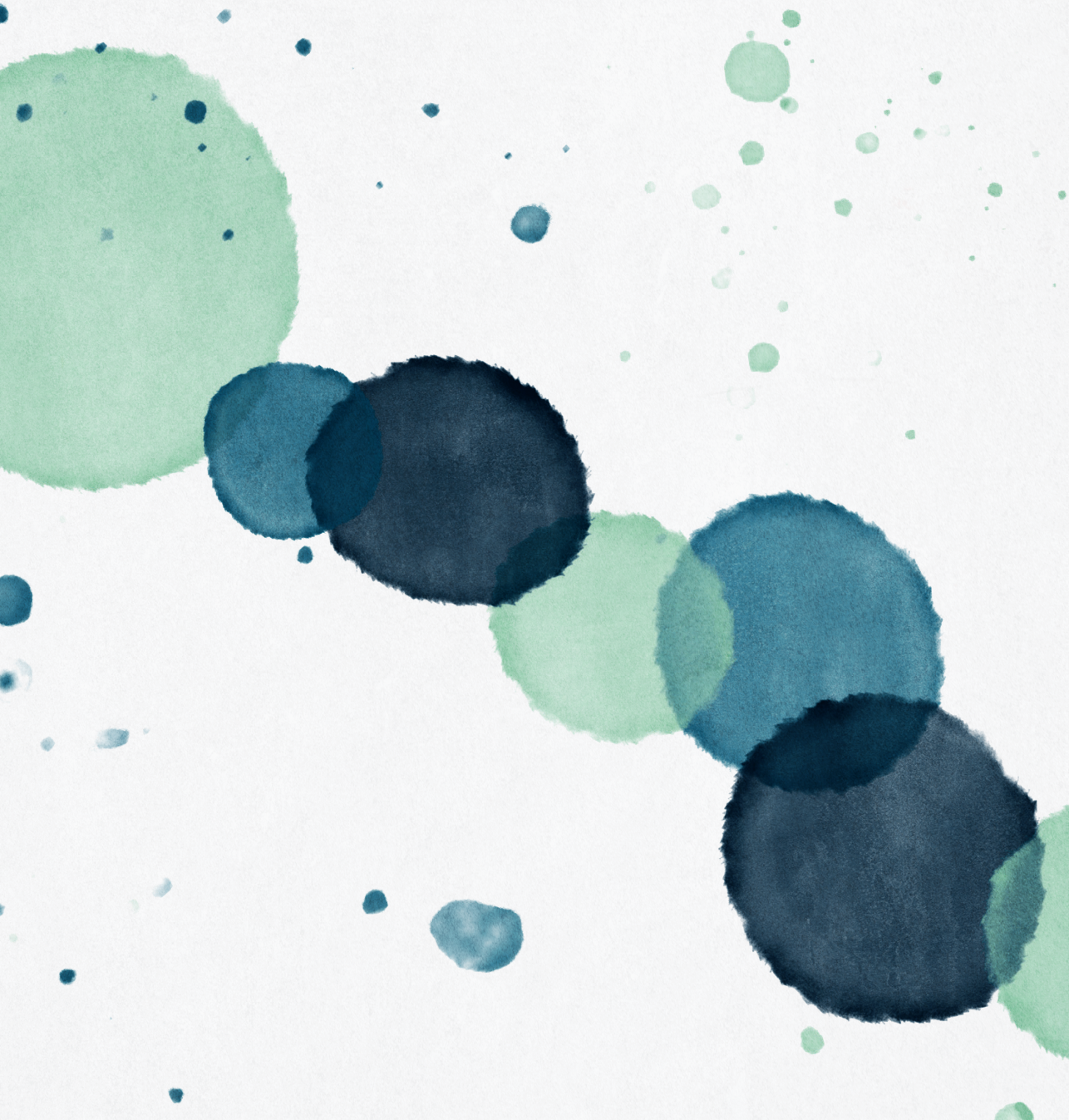

Part II

Hip fractures and daily functioning in old age

Chapter

3

Community-dwelling older hip fracture patients: characteristics and pre-fracture use of primary care

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Submitted

ABSTRACT

Background

Several studies showed that the hip fracture population is getting older and declines in functioning already before the hip fracture.

Aim

1) Describe characteristics of community-dwelling hip fracture patients, 2) assess whether pre-fracture decline in daily functioning is translated into an increased contact frequency with their general practitioner (GP).

Design and setting

Retrospective cohort study based on routine care data from general practices in the Netherlands (n=100) and microdata of Statistics Netherlands.

Method

Patient characteristics of community-dwelling older persons (≥65 years) who obtained a hip fracture between 2011 and 2020 were determined. GP contacts (in-practice, telephone and home visits) in the twelve months before the hip fracture were counted. Monthly change in contact frequency was assessed with a generalised estimating equation regression model.

Results

There were 2275 patients with a hip fracture included (70% women; median age 83 years (IQR 76-88), 52% polypharmacy, median frailty index (eFI-U) 0.20 (IQR 0.12-0.26)). In the year before the hip fracture patients had a median of 8 GP contacts (IQR 3-18), with a slightly increasing frequency in the months preceding the hip fracture (0.021 contacts/month, 95% CI 0.012-0.031, $p<0.001$). Younger patients (age 65-75) were less frail (median eFI-U 0.16, IQR 0.10-0.24), and had less polypharmacy (46%) and GP contacts (median 7 contacts, IQR 3-14) compared to the older patients.

Conclusion

Community-dwelling older hip fracture patients are mostly old and frail at the time of fracture. GPs do not see patients more frequently in the year before the hip fracture.

Keywords

Aged, hip fractures, primary health care, patient characteristics, routinely collected health data, electronic health records

HOW THIS FITS IN

What was known

- The overall hip fracture population, consisting of community-dwelling older persons and nursing home residents, changed towards an older population with more pre-fracture comorbidities

- Furthermore, decline in daily functioning, which is part of normal ageing, speeds up in the year before a hip fracture, ending in a low pre-fracture level of daily functioning.

What this study adds

- Community-dwelling hip fracture patients are mostly old and frail, and half of them have polypharmacy at the time of fracture

- There is only a limited change in GP contact frequency in the year before the hip fracture, so the pre-fracture decline in daily functioning is not reflected in an increased contact frequency.

INTRODUCTION

Hip fractures are prevalent at old age, with high mortality and institutionalisation rates, and low rates of recovery to pre-fracture level of daily functioning after the fracture.[1, 2] Several studies showed that there is vulnerability and a low level of daily functioning already before the hip fracture.[3, 4] Over the last few decades, the age-adjusted incidence rate of hip fractures changed.[5-7] In the same time period, the overall hip fracture population also changed towards an older population with more pre-fracture comorbidities.[8, 9] This overall hip fracture population consist of both community-dwelling older persons and nursing home residents. It is unclear whether the community-dwelling hip fracture population also became older and more vulnerable, as there are no recent descriptions of this population separately. The first aim of this study therefore was to describe the characteristics of the current community-dwelling older hip fracture patients at the time of fracture, thereby giving GPs more insight in the population of hip fracture patients they care for.

Besides the low pre-fracture level of daily functioning, decline in daily functioning, which is part of normal ageing, is known to speed up in the year before a hip fracture.[3, 10] This pre-fracture decline in daily functioning was observed retrospectively in population-based longitudinal cohort studies. However, in a clinical setting this decline will probably go unnoticed, as daily functioning is not regularly measured or reported by healthcare professionals. Contrary to changes in daily functioning, changes in contact frequency will be noticed by clinicians. In the Netherlands, general practitioners (GPs) are most likely to pick up changes in contact frequency first. Every older person is registered with a GP and GPs are the gatekeeper for other care services. If a decline in daily functioning leads to increased healthcare use, this will be picked up as a change in contact frequency by GPs first. Therefore, the second aim of this study was to assess whether GP contact frequency changes in the year before the hip fracture.

METHODS

For this retrospective population-based cohort study, routine electronic health record (EHR) data from GPs was used. In the Netherlands, the GP has a central role in the medical care for community-dwelling older persons, which makes routine care data of GPs an extensive and reliable source of health information of community-dwelling older persons.

Design

The current study used anonymised routine care data from 100 general practices participating in the Extramural LUMC University Medical Center Academic Network (ELAN) primary care network in the Netherlands. All practices were located in the Leiden-The Hague region. GP data used for the analyses included diagnoses with International Classification of Primary Care (ICPC)-1-NL codes (from both episode and contact registrations), prescriptions with Anatomical Therapeutical Chemical (ATC) codes, and registries of contact date and type. The EHR data were linked with non-public microdata from Statistics Netherlands (CBS) on living situation and date of death from the Dutch Personal Records Database using unique pseudonymised person identifiers. Data from the period 2010 up and till 2020 was used. The medical ethical committee Leiden-The Hague-Delft waived the need for ethical approval (number G21.077).

Study population

Inclusion criteria for the current study were 1) a hip fracture between 2011 and 2020 (as registered with ICPC-1-NL code L75 or L75.01), 2) age 65 years or older at time of hip fracture, and 3) enrolled with a participating GP practice for at least one year before the hip fracture. Enrolment was determined using quarterly payment data. For each patient, only the first hip fracture during the study period was used.

Outcomes

Living situation was defined as the last registered living situation before the hip fracture and retrieved from CBS microdata. It was categorised in independent with partner or other person, independent alone, or institutionalised. Polypharmacy, retrieved from GP routine care data, was defined as using five or more different medications. Medication was considered to be used if there were three or more prescriptions (ATC) in the past year and one or more prescription in the last six months. For the frailty score, the electronic frailty index as described by Drubbel et al. (eFI-U) was calculated on the day of the hip fracture.[11, 12] This eFI-U consists of a list of fifty deficits (i.e. physical, psychological, cognitive and social domain). Deficits are scored based on ICPC and ATC codes in the GP routine care data in the past six months or five years (depending on the deficit). Diagnostic measurement data were not included in the eFI-U of the current study.

Contact frequency was determined using data on financial declarations of GPs to health insurers. In the general practice, each type of contact or procedure (e.g. in-practice consultation, home visit, or small surgical procedure) has its own Vektis-code and corresponding financial reward. For this study, all codes representing

contact moments of patients with GPs were included. Diagnostic and small surgical procedures and routine vaccination contacts were excluded, as these often do not represent a separate contact moment. The included codes were categorised into in-practice consultations, telephone consultations, and home visits. In the year 2019 there were some changes to the financial declaration codes used in this study to determine contact frequency. From that year onwards, all telephone contacts were coded as an in-practice contact, thereby losing the distinction between in-practice consultations and telephone consultations.

Analysis

For age and frailty score the median (IQR), and for living situation and presence of polypharmacy numbers (percentage) at the time of hip fracture were determined. The mortality rate at one year after the hip fracture was determined using the date of death from the CBS microdata. Differences in patient characteristics between three age groups (i.e. 65-75 years, 75-85 years, 85 years and over) were assessed with Pearson's chi-squared tests (ordinal data) and Kruskal-Wallis tests (continuous data). Pre-fracture contact frequency was determined by counting the number of GP contacts (i.e. in-practice, telephone, home visits) in the year before the hip fracture. The monthly contact frequency in the twelve months before the hip fracture was also computed. A generalised estimating equation regression model (GEE; showing mean contact frequencies) was constructed (i.e. dependent=contact frequency, independent=time) to assess change in overall contact frequency and frequency of in-practice consultations, telephone consultations and home visits over time (per month). These models were also run separately for the three age groups. All analyses were performed with SPSS version 25.

RESULTS

There were 2275 older persons with a hip fracture included in the analyses (Figure 1). The median (IQR) age at hip fracture was 83 (76-88) years and 70% was female. Patients in the younger age group (i.e. 65-75 years old) were somewhat less frail and less often had polypharmacy (Table 1).

In the twelve months before the hip fracture, patients had a median number of contact moments with their GP of 8 (IQR 3-18) per year, which were mainly in-practice consultations. The contact frequency was significantly higher in the older age groups and this difference was mainly due to a larger number of home visits (Table 2).

Figure 1. Flowchart

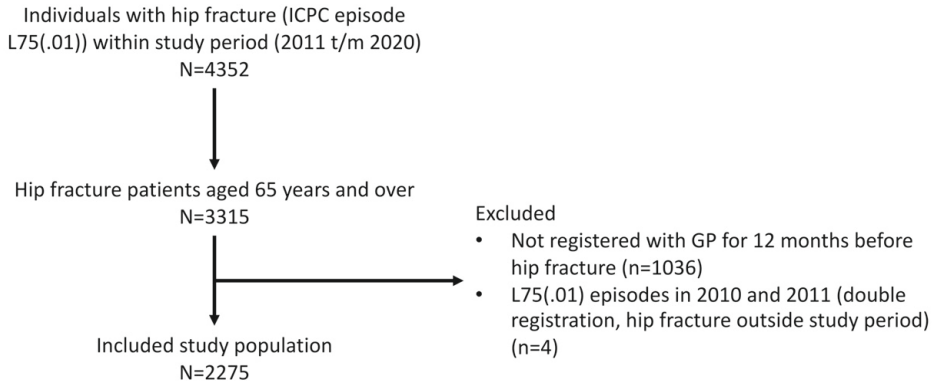


Table 1. Patient characteristics at time of hip fracture and mortality after the hip fracture

	Total (n=2275)	65-74 years (n=514)	75-84 years (n=847)	85+ years (n=914)	p-value
Age (years), median (IQR)	83 (76-88)	70 (68-73)	81 (78-83)	90 (87-93)	<0.001^
Female, n (%)	1593 (70)	329 (64)	591 (70)	673 (74)	0.001`
Living situation, n (%)					<0.001`
Independent with partner	948 (42)	154 (30)	387 (46)	555 (61)	
Independent alone	1096 (48)	347 (68)	405 (48)	196 (21)	
Institutionalised	231 (10)	13 (3)	55 (7)	163 (18)	
Polypharmacy*, n (%)	1181 (52)	212 (41)	454 (54)	515 (56)	<0.001`
Electronic frailty index (eFI-U)~, median (IQR)	0.20 (0.12-0.26)	0.16 (0.10-0.24)	0.20 (0.14-0.26)	0.20 (0.14-0.26)	<0.001^
Mortality at 1 year after hip fracture, n (%)	530 (23)	52 (10)	149 (18)	329 (36)	<0.001`

*Polypharmacy is defined as using 5 or more different medications, of which 3 or more prescribed in the past year and 1 or more prescribed in the last six months.

~eFI-U: range 0 to 1, (count number of deficits)/(potential number of deficits=50)

^Kruskal-Wallis test

`Pearson's chi-squared test

Table 2. Number of GP contacts in the twelve months before the hip fracture

	Total (n=2275)	65-74 years (n=514)	75-84 years (n=847)	85+ years (n=914)	p-value^
Overall contacts, median (IQR)	8 (3-18)	7 (3-14)	8 (2-17)	9.5 (2-20)	0.041
In-practice	3 (0-8)	5 (2-10)	3 (0-8)	2 (0-6)	<0.001
Telephone	1 (0-4)	1 (0-2)	1 (0-4)	1 (0-5)	0.083
Home visit	0 (0-4)	0 (0-1)	0 (0-3)	2 (0-7)	<0.001
Patients without any contact in year before hip fracture, n (%)	355 (16)	61 (12)	137 (16)	157 (17)	

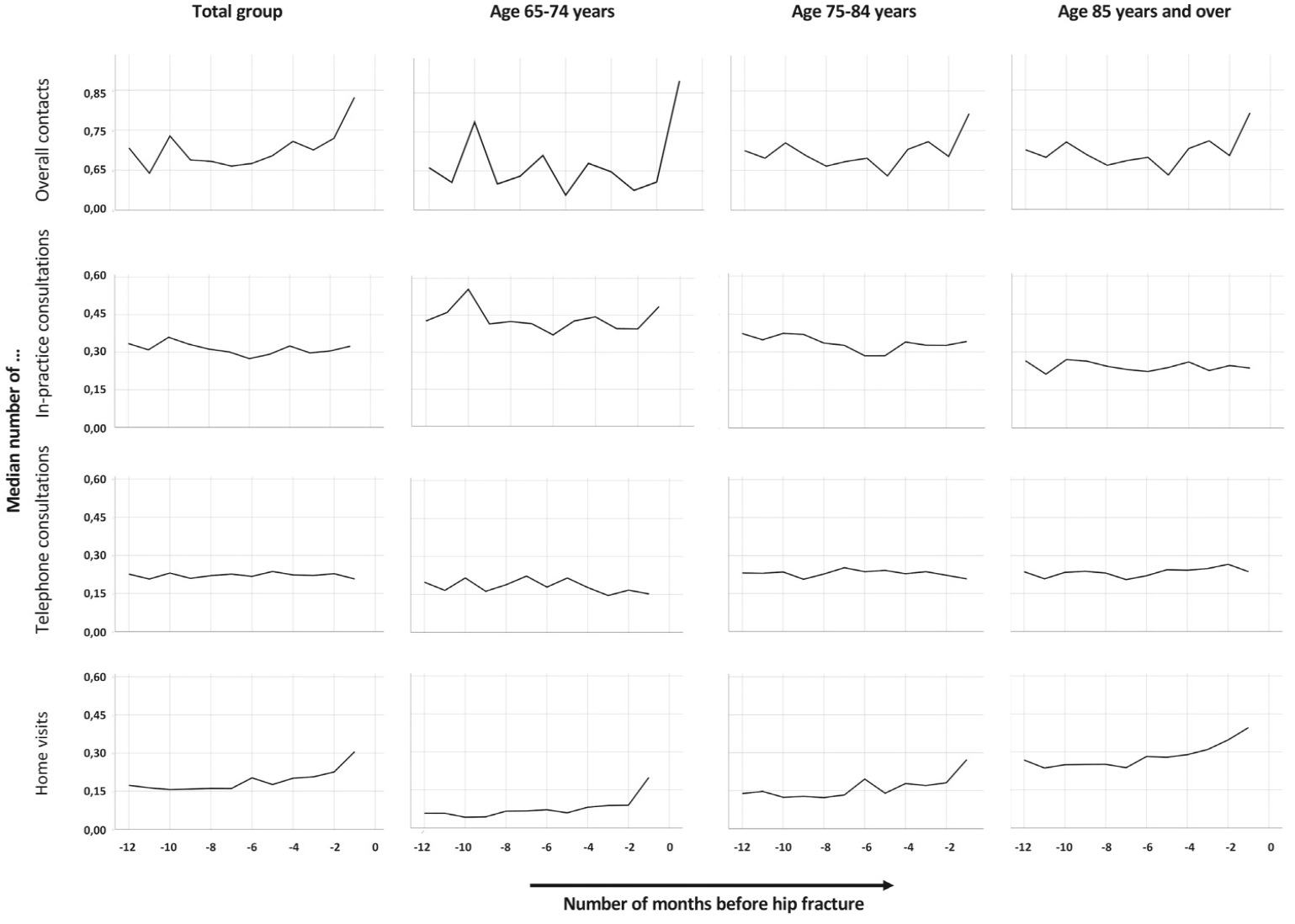
^Difference between age groups per contact type, Kruskal-Wallis test

The frequency of GP contacts per month slightly increased over the months closer to the hip fracture (Figure 2). Overall, the median number of contacts increased from 0 (IQR 0-2) in the twelfth month before the hip fracture to 1 (IQR 0-2) in the last month before the hip fracture. The generalised estimating equations model showed that in the year before the hip fracture the mean contact frequency increased with 0.021 contacts/month (95% CI 0.012 – 0.031, p<0.001). The increase in contact frequency in the last months before the hip fracture can be mainly attributed to an increase in home visits; the number of in-practice consultations and telephone consultations hardly changed (Table 3). In the youngest age group (i.e. 65-74 years), the contact frequency did not significantly change in the twelve months before the hip fracture.

Table 3. Generalised estimating equation parameter estimates of change in contact frequency in the twelve months before the hip fracture

Change per month (95% CI)	**Total (n=2275)**	p-value	**65-74 years (n=514)**	p-value	**75-84 years (n=847)**	p-value	**85+ years (n=914)**	p-value
Overall	0.021 (0.012 – 0.031)	<0.001	0.013 (-0.007 – +0.032)	0.211	0.020 (0.003 – 0.036)	0.022	0.027 (0.013 – 0.042)	<0.001
In-practice	-0.001 (-0.008 – +0.005)	0.734	-0.003 (-0.019 – +0.012)	0.668	-0.001 (-0.012 – +0.011)	0.920	-0.001 (-0.010 – +0.008)	0.867
Telephone	0.004 (0.0 – 0.007)	0.054	0.0 (-0.007 – +0.007)	0.976	0.002 (-0.004 – +0.008)	0.524	0.007 (0.001 – 0.014)	0.024
Home visits	0.019 (0.014 – 0.023)	<0.001	0.016 (0.009 – 0.023)	<0.001	0.018 (0.009 – 0.027)	<0.001	0.021 (0.013 – 0.028)	<0.001

Figure 2. Frequency overall contacts, in-practice consultations, telephone consultations and home visits in the twelve months before the hip fracture (total and by age group)



DISCUSSION

Summary

The community-dwelling hip fracture patients described in this study are mostly old and frail, and half of them have polypharmacy at the time of fracture. In the year before the hip fracture there is a wide variation in GP contact frequency. Overall, there is a limited but significant increase in contact frequency in the months preceding the hip fracture. This increase is mainly due to an increase in home visits; the number of in-practice and telephone consultations remains the same.

Strengths and limitations

To our knowledge this is the first study to describe GP contact frequency before a hip fracture in a large cohort of community-dwelling older persons. By using routine care data, we have been able to use prospectively collected information, which for example limits recall bias. Moreover, using these data enabled us to include a large number of hip fracture patients in our study. There are also several limitations to this study. The first relates to the nature of the data used. Routine care data is not collected for research purposes and therefore has several shortcomings when used for research. One of the shortcomings is that selection of the study population (i.e. hip fracture patients registered at least one year before their fracture) is not fault-proof, because of differential use of coding by GPs and because of mistakes in declaration and registration data. Another limitation is the use of GEE for the analyses, which assumes a linear relation. A possible distinction between changes in contact frequency over different periods in the year before the hip fracture will have been lost because of this.

Comparison with existing literature

The characteristics of the community-dwelling older hip fracture patients in this study are in agreement with the characteristics described in other recent studies which included both community-dwelling and nursing home residents, being that patients are mostly old and frail.[8, 9] However, one in five of the hip fracture patients in our population was younger than 75 years old. There was a significant difference between younger (i.e. aged 65-74 years) and older (i.e. aged 75 years and over) hip fracture patients. Younger patients were less frail, less often had polypharmacy, and their contact frequency in the year before the hip fracture was lower.

Overall, hip fracture patients seem to be vulnerable before their fracture, and to have an increased decline in daily functioning in the year before the hip fracture as well.[3, 4, 10] Expectations of recovery and treatment goals should be adjusted to

this pre-fracture decline in daily functioning. However, GPs often do not know their patients' (changes in) pre-fracture daily functioning. Based on a study by Cheung et al.[13] on the association between disability and healthcare use, one would expect that with the pre-fracture decline in daily functioning, healthcare use (which is something GPs are aware of) would increase. In the Netherlands, this increased healthcare use would first become apparent as an increased use of GP care. However, in the current study we only observed a small and clinically hardly relevant increase in contact frequency in the months preceding the hip fracture. A previous study on GP contacts before acute hospitalisation for, amongst others, hip fracture, also did not find an explicit increase in contact frequency before the hip fracture.[14] This finding suggests that, although earlier studies found that patients' daily functioning deteriorates before the hip fracture, there is no increased use of GP or hospital care. A possible explanation is that, because of the vulnerability and low level of daily functioning, patients already receive care from other care professionals than their GP before the hip fracture. Although the GP still has a central role in the care process, other care professionals (e.g. home care nurses) are the first to notice a decline in daily functioning and they will respond to or even solve it without needing the help of the GP. After all, changes in daily functioning at old age are often responded to with adaptations to the environment and care adjustments, and not with extensive diagnostic and therapeutic medical procedures. Thus, the pre-fracture decline in daily functioning does not translate into an increased GP contact frequency. Therefore, information on contact frequency cannot fill the gap of missing information on pre-fracture daily functioning. In an earlier study we already showed that a combined measure based on routine care data consisting of deficits and medication (i.e. eFI-U) does also not reflect daily functioning.[15]

The pre-fracture contact frequency found in the current study is lower than that described by the Netherlands Institute for Healthcare Services Research (Nivel).[16] This difference could be explained by inclusion of diagnostic/surgical procedures and routine vaccination contacts in the contact count in the Nivel report, while these were not counted as a contact in the current study. In addition, there were relatively many patients without any GP contact in the year before the hip fracture in the current study (Table 3), something also found in a study of Skarshaug et al..[14] Surprisingly, many of the patients without any pre-fracture contact in the current study were aged 85 years or older and institutionalised. Therefore, one of the possible explanations for the low pre-fracture contact frequency in this group could again be that there are already other care professionals involved who solve health problems before they can get to the GP. Although their GP is still the first

responsible medical professional (otherwise they would not be registered with a GP practice), they are mainly cared for by other care professionals (e.g. nurses).

Conclusion

To conclude, this study showed that community-dwelling older hip fracture patients are mostly old and frail, and half of them have polypharmacy at the time of fracture. Moreover, this study shows that GP contact frequency changes to a limited but statistically significant extent in the year before the hip fracture. In other words, the pre-fracture frailty is not translated into an increase in GP contact frequency.

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Chapter

4

Declining daily functioning as a prelude to a hip fracture in older persons – An individual patient data meta-analysis

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ABSTRACT

Background
Daily functioning is known to decline after a hip fracture, but studies of self-reported functioning before the fracture suggest this decline begins before the fracture.

Objective
Determine whether change in functioning in the year before a hip fracture in very old (80+) differs from change in those without a hip fracture.

Design
Two-stage individual patient data meta-analysis including data from the Towards Understanding Longitudinal International older People Studies (TULIPS)-consortium.

Setting
Four population-based longitudinal cohorts from the Netherlands, New Zealand and the UK.

Subjects
Participants aged 80+ years.

Methods
Participants were followed for 5 years, during which (instrumental) activities of daily living [(I)ADL] scores and incident hip fractures were registered at regular intervals. Z-scores of the last (I)ADL score and the change in (I)ADL in the year before a hip fracture were compared to the scores of controls, adjusted for age and sex.

Results
Of the 2357 participants at baseline, the 161 who sustained a hip fracture during follow-up had a worse (I)ADL score before the fracture (0.40 standard deviations, 95% CI 0.19 to 0.61, p=0.0002) and a larger decline in (I)ADL in the year before fracture (-0.11 standard deviations, 95% CI -0.22 to 0.004, p=0.06) compared to those who did not sustain a hip fracture.

Conclusions
In the very old a decline in daily functioning already starts before a hip fracture. Therefore, a hip fracture is a sign of ongoing decline and what full recovery is should be seen in light of the pre-fracture decline.

Keywords
Disability, hip fracture, function, older people

KEY POINTS

- Older people who experience a hip fracture have worse daily functioning before the fracture.
- The rate of decline in daily functioning leading up to the fracture is accelerated up to a year before the event.
- A hip fracture does not mark the start of decline, but it is a sign of ongoing decline.
- Treatment goals after a hip fracture should focus on optimising quality of life and stabilising further loss of function.

INTRODUCTION

With an ageing population the incidence of hip fractures is increasing from 1.6 million worldwide in 2000 to an expected 4.5-6.3 million in 2050.[1-3] After a hip fracture, the risk of death over the following 12 months is approximately 25% and permanent institutionalisation 20%. Of the surviving patients, about half regain their pre-fracture mobility after one year and about 40-70% regain their (retrospectively measured) overall pre-fracture daily functioning, expressed as (instrumental) activities of daily living [(I)ADL].[4-10] Also compared to age-matched controls, hip fracture patients are more likely to lose independence with (I)ADLs at one and two years after the fracture.[11]

Although there is considerable heterogeneity in functional recovery patterns, hip fractures are generally seen as a tipping point in an older person's life.[6, 12, 13] However, Ritchie et al. showed that hip fracture patients already had significantly more functional vulnerability (i.e. ADL dependent, presence of dementia or need for helpers) before the fracture compared to sex- and age-matched controls.[14] This raises the question whether a hip fracture really is the beginning of decline or just a sign of ongoing decline that started earlier. Therefore, the aim of this study is to determine in the very old whether the change in daily functioning (measured with (I)ADL) in the year before a hip fracture differs from the change in those without a hip fracture.

METHODS

The TULIPS (Toward Understanding Longitudinal Investigations of older People Studies) Consortium is an international collaboration of researchers from longitudinal studies of those in advanced age (aged 80 years and over). Data from three of those longitudinal population-based studies (i.e. the Leiden 85-plus Study, the Newcastle 85+ Study and the Life and Living in Advanced Age in New Zealand (LiLACS NZ) Study) were used in this case-cohort study.

Cohorts and procedures

Leiden 85-plus Study

In the population-based longitudinal Leiden 85-plus Study, all inhabitants of Leiden (the Netherlands) of the 1912-1914 birth cohort were eligible for study participation. Between September 1997 and September 1999, 705 inhabitants reached the age of 85 and were invited to participate. A total of 14 subjects died before enrolment and 92 subjects refused to participate. In total, 599 subjects were included in the

cohort (response rate 87%). For 5 years (starting at age 85), all participants were visited annually a few weeks after their birthday at their place of residence by a research nurse. Structured face-to-face interviews and (self-report) function tests were conducted. Information on the presence of known disease (including hip fracture) was obtained annually from general practitioners' (GP) and elderly care physicians' medical records. The study population has been described previously in more detail.[15]

Newcastle 85+ Study

In the population-based longitudinal Newcastle 85+ Study, all people registered with participating family practices in Newcastle upon Tyne or North Tyneside (the United Kingdom) who were aged around 85 years in 2006 or 2007 (i.e. born around 1921) were eligible for study participation (n=1470). Only those with end stage terminal disease and those who might pose a safety risk to the visiting research nurse were excluded (n=11). A total of 17 subjects died before enrolment, 33 subjects were unreachable, and 358 subjects refused to participate. Of the 1042 eligible subjects in the cohort, 849 were included in this study because they had both a complete health assessment and a GP record review. At baseline and after 1.5, 3 and 5 years (starting at age 85), participants were visited at their place of residence by a research nurse for a structured face-to-face interview and (self-report) function tests. Information on the presence of known disease (including hip fracture) was obtained from the GPs' medical records at baseline and after 3- and 5-years follow-up. The study population has been described previously in more detail.[16, 17]

Life and Living in Advanced Age in New Zealand (LiLACS NZ)

In the longitudinal LiLACS NZ Study, all inhabitants of the Lakes or Bay of Plenty District Health Board areas (New Zealand) of the 1920-1930 birth cohorts (Māori) or the 1925 birth cohort (non-Māori) were eligible for study participation. Of the 1636 eligible subjects in 2010 (766 Māori and 870 non-Māori), 17 died before enrolment and 699 refused to participate. In total, 937 participants (421 Māori and 516 non-Māori) were included in the cohort. For 5 years (starting at age 85 for non-Māori and between age 80 to 90 for Māori), all participants were visited annually at their place of residence by a research nurse. Structured face-to-face interviews and (self-report) function tests were conducted. Information on the presence of known disease (including hip fracture) was obtained annually from GPs' medical records and hospital data. The study population has been described previously in more detail.[18, 19] Throughout the rest of the manuscript the Māori and non-Māori cohorts

will be reported separately, because of known health differences between these cohorts.[18, 20]

Daily functioning

Participant's daily functioning was measured with a self-report questionnaire including questions on basic activities of daily living (ADL) and instrumental activities of daily living (IADL) at each follow-up visit during the face-to-face interviews. ADL items in these combined questionnaires included amongst others bathing, toileting and transferring in and out of bed, while IADL items in the questionnaires included for example shopping and going up and down stairs (Appendix 1).

- In the Leiden 85-plus cohort, the 18-item Groningen Activities Restriction Scale (GARS) was used, which includes 11 ADL and seven IADL questions. Each question had four answer categories (i.e. (1) fully independent without problems; (2) fully independent, but with some difficulty; (3) fully independent, but with a lot of difficulty; (4) only with another person's help). The total score ranged from 18 to 72, with a higher score indicating worse daily functioning.

- In the Newcastle 85+ cohort, a summed score of 12 ADL and five IADL questions (Summed Score) was used. Each question had four answer categories (i.e. (1) I have no difficulty doing this by myself; (2) I have some difficulty doing this by myself; (3) I can only do this by myself if I use an aid or appliance; (4) I am unable to do this by myself, I need someone else's help). The first answer category (1) was coded as 0 'activity performed without difficulty' and the other categories (2, 3 and 4) were coded as 1 'activity performed with difficulty'. This gave a total score ranging from 0 to 17, with a higher score indicating worse daily functioning.

- In the LiLACS NZ cohort, daily functioning was assessed with seven ADL and four IADL items derived from the Nottingham Extended Activities of Daily Living questionnaire (core NEADL). Each item had three answer categories (i.e. (0) not able at all; (1) able with help; (2) on my own with difficulty or on my own). The total score ranged from 0 to 22, with a lower score indicating worse daily functioning. To standardise the direction of the daily functioning scales, the individual core NEADL scores in the LiLACS NZ cohort were inverted (i.e. $score_{maximum} - score_{individual}$).

For the analyses the daily functioning scales were standardised by subtracting in each cohort the sample mean of the baseline measurement from the individual score and dividing that by the sample's standard deviation of the baseline measurement (i.e. standardised z-score = [$score_{individual}$–mean $score_{sample\_baseline}$]/ $SD_{sample\_baseline}$). In case of a missing (I)ADL score, which occurred less than 20 times per measurement moment, that measurement was excluded from the analyses.

Participants

All studies obtained ethical approval [Medical Ethics Committee of the Leiden University Medical Center (1997); Newcastle and North Tyneside Local Research Committee One (Ref: 06/Q0905/2); national New Zealand Ministry of Health ethics Committee (NTX/09/09/088)] and all participants gave informed consent. An additional exclusion criterion for the present study was a hip fracture in the 12 months before the baseline visit.

Hip fractures

In all three studies, incident hip fractures during follow-up were extracted from the medical records from the GP (Leiden 85-plus and Newcastle 85+ cohorts) or the hospital records (LiLACS NZ cohort). In the LiLACS NZ cohort, the presence of a hip fracture was cross-checked with the Accident Compensation Corporation (ACC) records. All (proximal) femur fractures and intertrochanteric fractures were counted as a hip fracture. Only the first incident hip fracture during follow-up was counted as an event. In the Newcastle 85+ cohort and the LiLACS NZ cohort, the exact date of hip fracture during follow-up was also extracted from the GP or hospital records, respectively. In the Leiden 85-plus cohort, GP records were checked annually for incident hip fractures in the previous year, but no date of the hip fracture was registered. For the analyses, the date of hip fracture in the Leiden 85-plus cohort was set to the middle of the date of the visit at which the hip fracture was reported and the previous visit date (or to the date of death if there was no visit after the hip fracture). Only the two (I)ADL measurements before the fracture (t) were used (i.e. t_{-1} and t_{-2}, with t = time of hip fracture). As a result, in the analyses on pre-fracture (I)ADL score and on change in pre-fracture (I)ADL score only participants with at least one (i.e. hip fracture at age 86 or older) and two (i.e. hip fracture at age 87 or older) measurements before the hip fracture were included, respectively.

Control subjects

All participants without a hip fracture were included as controls. Those without a hip fracture could potentially contribute five measurements (three in the Newcastle 85+

cohort). In univariate analysis of change in pre-fracture (I)ADL, an average yearly change was computed using all available measurements. In the other analyses, all measurements of those without a hip fracture were included separately.

Statistical analyses

A two-stage individual participant data (IPD) meta-analysis approach was used for all analyses. In the first stage, the change in (I)ADL prior to a hip fracture was compared to change in (I)ADL for subjects without a hip fracture. This analysis was performed in each cohort separately. In the second stage, the results from each of the cohorts were pooled using methods that are commonly used in meta-analysis (details are described below).

The first stage (cohort level) analyses were performed using IBM SPSS Statistics version 27.0 (IBM, Armond, NY, USA). The second stage analyses (i.e. pooling of cohort results) were performed using Review Manager 5.4.1 (The Cochrane Collaboration, Copenhagen, Denmark).

Cohort level analyses

Categorical variables were presented as frequency with percentage of the total. Continuous variables were described as median with interquartile range (IQR). Data were analysed using linear regression.[21]

Last pre-fracture (I)ADL measurement

The (I)ADL score in the year before a hip fracture (i.e. pre-fracture (I)ADL) was compared to the (I)ADL score of those without a hip fracture with a univariate linear regression model with the last of the (I)ADL measurements (i.e. t_{-1}) as dependent and the presence of hip fracture (yes/no) as independent variable. To be able to correct for age and sex, the data were also analysed with a multivariate linear regression model, with the last of the (I)ADL measurements (i.e. t_{-1}) as the dependent variable, and the presence of hip fracture (yes/no), age at t_{-1}, and sex (male/female) as independent variables (Appendix 2). To take correlation between the measurements within subjects into account, we used non-parametric bootstrapping (1000 bootstrap samples with replacement), stratified by hip fracture status and measurement moment.

Change in pre-fracture (I)ADL

With a univariate linear regression model, change in (I)ADL in the year before a hip fracture (i.e. pre-fracture delta (I)ADL = $(I)ADL_{t-1}$–$(I)ADL_{t-2}$) was compared to an average yearly change in those without a hip fracture (i.e. the last observed (I)ADL

score minus the first observed (I)ADL score divided by the number of observed years: [(I)ADL$_{tlast}$–(I)ADL$_{t0}$]/t). The univariate model included the delta (I)ADL score as dependent and the presence of hip fracture (yes/no) as independent variable.

To be able to correct for age, sex and the last pre-fracture (I)ADL measurement, the data were also analysed with multivariate linear regression. The multivariate model assessed whether there was a difference in change in (I)ADL in the year before hip fracture even if there would be no difference in (I)ADL score in the year before hip fracture. The model included the first of the two (I)ADL measurements (i.e. t_{-2}) as dependent, and the presence of hip fracture (yes/no), age at t_{-1}, the last of the two (I)ADL measurements (i.e. t_{-1}), and sex (male/female) as independent variables (Appendix 2). Again, bootstrap resampling was used to correct the standard error for recurrence of controls.

Pooled analyses

Standardised z-scores were pooled using a random-effects model with inverse variance weighting. In addition, results were presented using forest plots. Heterogeneity between cohorts was quantified using the I^2-statistic. Because of a different timing of measurements in the Newcastle 85+ cohort, the scores at 1, 2 and 4 years follow-up were computed based on the available measurements by assuming a linear change between the measurements. These computed values were included in all pooled analyses.

Sensitivity analyses

The time between the last (pre-fracture) measurement and the hip fracture was included in the multivariate regression models on pre-fracture (I)ADL and pre-fracture change in (I)ADL for additional sensitivity analyses. To assess whether the assumption of a linear effect of age was correct, the analyses on pre-fracture (I)ADL and pre-fracture change in (I)ADL were repeated with age as a categorical factor in the multivariate regression models. Age categories were based on the age participants were supposed to have at the different measurement moments (e.g. 85 years at baseline, 86 years at 1-year follow-up, etc.).

RESULTS

The combined cohort included 2357 participants of which 161 had a hip fracture during the 5-year follow-up (Figure 1). Mean age was 85 years (range 79 to 91) and 39% was male (n=930). The mean age of hip fracture during follow-up was 88 (range 84 to 91) (Table 1).

Table 1. Characteristics at baseline of participants with (HF) and without (nonHF) a hip fracture during follow-up in the four cohorts separately

Cohort	Total		Leiden 85-plus		Newcastle 85+		LiLACS NZ			
							Māori		Non-Māori	
	HF	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*
N	161	2196	42	552	67	770	15	400	37	474
Sociodemographic characteristics										
Age, mean (range)	85 (81-87)	85 (79-91)	85 (85-86)	85 (84-86)	85 (84-86)	85 (84-87)	84 (81-87)	83 (79-91)	85 (84-86)	85 (84-86)
Male, n (%)	52 (32.3)	878 (40.0)	10 (23.8)	192 (34.8)	22 (32.8)	297 (38.6)	8 (53.3)	167 (41.8)	12 (32.4)	222 (46.8)
Living situation, n (%)										
Institutionalised	18 (11.2)	235 (10.7)	7 (16.7)	94 (17.0)	6 (9.0)	74 (9.6)	2 (13.3)	28 (7.0)	3 (8.1)	39 (8.2)
Independent alone	86 (53.4)	1128 (51.4)	19 (45.2)	261 (47.3)	39 (58.2)	424 (55.1)	7 (46.7)	242 (60.5)	21 (56.8)	201 (42.4)
Independent with partner	51 (31.7)	751 (34.2)	16 (38.1)	197 (35.7)	22 (32.8)	272 (35.3)	5 (33.3)	118 (29.5)	8 (21.6)	164 (34.6)
Functional parameters										
(I)ADL										
Questionnaire			GARS	GARS	Summed Score	Summed Score	NEADL core	NEADL core	NEADL core	NEADL core
Median (IQR)			25.5 (21 to 42.5)	28 (21 to 40)	4.5 (1 to 8.25)	3 (1 to 7)	3 (0 to 7)	1 (0 to 4)	1 (0 to 4)	1 (0 to 4)
Z-score, median (IQR)	-0.22 (-0.69 to 0.63)	-0.39 (-0.69 to 0.29)	-0.52 (-0.83 to 0.67)	-0.34 (-0.83 to 0.50)	-0.08 (-0.81 to 0.70)	-0.39 (-0.81 to 0.44)	-0.03 (-0.67 to 0.83)	-0.46 (-0.67 to 0.19)	-0.46 (-0.69 to 0.24)	-0.46 (-0.69 to 0.24)
Mobility (yes), n (%)										
Indoors	107 (66.5)	1250 (56.9)	42 (100)	516 (93.5)	65 (97.0)	734 (95.3)				
Outdoors	140 (87)	1852 (84.3)	35 (83.3)	460 (83.3)	57 (85.1)	620 (80.5)	13 (86.7)	352 (88.0)	35 (94.6)	420 (88.6)
Stairs	118 (73.3)	1546 (70.4)	33 (78.6)	444 (80.4)	54 (80.6)	640 (83.1)	8 (53.3)	170 (42.5)	23 (62.2)	292 (61.6)

Table 1 (continued). Characteristics at baseline of participants with (HF) and without (nonHF) a hip fracture during follow-up in the four cohorts separately

Cohort	Total		Leiden 85-plus		Newcastle 85+		LiLACS NZ			
							Māori		Non-Māori	
	HF	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*	*HF*	*nonHF*
N	161	2196	42	552	67	770	15	400	37	474
MMSE, median (IQR)	27 (24 to 29)	27 (25 to 29)	25.5 (19.75 to 28)	26 (22 to 28)	28 (25 to 29)	28 (25 to 29)	27 (24 to 28.5)	28 (26 to 29)	27 (24 to 28)	28 (26 to 29)
Hip fracture during follow-up										
N (% study population)	161 (6.8)		42 (7.1)		67 (8.0)		15 (3.6)		37 (7.2)	
Age at hip fracture, mean (range)	88 (84-91)		87 (85-90)		88 (85-91)		87 (84-91)		89 (86-91)	

HF Hip fracture; **nonHF** No hip fracture (control); **(I)ADL** (Instrumental) activities of daily living; **MMSE** Mini-mental state examination; **Missings (n):**

~ Leiden 85-plus: non-HF mobility indoors/outdoors/stairs 2, (I)ADL (z-score) 2; HF none

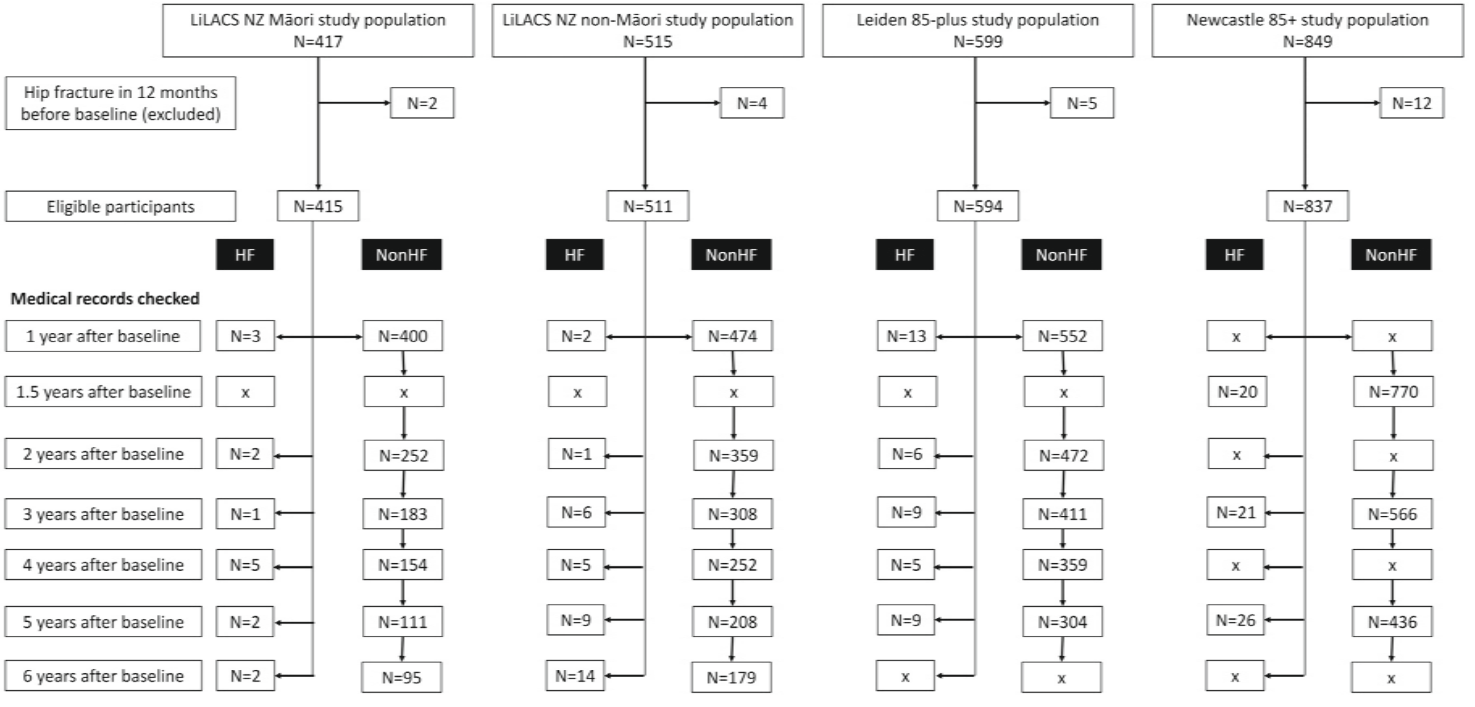
Newcastle 85+: non-HF mobility outdoors 1, mobility stairs 2, (I)ADL (z-score) 8, MMSE 6; HF mobility outdoors 1, (I)ADL (z-score) 1

^LiLACS NZ Māori: non-HF living situation 12, mobility outdoors 6, mobility stairs 153, (I)ADL (z-score) 10, MMSE 143; HF living situation 1, mobility stairs 6, MMSE 6

*LiLACS NZ non-Māori: non-HF living situation 70, mobility outdoors 3, mobility stairs 108, (I)ADL (z-score) 5, MMSE 113; HF living situation 5, mobility stairs 6, MMSE 6

% Total study population: non-HF living situation 82, mobility indoors 876, mobility outdoors 12, mobility stairs 265, (I)ADL (z-score) 25, MMSE 262; HF living situation 6, mobility indoors 52, mobility outdoors 1, mobility stairs 12, (I)ADL (z-score) 1, MMSE 12

Figure 1. Study participants with (HF) and without (non-HF) hip fracture in the four study cohorts



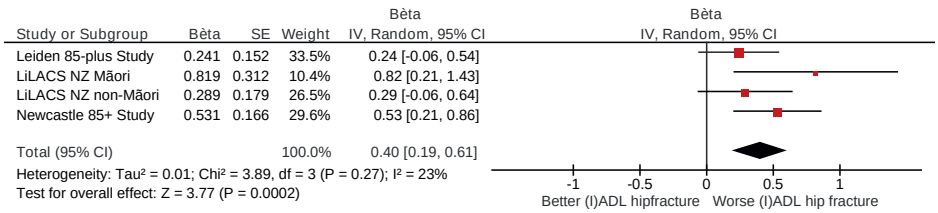
Note 1. Medical records were checked on hip fracture incidence in the previous year. Corresponding pre-fracture (I)ADL scores were also from the previous year(s). For example, for a participant with a hip fracture registered at 'medical records checked 3 years after baseline', the (I)ADL scores at 2 years and 1 year after baseline were used in the analyses. In the LiLACS NZ Study, interview data were available up to 5 years after baseline (just like the other cohorts), but medical records were checked up to 6 years after baseline. **Note 2.** For the Newcastle 85+ cohort, hypothetical scores at follow-up years 1, 2 and 4 were computed by assuming a linear change in (I)ADL between the available measurements (i.e. at 0, 1.5, 3 and 5 years). As a result, the pre-fracture scores for participants with a hip fracture reported at follow-up years 3 and 5 were absent, because imputed scores (at follow-up years 2 and 4) would be based on post-fracture measurements.

Inconsistency between cohorts due to heterogeneity was limited in all adjusted analyses ($I^2 < 30\%$) and was therefore not considered important for the summarised values.[22]

Last (I)ADL measurement before hip fracture

Participants had a worse (I)ADL score in the year before the fracture compared to those without a fracture. This difference was 0.45 (95% CI 0.21 to 0.68) standard deviations (p=0.0002) before correction, and 0.40 (95% CI 0.19 to 0.61) standard deviations (p=0.0002) after correction for age and sex (Figure 2 and Appendix 2). In the cohorts this corresponds with a difference of 5.7 points (95% CI 2.7 to 8.7) on the GARS scale, 1.9 points (95% CI 0.9 to 2.9) on the Summed Score, and 1.9 (95% CI 0.9 to 2.9) for Māori and 1.7 (95% CI 0.8 to 2.6) for non-Māori on the NEADL core questions.

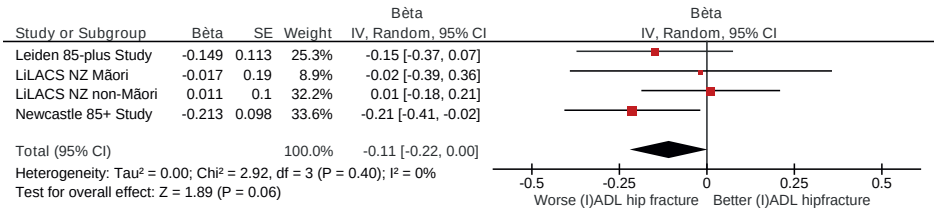
Figure 2. Last (I)ADL measurement (in z-scores) before a hip fracture compared to very old without a hip fracture after correction for age and sex (multivariate)



Change in (I)ADL score year before hip fracture

In all four cohorts, the mean (I)ADL score slightly increased over time in the total population. Compared to the average yearly change in (I)ADL in those without a hip fracture, participants with a hip fracture showed an additional change in (I)ADL score in the year before the fracture of 0.15 standard deviations per year (95% CI 0.02 to 0.28; p=0.02) (Appendix 2). After correction for age, sex and the last measurement before the fracture, this difference in change in (I)ADL score was -0.11 standard deviations per year (95% CI 0.004 to -0.22; p=0.06) (Figure 3 and Appendix 2). This corresponds to an additional change of -1.6 points (95% CI 0.06 to -3.1) on the GARS scale, -0.5 points (95% CI 0.02 to -1.1) on the Summed Score, and -0.5 (95% CI 0.02 to -1.0) for Māori and -0.5 (95% CI 0.02 to -1.0) for non-Māori on the NEADL core questions.

Figure 3. Change in (I)ADL (z-score) in year before a hip fracture compared to very old without a hip fracture after correction for age, sex and last measurement (multivariate)



Sensitivity analyses

Adding the time between the last (pre-fracture) measurement and the hip fracture to the multivariate regression models did not change the effect estimates substantially in either direction of effect or significance. The same applies for including age as a categorical instead of a linear factor in the models.

DISCUSSION

This study shows that before a hip fracture older adults already had a worse (I)ADL score compared to subjects of the same age who did not get a hip fracture. Furthermore, a larger decline in (I)ADL was observed in the year before fracture compared to the normal decline observed at that age in those without a hip fracture.

Previous research mostly focused on the change in daily functioning after a hip fracture. There are some studies that used retrospective self-report to describe the pre-fracture (I)ADL score.[10, 12, 23, 24] Although these studies also found a worse score just before the fracture, the results were prone to (recall) bias and thus could not be reliably interpreted. In a longitudinal study by Ritchie et al., the pre-fracture (I)ADL score of participants with an incident hip fracture during study follow-up was compared to the (I)ADL score of age, gender and race-matched controls. The results of this study were less prone to (recall) bias, but the functional status before the hip fracture was not accurately captured because of a time gap of up to 30 months between the pre-fracture (I)ADL measurement and the fracture. In the current study, the last pre-fracture measurement was better able to reflect the functional status right before the hip fracture. Furthermore, the current study went one step further by also assessing change in (I)ADL in the year before the fracture.

Several differences between the cohorts included in the current IPD meta-analysis should be mentioned. In the Leiden 85-plus and the Newcastle 85+ cohorts,

both a worse pre-fracture (I)ADL score and a larger decline in the year leading up to that worse function were observed. This means that the decline in daily functioning could be captured in the last year before the hip fracture in these cohorts. However, although both in the Māori and non-Māori LiLACS NZ cohorts a worse pre-fracture (I)ADL score was observed, the larger decline leading up to that worse score was not captured in the last pre-fracture year. This could suggest that in these cohorts, the decline in daily functioning already started earlier than the one year before the fracture assessed in this study.

Strengths and limitations

In this study, data from four unique population-based observational cohorts of community-dwelling older people aged 80 years and over were combined. Combining these cohorts allowed for analyses that would be impossible in the individual cohorts because of the high number of incident hip fractures needed to have sufficient power. Furthermore, the considerable follow-up time with extensive measurements of functional status at regular intervals gave the opportunity to assess pre-fracture functioning without having to rely on retrospective self-report and with the advantage to come close to the functional status right before the hip fracture. A limitation of this study is the subtle but relevant difference between the (I)ADL scales used in the Leiden 85-plus Study and Newcastle 85+ Study as compared to the (I)ADL scale used in the LiLACS NZ Study. The first two studies asked participants whether they 'can do' a certain activity, while the latter asked whether they 'do do' the activity.[25] The influence of this difference in wording on the direction and magnitude of effect in the four cohorts cannot be assessed. Another limitation that should be mentioned is the inclusion of multiple birth cohorts in this IPD meta-analysis. Several studies have shown differences in hip fracture incidence between birth cohorts over the last decades and thus the cohorts included in this study might be more heterogeneous than expected.[26, 27] The lower hip fracture rate in the Māori-cohort observed in this study also suggests there is heterogeneity between the cohorts.

To conclude, older people who experience a hip fracture have worse daily functioning before the fracture and the rate of decline in the (I)ADL score leading up to the fracture is accelerated up to a year before the event. This means that a decline in daily functioning already starts before the hip fracture. It is important for clinicians to keep these findings in mind when determining the treatment goals for octogenarians after a hip fracture. If the decline already started before the fracture, expectations about a full functional recovery should possibly be more tailored. Furthermore, our findings suggest that a hip fracture could sometimes

be more of a symptom of an underlying medical problem and therefore should prompt a clinician to screen for other (acute) medical problems at hand. A focus on optimising quality of life, stabilising further loss of function and a less stringent focus on full functional recovery might be more appropriate.

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SUPPLEMENTARY DATA

Appendix 1. Items included in the (I)ADL questionnaires of the four cohorts

Appendix 2. Regression models used in analyses

- Last pre-fracture measurement – univariate
- Last pre-fracture measurement – multivariate
- Change in pre-fracture (I)ADL – univariate
- Change in pre-fracture (I)ADL – multivariate

Appendix 3. Additional figures and tables

- Figure S3.1. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture (univariate)
- Figure S3.2. Change in (I)ADL (z-score) in year before a hip fracture compared to very old without a hip fracture (univariate)
- Figure S3.3. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1)
- Figure S3.4. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with days before hip fracture (sens2)
- Figure S3.5. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1)
- Figure S3.6. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with days before hip fracture (sens2)
- Table S3.1. Last (I)ADL measurement (in z-score) before a hip fracture compared to very old without a hip fracture
- Table S3.2. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture
- Table S3.3. Last (I)ADL measurement (in z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1) and days before hip fracture (sens2)
- Table S3.4. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1) and days before hip fracture (sens2)

Appendix 1. Items included in the (I)ADL questionnaires of the four cohorts

	GARS (Leiden 85-plus Study)	Summed Score (Newcastle 85+ Study)	NEADL core (LiLACS NZ Study)
Answer option wording	Can do	Can do	Do do
ADL			
Get in/out of bed	x	x	x
Stand up from chair	x	x	
Get on/off toilet	x	x	x
Wash face and hands	x	x	x
Wash/dry body	x	x	
Dress yourself	x	x	
Take care of feet/toenails	x	x	
Get around inside house	x		
Walk outdoors	x		x
Go up/down stairs	x	x	
Feed yourself	x	x	x
Make a hot drink			x
Take hot drink to another room			x
IADL			
Prepare breakfast/lunch	x		
Prepare dinner	x	x	
Wash/iron clothes	x		x
Make beds	x		
Do shopping	x	x	x
Do light cleaning	x	x	x
Do heavy cleaning	x	x	
Manage medications		x	
Manage money		x	
Use a telephone			x

Appendix 2. Regression models used in analyses

Last pre-fracture measurement – univariate

$(I)ADL_{t-1} = \alpha + \beta 1 * \text{hip fracture (yes/no)} + \varepsilon$

Last pre-fracture measurement – multivariate

$(I)ADL_{t-1} = \alpha + \beta 1 * \text{hip fracture (yes/no)} + \beta 2 * \text{age} + \beta 3 * \text{sex} + \varepsilon$

Change in pre-fracture (I)ADL – univariate

$\text{delta } (I)ADL = \alpha + \beta 1 * \text{hip fracture (yes/no)} + \varepsilon$

Change in pre-fracture (I)ADL – multivariate

$(I)ADL_{t-2} = \alpha + \beta 1 * \text{hip fracture (yes/no)} + \beta 2 * \text{age} + \beta 3 * (I)ADL_{t-1} + \beta 4 * \text{sex} + \varepsilon$

This model assessed the difference in change in (I)ADL in the year before hip fracture as compared to age- and sex-matched controls given the same (I)ADL score just before the fracture (i.e. difference in slope).

Appendix 3. Additional figures and tables

Figure S3.1. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture (univariate)

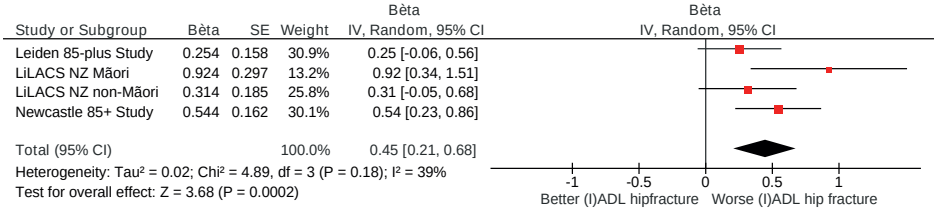

Figure S3.2. Change in (I)ADL (z-score) in year before a hip fracture compared to very old without a hip fracture (univariate)

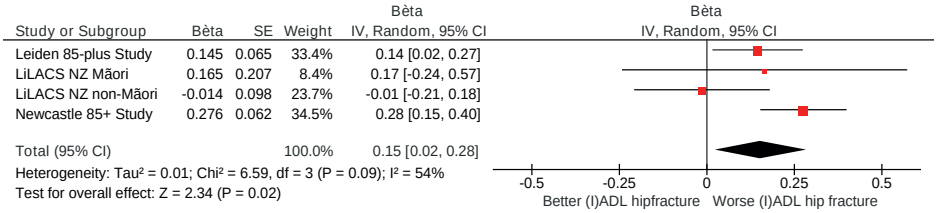

Figure S3.3. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1)

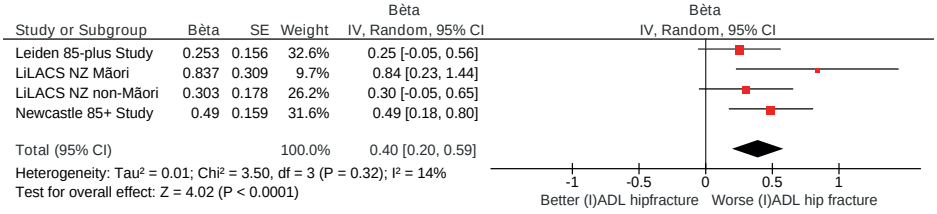

Figure S3.4. Last (I)ADL measurement (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with days before hip fracture (sens2)

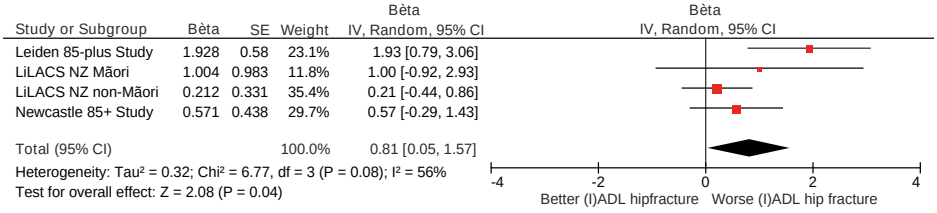

Figure S3.5. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1)

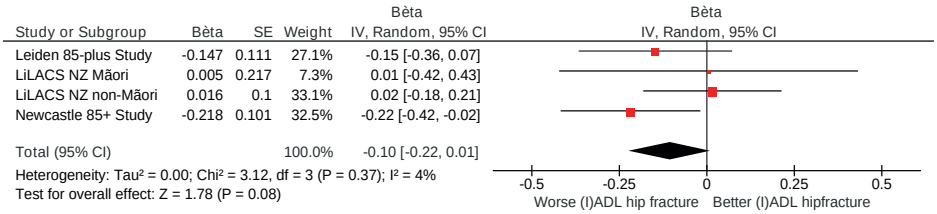

Figure S3.6. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with days before hip fracture (sens2)

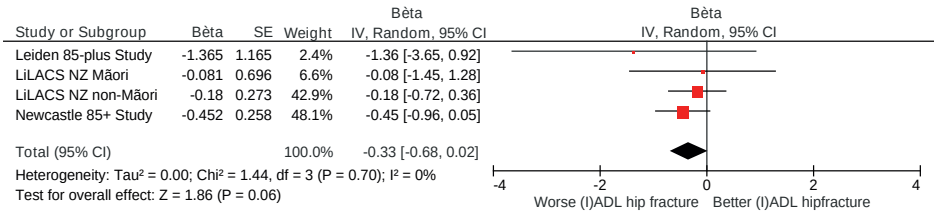

Table S3.1. Last (I)ADL measurement (in z-score) before a hip fracture compared to very old without a hip fracture

	Leiden 85-plus			LiLACS NZ Māori			LiLACS NZ non-Māori			Newcastle 85+		
Univariate~	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE
Hip fracture	0.254 (-0.063 to 0.572)	0.109	0.158	0.924 (0.356 to 1.512)	0.001	0.297	0.314 (-0.034 to 0.698)	0.098	0.185	0.544 (0.241 to 0.857)	0.002	0.162
Multivariate~												
Hip fracture	0.241 (-0.059 to 0.551	0.117	0.152	0.819 (0.212 to 1.425)	0.006	0.312	0.289 (-0.014 to 0.686)	0.090	0.179	0.531 (0.211 to 0.859)	0.003	0.166

~Stratified bootstrapping on episode and presence of hip fracture yes/no

Table S3.2. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture

	Leiden 85-plus			LiLACS NZ Māori			LiLACS NZ non-Māori			Newcastle 85+		
Univariate*	**Change in (I)ADL z-score (95% CI)**	p-value	SE	**Change in (I)ADL z-score (95% CI)**	p-value	SE	**Change in (I)ADL z-score (95% CI)**	p-value	SE	**Change in (I)ADL z-score (95% CI)**	p-value	SE
Hip fracture	0.145 (0.017 to 0.274)	0.026	0.065	0.165 (-0.242 to 0.573)	0.425	0.207	-0.014 (-0.207 to 0.180)	0.891	0.098	0.276 (0.154 to 0.399)	<0.001	0.062
Multivariate~												
Hip fracture	-0.149 (-0.397 to 0.050)	0.175	0.113	-0.017 (-0.445 to 0.351)	0.930	0.190	0.011 (-0.192 to 0.205)	0.913	0.100	-0.213 (-0.416 to -0.024)	0.032	0.098

* In the univariate analysis, the average yearly delta (I)ADL score is used for the participants without a hip fracture. For the participants with a hip fracture, the delta (I)ADL score in the year before the hip fracture is used.

~Stratified bootstrapping on episode and presence of hip fracture yes/no

Table S3.3. Last (I)ADL measurement (in z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1) and days before hip fracture (sens2)

	Leiden 85-plus			LiLACS NZ Māori			LiLACS NZ non-Māori			Newcastle 85+		
Sensitivity 1 (age categorical)˜	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE	**(I)ADL z-score (95% CI)**	p-value	SE
Hip fracture	0.253 (-0.048 to 0.582)	0.109	0.156	0.837 (0.215 to 1.422)	0.011	0.309	0.303 (-0.008 to 0.684)	0.086	0.178	0.490 (0.191 to 0.805)	0.010	0.159
Sensitivity 2 (correction for days before hip fracture)˜												
Hip fracture	1.928 (0.980 to 3.369)	0.004	0.580	1.004 (-1.125 to 2.581)	0.216	0.983	0.212 (-0.505 to 0.866)	0.494	0.331	0.571 (-0.274 to 1.452)	0.191	0.438

˜Stratified bootstrapping on episode and presence of hip fracture yes/no

Table S3.4. Change in (I)ADL (z-score) before a hip fracture compared to very old without a hip fracture, multivariate with age categorical (sens1) and days before hip fracture (sens2)

	Leiden 85-plus			LiLACS NZ Māori			LiLACS NZ non-Māori			Newcastle 85+		
Sensitivity 1 (age categorical)˜	**Change in (I) ADL z-score (95% CI)**	p-value	SE	**Change in (I) ADL z-score (95% CI)**	p-value	SE	**Change in (I)ADL z-score (95% CI)**	p-value	SE	**Change in (I)ADL z-score (95% CI)**	p-value	SE
Hip fracture	-0.147 (-0.375 to 0.049)	0.170	0.111	0.005 (-0.457 to 0.410)	0.987	0.217	0.016 (-0.187 to 0.210.0161)	0.868	0.100	-0.218 (-0.426 to -0.032)	0.034	0.101
Sensitivity 2 (correction for days before hip fracture)˜												
Hip fracture	-1.365 (-2.732 to 1.182)	0.205	1.165	-0.081 (-2.297 to 0.750)	0.785	0.696	-0.180 (-0.780 to 0.286)	0.512	0.273	-0.452 (-0.948 to 0.042)	0.073	0.258

˜Stratified bootstrapping on episode and presence of hip fracture yes/no

Chapter

5

The relation between daily functioning after a hip fracture and pre-fracture functioning in older persons – an individual patient data meta-analysis

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Submitted

ABSTRACT

Background
Daily functioning of older people tends to decline prior to a hip fracture (HF) and is worse in comparison to that of age-related peers.

Objective
Determine whether the rate of decline of daily functioning before a HF is associated with the change in daily functioning directly after the HF.

Design
One-stage individual patient data meta-analysis from the Towards Understanding Longitudinal International older People Studies (TULIPS)-consortium.

Setting
Four population-based longitudinal observational cohorts from the Netherlands, New Zealand and the United Kingdom.

Subjects
Persons aged 80 years and over with incident HF.

Methods
Participants were followed for five years, with (instrumental) activities of daily living [(I)ADL] scores and incident HF recorded at regular intervals. The association between change in (I)ADL z-score in the year before HF (independent variable) and change in (I)ADL z-score across the HF (from before to after HF; dependent variable) was assessed with multivariable regression models.

Results
In 101 patients with incident HF (63 women, mean age 88 years) the change in (I)ADL in the year before the HF was not associated with the change across the HF (0.069 standard deviations, 95%CI -0.514 to 0.652; p=0.814). However, the last pre-fracture (I)ADL z-score was associated with the first post-fracture (I)ADL z-score (0.905 standard deviations, 95%CI 0.549 to 1.261; p<0.001; more limitations before means more limitations after HF).

Conclusions
Level of daily functioning before a HF is more useful to estimate post-fracture potential for recovery in daily functioning of older patients than the change in daily functioning before the HF.

Keywords
Disability, hip fracture, pre-fracture function, older people

KEY POINTS

- Older people with a hip fracture experience more limitations in ADL and IADL [(I)ADL] and a quicker decline prior to the hip fracture.
- More limitations in (I)ADL before the hip fracture is associated with a larger decline in (I)ADL across (i.e. before to after) the hip fracture.
- However, a faster decline in (I)ADL abilities before the hip fracture is not associated with more decline in (I)ADL abilities across the hip fracture
- To estimate post-fracture potential of (I)ADL recovery, the level of (I)ADL before the fracture is more relevant and easier to establish.

INTRODUCTION

Hip fracture is a common age-related problem and has a high disease burden.[1-4] Of all hip fracture patients, an estimated 70% recover to their pre-fracture independence in terms of basic activities daily living (ADL) and half of the patients to their pre-fracture independence in instrumental activities of daily living (IADL).[5] Several studies showed that older people who had a hip fracture had more limitations in ADL and IADL [(I)ADL] and a faster decline in these abilities already before their hip fracture compared to others of their age without a hip fracture.[6-8] The aim of this study was to assess whether the change in (I)ADL abilities before the hip fracture is associated with the change across the hip fracture (i.e. change in (I)ADL from before to after the hip fracture) in several cohorts around the world, including an indigenous population (New Zealand Māori).

METHODS

The TULIPS (Toward Understanding Longitudinal Investigations of older People Studies) Consortium is an international collaboration of researchers from longitudinal studies of those aged 80 years and over. The study cohorts were described in more detail previously.[8]

Cohorts and procedures

Leiden 85-plus Study

In the Leiden 85-plus Study, the 599 included participants were visited annually for five years (starting at age 85). Structured face-to-face interviews and (self-report) function tests were conducted.[9]

Newcastle 85+ Study

In the Newcastle 85+ Study, the 849 included participants were visited at their place of residence at baseline and after 1.5, 3 and 5 years (starting at age 85) for a structured face-to-face interview and (self-report) function tests.[10, 11]

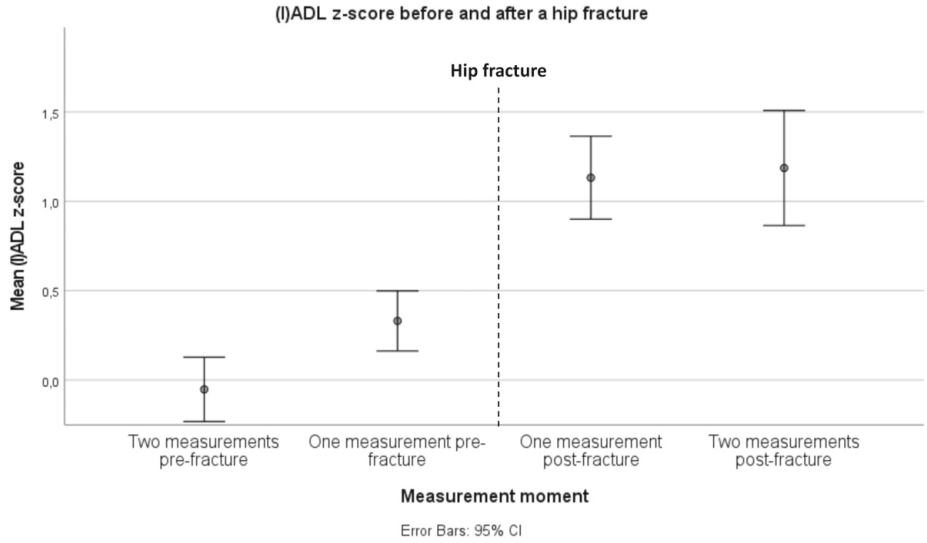
Life and Living in Advanced Age in New Zealand (LiLACS NZ)

In the LiLACS NZ Study, the 937 included participants (421 Māori and 516 non-Māori) were visited annually for five years (starting at age 85 for non-Māori and between age 80 to 90 for Māori) for structured face-to-face interviews and (self-report) function tests.[12, 13]

Participants

In all three studies, incident hip fractures during follow-up and the date of fracture were extracted regularly from the medical records from the GP (Leiden 85-plus and Newcastle 85+ cohorts) or the hospital records (LiLACS NZ cohort). The pre- and post-fracture (I)ADL scores of all participants with a hip fracture during follow-up were plotted in a graph (Figure 1). Since two (I)ADL measurements before and one measurement after the hip fracture (t) were needed for the analyses (i.e. measurements at t_{-2}, t_{-1} and t_{+1}), only participants with a hip fracture reported at 3 or 5 years follow-up were included in the analyses.

Figure 1. Change in in (I)ADL (in standard deviations) from two measurements before the hip fracture till two measurements after the hip fracture



Graph includes all cohorts combined, including all participants with incident hip fracture during follow-up (i.e. from baseline till five years follow-up; n=145).
Time between measurement moments is on average 18 months.

Daily functioning

To measure participant's daily functioning, the 18-item Groningen Activities Restriction Scale (GARS; 11 ADL and 7 IADL questions; higher score is worse daily functioning) was used in the Leiden 85-plus cohort. In the Newcastle 85+ cohort, a summed score of twelve ADL and five IADL questions (Summed Score) was used (higher score is worse daily functioning). In the LiLACS NZ cohort, a short version of the Nottingham Extended Activities of Daily Living questionnaire (core NEADL; 7 ADL and 4 IADL questions; lower score is worse daily functioning). To standardise the direction of the daily functioning scales, the individual core NEADL scores

in the LiLACS NZ cohort were inverted (i.e. $score_{maximum}$–$score_{individual}$). The daily functioning scales were standardised by subtracting in each cohort the mean of the baseline measurement of participants with a hip fracture from the individual score and dividing that by the sample's standard deviation of the baseline measurement (i.e. standardised z-score = [$score_{individual}$–mean $score_{sample\_baseline}$]/$SD_{sample\_baseline}$). Furthermore, because of a different timing of measurements in the cohorts, (I)ADL scores at 1.5 years follow-up were computed for the Leiden 85-plus and the LiLACS NZ cohorts based on the measurements at one and two years follow-up by assuming a linear change between the measurements. The measurements at baseline and on follow-up years 1.5, 3 and 5 were used for the analyses.

Statistical analyses

A one-stage individual participant data (IPD) meta-analysis approach was used. Potential cohort effects were adjusted for in the regression analyses. All analyses were performed using IBM SPSS Statistics version 28.0 (IBM, Armond, NY, USA).

The association between last pre-fracture (I)ADL z-score and first post-fracture (I)ADL z-score was tested with a multivariable linear regression model, correcting for sex, cohort (i.e. ethnic group) and time between hip fracture and next post-facture measurement (in months). The association between pre-fracture change in (I)ADL z-score (i.e. delta pre-fracture = (I)ADL $z\text{-score}_{t-1}$–(I)ADL $z\text{-score}_{t-2}$) and change in (I)ADL across the fracture (i.e. from measurement before the fracture till measurement after the fracture = (I)ADL $z\text{-score}_{t+1}$–(I)ADL $z\text{-score}_{t-1}$) was investigated using a multivariable linear regression model, adjusting for possible confounders: sex, last pre-fracture (I)ADL, cohort, and time between hip fracture and first post-fracture measurement (in months). Participants with missing (I)ADL scores were excluded from the analyses.

RESULTS

There were 101 older persons with an incident hip fracture at 3 or 5 years follow-up included. Median age at hip fracture was 88 years (range 84 to 91) and 38% were male (n=38)(Table 1). Across the hip fracture, (I)ADL changed with 0.83 (IQR 0.30 to 1.66) standard deviations, which corresponds to 13 points on the GARS (IQR 5 to 26), and 4 points (IQR 1 to 7) on the NEADL and the Newcastle aggregated score. The last pre-fracture (I)ADL score was associated with the first post-fracture (I)ADL score (0.905 standard deviations, 95%CI 0.549 to 1.261; p<0.001). The change in (I)ADL in the year before the hip fracture was not associated with the change in (I)ADL across the hip fracture (0.069 standard deviations, 95%CI -0.514 to 0.652;

p=0.814), neither for the (I)ADL score directly after the hip fracture. Those without post-fracture measurements (n=28; i.e. not included in the regression models) had a larger pre-fracture (I)ADL change (median standard deviations 0.42 (IQR 0.21-1.04) vs 0.19 (IQR 0.0-0.74)) and worse (I)ADL pre-fracture scores (median standard deviations 0.44 (IQR -0.18-1.25) vs 0.15 (IQR -0.39-0.80)).

DISCUSSION

This study shows that the change in (I)ADL abilities before the hip fracture is not associated with change in (I)ADL abilities across the hip fracture. However, having more (I)ADL limitations just before the hip fracture was associated with more (I)ADL limitations after the hip fracture.

This is the first study that describes the association between pre- and post-fracture change in daily functioning. Our results are in line with previous research, which showed that a worse self-reported pre-fracture (I)ADL was associated with less recovery to pre-fracture (I)ADL levels one year after a hip fracture.[5, 14-16] Other studies showed that older people with a hip fracture have more (I)ADL limitations compared to age-related peers without a hip fracture already before the fracture, but also have a faster decline in (I)ADL abilities after their hip fracture even when correcting for pre-fracture (I)ADL level. Furthermore, the speed at which older people lose their (I)ADL abilities within one year is faster for those who are about to get a hip fracture compared to those who do not get a hip fracture.[6-8, 17, 18] These findings suggest that a hip fracture is not the beginning of functional decline, but both a manifestation of a trajectory of functional decline that already started earlier and an accelerator of that decline. The results of the current study suggest that, even though (I)ADL does decline before the fracture, the (I)ADL level before the fracture matters more for post-fracture (I)ADL level than the (I)ADL trajectory that led to the pre-fracture (I)ADL level.

Table 1. Characteristics at baseline (i.e. two measurements before the hip fracture) of participants with a hip fracture at 3 and 5 years follow-up in the four cohorts separately

Cohort	Total	Leiden 85-plus	Newcastle 85+	LiLACS NZ	
				Māori	Non-Māori
N	101	23	47	10	21
Sociodemographic characteristics					
Age at hip fracture, median (range)	88 (84-91)	89 (87-90)	89 (86-91)	86 (84-89)	89 (87-91)
Male, n (%)	38 (38)	6 (26)	17 (36)	6 (60)	9 (43)
Living situation, n (%)					
Institutionalised	7 (7)	3 (13)	2 (4)	1 (10)	1 (5)
Independent alone	50 (50)	11 (48)	26 (55)	3 (30)	10 (48)
Independent with partner	33 (33)	8 (35)	18 (38)	3 (30)	4 (19)
Functional parameters at baseline					
(I)ADL					
Questionnaire		GARS	Summed Score	NEADL core	NEADL core
Median (IQR)		32 (23 to 41.75)	4 (1 to 8)	1.5 (0 to 12)	1.5 (1 to 3)
Z-score, median (IQR)	-0.30 (-0.77 to 0.44)	-0.28 (-0.85 to 0.34)	-0.18 (-0.81 to 0.65)	-0.67 (-1.02 to 1.82)	-0.41 (-0.52 to -0.05)
Mobility (yes), n (%)					
Indoors	67 (66)	21 (91)	46 (98)		
Outdoors	87 (86)	17 (74)	42 (89)	9 (90)	19 (91)
Stairs	71 (70)	15 (65)	36 (77)	6 (60)	14 (67)
MMSE, median (IQR)	27 (24 to 28)	26 (19.25 to 28)	27 (24.625 to 28.375)	24.25 (16 to 28.25)	27.25 (24.125 to 27.875)

(I)ADL (Instrumental) activities of daily living; **MMSE** Mini-mental state examination; **GARS** Groningen Activities Restriction Scale (range 18 to 72); **Summed Score** composite (I)ADL scale (range 0 to 17); **NEADL core** Nottingham Extended Activities of Daily Living (core) scale (range 0 to 22; inverted, higher score means worse daily functioning)

Missings (n):
~ Leiden 85-plus: living situation 1, (I)ADL 2, mobility indoors 1, mobility outdoors 1, mobility climbing stairs 1, MMSE 2
# Newcastle 85+: living situation 1, (I)ADL 1, mobility indoors 1, mobility outdoors 1, mobility stairs 1, MMSE 3
^LiLACS NZ Māori: living situation 3, (I)ADL 3, mobility indoors 10, mobility outdoors 1, mobility stairs 3, MMSE 4
*LiLACS NZ non-Māori: living situation 6, (I)ADL 5, mobility indoors 21, mobility outdoors 2, mobility stairs 5, MMSE 9
% Total study population: living situation 11, (I)ADL 11, mobility indoors 33, mobility outdoors 5, mobility stairs 10, MMSE 18

Strengths and limitations

In this study, data from four unique population-based observational cohorts of community-dwelling older people aged eighty years and over were combined. The considerable follow-up time with measurements at yearly intervals gave the opportunity to assess pre-fracture functioning without having to rely on retrospective self-report and to come close to the daily functioning right before and after the hip fracture. A limitation of this study is that the time between pre- or post-fracture measurement and the incident hip fracture was not the same for every participant. Especially for the post-fracture measurement, this means that we measured participants at different moments in their recovery process (i.e. median time between hip fracture and first post-fracture measurement 7 months (IQR 6-16, range 3-24)). From previous literature we know that (I)ADL fluctuates in the first 12 months post-fracture.[5, 15] This could have attenuated the effects found. The effect found was probably also attenuated by the high post-fracture mortality and loss to follow-up. Those who dropped out indeed had a larger pre-fracture (I)ADL change and a worse pre-fracture (I)ADL level compared to the rest of the participants in the analysis. Last, we have combined several cohorts gathered in different periods and combined them adjusting for cohort effect. This may not adequately show intra cohort effects; the numbers from each cohort are small and thus findings should be interpreted with caution and individual ethnic, country, and system effects may be important but not possible to be shown here.

To conclude, even though a high level of (I)ADL disabilities just before the hip fracture is associated with increased (I)ADL disabilities after the hip fracture, the change in (I)ADL abilities in the year before the fracture is not associated with the change in (I)ADL abilities across the hip fracture. The previously reported accelerated decline in (I)ADL abilities before the hip fracture does suggest that a trajectory of functional decline already starts before the hip fracture. However, for clinicians and researchers the level of (I)ADL just before the fracture is more relevant and easier to establish when determining the post-fracture potential of (I)ADL recovery of their patients.

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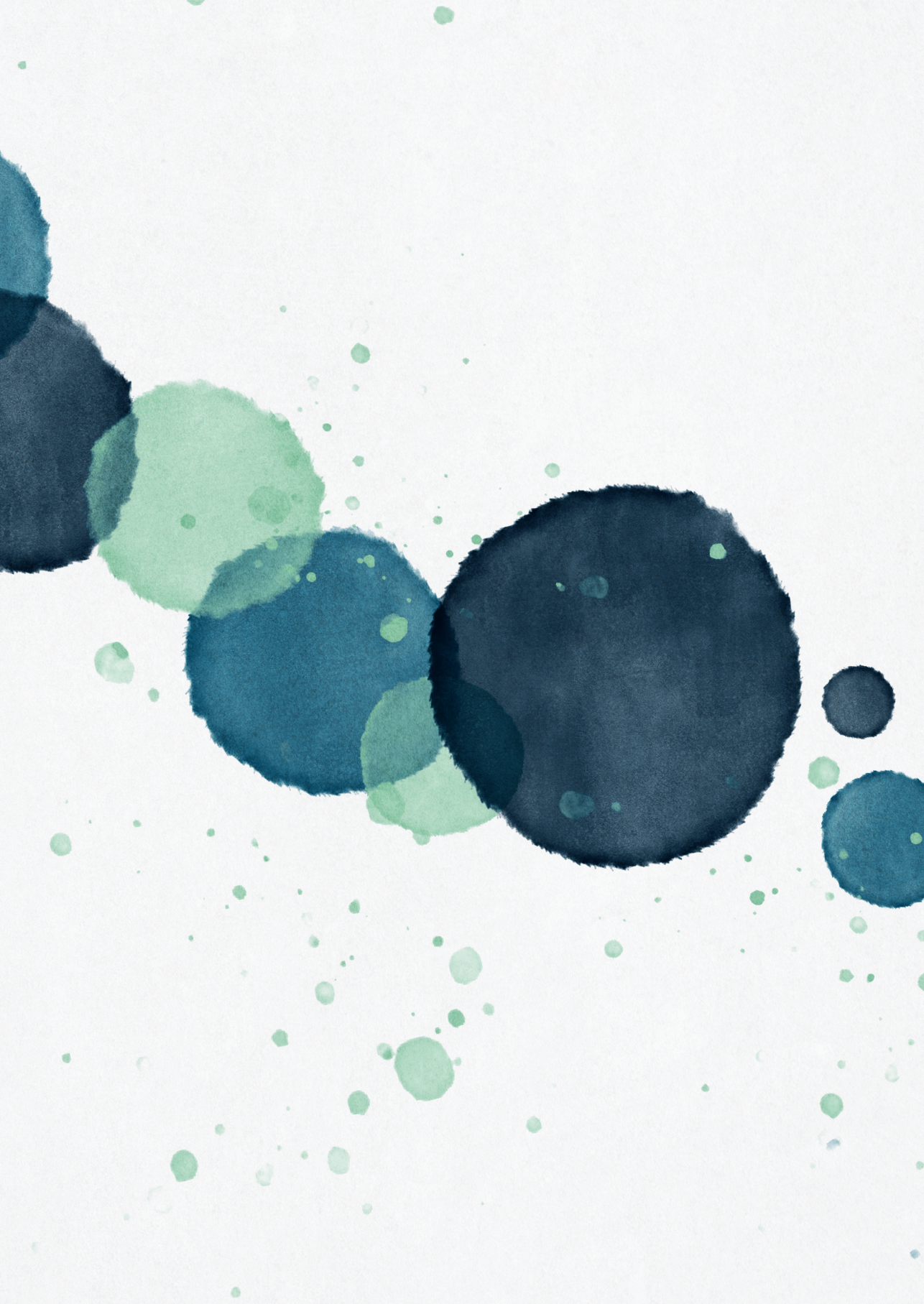

Part III

Measuring daily functioning

Chapter

6

Measuring daily functioning in older persons using a frailty index: a cohort study based on routine primary care data

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ABSTRACT

Background

Electronic health records (EHRs) are increasingly used for research; however, multicomponent outcome measures such as daily functioning cannot yet be readily extracted.

Aim

To evaluate whether an electronic frailty index based on routine primary care data can be used as a measure for daily functioning in research with community-dwelling older persons (aged ≥75 years).

Design and Setting

Cohort study among participants of the Integrated Systemic Care for Older People (ISCOPE) trial (11 476 eligible; 7285 in observational cohort; 3141 in trial; overrepresentation of frail people)

Method

At baseline (T0) and after 12 months (T12), daily functioning was measured with the Groningen Activities Restriction Scale [GARS, range 18-72]. Electronic frailty index scores (range 0-1) at T0 and T12 were computed from the EHRs. The electronic frailty index (electronic Frailty Index – Utrecht) was tested for responsiveness and compared with the GARS as a gold standard for daily functioning.

Results

In total, 1390 participants with complete EHR and follow-up data were selected (31.4% male; median age = 81 years, interquartile range = 78-85). The electronic frailty index increased with age, was higher for females, and lower for participants living with a partner. It was responsive after an acute major medical event; however, the correlation between the electronic frailty index and GARS at T0 and over time was limited.

Conclusion

Because the electronic frailty index does not reflect daily functioning, further research on new methods to measure daily functioning with routine care data (for example, other proxies) is needed before EHRs can be a useful data source for research with older persons.

Keywords
Activities of daily living, electronic health records, general practice, aged, frail older persons

HOW THIS FITS IN

Daily functioning is an often used outcome measure in the older population. If it could be extracted from routine care data it could save cost and time for both research and general practice. Although there are currently no established methods to measure daily functioning with routine primary care data, an electronic frailty index was suggested as a potentially useful evaluative measure for functioning. The electronic frailty index tested in this study (electronic Frailty Index — Utrecht) was responsive after an acute major medical event, but did not compare well with the gold standard for daily functioning (that is, the Groningen Activities Restriction Scale). Therefore, in its current state and context, the electronic frailty index cannot be used in research or general practice because of its limited ability to reflect daily functioning.

INTRODUCTION

The use of routine care data such as electronic health records (EHRs) of general practitioners (GPs) for research and population health management is increasing. These EHRs could be a valuable data source for research with older persons, which is often expensive and time-consuming. Some variables (for example, diagnoses, death, hospital admissions, polypharmacy, and multimorbidity) can be easily extracted from GPs' EHRs. However, often in research with older persons, complex, multicomponent outcome measures such as quality of life and functioning are used. These variables cannot be readily extracted from EHR data.[1, 2] Daily functioning, which is often used as an outcome measure in the older population, is such a variable.[3-7] It is described in terms of basic Activities of Daily Living (ADL) and instrumental Activities of Daily Living (iADL). Both in research and clinical practice, these are currently assessed with questionnaires such as the Katz ADL scale, the Lawton iADL scale, or the Groningen Activities Restriction Scale (GARS [ADL and iADL]).[8-10] As reflected in those questionnaires, daily functioning is the resultant of a patient's physical, psychological, cognitive, and social status.[11] A potential measure of daily functioning based on items of the EHR should therefore incorporate these different aspects.

The frailty index (FI), as outlined by Rockwood et al[12], integrates the different aspects mentioned above (that is, physical, psychological, cognitive, and social functioning) into one measure.[13, 14] An FI consists of a comprehensive list of deficits and functional losses in different domains, from which a continuous score is calculated by dividing the number of deficits present in an individual by the total number of deficits from the list (score range 0-1).[15, 16] Most FIs are derived from questionnaires, but more recently FIs were developed that were derived from routine care data.[12, 17] Previous research showed that the scores of the FI are stable across different versions of the FI and across different data sources used.[15, 16]

Some researchers have suggested that the integration of multiple domains of functioning into the FI make it a potentially useful evaluative measure for health status or functioning.[13, 15, 18] However, other researchers state that a measure of functional decline should not only include the number of deficits, but also the severity and impact of each deficit, which would make the FI unfit as a measure of daily functioning.[19, 20] If an older person's daily functioning can be extracted from routine care data it opens new opportunities for research in large datasets, potentially saving costs and time in research. The FI is currently the only multicomponent outcome measure that can be extracted from EHRs, but it is still

unclear whether it could serve as a proxy for daily functioning. The aim of this study was to test whether an electronic FI based on routine primary care data can be used as an evaluative measure for daily functioning in research with older persons.

METHOD

Design

This was a prospective cohort study embedded in the Integrated Systemic Care for Older People (ISCOPE) trial (Netherlands trial register, NTR1946). Further details about the trial are described elsewhere.[21]

ISCOPE study

The ISCOPE study included 59 general practices from the Leiden region (The Netherlands). All patients aged ≥ 75 years enlisted in these practices were invited to participate. Exclusion criteria were: 1) life expectancy <3 months; 2) nursing home resident; 3) non-Dutch speaking; and 4) considered to be too ill to participate by the general practitioner (GP). Postal screening questionnaires together with an invitation to participate in the study were sent to 11 476 older persons. The ISCOPE screening questionnaire consisted of questions on four health domains (that is, functional; somatic; psychological; and social). Those who filled in and returned the ISCOPE screening questionnaire and the informed consent form (n=7285) were included in the study. Inclusion took place from September 2009 until September 2010. The study was approved by the Medical Ethical Committee of the Leiden University Medical Center (P09.096). All participants gave informed consent.[21]

For the trial, a selection of the participants (n=3141) were included for a 12-month follow-up. This sample consisted of all participants with problems on three or four domains of the ISCOPE screening questionnaire, a random sample of 60% of participants with problems on two domains and a random sample of 15% of participants with problems on one or no domain. At baseline (T0) they were visited at home by a research nurse to collect extra information on sociodemographic characteristics and to administer additional questionnaires (that is, GARS and Mini-Mental State Examination [MMSE]; range = 0 to 30). After 12 months (T12) the measurements were administered again. In addition, data over a period of 5 years before until 1 year after the first home visit were extracted from the participants' EHRs. The extracted data contained both diagnoses with International Classification of Primary Care (ICPC)-1-NL codes, prescriptions with Anatomical Therapeutic Chemical (ATC) codes, and free text. The EHR data were linked to the study data on a person-level using a personal identification number.

Participants

Inclusion criteria for this secondary analysis were a complete follow-up (T12), an available EHR, and at least one ICPC or ATC code registered in the EHR (that is, necessary to compute the electronic FI). Participants with missing values on either the GARS or the electronic FI were also excluded from the analyses (n=23).

Measures

Electronic Frailty Index - Utrecht (eFI-U)

In this study the electronic frailty index was used as developed by Drubbel et al.[22-26] (the eFI-U). This FI is generated from routine primary care data and consists of a list of 50 deficits (Supplementary Table 1). It includes physical, psychological, cognitive, and social deficits. Each deficit again consists of a list of ICPC and ATC codes related to that deficit. If one ICPC or ATC code was present in the previous 6 months or 5 years (depending on the code), the corresponding deficit scores positive (that is, one point). Diagnostic measurement data were not included in the eFI-U of this study, because these data were not extracted in the ISCOPE study.

Groningen Activities Restriction Scale (GARS)

The Groningen Activities Restriction Scale (GARS) was used as a gold standard for measuring daily functioning. The GARS is an 18-item questionnaire with 11 questions on basic Activities of Daily Living (ADL) and seven questions on Instrumental Activities of Daily Living (iADL). Each question has four answer categories: (1) fully independent without problems; (2) fully independent, but with some difficulty; (3) fully independent, but with a lot of difficulty; (4) only with another person's help). The total score ranges from 18 to 72 points, with a higher score indicating a lower level of daily functioning or more dependency. Previous research showed that GARS scores were higher with advancing age, in females, and in older persons who are institutionalised or living independently without a partner.[27-30]

Subgroups

Subgroups based on the occurrence of an acute major medical event during follow-up were compared. In this study, an acute major medical event was defined as a medical event with a sudden onset, which is likely to have a large impact on a person's daily functioning. In this study, hip fracture, myocardial infarction, and stroke were included as acute major medical events. These events were considered to be present either if participants reported them in the follow-up questionnaire, or if corresponding ICPC codes were registered during the follow-up period. This was done to assure that all participants with an event during the follow-up period were identified. The ICPC codes included were L75 (femur

fracture), K75 (acute myocardial infarction), K89 (transient cerebral ischaemia), and K90 (stroke).

Statistical analysis

Characteristics of the population at baseline were described. The construct validity of the eFI-U was assessed by comparing subgroups based on age, sex and living status. Based on previous findings with the GARS, is was hypothesised that, if the baseline eFI-U measured daily functioning, average scores would increase with age, be higher for females compared with males, and be highest for those living in a residential care facility and lowest for those living independently with a partner. This was tested with Spearman's correlation (age), the Mann-Whitney U test (sex), and the Kruskal Wallis test (living status: independently alone, independently with partner, or residential care facility).[27-32]

To test the eFI-U for floor and ceiling effects, a histogram of the eFI-U at baseline was created for visual inspection. Floor or ceiling effects were considered to be present if >15% of participants reached the lowest or highest possible score, which was also tested. The upper limit of the eFI-U was assessed by plotting the 99th percentiles of the baseline eFI-U in the cohort against age.

For both the eFI-U and the GARS the difference between the follow-up and baseline scores was calculated (delta = measurement at 12 months minus measurement at baseline). The delta scores were also corrected for the baseline scores, because the latter influence the potential change over time. The resulting relative deltas were calculated as the actual delta divided by the maximum delta possible for that patient (relative delta = [measurement at 12 months minus measurement at baseline] divided by [total score minus measurement at baseline plus 0.01]). An extra 0.01 was added to the denominator to avoid a value of zero.

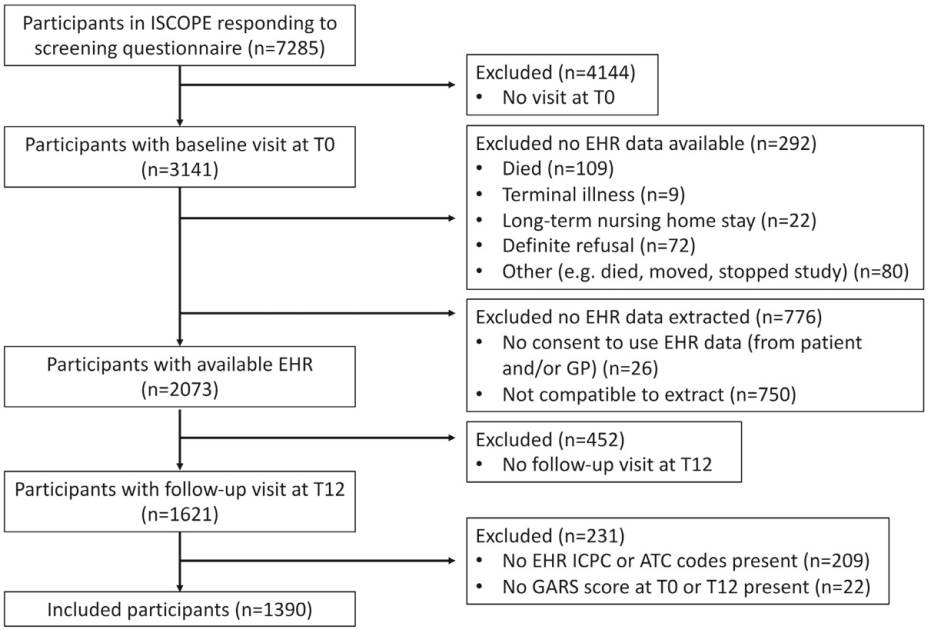
To explore responsiveness, the occurrence of an acute major medical event during follow-up was used as an implicit external criterion of larger change. The delta and relative delta eFI-U scores of the groups with and without event were described and compared with a Mann-Whitney U test. Standardised effect sizes (Cohen's d) were calculated for both the (relative) delta eFI-U and the (relative) delta GARS. The standardised effect sizes of the eFI-U and the GARS were expected to be similar and both were expected to be small to moderate.

Criterion validity of the eFI-U was assessed with Spearman's correlation between the baseline eFI-U and the baseline GARS. The association between changes

(delta and relative delta) in the eFI-U and the GARS was also tested with Spearman's correlation. If the eFI-U measured daily functioning, the correlation coefficient was expected to be ≥0.70 in both cases.[32-34]

To get a better understanding of the relationship between the eFI-U and the GARS over time, participants were grouped in quartiles according to their delta GARS scores. All delta GARS quartiles were compared on delta eFI-U scores (Jonckheere-Terpstra test) and on the number of acute major medical events during follow-up (X^2 test for trend). In addition, the baseline GARS scores were compared between the delta GARS quartiles to check whether correction for baseline scores was needed. Because of significant differences between the quartiles in GARS score at baseline, the same analyses were repeated with quartiles based on the relative delta. The same analyses were also carried out with quartiles based on the (relative) delta eFI-U scores (Supplementary Tables S2 and S3).

Figure 1. Flowchart



RESULTS

A flowchart of the participants is presented in Figure 1. Table 1 displays the characteristics of the 1390 older persons included in the analyses. The delta eFI-U was approximately normally distributed and ranged from −0.14 to +0.20 (Supplementary Table S4).

Table 1. Sociodemographic and functional characteristics of the total study population at T0

	Total population (n=1390)
Age#	81 (78-85)
Male, n (%)	436 (31.4)
Living situation, n (%)~	
Independent alone	768 (55.3)
Independent together	507 (36.5)
Residential care facility	114 (8.2)
Low education, n (%)*~	509 (36.6)
Low income, n (%)^~	206 (14.8)
MMSE#~	28 (26-29)
GARS#	30 (24-38)
eFI-U#	0.16 (0.10-0.22)

#Continuous data are presented by median and interquartile range (25th and 75th percentile)
~Missing n (%): living situation 1 (0.1), low education 1 (0.1), low income 1 (0.1), MMSE 11 (0.8)
*Low education defined as primary school only
^Low income defined as state pension only (no additional pension)

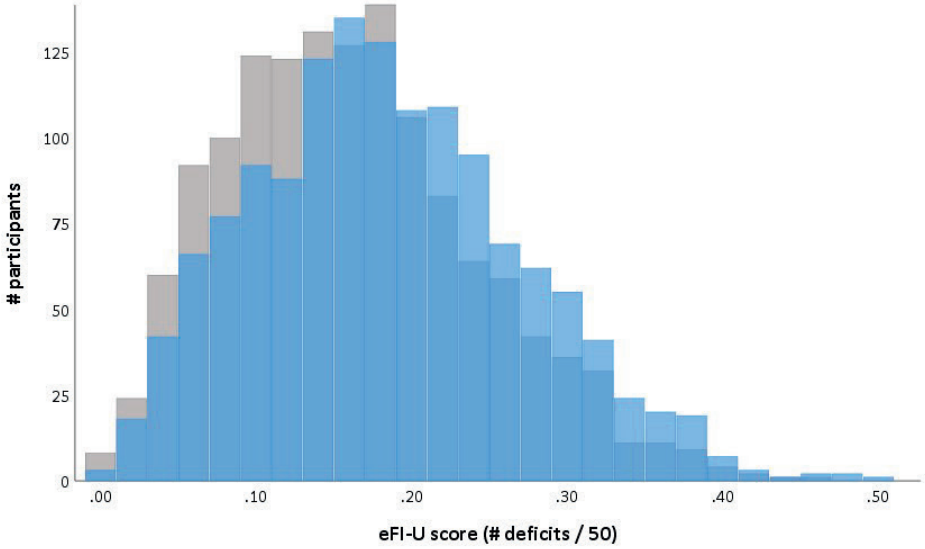
Construct validity

The baseline eFI-U scores were higher in the older participants, but the association with age was smaller than expected (Spearman's rho = 0.071; p=0.008). As expected, females on average had a higher eFI-U score at baseline compared with males (Mann-Whitney U test, p<0.001; median females = 0.16, interquartile range [IQR] = 0.10 to 0.22 versus males = 0.14, IQR = 0.08 to 0.20). Furthermore, participants who lived in a residential care facility had the highest eFI-U score at baseline and those living independently with a partner the lowest (Kruskal Wallis test, p<0.001; median institutionalised = 0.18, IQR = 0.12 to 0.26; median independently alone = 0.16, IQR = 0.10 to 0.22; median independently with partner = 0.14, IQR = 0.10 to 0.20) (data not shown).

Floor or ceiling effects

The histogram of the baseline eFI-U showed a slight right-skewed distribution, approaching a gamma distribution (Figure 2). The baseline eFI-U score in the total group ranged from 0.00 to 0.46. The 15% highest score was ≥0.25 and the 15% lowest score was ≤0.08, suggesting there was no floor or ceiling effect. No common maximum of the eFI-U at every age was observed, which again suggested that there was no ceiling effect.[16]

Figure 2. Distribution of the eFI-U scores at T0 and T12 of the total population (n=1390)



Legend
T0=grey, T12=blue

Responsiveness eFI-U (acute major medical events)

During follow-up, 193 participants (13.9%) experienced an acute major medical event (that is, hip fracture, myocardial infarction, and/or stroke) (Table 2). Of those 193 participants, 185 had one type of event and eight had two different types of events during follow-up. In total, 22 (1.6%) participants had a hip fracture, 64 (4.6%) a myocardial infarction, and 115 (8.3%) a stroke (data not shown). Characteristics of the participants with and without an acute major medical event during follow-up are described in Table 2.

There was a significant difference in (relative) delta eFI-U between participants with and without an acute major medical event during follow-up (mean absolute delta = 0.039, standard deviation (SD) 0.052 versus 0.020, SD 0.043, p<0.001;

relative delta = 0.047, SD 0.064 versus 0.023, SD 0.051, p<0.001) (Table 2). The standardised effect sizes were 0.42 (delta) and 0.45 (relative delta), which can both be considered small but present (data not shown). The difference in delta and relative delta GARS between participants with and without an acute major medical event during follow-up was also significant. The standardised effect size was 0.21 for the delta GARS and 0.23 for the relative delta GARS, which can both be considered small but present, just like the standardised effect sizes of the (relative) delta eFI-U (data not shown).

Table 2. Characteristics of subgroups based on the presence of an acute major medical event during follow-up

	Acute major medical event		p-value
	Yes (n=193)	**No (n=1197)**	
Population characteristics			
Age#	82 (78-86)	81 (78-85)	
Male, n (%)	76 (39.4)	360 (30.1)	
MMSE at T0#~	28 (27-29)	28 (26-29)	
Living situation, n (%)~			
Independent alone	101 (52.3)	667 (55.7)	
Independent together	78 (40.4)	429 (35.8)	
Residential care facility	14 (7.3)	100 (8.4)	
eFI-U#			
Baseline	0.20 (0.13-0.26)	0.14 (0.10-0.20)	
Follow-up	0.24 (0.16-0.30)	0.18 (0.12-0.24)	
Δ^	0.0392 (0.05239)	0.0202 (0.04284)	<0.001
Relative Δ^	0.0472 (0.06421)	0.0229 (0.05141)	<0.001
GARS#			
Baseline	34 (26.5-43)	29 (23-37.5)	
Follow-up	39 (30-48)	32 (25-41)	
Δ^	3.7927 (6.88889)	2.4436 (6.31102)	0.012
Relative Δ^	0.1082 (0.22952)	0.0547 (0.23711)	0.003

#Continuous data are presented by median and interquartile range (25th and 75th percentile)

~Missing n (%): living situation 1 (0.1), MMSE 11 (0.8)

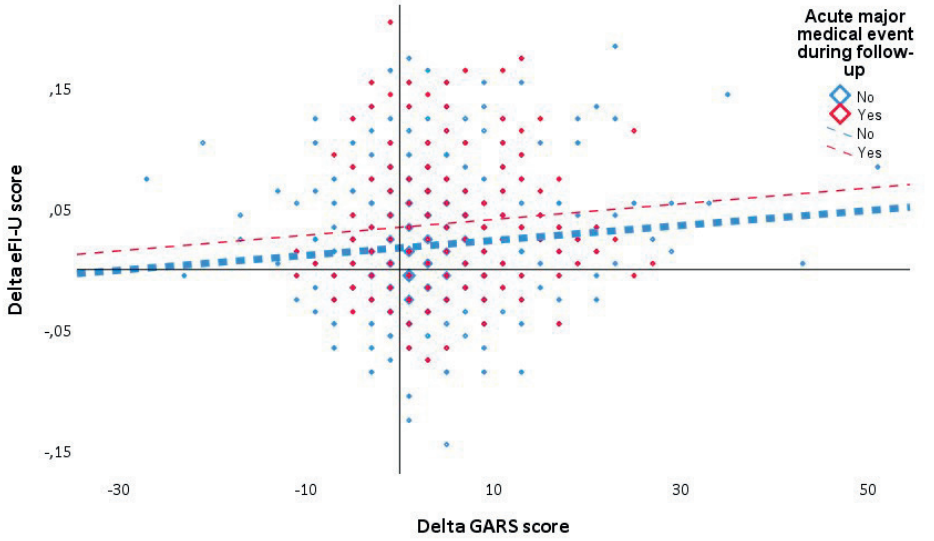
^Approximately normal distribution (visual)

Criterion validity

At baseline the Spearman's ρ between the eFI-U and the GARS was 0.374 (p<0.001). Figure 3 is a graphic representation of the relationship between the delta eFI-U and the delta GARS. The correlation coefficient between the delta

eFI-U and the delta GARS was 0.088 and the correlation coefficient of the relative deltas was 0.097 (both p≤0.001). No regression analysis was done because of the low correlation between the delta GARS and the delta eFI-U.

Figure 3. Delta eFI-U scores against delta GARS scores for those with and without an acute major medical event during follow-up



Legend
N=1390
with event (red) n=193, without event (blue) n=1197

Comparison GARS quartiles

More in depth, the median delta eFI-U across the quartiles of the delta GARS was 0.02 (IQR = 0.00 to 0.04) for the first quartile, 0.02 (IQR = 0.00 to 0.04) for the second quartile, 0.02 (IQR = 0.00 to 0.06) for the third quartile, and 0.02 (IQR = 0.00 to 0.04) for the fourth quartile (p=0.003)(Table 3). By contrast, there was a large and significant difference in median delta GARS over the delta GARS quartiles, as expected (p<0.001). Furthermore, the incidence of acute major medical events during follow-up increased over the quartiles (13,0% in lowest quartile compared with 20.5% in highest quartile; p=0.005). The baseline GARS was highest for the participants in the lowest delta GARS quartile (p=0.029). These differences in GARS at baseline suggest that the low change of the GARS during follow-up in the lowest quartile might be partly due to a high baseline GARS (that is, participants are not able to get much higher). Therefore, the same analyses were repeated with quartiles based on the relative delta GARS. Apart from the baseline GARS score the findings did not change much (Supplementary Table S5).

Table 3. Comparison between lowest and highest delta Groningen Activities Restriction Scale (GARS) quartiles

	Δ GARS			
	Quartile 1 (0%-<25%)	**Quartile 2 (25%-<50%)**	**Quartile 3 (50%-<75%)**	**Quartile 4 (75%-100%)**
GARS (median, IQR)*				
Baseline~	33 (27; 42,5)	25 (20; 34)	30 (23; 37)	30 (25; 38)
Follow-up	29 (23; 38)	26 (21; 35)	33 (26; 41)	41 (35; 51)
Δ~	-3 (-5; -2)	0 (0; 1)	3 (2; 4)	9 (7; 12)
eFI-U (median, IQR)				
Baseline	0.16 (0.10; 0.22)	0.14 (0.08; 0.18)	0.16 (0.12; 0.22)	0.18 (0.10; 0.22)
Follow-up	0.18 (0.12; 0.24)	0.16 (0.10; 0.20)	0.18 (0.12; 0.24)	0.18 (0.14; 0.26)
Δ~	0.02 (0.00; 0.04)	0.02 (0.00; 0.04)	0.02 (0.00; 0.06)	0.02 (0.00; 0.04)
Major medical events (n, %)~	50 (13.0)	29 (10.0)	42 (11.6)	72 (20.5)

*The GARS and eFI-U were not normally distributed for any of the variables.

~p-value for trend: baseline GARS p=0.029, delta GARS p<0.001, delta eFI-U p=0.003, major medical events p=0.005

DISCUSSION

Summary

This study explored whether an electronic FI based on routine primary care data can be used as an evaluative measure for daily functioning in research with older persons. As the electronic FI tested in this study (eFI-U) changed over time and did not have floor or ceiling effects, it might be useful as an evaluative measure; however, there was a moderate overlap between the eFI-U and the GARS. Furthermore, the eFI-U was responsive after an acute major medical event, just like the GARS, but it was barely responsive over time in the population as a whole, which was different from the GARS. These findings suggest that the eFI-U does not reflect daily functioning in older persons.

Strengths and limitations

The main strength of this study is the high generalisability of the results because of the data and the instrument used. Previous studies already showed that the FI, because of the underlying concept of deficit accumulation, is a flexible instrument that can be based on different deficits and data sources and still give the same results.[15, 16] The data used in this study (EHRs from Dutch general practices) are similar to many other routine care data in that they contain both codes and free text, which increase the generalisability of the results of this study. Another

strength is the availability of a combination of routine care data and standardised questionnaires from the same community-dwelling older population and time period. Combining these data sources allows for a direct comparison of the EHR-derived instrument with a gold standard for daily functioning (that is, GARS). Furthermore, because of the availability of extensive prospective data, the authors were able to assess responsiveness by looking both over time (gradual decline in ADL/iADL) and after an event (sudden change in ADL/iADL).

This study also has some limitations. First, part of the lack of correlation in our study might be explained by the EHR data on which the electronic FI was based. Quality and completeness of coded routine care data fully rely on the ability and willingness of the primary care team to code and prioritise their findings in routine healthcare systems. Second, quite a few patients had to be excluded because they were not selected for follow-up or were lost to follow-up in the ISCOPE trial. This drop out is likely to be associated with poor daily functioning and/or a higher level of deficits. The attrition and complete case analysis in this study, therefore, might have skewed the responses and weakened the effects found. Some patients were also excluded because of missing or unavailable EHRs; however, most of these missing EHRs are expected to be completely random as they were missing at practice level because of software problems. Thus, the influence on the results is expected to be limited.

Another limitation concerns the combination of the electronic FI tested in this study with the type of data from which it is derived. The eFI-U is a cumulative score based on EHRs of general practices. As a result, those patients who have been registered with their GP for a long time and those who visit more often are more likely to accumulate recorded deficits and thus have a higher eFI-U score compared to other patients. For any instrument based on EHR data, the influence of consultation frequency and registration period, among other factors, should be taken into account.

Comparison with existing literature

In previous literature some researchers suggested that an FI could serve as an evaluative measure for daily functioning because of its multicomponent nature.[13, 15, 18] However, other researchers stated that this was not possible because frailty and disability are different constructs and because no information on severity and impact is included in an FI.[19, 20, 35, 36]

The results of this study using the eFI-U are in line with the studies that showed a limited association between frailty and daily functioning.[35, 36] The authors of these studies pose that frailty and disability are overlapping but distinct concepts. Thus, an instrument that is designed to measure frailty will not be able to measure disability and vice versa. The findings of this study show that an FI based on EHR data also does not reflect measurements of (daily) functioning. Furthermore, these findings are in line with studies on the relationship between the number of diseases or deficits and functional decline.[19, 20] As was already concluded in those studies, functioning or daily functioning is not only a matter of the number of deficits (which is the approach of an FI), but also of the severity and impact of each deficit. The current study shows that this is also the case when routine primary care data is used to count deficits. An electronic FI could be enriched with information on severity, and more importantly impact, through the use of new techniques such as plain-text mining and other advanced reading techniques, which are a proven approach to increase the quality of algorithms like an electronic FI. However, it is doubtful whether EHRs contain enough information on severity and impact.

Implications for research and practice

An evaluative measure for daily functioning that can be obtained from routine care data could be useful both for research (to replace time-consuming questionnaires) and clinical purposes (to monitor patients). In research such a measure may save costs and time for both the researcher and the clinician. Furthermore, it may allow for more efficient and faster research, which might in the end improve patient outcomes and day to day general practice management. This study showed that the FI (with a deficit counting approach), in its current state and context, has a limited ability to reflect daily functioning. As the electronic FI does not measure the aimed construct it cannot be used as an evaluative measure of daily functioning for research. The lack of precision and congruence of the eFI-U with the GARS means that it is even further away from use in clinic to monitor individual patients' daily functioning. Further research could focus on other approaches (that is, other proxies or adjusted versions of the electronic FI) to measure daily functioning with routine care data. It must be noted that previous research has shown that the eFI-U can be used in population health management as a frailty identification instrument on a population level.[23, 25]

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SUPPLEMENTARY DATA

Table S1. Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
1	General signs and symptoms	A01		Pain general/multiple sites	6 months
		A03		Fever	6 months
		A04		Weakness/tiredness general	6 months
		A05		General deterioration	6 months
		A29		General symptom/complaint other	6 months
		B29		Sympt/complt lymph/immune other	6 months
			N02	Analgesics	6 months
2	Instability / immobility	A06		Fainting/syncope	6 months
		A10		Bleeding-haemorrhage NOS	6 months
		A28		Limited function/disability NOS	5 years
		A80		Trauma/injury NOS	6 months
		H82		Vertiginous syndrome/labyrinthitis	5 years
		K88		Postural hypotension	5 years
		L02		Back symptom/complaint	6 months
		L03		Low back symptom/complaint without radiating pain	6 months
		L13		Hip symptom/complaint	6 months
		L14		Leg/thigh symptom/complaint	6 months
		L15		Knee symptom/complaint	6 months
		L16		Ankle symptom/complaint	6 months
		L17		Foot/toe symptom/complaint	6 months
		L28		Limited function/disability	5 years
		L72		Fracture: radius/ulna	5 years
		L73		Fracture: tibia/fibula	5 years
		L74		Fracture: hand/foot bone	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		L75		Fracture: femur	5 years
		L76		Fracture: other	5 years
		L77		Sprain/strain of ankle	6 months
		L78		Sprain/strain of knee	6 months
		L79		Sprain/strain of joint NOS	6 months
		L80		Dislocation/subluxation	5 years
		L81		Injury musculoskeletal NOS	6 months
		L86		Low back symptom/complaint with radiating pain	6 months
		L96		Acute internal damage knee	5 years
		N17		Vertigo/dizziness	6 months
		N18		Paralysis/weakness	5 years
		N79		Concussion	5 years
		N80		Head injury other	5 years
		S16		Bruise/contusion	6 months
		S17		Abrasion/scratch/blister	6 months
		S18		Laceration/cut	6 months
		S19		Skin injury other	6 months
			N07C	Antivertigo drugs	5 years
3	Treatment complications	A13		Concern/fear of medical treatment	6 months
		A85		Adverse effect medical agent	6 months
		A87		Complication of medical treatment	6 months
		A89		Effect prosthetic device	6 months
4	Cancer	A79		Malignancy NOS	5 years
		B72		Hodgkin's disease	5 years
		B73		Leukaemia	5 years
		B74		Malignant neoplasm blood other	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		D74		Malignant neoplasm stomach	5 years
		D75		Malignant neoplasm colon/rectum	5 years
		D76		Malignant neoplasm pancreas	5 years
		D77		Malignant neoplasm digest other/NOS	5 years
		F74		Neoplasm of eye/adnexa	5 years
		H75		Neoplasm of ear	5 years
		K72		Neoplasm cardiovascular	5 years
		L71		Malignant neoplasm musculoskeletal	5 years
		N74		Malignant neoplasm nervous system	5 years
		R84		Malignant neoplasm bronchus/lung	5 years
		S77		Malignant neoplasm of skin	5 years
		T71		Malignant neoplasm thyroid	5 years
		U75		Malignant neoplasm of kidney	5 years
		U76		Malignant neoplasm of bladder	5 years
		U77		Malignant neoplasm urinary other	5 years
		X75		Malignant neoplasm cervix	5 years
		X76		Malignant neoplasm breast female	5 years
		X77		Malignant neoplasm genital other (f)	5 years
		Y77		Malignant neoplasm prostate	5 years
		Y78		Malignant neoplasm male genital/mammae	5 years
			L01	Antineoplastic agents	5 years
			L02	Hormonal agents given in malignant conditions	5 years
5	Anaemia	B80		Iron deficiency anaemia	5 years
		B81		Anaemia, Vitamin B12/folate def.	5 years
		B82		Anaemia other/unspecified	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		B03		Antianaemic medications	5 years
6	GI tract symptoms	D01		Abdominal pain/cramps general	6 months
		D02		Abdominal pain epigastric	6 months
		D03		Heartburn	6 months
		D06		Abdominal pain localized other	6 months
		D09		Nausea	6 months
		D10		Vomiting	6 months
		D11		Diarrhoea	6 months
		D12		Constipation	6 months
		D14		Haematemesis/vomiting blood	6 months
		D15		Melena	6 months
		D16		Rectal bleeding	6 months
		D17		Incontinence of bowel	6 months
		D18		Change faeces/bowel movements	6 months
		D20		Mouth/tongue/lip symptom/complaint	6 months
		D29		Digestive symptom/complaint other	6 months
			A04	Antiemetics and antinauseants	6 months
			A07	Antidiarrhoeals, intestinal anti-inflammatory/anti-infective agents	6 months
			A06	Drugs for constipation	6 months
7	Liver / gallbladder disease	D72		Viral hepatitis	5 years
		D97		Cirrhosis / liver disease NOS	5 years
		D98		Cholecystitis/cholelithiasis	5 years
			A05	Bile and liver therapy	5 years
8	Upper GI tract disease / GI tract hernia	D73		Gastroenteritis presumed infection	6 months
		D84		Oesophagus disease	5 years
		D85		Duodenal ulcer	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		D86		Peptic ulcer other	5 years
		D87		Stomach function disorder	5 years
		D89		Inguinal hernia	5 years
		D90		Hiatus hernia	5 years
			A02	Drugs for acid related disorders	5 years
9	Lower GI tract disease	D92		Diverticular disease	5 years
		D93		Irritable bowel syndrome	5 years
		D94		Chronic enteritis/ulcerative colitis	5 years
		K96		Haemorrhoids	6 months
			A03	Drugs for functional gastrointestinal disorders	5 years
10	Eye symptoms / infections	F02		Red eye	6 months
		F03		Eye discharge	6 months
		F04		Visual floaters/spots	6 months
		F05		Visual disturbance other	6 months
		F13		Eye sensation abnormal	6 months
		F15		Eye appearance abnormal	6 months
		F16		Eyelid symptom/complaint	6 months
		F70		Conjunctivitis infectious	6 months
		F72		Blepharitis/stye/chalazion	6 months
		F85		Corneal ulcer	6 months
			S01A	Anti-infectives	6 months
			S01X	Other ophthalmologicals	6 months
11	Visual impairment	F83		Retinopathy	5 years
		F84		Macular degeneration	5 years
		F92		Cataract	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		F93		Glaucoma	5 years
		F94		Blindness	5 years
			S01E	Antiglaucoma preparations and miotics	5 years
12	Ear symptoms / infection	H02		Hearing complaints	6 months
		H03		Tinnitus, ringing/buzzing ear	6 months
		H13		Plugged feeling ear	6 months
		H70		Otitis externa	6 months
		H81		Excessive ear wax	6 months
			S02	Otologicals	6 months
13	Hearing impairment	H84		Presbycusis	5 years
		H86		Deafness	5 years
14	Circulatory tract symptoms	K01		Heart pain	6 months
		K02		Pressure/tightness of heart	6 months
		K04		Palpitations/awareness of heart	6 months
		K07		Swollen ankles/oedema	6 months
		K29		Cardiovascular sympt/complt other	6 months
15	Ischaemic heart disease	K74		Angina pectoris	5 years
		K75		Acute myocardial infarction	5 years
		K76		Other/chronic ischaemic heart disease	5 years
			C01DA	Organic nitrates	5 years
16	Heart failure	K77		Heart failure	5 years
17	Cardiac arrhythmias / heart valve disease	K78		Atrial fibrillation/flutter	5 years
		K79		Paroxysmal tachycardia	5 years
		K80		Cardiac arrhythmia NOS	5 years
		K83		Heart valve disease NOS	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
			C01A	Cardiac Glycosides	5 years
			C01B	Antiarrhythmics class I and III	5 years
18	Hypertension	K85		Elevated blood pressure	5 years
		K86		Hypertension uncomplicated	5 years
		K87		Hypertension complicated	5 years
			C02	Antihypertensives	5 years
19	TIA/CVA	K89		Transient cerebral ischaemia	5 years
		K90		Stroke/cerebrovascular accident	5 years
20	Peripheral vascular disease / thrombotic disease	K91		Atherosclerosis	5 years
		K92		other PVD	5 years
		K93		Pulmonary embolism	5 years
		K94		Phlebitis/thrombophlebitis	5 years
		K99		Cardiovascular disease other	5 years
21	Locomotor tract symptoms	L01		Neck symptom/complaint	6 months
		L04		Chest symptom/complaint	6 months
		L05		Flank/axilla symptom/complaint	6 months
		L08		Shoulder symptom/complaint	6 months
		L09		Arm symptom/complaint	6 months
		L10		Elbow symptom/complaint	6 months
		L11		Wrist symptom/complaint	6 months
		L12		Hand/finger symptom/complaint	6 months
		L18		Muscle pain	6 months
		L19		Muscle symptom/complaint NOS	6 months
		L20		Joint symptom/complaint NOS	6 months
		L29		Sympt/complt musculoskeletal other	6 months

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		L92		Shoulder syndrome	6 months
22	Arthritis / Osteoarthritis	L84		Arthrosis/spondylosis back	5 years
		L88		Rheumatoid arthritis/related condition	5 years
		L89		Osteoarthrosis of hip	5 years
		L90		Osteoarthrosis of knee	5 years
		L91		Osteoarthrosis other/related condition	5 years
			M01AH	Coxibs	5 years
23	Osteoporosis	L95		Osteoporosis	5 years
			M05	Drugs for treatment of bone diseases	5 years
24	Neurologic symptoms	N01		Headache	6 months
		N04		Restless legs	6 months
		N05		Tingling fingers/feet/toes	6 months
		N06		Sensation disturbance other	6 months
		N19		Speech disorder	6 months
		N86		Multiple sclerosis	5 years
		N87		Parkinsonism, Parkinson's disease	5 years
		N88		Epilepsy	5 years
		N89		Migraine	5 years
		N93		Carpal tunnel syndrome	5 years
		N94		Peripheral neuritis/neuropathy	5 years
			N03	Antiepileptics	5 years
			N04	Anti-parkinson drugs	5 years
26	Mood symptoms	P01		Feeling anxious/nervous/tense	6 months
		P03		Feeling depressed	6 months
		P05		Senility, feeling/behaving old	6 months

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
27	Sleep disturbance	P06		Sleep disturbance	6 months
			N05C	Hypnotics and sedatives	6 months
28	Substance abuse	P15		Chronic alcohol abuse	5 years
		P18		Medication abuse	5 years
			N07B	Drugs used in substance abuse	5 years
		P17		Tobacco abuse	5 years
29	Cognitive impairment	P20		Memory/concentration/orientation disturbance	6 months
		P70		Dementia/Alzheimer's disease	5 years
		P71		Organic psychosis other	5 years
		P73		Affective psychosis	5 years
			N05A	Antipsychotics	5 years
			N06D	Anti-dementia drugs	5 years
30	Anxiety disorder	P74		Anxiety disorder/anxiety state	5 years
			N05B	Anxiolytics	5 years
31	Depression	P76		Depressive disorder	5 years
			N06A	Antidepressants	5 years
32	Respiratory tract symptoms	R02		Shortness of breath/dyspnoea w/o K02	6 months
		R05		Cough	6 months
		R06		Nose bleed/epistaxis	6 months
		R08		Nose symptom/complaint other	6 months
		R21		Throat symptom/complaint	6 months
			R05	Cough and cold preparations	6 months
			R01	Nasal preparations	6 months
33	Respiratory infection	R74		Upper respiratory infection acute	6 months
		R75		Sinusitis acute/chronic	6 months

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		R78		Acute bronchitis/bronchiolitis	6 months
		R81		Pneumonia	6 months
34	COPD/Asthma	R91		Chronic bronchitis/bronchiectasis	5 years
		R95		Chronic obstructive pulmonary disease	5 years
		R96		Asthma	5 years
			R03	Drugs for obstructive airway diseases	5 years
35	Skin symptoms	S02		Pruritus	6 months
		S04		Lump/swelling localized	6 months
		S06		Rash localized	6 months
		S10		Boil/carbuncle	6 months
		S20		Corn/callosity	6 months
		S21		Skin texture symptom/complaint	6 months
		S03		Warts	6 months
		S70		Herpes zoster	6 months
		S74		Dermatophytosis	6 months
		S75		Moniliasis/candidiasis skin	6 months
		S76		Skin infection other	6 months
			D01	Antifungals for dermatological use	6 months
			D06	Antibiotics and chemotherapeutics for dermatological use	6 months
37	Eczema, Psoriasis	S87		Dermatitis/atopic eczema	5 years
		S88		Dermatitis contact/allergic	5 years
		S91		Psoriasis	5 years
			D05	Antipsoriatics	5 years
			D07	Corticosteroids, dermatological preparations	5 years
38	Skin ulcus / other skin disease	S97		Chronic ulcer skin	5 years

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		S99		Skin disease, other	5 years
39	Intake / weight problems - nutritional deficiencies	T03		Loss of appetite	6 months
		T11		Dehydration	6 months
		T82		Obesity	5 years
		T83		Overweight	5 years
		T91		Vitamin/nutritional deficiency	6 months
		T08		Weight loss	6 months
			A11	Vitamins	6 months
			A12	Mineral supplements	6 months
40	Thyroid disorder	T85		Hyperthyroidism/thyrotoxicosis	5 years
		T86		Hypothyroidism/myxoedema	5 years
			H03	Thyroid therapy	5 years
41	Diabetes mellitus	T90		Diabetes mellitus	5 years
			A10	Drugs used in diabetes	5 years
42	Gout	T92		Gout	5 years
			M04	Antigout preparations	5 years
43	Lipid disorder	T93		Lipid disorder	5 years
			C10	Lipid modifying agents	5 years
44	Urinary incontinence	U04		Incontinence urine	5 years
			G04BD	Drugs used for urinary frequency and incontinence	5 years
45	Other urinary tract symptoms	U02		Urinary frequency/urgency	6 months
		U05		Urination problems other	6 months
		U06		Haematuria	6 months
		U29		Urinary symptom/complaint other	6 months

Table S1 (continued). Complete list eFI-U (50 deficits)

Deficit nr.	Deficit name	ICPC	ATC	Description	Period: in the last
		Y06		Prostate symptom/complaint	6 months
46	Urinary tract infection	U71		Cystitis/urinary infection other	6 months
47	Other urinary tract disease	U95		Urolithiasis	5 years
		U99		Urinary disease, other	5 years
48	Reproductive tract problems	X87		Uterovaginal prolapse	5 years
		Y07		Impotence NOS	5 years
		Y85		Benign prostatic hypertrophy	5 years
			G01	Gynaecological anti-infectives and antiseptics	6 months
			G03	Sex hormones and modulators of the genital system	5 years
			G04BE	Drugs used in erectile dysfunction	5 years
			G04C	Drugs used in benign prostatic hypertrophy	5 years
49	Social problems	Z01		Poverty/financial problem	5 years
		Z03		Housing/neighbourhood problem	5 years
		Z04		Social cultural problem	5 years
		Z10		Health care system problem	5 years
		Z11		Compliance/being ill problem	5 years
		Z12		Relationship problem with partner	5 years
		Z13		Partner's behaviour problem	5 years
		Z14		Partner illness problem	5 years
		Z15		Loss/death of partner problem	5 years
		Z16		Relationship problem with child	5 years
		Z18		Illness problem with child	5 years
		Z19		Loss/death of child problem	5 years
50	Medication			Number of drugs prescribed at least 3 times in last year of which at least 1 prescription in last 6 months ≥ 5	1 year

Table S2. Comparison between lowest and highest delta eFI-U quartiles

	Δ eFI-U			
	Quartile 1 (0-25%)	**Quartile 2 (25-50%)**	**Quartile 3 (50-75%)**	**Quartile 4 (75-100%)**
eFI-U (median, IQR)*				
Baseline~	0.18 (0.14; 0.26)	0.14 (0.08; 0.20)	0.14 (0.10; 0.20)	0.16 (0.10; 0.20)
Follow-up	0.16 (0.10; 0.22)	0.14 (0.08; 0.20)	0.18 (0.14; 0.22)	0.24 (0.18; 0.30)
Δ~	-0.02 (-0.04; -0.02)	0.00 (0.00; 0.00)	0.02 (0.02; 0.04)	0.08 (0.06; 0.10)
GARS (median, IQR)*				
Baseline	31 (23.25; 40)	29 (23; 37)	30 (23; 38)	30 (25; 40)
Follow-up	34 (26; 43)	31 (24; 40)	34 (25; 43)	34 (26; 44)
Δ~	1 (-1; 4)	1 (-1; 5)	2 (-1; 7)	2 (-1; 6)
Major medical events (n, %)~	32 (10.5)	31 (11.2)	63 (13)	67 (20.6)

*The eFI-U and GARS were not normally distributed for any of the variables.

~p-value for trend: baseline eFI-U p<0.001, delta eFI-U p<0.001, delta GARS p=0.008, major medical events p<0.001

Table S3. Comparison between lowest and highest relative delta eFI-U quartiles

	Relative Δ eFI-U			
	Quartile 1 (0-25%)	**Quartile 2 (25-50%)**	**Quartile 3 (50-75%)**	**Quartile 4 (75-100%)**
eFI-U (median, IQR)*				
Baseline~	0.18 (0.14; 0.26)	0.12 (0.08; 0.18)	0.18 (0.14; 0.22)	0.16 (0.10; 0.20)
Follow-up	0.16 (0.10; 0.22)	0.12 (0.08; 0.18)	0.20 (0.16; 0.24)	0.24 (0.18; 0.30)
Δ~	-0.02 (-0.04; -0.02)	0.00 (0.00; 0.02)	0.04 (0.02; 0.04)	0.08 (0.06; 0.10)
GARS (median, IQR)*				
Baseline	31 (23.25; 40)	28 (22; 36)	30 (25; 38)	31 (25; 40.5)
Follow-up	34 (26; 43)	30 (23; 39.25)	34 (27; 43)	34 (26; 45)
Δ~	1 (-1; 4)	1 (-1; 5)	2 (0; 7)	2 (-1; 6)
Major medical events (n, %)~	32 (10.5)	42 (10.6)	45 (13)	74 (21.7)

*The GARS and eFI-U were not normally distributed for any of the variables.

~p-value for trend: baseline eFI-U p=0.264, delta eFI-U p<0.001, delta GARS p=0.001, major medical events p<0.001

Quality implicit external criterion of change

No minimal clinically important difference for functional decline has been defined.[1, 2-4, 5] However, a basic annual change in participants (85+) without chronic diseases of 1.2 points per year (95% CI 1.0-1.4) was described by Drewes et al.[6] The change in GARS score we found for participants both without and with event is higher, and the difference between those groups is also more than those 1.2 points. This suggests that the difference between the group with and without event in GARS score is clinically relevant and thus the occurrence of an acute major medical event is a good implicit external criterion of change.

Table S4. Baseline, follow-up and delta eFI-U and GARS

	Baseline (median, IQR)	Follow-up (median, IQR)	Δ (mean, SD)*	Relative Δ (median, IQR)
eFI-U	0.16 (0.10; 0.22)	0.18 (0.12; 0.24)	0.0228 (0.04476)	0.0225 (0.00; 0.0533)#
GARS	30 (24; 38)	33 (25; 43)	2.6309 (6.40878)	0.0417 (-0.0227; 0.1459)~

*Approximately normal distribution (visual)

#Possible range -100 to 0.99

~Possible range -5400 to 0.99

Table S5. Comparison between lowest and highest relative delta GARS quartiles

	Relative Δ GARS			
	Quartile 1 (0-25%)	**Quartile 2 (25-50%)**	**Quartile 3 (50-75%)**	**Quartile 4 (75-100%)**
GARS (median, IQR)*				
Baseline~	34 (28; 43)	24 (20; 30,25)	29 (23; 35)	34 (27; 42)
Follow-up	30 (24; 39)	24 (20.75; 31)	32 (28; 38)	44 (37; 53)
Δ~	-3 (-6; -2)	0 (0; 1)	3 (2; 5)	9 (7; 12)
eFI-U (median, IQR)				
Baseline	0.16 (0.10; 0.22)	0.12 (0.08; 0.18)	0.16 (0.105; 0.22)	0.18 (0.12; 0.24)
Follow-up	0.18 (0.12; 0.24)	0.16 (0.10; 0.20)	0.18 (0.12; 0.24)	0.20 (0.14; 0.28)
Δ~	0.02 (0.00; 0.04)	0.02 (0.00; 0.04)	0.02 (0.00; 0.04)	0.02 (0.00; 0.06)
Major medical events (n, %)~	46 (13.2)	33 (9.4)	38 (11.0)	76 (21.9)

*The GARS and eFI-U were not normally distributed for any of the variables.

~p-value for trend: baseline GARS p=0.585, delta GARS p<0.001, delta eFI-U p=0.003, major medical events p=0.001

Comparison eFI-U quartiles

The median (IQR) delta GARS was similar across the delta eFI-U quartiles, even though the differences in delta eFI-U were, as expected, relatively large (Table S3). For both scores the differences between the lowest and highest quartile were significant (GARS p=0.028; eFI-U p<0.001). Furthermore, the incidence of acute major medical events during follow-up increased over the quartiles (11% in lowest quartile compared to 21% in highest quartile; p<0.001).

The baseline eFI-U was highest for the participants in the lowest delta eFI-U quartile. The difference was relevant and significant (p<0.001). These differences in eFI-U at baseline suggest that the low change of the eFI-U during follow-up in the lowest quartile might be partly due to a high baseline eFI-U (i.e. participants are not able to get much higher). Therefore, the same analyses were repeated with quartiles based on the relative delta eFI-U. This produced similar results (Table S4).

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Chapter

7

Self-perceived functioning and (instrumental) activities of daily living questionnaires after a hip fracture: Do they tell the same story?

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ABSTRACT

Background
(Instrumental) activities of daily living ((I)ADL) questionnaires are often used as a measure of functioning for different purposes. Depending on the purpose, a measurement of functioning that includes subjective patient perspectives can be relevant. However, it is unclear to what extent (I)ADL instruments capture self-perceived functioning.

Objective
Explore what functioning means to older persons after a hip fracture and assess the extent to which (I)ADL instruments align with self-perceived functioning.

Design
Qualitative interview study with framework analysis.

Setting
Prospective cohort study on recovery after a hip fracture among older persons in a hospital in a large city in the west of the Netherlands.

Subjects
Eighteen home-dwelling older persons (≥70 years) who had a hip fracture 6-12 months ago.

Methods
Telephone interviews about functioning before and after the hip fracture were coded and analysed using the framework method.

Results
The activities mentioned by participants to be part of their self-perceived functioning could be split into activities necessary to maintain the desired level of independence, and more personal activities that were of value to participants. Both the 'independence activities' and the 'valued activities' mentioned went beyond the activities included in (I)ADL questionnaires. Due to various coping strategies, limitations in activities that were measured in the (I)ADL questionnaires did not necessarily lead to worse self-perceived functioning.

Conclusion
Self-perceived functioning differs from functioning measured with (I)ADL questionnaires in the items included and the weighing of limitations in activities. Thus, (I)ADL instruments alone are not enough to measure functioning from the perspective of the older person.

Keywords
Self-perceived functioning, (instrumental) activities of daily living, hip fracture, older people, qualitative research.

KEY POINTS

- (Instrumental) activities of daily living ((I)ADL) questionnaires do not measure what older persons consider to be functioning.
- Self-perceived functioning includes a broader scope of activities, such as participation and personally valued activities.
- Coping strategies and pre-fracture functioning play a role in post-fracture self-perceived functioning.
- To measure functioning from the perspective of the older person (I)ADL questionnaires are not enough.

INTRODUCTION

Hip fractures are seen as a tipping point in an older person's life. The 1-year mortality is about 25% and, of those surviving, another 20% is permanently institutionalised. Furthermore, they have a major impact on multiple aspects of physical functioning. About half of the surviving patients fail to return to their previous mobility and only 40-70% regain their overall pre-fracture level of activities of daily living (ADL) and instrumental activities of daily living (IADL) within 1 year after the hip fracture.[1-3]

Both in research and clinical practice, outcome after a hip fracture is usually expressed in terms of mortality, institutionalisation, mobility and functional status.[4] Functional status, measured with instruments such as the Barthel Index, Katz ADL and Lawton IADL, is measured for different purposes, for example to assess level of recovery or support needed. An inherent part of level of recovery or support needed is a patient's own perspective on his/her functioning. Thus, to be able to measure level of recovery or support needed, (instrumental) activities of daily living ((I)ADL) instruments should align with patient perspectives on their own functioning, which are affected by for example personal factors such as coping styles and environmental factors such as existing support.[5-7]

Despite the frequent use of instruments such as the Barthel Index, Katz ADL and the Lawton IADL, it is unclear to what extent these instruments capture patients' own perspective on their functioning.[8-10] Involvement of patients (or older persons in general) in the development or evaluation of these instruments was not reported, and there are no other studies known by the authors that compare these (I)ADL instruments to patients' perspectives on functioning.[9, 11-14] Therefore, the aim of this study was to explore what functioning means to older persons after a hip fracture and to assess the extent to which frequently used (I)ADL instruments align with this self-perceived functioning.

METHODS

Study setting and design

This qualitative study was part of the prospective cohort study HIP CARE (Hip fractures: Inventarisation of Prognostic factors and Their Contribution towArds Rehabilitation in older pErsons) (NTR NL7491). In the HIP CARE study, which started in December 2018, patients who were admitted with a hip fracture to the emergency department of the Haaglanden Medical Center, one of the largest teaching hospitals in the west of the Netherlands, were included. Questionnaires and function tests

were administered at hospitalisation and at 6 weeks and 3 and 12 months after discharge at regular outpatient visits. The aim of the HIP CARE study was to describe recovery patterns up and till 1 year after a hip fracture.[15] For the qualitative study, patients from the HIP CARE study cohort were invited for semi-structured in-depth interviews to explore patients' perspectives on the concept and own level of functioning. The interviews were enriched with quantitative data of ADL and IADL questionnaires taken at hospitalisation and at the end of the interview. The HIP CARE study, including the qualitative study described in this paper, was approved by the Medical Ethics Committee Southwest Holland (P18.029).

Participants

Patients were eligible for the HIP CARE study if they met the following criteria: 1) a unilateral proximal femoral fracture, 2) aged ≥ 70 years, 3) no pre-fracture nursing home residence, 4) eligible for geriatric rehabilitation, and 5) no pathological fracture. Additional inclusion criteria for the qualitative study were 1) no known dementia or cognitive impairment (6CIT ≤ 11 points), and 2) between 6 to 12 months after the hip fracture at the time of sampling. At the time of sampling (March 2020), there were 95 patients included in the HIP CARE study, of which 42 were between 6 to 12 months after their hip fracture and alive. Thirty-five of these did not have cognitive impairment and were eligible for this qualitative study. They received an information letter about the study with the invitation to participate. After 1 week, they were contacted by telephone to provide clarifying information and to ask consent for an interview by phone. Reasons for refusal were listed when provided. Participants were recruited using consecutive sampling and recruitment continued until no new insights or ideas came up during the interviews. All included participants gave verbal (recorded) informed consent for the interviews.

Data collection

Data were collected in April and May 2020 by two members of the research team, who had a background in health and life science (ILT), medicine (WMR) and vitality and ageing (ILT and WMR). The research team as a whole had extensive experience in qualitative research and research with older persons. In total, 18 out of 35 invited older persons agreed to participate.

The interviews, with a median duration of 58 minutes (range 26 – 100 minutes), were conducted in Dutch using a semi-structured topic list containing questions about participants' current functioning, the change in functioning they experienced due to the hip fracture and their interpretation of the term functioning (Appendix 1). Follow-up questions were posed when needed. In everyday life, the terms functioning,

independent functioning and daily functioning are used interchangeably to describe the same concept. Although these terms overlap, there are also subtle differences between them. All three terms were included in the questions of the topic list to ensure that participant's views on functioning were fully captured. The topic list was pilot tested by both interviewers (ILT and WMR) and subsequently minor adjustments to the questions were made to make them easier to understand. One of the pilot interviews was valuable enough to include in the data-analysis, the other was excluded because the participant did not meet the inclusion criteria of this study (i.e. interview was not at 6-12 months after the hip fracture).

At the end of each interview, the Katz ADL (scale 0-6, higher score means more dependence), Lawton IADL (scale 0-12, higher score means more dependence) and Parker Mobility Score (PMS; scale 0-9, higher score means better mobility) questionnaires were conducted and a few questions about participants' opinion on these questionnaires were asked (Appendix 1).[13, 14, 16] Participants were given the opportunity to do this last part of the interview (i.e. questionnaires and questions on opinion) at a later moment if they were tired after the first part of the interview. Three participants used this option. Field notes were made directly after the interviews and all interviews were audio recorded, transcribed ad verbatim and de-identified.

Data analysis

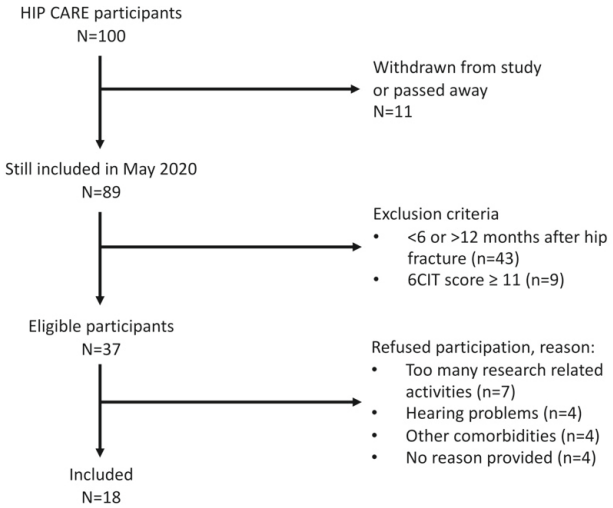
Data were analysed using the framework method.[17] Coding and analysis of the interviews started during data collection. Transcripts were read multiple times and coded by two members of the research team (ILT and WMR). To be able to extract information from the interviews without imposing preconceived categories or theoretical perspectives, the first two transcripts were coded by ILT and WMR using open, inductive coding. Emerging codes were discussed and compared within the research team, consensus was reached on the codes, and a structured codebook with the inductively derived codes was made (i.e. 80 codes in 9 categories). ILT used this list of codes to code the other transcripts and when new codes emerged from the data they were added to the codebook. Subsequently, the inductively derived codes were rearranged into overarching categories. Based on scientific models and theories on functioning and coping, namely the ICF-model, the SOC-model and a study by Huijg et al. on successful ageing, codes and categories were added to make the codebook more comprehensive (i.e. 93 codes in 21 categories).[5, 18, 19] On completion of data collection, all transcripts were also fully coded by WMR using the categorised and enriched codebook, and consensus on the coding of all transcripts was reached between ILT and WMR. Throughout the coding process, the codebook was adjusted when needed and notes on emerging

ideas and concepts were taken. The analysis continued by grouping codes within the overarching categories into meaningful clusters. Relations between categories were explored and themes were identified resulting in a conceptual model of self-perceived functioning. Congruence between self-perceived functioning and the results of the (I)ADL questionnaires was assessed by comparing the (I)ADL domains with the related findings in the interviews. Furthermore, throughout the analysis there seemed to be differences in self-perceived functioning and how this functioning changed after the hip fracture depending on pre-fracture self-perceived functioning. Therefore, we explored what contributed to this difference by using a matrix (i.e. a chart) which enabled us to order mentioned activities and coping strategies grouped by self-perceived pre-fracture functioning. Atlas.ti version 9, a computer assisted data analysis programme, was used to code and analyse all the data. Quotations from the interviews included in this paper were translated from Dutch to English by a native English speaker in collaboration with one member of the research team (WMR).

RESULTS

A total of 18 patients were interviewed between 6 and 12 months after their hip fracture (Figure 1). Their median age was 79 years (range 71-95) and 11 (61%) were female (Table 1). At hospitalisation, they reported to have a median Katz ADL of 0 (range 0-3), Lawton IADL of 1.5 (IQR 0-5) and PMS of 8 (IQR 6.75-9) before their hip fracture. At the time of the interview, participants had a median Katz ADL of 0 (IQR 0-4), Lawton IADL of 3.5 (IQR 1.5-6.25), and PMS of 6 (IQR 5-7.25).

Figure 1. Flowchart



The themes and relations observed in the interviews were summarised in a conceptual model comprising 1) components of self-perceived functioning, 2) the effect of coping strategies on self-perceived functioning, and 3) the influence of pre-fracture self-perceived functioning on post-fracture self-perceived functioning. The components could be split into two main types: on the one hand activities necessary to maintain the desired level of independence, such as driving a car, on the other hand more personal, often participation related activities that were of value to participants, such as gardening or going out. Both the 'independence activities' and the 'valued activities' mentioned went beyond the activities included in ADL and IADL questionnaires. Limitations in these did not necessarily lead to worse self-perceived functioning (i.e. second part of the model). Different coping strategies to deal with limitations could be observed. For example, participants who had to use a walker since the hip fracture described their aid as just a useful tool that made life easier but did not change their self-perceived functioning. Finally, self-perceived pre-fracture functioning also seemed to be related to self-perceived post-fracture functioning. Both participants who were still very active before their hip fracture and participants who already had several limitations before the fracture felt more comprised in their functioning because of their limitations than the other participants.

Table 1. Characteristics of participants

	Included participants
N	18
Female, n (%)	11 (61)
Age at interview, median (range)	79 (71 to 95)
Months since hip fracture, median (range)	9 (5 to 12)
Functioning before the hip fracture	
Katz ADL, median (range)^	0 (0 to 3)
Lawton IADL, median (IQR)*	1.5 (0 to 5)
Parker mobility score, median (IQR)#	8 (6.75 to 9)
Functioning at time of interview	
Katz ADL, median (range)^	0 (0 to 4)
Lawton IADL, median (IQR)*	3.5 (1.5 to 6.25)
Parker mobility score, median (IQR)#	6 (5 to 7.25)

ADL activities of daily living, IADL instrumental activities of daily living, IQR interquartile range

^ Katz ADL range 0-6, higher score means more dependence

* Lawton IADL range 0-12, higher score means more dependence

Parker Mobility Score (PMS) range 0-9, higher score means better mobility

Components of self-perceived functioning

For participants, self-perceived functioning consisted of two types of activities. The first type was activities needed to maintain the desired level of independence, as shown by the often used generic reply 'being able to do everything myself'. Which specific activities participants had in mind with 'everything' differed, but for all of them these activities included not only ADL and IADL items, but also other, more advanced, activities. More advanced or heavier (household) activities that came up were for example managing administrative tasks or window cleaning.

> *'Well yeah [my independent functioning has changed], you are of course a bit limited with some things. Like I just mentioned, vacuuming, and you know, cleaning the shower and the toilet. Yes, and cleaning the windows of course. You sometimes have to do a little extra. So, uh I did that of course before, of course I did. I just can't do it anymore, I sometimes just can't.' (P3)*

In many of these independence activities mobility played an important role. Participants for example said it was necessary to be able to walk outside or drive a car in order to be able to do the grocery shopping. In these cases, mobility was often more a means to an end. Participants facing limitations in mobility said these limitations hindered them in their independent functioning.

> *'Yes I mean I can write a letter, but I can't post that letter because I can't get to post box. (...) Well, independent functioning doesn't really happen' (P11)*

The second type of activities that were part of self-perceived functioning were more personal, "valued" activities.[20, 21] Many of these valued activities had to do with participation, for example going out, (voluntary) work and visiting friends and family, but also included activities such as gardening or reading a book. An important aspect of the valued activities was that they either gave participants a sense of fulfilment, or they were an enjoyable pastime for participants.

> '*Yes, that is, the work also involves social contacts, of course. With the wholesaler or so you would have a chat, you would have a chat with the client and uh. Yeah uh that just still gave satisfaction, that uh that work, and that uh you'd miss that.' (P18)*

Again, mobility played an important role, but in this case more as an end in itself rather than a means to an end. Activities such as biking or driving a car gave participants a feeling of freedom and allowed them to do whatever and go

wherever they wanted. A participant who could not bike anymore described it as follows:

> *'I'm an outdoors person, I want to go into nature, I uh I'd cycle to Schiphol to look at the aeroplanes. I, I, I know all of South Holland. Uh and I miss it a lot.' (P1)*

The effect of coping strategies on self-perceived functioning

Almost all participants described some loss of function in the above mentioned activities after their hip fracture. Most of these losses hindered participants. Where possible they compensated their losses by using aids or help from formal and informal caregivers. These aids and help were considered to be a necessary evil by most, although a few were more positive about their aid, describing it as something they did not want to use at first but over time they came to consider their aids as just a useful tool that made their life easier. However, a few participants noted that the strain their limitations put on their informal caregivers also played a role in their own evaluation of functioning. They thought this aspect was insufficiently included in the ADL and IADL questionnaire.

In addition, some participants also changed the way they performed activities, for example cleaning the house a bit less thoroughly or using furniture to move through the house. Despite these limitations and necessary adjustments, overall self-perceived functioning was said to be good by most or even unaffected by some. However, when losses led to a complete inability to do an activity, this had more influence on self-perceived functioning.

> *'I can just do my own thing. I can walk to the shed. I can walk outside. And that's no problem. I can walk the dog. Well yeah, with the walker but yeah. But I can still take him out and I make long walks. That's why I use my walker, because I also go for long walks of at least four kilometres and I enjoy that.' (P2)*

> *'And then I do the dusting and check whether things are dirty, check whether I feel I should clean something. And then, well uh, I do, I do it my way. I used to do it differently, better probably, but I don't know, it's also good in this way.' (P7)*

> *'Well, honestly I'd like that (cycling) a lot, but I don't dare to do it. Because I know that my, that my leg with the broken hip, my left leg, isn't stable enough if I have to get off the bicycle, suddenly. Then I don't trust myself. And yes you*

want to especially avoid that it happens again of course. And personally, I find it a big, a really big limitation.' (P12)

Participants also described accommodative strategies to deal with their limitations and adjustments. For example, some said their limitations were part of the process of getting older and thus not something that said anything about their level of functioning. Comparison with others who were worse off or with a hypothetical worse scenario was also used to minimize the importance of the own limitations. Furthermore, participants justified their disabilities by framing it as their own choice of not doing something anymore. All of these assimilative and accommodative strategies were used to accept the current situation and to unlink limitations from the overall evaluation of their own functioning.

'I have no limitations. (...) That I'm not cycling anymore, well yes that is my own choice. Because I am cautious.' (P2)

Influence of self-perceived pre-fracture level of functioning

However, there were two groups of participants who felt more compromised in their functioning because of their limitations. The first group included participants who were still very active before the fracture, for example those who still had a paid job, and therefore were prone to lose a lot of their usual, and often valued, daily activities due to the hip fracture. They felt severely compromised in their functioning. Some of them felt they were all of a sudden confronted with getting older and losing function because of that, which came with more negative feelings and judgements of the current situation. At the same time, they did not recognise themselves in their (often unchanged) questionnaire score and thought the items in the questionnaire did not cover their true functioning.

'But when I get these questions I think yes ... I feel that actually I can do quite a lot still if I can answer alle these questions with dependent uh or independent, than I think well, it isn't that bad, but let me say it doesn't feel like that.' (P18)

The second group included participants who already had limitations in (more basic) ADL and IADL activities before the fracture. They felt that the new, additional limitations resulting from the hip fracture took away even more of their independence. Their questionnaire score changed similarly to that of other participants, but these participants felt they could not compensate for their additional limitations anymore.

DISCUSSION

Functioning of patients after a hip fracture is often measured with (I)ADL questionnaires in research and clinic. However, this study shows that what is measured with (I)ADL questionnaires is different from functioning as perceived by the older patients themselves. Firstly, for the older patient a broader scope of activities is part of self-perceived functioning than what is included in (I)ADL questionnaires. Besides (I)ADL activities, self-perceived functioning included more advanced activities needed to maintain independence, activities related to participation and other valued activities that gave a sense of fulfilment. Second, the effect of a limitation on self-perceived functioning differed between activities, whilst limitations are weighed equally in (I)ADL questionnaires. Limitations that could be compensated for, and those that were considered to be normal in the current situation or age hardly changed self-perceived functioning in the current study. On the other hand, limitations that led to a large change in functioning or to a high level of dependence had a large effect on self-perceived functioning. In other words, different coping strategies and pre-fracture abilities and inabilities played an important role in post-fracture self-perceived functioning, something that is not taken into account in (I)ADL questionnaires.

There are many different types of instruments that aim to measure functioning. They differ from each other in what they exactly measure, in particular the items included and how much room they leave for subjective interpretation.[7] Previous research on assessment of recovery and on successful ageing already described a broader scope of activities being relevant to patients themselves.[20,5,21] In these studies mobility, valued day-to-day activities, activities related to independence, social contacts and engagement with life were reported by older persons to be important. The findings in the current study show that the same components play a role in self-perceived functioning. These components cover both the 'activities' as well as the 'participation' of the ICF model.[18] Contrary, (I)ADL questionnaires, or instruments such as the PROMIS physical functioning questionnaire which include a broader scope of activities, only cover some of the 'activities' of the ICF model, while other instruments are used to measure participation, for example the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P).[22,23] Thus, what older persons consider to be functioning is measured with multiple instruments in research and clinic.

Concerning the room for subjective interpretation, Griffiths et al. (2015) already observed the influence of pre-fracture functioning and the ability to make

adaptations on the perceived level of recovery, something also described in research on the disability paradox.[20, 24] Viret et al. (2019) further explored this relationship by looking at the relation between autonomy and functional decline. They described a difference in what autonomy consists of depending on the current amount of limitations. For those with less limitations autonomy is 'to do what I want', while for those with more limitations autonomy is 'to do what I can'. Autonomy was always expressed as relative to others or to previous autonomy. In other words, limitations are not weighed equally by patients themselves (i.e. because of recalibration, reprioritisation or reconceptualization), something also observed in the current study.[7] Many instruments that are currently used to measure functioning (i.e. activities or participation) do not leave room for interpretation in the rating. Concerning both the activities measured and the weighing of limitations, Huijg et al. (2017) concluded that solely applying objective criteria results in a mismatch between how successful older individuals feel and how successful they are classified by these objective criteria. They state that a mix of objective and subjective measures are needed to measure the patient perspective on successful ageing.[5] In the current study, the same mismatch was observed for the concept of self-perceived functioning, both in what is actually measured, the items included and the weighing of limitations.

Strengths and limitations

As far as the authors are aware of, this is the first study to combine both quantitative questionnaire data with qualitative interview data on functioning. This allowed a comparison between the two and thus a better exploration of what is relevant for patients and how this differs from the objective criteria of (I)ADL questionnaires. In particular, the reflections of patients on the questionnaire directly after administering them were very helpful on this point. Another strength of this study is the chosen time frame within the recovery process (i.e. 6-12 months after hip fracture). Most of the recovery after a hip fracture is expected within these first six months. Thus, the participants of this study were at the end of their recovery process and had a clear idea of what was relevant for their functioning. An important limitation of this study is the over-the-phone instead of real-life interviewing. In an over-the-phone interview non-verbal cues are less prominent. Without these cues it is hard to interpret the meaning of a response, to evaluate whether the response is valid and to judge the emotional state of the respondent. Despite these missing non-verbal cues, the interviews provided relevant new information on self-perceived functioning. Another limitation of this study is related to its position as a sub study in a larger study on recovery after a hip fracture. As a result, participants were frequently contacted for study purposes and some felt

overloaded by it. This might have resulted in the low inclusion rate in the study currently reported. Furthermore, participants who were included in the current study sometimes felt the same things had been asked in previous contacts and therefore might have been less elaborate in their responses.

Conclusion

To conclude, self-perceived functioning is different from functioning as measured with (I)ADL instruments. Firstly, they differ in the items included, as self-perceived functioning includes more advanced and more personal valued activities, such as participation activities, besides the (I)ADL activities. Secondly, contrary to how limitations are weighed in (I)ADL instruments, the weighing of limitations in self-perceived functioning is influenced by pre-fracture status and different coping strategies applied. When using an (I)ADL instrument, researchers and clinicians should be aware of these limitations of the instruments. Although (I)ADL questionnaires can be useful to measure functional status according to a fixed set of objective criteria, they do not include patient perspectives on functioning and are therefore not fit for every purpose they are currently used for. In research, where objectivity and inter-person comparability of an instrument is important, measuring participation and a broader scope of activities with more extensive instruments or with additional instruments can bring the measurement of functioning closer to self-perceived functioning. However, when patient perspectives are important, for example in clinical practice when assessing level of recovery or support needed, it is better to engage directly with patient view and experience rather than using (extensive) (I)ADL instruments.

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SUPPLEMENTARY DATA

Appendix 1. Semi-structured topic list

Guide used for interviews on self-perceived functioning after a hip fracture.

Functioning in general

1. How are you doing at the moment?
   a. Is this different from before the hip fracture?

2. For this study we are interested in functioning. What is functioning according to you?
   a. Did your functioning change after the hip fracture?
   b. Has your idea of what functioning is changed after the hip fracture?

Independent functioning

3. How independent are you at the moment?
   a. Can you give some examples?
   b. Is independent functioning for you different from the functioning we talked about previously?

4. Did your independent functioning change after the hip fracture?
   a. If yes, what changed?
   b. Can you give an example of a difference?
   c. Did this change because you can't do it or because you don't dare to do it anymore?

5. Which score would you give your own independent functioning, with 0 being completely dependent and 10 being completely independent?
   a. Which score would you give your independent functioning before the hip fracture?
   b. Why do/don't these scores differ?
      i. What is the reason for this difference? Can you give some examples?

6. What is important to you when talking about independent functioning?
   a. What do you take into account when you evaluate your own independent functioning?
   b. Can you give examples of activities?
   c. Which activities are most important for independent functioning according to you?
   d. Was it the same before the hip fracture?

7. Are there valuable activities you cannot do anymore since the hip fracture?
    a. Are there also activities you didn't like which you cannot do anymore since the hip fracture?

Daily functioning

8. Can you tell me what you are normally doing on a day?
    a. Is it different from before the hip fracture?
    b. What is the reason for this difference?

9. Do you have any formal or informal support in or around your house?
    a. Do you feel you are still independent even though you have support with certain activities?

Conduct questionnaires (Katz ADL, Lawton IADL and Parker mobility score (PMS)) and report scores on questionnaires back to participant (i.e. based on these questionnaires your independent functioning deteriorated / remained stable / improved compared to before the hip fracture)

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10. Can you identify yourself with these scores?
    a. Can you explain why you do/do not?
    b. Are there important topics missing in these questionnaires according to you?
    c. Are there topics in these questionnaires you feel are not relevant?
    d. Are there topics you would like to add to these questionnaires?

Chapter

8

General discussion

Hip fractures are relatively common at old age and put a major health and socioeconomic burden on society. What the exact impact of a hip fracture is on daily functioning and healthcare use, both now and in the future, is not evident. This thesis aimed to 1) describe the characteristics and healthcare use of the community-dwelling hip fracture patients of today and expectations on how healthcare use will change in the future, 2) assess the relation between daily functioning and hip fractures, and 3) explore different aspects of how to measure daily functioning in clinical practice and research.

This general discussion will present the main findings and their implications for future healthcare and research. The relation between a hip fracture and daily functioning will be put into the broader context of ageing and decline, and the question of how to measure daily functioning in research will be discussed. Suggestions for clinical practice and directions for future scientific research will be made.

PATIENT CHARACTERISTICS AND HEALTHCARE USE

In **Chapter 3** of this thesis we described the characteristics of the current, community-dwelling, hip fracture patient. Just like in other recent literature, we found a median age at fracture of 83 (IQR 76-88) and 70% was female. As already mentioned in the introduction of this thesis, these characteristics have changed over the years. Meyer et al. and Trevisan et al. described an increasing age and number of comorbidities at fracture over the last two decades.[1, 2] In other words, the average hip fracture patient of today is frailer than the average hip fracture patient of the past. The limited but statistically significant increase in the number of consultations with the general practitioner (GP) in the months before the hip fracture as described in **Chapter** 3 also suggests that hip fracture patients are already frail before their fracture. At the same time, this finding on pre-fracture change in consultation frequency shows that the relation between certain diseases and healthcare use is not so straightforward. Already before the disease occurs or is diagnosed, a patient changes and thus the effect of the disease might be different than expected at first sight. The relation is also not so straightforward because of the many patient and population characteristics that influence the relation between a disease and healthcare use. The results of **Chapter 2** show that concurrent changes in these characteristics (for example more older persons living independently and decreasing parent support ratio) are expected to give an additional increase in healthcare use (mainly GP, home and informal care) that was not foreseen previously by extrapolation of single trends. The relation between

disease and healthcare use is further complicated by the influence of health policy. This is also the case for the association between a hip fracture and healthcare use. Thus, the impact of a hip fracture cannot be fully understood by looking at healthcare use alone. The rest of this thesis therefore focussed on the impact of hip fractures on daily functioning, which is influenced by health policy to a lesser extent.

IMPACT HIP FRACTURE ON DAILY FUNCTIONING

Hip fractures are often seen as a starting point of decline in daily functioning at old age, because of the high mortality and low recovery rates post-fracture. However, since the average hip fracture patient is relatively old and already has multiple comorbidities before the fracture, one might wonder whether the hip fracture really is a standalone event causing decline in functioning. In this thesis we looked at the role of the hip fracture in the pathway of decline of daily functioning.

In **Chapter 4** we established that in four international cohorts of community-dwelling oldest old (i.e. 80 years and over) decline in daily functioning already starts before a hip fracture. This decline in functioning before the hip fracture is larger than the decline in functioning in the rest of the oldest old population. This finding is in line with and elaborates on the results of a previous cross-sectional study that described decline in daily functioning on a population level ten months before a hip fracture.[3] Both in chapter 4 and in previous studies, this pre-fracture decline in functioning has been shown to end in a pre-fracture level of functioning that is worse than the level of functioning of age and sex matched controls.[4] This lower level of functioning before the event, when compared to age-related peers, has also been reported for older persons with falls.[5] But, contrary to what we found in chapter 4, in the year before the fall daily functioning did not decline faster than it did in those without falls. A year before a hip fracture, decline in daily functioning already speeds up, ending in a lower pre-fracture level of daily functioning than that of age-related peers.

All in all, hip fractures do seem to modify the trajectory of decline in daily functioning. They are known to add extra decline in functioning up and till two years after the fracture, even when correcting for pre-fracture level of functioning.[6] In addition, older persons who have had a hip fracture have a lower level of functioning than older persons who have never had a hip fracture. This difference in level of functioning has been shown for up to seven years after the hip fracture.[7-9] In other words, hip fractures do modify the trajectory of decline in functioning by

adding extra decline, leading to a difference in level of functioning that can be observed till many years after the hip fracture.

Although the long-term effect of hip fractures on daily functioning has been established, there also seem to be differences within the hip fracture population in the extent to which hip fractures add to the decline in functioning. Previous studies already showed that in the total hip fracture population most recovery takes place in the first six months after the hip fracture.[9, 10] Based on the extent and the speed of recovery three different recovery trajectories can be identified: poor recovery (i.e. some recovery in the first six months, a rapid decline in functioning afterwards), intermediate recovery (i.e. recovery to just below pre-fracture level of functioning in the first six months, stable afterwards), and good recovery (i.e. fastest recovery to pre-fracture level in the first six months, stable afterwards). In **Chapter 5** of this thesis we showed that the pre-fracture level of daily functioning is associated with the post-fracture level of functioning in four international cohorts of community-dwelling oldest old. In line with this, previous studies showed that the recovery group to which a patient belongs is mainly related to the pre-fracture level of daily functioning. Those with many limitations in their functioning before the fracture are more likely to be in the poor recovery group after their fracture.[11-15] In some studies age also plays a role in this (i.e. those who were older were less likely to be in the good recovery groups, even if their pre-fracture functioning was unimpaired).[12] Although pre-fracture level of daily functioning is associated with post-fracture daily functioning, **Chapter 5** also showed that the speed with which functioning declined before the hip fracture is not associated with the post-fracture functioning level. In other words, the trajectory of daily functioning after the hip fracture is not an extension of the pre-fracture trajectory of daily functioning.

The good recovery at twelve months in those with pre-fracture good functioning seems to be contradictory to the long-term effect of a hip fracture on daily functioning described earlier. The relation between mortality and hip fractures could help to understand this seemingly contradictory finding. Both declining daily functioning and mortality can be seen as a result of deficit accumulation (i.e. mortality as the ultimate endpoint). A study by Magaziner et al. showed that hip fractures had an independent impact on mortality.[16] What the impact was depended on the pre-fracture status of the patient. Those who were frail before the fracture (i.e. many comorbidities and low level of activities of daily living (ADL)) had an acceleration in mortality immediately after the fracture but a limited increase in mortality in later years. In contrast, those who were relatively fit before the fracture (i.e. limited comorbidities and good ADL) had a low mortality rate in the first year

but an increased risk of mortality up and till five years after the fracture.[16] In other words, the effect of the hip fracture on mortality, just like on daily functioning, lasted till years after the fracture, and this effect was associated with pre-fracture comorbidity and daily functioning.

The different post-fracture daily functioning-recovery trajectories described earlier suggest that a similar association exists between pre-fracture level of functioning and long-term post-fracture level of functioning. Those who are relatively vulnerable before the hip fracture have high chances not only of mortality but also of large decline in daily functioning just after the hip fracture (i.e. the poor recovery group). Nevertheless, their daily functioning will remain relatively stable at a low level on the long-term. In terms of deficit accumulation, these patients already have multiple deficits before the fracture and the hip fracture adds another one which can be a tipping point on the short term (i.e. mortality or large decline in daily functioning), but is 'just another deficit' on the long term. On the contrary, those who are relatively vital pre-fracture are known to have low chances of mortality and only limited decline in daily functioning in the first year post-fracture (i.e. moderate to good recovery groups). Despite these good outcomes on the short-term, the hip fracture marks the starting point of deficit accumulation for these patients, ultimately leading to declining daily functioning and mortality on the long-term. Our results on declining pre-fracture functioning (**Chapter 4**) suggests that this relatively vital group is small, most older people already have accelerated deficit accumulation before their hip fracture and thus could be marked frail. To conclude, hip fractures can be seen as the starting point of decline for a small group of vital patients. However, for most patients a hip fracture is just another transitional factor in a trajectory of declining daily functioning.

MEASURING IMPACT ON FUNCTIONING

Daily functioning is an important concept for clinical practice and research with older people. This concept is often operationalised with activities of daily living (ADL) and instrumental activities of daily living (IADL) questionnaires. These instruments are used to assess level of recovery (of daily functioning), effectiveness of interventions and need for help after a hip fracture. They are relatively easy to use and their wide distribution in both clinical practice and research supports information exchange and comparison across different settings. However, these instruments are only used in clinical practice when there is a reason to do so, for example to monitor recovery after a hip fracture. This means that there is no registration of (I)ADL status in the older population at a large scale outside of

a research setting. As a result, the level of (I)ADL before events such as a hip fracture is often unknown. As apparent from chapter 4 of this thesis, this pre-event (I)ADL status can be informative for clinicians and researchers. Nonetheless, implementation of routine (I)ADL measurement by clinicians on a large scale will be expensive and difficult to realise (because of limited time availability among others).[17] Therefore, other ways to ascertain pre-event level of functioning should be sought.

Daily functioning from routine care data

An alternative way to ascertain pre-event level of functioning is to extract or deduce the level of daily functioning at a certain timepoint from routine care data. The routine care data from GPs seems the best source to extract level of daily functioning from. In the Netherlands, the GP has a central role in the medical care for all community-dwelling older people. As a result, the GP is aware of and has registered almost every relevant (medical) problem in the electronic health record (EHR) of his/her patients.

However, GPs do not measure or register level of daily functioning in their EHR directly, so to extract level of daily functioning from their EHR we are dependent on composite measures. A good composite measure does not exist yet, but there are good (composite) measures for frailty that can be extracted from EHRs.[18] Frailty and daily functioning are overlapping but distinct concepts. They are similar in that they both have a connection to deficit accumulation. Because of this overlap, an electronic frailty index (eFI) could potentially be used as a proxy for daily functioning in research with routine care data. This hypothesis is supported by earlier research which showed that for prediction models, a count of the number of chronic diseases, which is closely related to the frailty index, could be used interchangeably with (I)ADL status.[19] Having said that, we established in **Chapter 6** of this thesis that, despite the overlap, an electronic frailty index based on routine care data does not reflect daily functioning. Frailty (as operationalised by Rockwood et al.[20]) is purely a measure of deficit accumulation. Daily functioning on the other hand is the result of deficit accumulation, but it is also determined by coping mechanisms and environmental factors. Although most deficits can be extracted from routine care data relatively easily, coping mechanisms and environmental factors cannot because they are rarely registered by healthcare professionals.[21] In other words, deducing level of daily functioning from routine care data is difficult because part of what constitutes to daily functioning is not registered routinely at the moment. There have been attempts to extract level of daily functioning from routine GP care data in other ways as well. Many of these studies focussed

on natural language processing, using the free text from the EHRs. Problems encountered in these studies included keeping the list of keywords up-to-date and correct, correctly interpreting the context in which keywords were mentioned, and determining the contemporaneity of the reported level of daily functioning (e.g. current status or just copy-paste from previous report).[22, 23] Moreover, with these methods you are still dependent on whether GPs recorded anything about level of daily functioning, which is not done routinely or consistently.[24, 25]

Self-perceived functioning

Chapter 7 of this thesis also touched upon what constitutes to daily functioning and how to measure that. In this chapter we explored whether daily functioning as measured with often used (I)ADL questionnaires reflected self-perceived daily functioning of older persons. We found that, compared to (I)ADL questionnaires, self-perceived functioning included a larger range of activities/abilities, and limitations in these activities differentially affected self-perceived functioning.

Concerning the activities included, the interviewees often did not have limitations in the (I)ADL activities included in questionnaires, as these were too basic. Their level of daily functioning was relatively high (e.g. volunteer work, paid jobs, active sports) and their self-perceived functioning was related to their level of functioning at that moment. Thus, the basic ADL and IADL activities did not even come to their mind when talking about daily functioning. Concerning the effect of limitations on self-perceived functioning, limitations were often considered to affect self-perceived functioning only to a limited extent or not at all because older persons found ways to work around the limitation to reach their goals or, if this was not possible anymore, to downplay the importance of the goal. Thus, the influence of a limitation on self-perceived functioning was appraised differently per person and per situation.

These findings show that (I)ADL instruments do not measure self-perceived daily functioning. Although this is not necessarily a problem, depending on the aim of the measurement, the current wide application of the ‘standard’ (I)ADL instruments such as the Katz ADL or the Lawton IADL questionnaires is a problem. In many situations, for example when evaluating recovery or effectiveness or the need for help, the patient perspective is more important than the more general impression of functioning given by the ‘standard’ (I)ADL instruments. As mentioned in the introduction of this thesis, there are already alternative (I)ADL instruments, although not common, that seem to come closer to this patient perspective. Some instruments focus on a larger scope of abilities/activities (or are more flexible in

the items included) and others leave more room for subjectivity in the weighing of limitations. To get closer to the patient perspective, flexibility in included items and individualised weighing of limitations are important characteristics for an instrument. Results from such instruments will be more informative and relevant for both patient and professional. Small but relevant changes in daily functioning will be picked up faster, which will facilitate timely proactive care. Moreover, improving the relevance of the instrument for patients and professionals will support the integration of the instrument in routine care processes.

METHODOLOGICAL CONSIDERATIONS

The concept of daily functioning

Daily functioning is an often used concept with a considerable, long debated, theoretical construct behind it. It is a broad concept which, according to the definition from the International Classification of Functioning, Disability and Health (ICF), includes body functions, performance of activities, and participation in different areas of life. Daily functioning is the result of interactions between health conditions, such as diseases, and contextual factors (both environmental and personal), such as living environment and coping styles. Decline in a person's intrinsic capacity, for example caused by disease, does not necessarily lead to decline in daily functioning (i.e. loss of performance) if that person can compensate this loss with contextual, or environmental, factors. If a loss of intrinsic capacity cannot be compensated for by the environment this leads to disability. Disability is loss of functioning on either of the three aspects of functioning previously mentioned, leading to impairments, activity limitations or participation restrictions, respectively.[26-28]

Despite this clear definition and theoretical construct of daily functioning in the ICF, in literature a plethora of terms (and definitions) is used (e.g. daily functioning, disability, (in)dependence, dependency, functional status, functioning, physical function, etc). Although the use of all these different terms implies a slightly different focus and aim of the measurements they describe, each needing a somewhat different approach, they are often operationalised in the same way with (I)ADL instruments. Because of this uniform use of (I)ADL instruments, the nuances between the terms and concepts behind them are lost.

Over the years, the measurement of daily functioning (also called functioning, physical function, independence or functional status) has replaced the measurement of disability in both clinical practice and research.[29] One important

reason is that disability only measures loss of function on either body functions, performance of activities or participation (i.e. impairments, limitations and restrictions) and is therefore limited by illogical ceiling effects (i.e. someone can never improve if the disability level was already zero). At the same time, daily functioning can also be operationalised in multiple models, as already described by Ziebland et al. in 1993.[30] The most basic model (i.e. functional model) measures (a wide range of) activity limitations with a yes/no answer, which makes it insensitive to negative change. In the subjective distress model, the difficulty experienced when performing an activity is included in the measurement, giving it an element of comparison to previous experience or to others. However, this subjective stress model measures the net result of activity limitations and contextual factors (e.g. coping). Problems in activities are therefore underestimated and changes need to be large to be picked up by the instrument. The comparative model gives an impression of the impact of limitations on usual activities by asking someone to compare to others (which is influenced by age, circumstances and setting) or to one's own previous health/functioning. This comparative model also measures the net result of activity limitations and contextual factors, but it is a bit more explicit on which activity limitations and which contextual factors play a role. Moreover, it also leaves room for individuals to include participation-items that are important to them. The comparative model can be used to pick up temporary changes in daily functioning, but not for long-term effects of chronic conditions. Finally, there is the dependence model which focusses on the amount of help needed to perform an activity. It gives an indication of both activity limitations and adaptive capacities that arise from personal and environmental factors, with a stronger focus on the contextual factors.

These four models according to Ziebland differ in activities included (e.g. the activities and participation items included in the comparative model depend on an individual's reference standard) and room for individualised weighing of limitations and restrictions.[30] In Chapter 5 of this thesis, these aspects – in particular the absence of participation items in the questionnaires – also came up as the main causes for the mismatch between self-perceived functioning and functioning as measured with (I)ADL questionnaires.

For this thesis, daily functioning based on the dependence model was mainly used, being operationalised with the (I)ADL questionnaires GARS (Groningen Activities Restriction Scale), Katz ADL and Lawton IADL. In hindsight, this model was not the best choice in all studies described in this thesis. For example in chapters 4 and 5, about pre-fracture change in functioning, a comparative model might fit

better because of the short-term, relative to previous functioning, changes we tried to pick up. However, as most of the studies described in this thesis were part of larger projects, we could not adjust the measurement instruments used to our measurement aims. On the other hand, the use of the dependence model (operationalised with the GARS) in chapter 6 did fit the measurement aim. For healthcare professionals, the need for help is the most important aspect of daily functioning, as this will guide the care they provide. Thus, extraction or deduction of daily functioning from electronic health records is most likely to be possible when using a dependence (or need for help) model for daily functioning. Contrary, for chapter 7, where the dependence model was also used, an instrument based on the subjective distress model might have been a better choice. Self-perceived functioning likely includes a comparison to previous functioning and to functioning of others, and limitations and restrictions that are well coped with will have a smaller effect on functioning. An instrument based on the subjective distress model might therefore better approximate self-perceived functioning.

IMPLICATIONS OF FINDINGS AND DIRECTIONS FOR FUTURE RESEARCH

Impact hip fracture on daily functioning

In the first part of this thesis (chapters 3, 4 and 5) we showed that the older person with a hip fracture is already frail and deteriorating in daily functioning before the hip fracture. The decline in functioning before the hip fracture shows that the hip fracture can serve as a warning to clinicians that their patient is in a trajectory of decline. Frailty and decline is not something that can still be averted, it is reality that should be acted upon. The hip fracture, as a symptom of decline, can prompt clinicians to screen for other (acute) medical problems at hand. Furthermore, the pre-fracture decline in functioning suggests that 'back to pre-fracture level' is often not a realistic goal for rehabilitation after the hip fracture. Clinicians can help patients to adjust their expectations to this fact. In line with this, conversations about plans and wishes for the last part of life can be initiated. In this way, the focus is on optimising quality of life and limiting further loss of function.

Picking up the decline in daily functioning before a hip fracture will be difficult for clinicians, as they do not measure or register daily functioning, and daily functioning can neither be extracted from GP routine care data in other ways yet. GPs are the professionals that are closest to their patients and know most about them, but even they often do not know the level of (let alone changes in) daily functioning of their patients. Nonetheless, they might note the increase in consultation frequency

which we found to occur before a hip fracture. Being alert to this increase in consultation frequency could help to initiate conversations about (disability-free) life-expectancy and plans and wishes for the future. Although it might not help to prevent a hip fracture, it will help patients to create realistic expectations of their future health and rehabilitation possibilities in case of a hip fracture.

Measuring daily functioning

In the third part of this thesis, we showed that daily functioning can still not be extracted or deduced from routine care data of GPs because of missing information on environmental factors and coping mechanisms. It is worth it to keep searching for ways to extract or deduce level of daily functioning from routine care data because of the importance of daily functioning monitoring in older people in both clinical care and research, and because of the many benefits of research with routine care data (e.g. cheap, large populations available, etc) and the increased use of these data for research. Valuable information would be lost if, because of the movement towards using routine care data for research, we would slowly move from outcome measures such as daily functioning towards outcome measures that are less relevant to patients themselves (e.g. consultation frequency, number of referrals or mortality). Future efforts could be directed at creating a new composite measure for daily functioning solely based on diseases that are almost always disabling (e.g. fragility fractures) in combination with markers of decline in functioning (e.g. number of home visits by the GP, or referrals to a physiotherapist). The problem of missing routine registration of the items relevant for level of daily functioning (such as coping strategies and environmental factors) will persist, but items such as referrals or home visits might prove an acceptable proxy for these.

Efforts in future research could also be directed at linking GP routine care data with data from other organisations that already collect information on daily functioning (e.g. home care organisations, nursing homes, organisations that asses eligibility for support at home or long-term care). As this will likely lead to fragmented information (i.e. no measurements at regular timepoints and for part of the community-dwelling older population no information at all), this option is least preferable.

Another path to explore is integration of (yearly) measurements of daily functioning in the work processes of general practices. There are examples of attempts of this, one of which was reflected on in a study by Nicosia et al..[17] They described several criteria for successful implementation of yearly routine measurement of daily functioning in older people in primary care. One of these criteria is a standardised process for assessment that is integrated in the workflow, and a standardised place

and format of documentation. Moreover, the routine measurements must have implications for clinical practice, and therefore should move beyond a numeric score by including individualised patient information on specific (I)ADL limitations. Because of the large impact that this integration of routine measurement of daily functioning could potentially have on the work processes of general practices, feasibility and added value for both research and clinical practice should be carefully assessed in a study-setting before implementation on a large scale.

Applying the concept of daily functioning

Finally, some notes on how daily functioning is currently measured and termed in both research and clinical practice. As said before, there are four underlying models of daily functioning, with clear differences between them in the items included and the weighing of limitations and restrictions. Which model, and thus balance between included items and weighing, is best depends on the measurement aim. However, researchers and clinicians often do not explicitly state the aim of their measurement nor the underlying model they use. Instead they use a plethora of terms for daily functioning, without clear distinct definitions, thereby only creating more confusion. Apparently, there is no consensus on which terms and instruments are appropriate for different measurement aims. Systematic research that compares the different instruments and what they exactly measure could help future researchers and clinicians to choose the instrument that best fits their aim. For both research and clinical practice, explicit naming of the underlying model of daily functioning used, might also help to choose the measurement instrument(s) that best fit(s) the measurement aim. Moreover, for situations in clinical practice where the patient perspective is important, for example when determining the need for help, it might be best to engage directly with patient view and experience (i.e. asking the patient about his/her functioning and need for help) instead of using (I)ADL instruments.

CONCLUDING REMARKS

The findings of this thesis demonstrate that older people with a hip fracture are already deteriorating before their fracture, with a larger pre-fracture decline in and lower pre-fracture level of daily functioning before the hip fracture (as compared to age-related peers). Monitoring the trajectory of daily functioning, something that could make GPs aware of the already started decline in functioning, is not possible with routine care data (yet). Moreover, the (in the research setting often used) (I)ADL questionnaires are not always the best instruments to monitor this trajectory either, since they do not measure self-perceived functioning and because they

are less sensitive to small but relevant changes. The insight this thesis gives on the role of the hip fracture in the trajectory of decline in daily functioning is not only informative for clinical practice and research, but can also help to improve predictions of health and healthcare use of the future older population.

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Chapter

9

English summary

The number of older people with chronic diseases and multimorbidity (i.e. the presence of two or more long-term conditions) increases. Accumulation of chronic diseases and other age-related problems, such as incontinence, decreased mobility or loneliness, results in complex problems with corresponding complex healthcare needs. This will have vast consequences for the healthcare sector and for society in general, but what it will mean precisely, for example for future daily functioning or healthcare use of the older population, is not evident as studies show mixed results. **Chapter 2** of this thesis describes a qualitative Delphi study among experts in the field of ageing about the effect of predicted trends in health, healthcare and the social domain on healthcare use of the older population in the future. It shows that concurrent changes in patient and population characteristics (for example more older persons living independently and decreasing parent support ratio) are expected to give an additional increase in healthcare use (mainly general practitioner (GP), home and informal care) that was not foreseen previously by extrapolation of single trends.

To make reliable predictions about future health trends on a population level, detailed information on the individual influencing factors, for example the impact of a certain disease, is needed. In **Part 2** of this thesis, the impact of hip fractures, a prevalent disease that influences health and daily functioning at old age, is further studied to eventually better inform future research on health trends and predictions. Just like the overall population, the hip fracture population is changing, both in number and in complexity of (health) problems. Compared to patients who presented two decades ago, current hip fracture patients (i.e. community-dwelling and nursing home residents combined) are known to be older and to have more comorbidities at presentation. In **Chapter 3** we used routine care data from GPs and data from Statistics Netherlands (CBS) to describe the current community-dwelling older hip fracture patients and their use of GP care in the year before the hip fracture. It shows that community-dwelling older hip fracture patients have a median age at fracture of 83 years (IQR 76-88), 70% is female, half has polypharmacy, and the median frailty score (electronic Frailty Index-Utrecht) is 0.20 (IQR 0.12-0.26). The chapter also shows a limited but statistically significant increase in the number of consultations with the general practitioner (GP) in the months before the hip fracture. This supports previous findings that hip fracture patients are getting frailer before their fracture.

Impact of a disease is preferably expressed in terms of for example daily functioning or self-rated health, as these are less influenced by health policy than healthcare use. Daily functioning declines with age, even in the absence of disease or acute

events. After a hip fracture, daily functioning is known to decline even faster, with worse scores both on the short and the long term. Therefore, hip fractures are generally seen as the beginning of functional decline at old age. Considering the advanced age and high levels of multimorbidity of hip fracture patients, one might wonder whether the hip fracture truly is the start of decline, or just one of the contributing factors in a pathway of decline in daily functioning that already started earlier, before the hip fracture. **Chapter 4** of this thesis investigates whether the decline in daily functioning in the year before a hip fracture is faster than the decline in age-matched controls using an individual patient data meta-analysis. The study includes four prospective cohorts including 161 hip fracture patients and 2196 controls aged 80 years and over from the Netherlands, New Zealand (Māori and non-Māori) and United Kingdom. It shows daily functioning already declines in the year before a hip fracture. This decline in functioning before the hip fracture is larger than the decline in functioning in the rest of the older population, and ends in a lower pre-fracture level of daily functioning than that of age-related peers. **Chapter 5**, another individual patient data meta-analysis including the same four study cohorts, assesses the relation between the observed pre-fracture decline in daily functioning and the post-fracture daily functioning level. It shows that the pre-fracture level of daily functioning is associated with the post-fracture level of functioning: those with many limitations before the fracture show less recovery after the hip fracture. However, the chapter also shows that the speed with which functioning declined before the hip fracture is not associated with post-fracture functioning level. In other words, the trajectory of daily functioning after the hip fracture is not an extension of the pre-fracture trajectory of daily functioning.

The last part of this thesis (**Part 3**) explores different aspects of how to measure daily functioning in clinical practice and research. Daily functioning has a central role in research and clinical practice in the older population, therefore correct measurement of this outcome measure is important. It is often operationalised with Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) questionnaires. The use of (I)ADL instruments is time and labour intensive, which hinders collecting these data on a large scale for research. Routine care data might be an interesting source of information on daily functioning on a larger scale, and might also help to ascertain pre-event level of daily functioning, but (I)ADL measures are usually not reported in these data. Moreover, there are no composite measures of daily functioning based on routine care data yet. However, there are measures of frailty based on routine care data. **Chapter 6** of this thesis describes a cohort study which evaluated whether an electronic frailty index (approach) based on routine (primary) care data could be used as a measure for

daily functioning, with the underlying idea that frailty and daily functioning are overlapping concepts. The cohort was extracted from the ISCOPE (Integrated Systemic Care for Older People) trial, which contained both daily functioning measurements (with questionnaires) and routine primary care data from which electronic frailty index scores could be computed. It shows that an electronic frailty index (eFI-Utrecht) based on routine care data from GPs cannot be used as a proxy for daily functioning. Daily functioning is likely to go beyond the deficit accumulation that is measured with the frailty index, as it is also influenced by coping mechanisms and environmental factors, which are rarely registered or captured in routine care data. **Chapter 7** also touches upon what contributes to daily functioning and how well it is currently measured. It describes a qualitative interview study, which was part of the HIP CARE (Hip fractures: Inventarisation of Prognostic factors and Their Contribution towards Rehabilitation in older pErsons) prospective cohort study, where older hip fracture patients were asked what daily functioning meant to them. It shows that daily functioning as measured with (I)ADL questionnaires does not reflect self-perceived functioning of older hip fracture patients. Self-perceived functioning includes a larger range of activities/abilities, and limitations in these activities differentially affect self-perceived functioning, which is not taken into account in the often used (I)ADL questionnaires.

Conclusion

To conclude, this thesis shows that older people with a hip fracture are already deteriorating before their fracture, with a larger pre-fracture decline in and lower pre-fracture level of daily functioning as compared to age-related peers. Picking up the decline in daily functioning before a hip fracture for individual patients is not possible yet, as it is not measured routinely in clinical practice and currently there is also no other way to extract daily functioning from routine care data. However, the last pre-fracture daily functioning level, which can often be reconstructed at the time of fracture, is informative on its own for post-fracture recovery potential. In any case, a hip fracture is a signal of ongoing decline, which can warn clinicians that their patient is in a trajectory of decline and thus expectations of recovery should be adjusted correspondingly.

When measuring this recovery in daily functioning, researchers and clinicians should be aware that (I)ADL questionnaires hardly correspond with self-perceived functioning of older people and are not so sensitive to small but (for older people) relevant changes. Thus, when the aim is to measure post-fracture recovery, it might be best to engage directly with patients' view and experience (i.e. asking

the patient about his/her functioning and need for help) instead of using (I)ADL questionnaires.

Finally, this thesis gives a better insight in the impact of hip fractures on daily functioning in old age. This insight can help to improve predictions of health trends and healthcare use of the future older population.

Chapter

10

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NEDERLANDSE SAMENVATTING

Het aantal ouderen met chronische ziekten en multimorbiditeit (i.e. de aanwezigheid van twee of meer chronische aandoeningen) neemt toe. Opeenstapeling van chronische ziekten en andere leeftijd gerelateerde problemen, zoals incontinentie, afname van mobiliteit of eenzaamheid, leidt tot complexe problemen met bijbehorende complexe zorgbehoeften. Dit heeft grote gevolgen voor de zorg en voor de maatschappij, maar wat de gevolgen precies zullen zijn, bijvoorbeeld voor het dagelijks functioneren en zorggebruik van toekomstige ouderen, is niet bekend. Studies hiernaar laten een wisselend beeld zien. **Hoofdstuk 2** van dit proefschrift beschrijft een kwalitatieve Delphi studie onder experts binnen de ouderengeneeskunde naar het effect van verwachte trends in gezondheid, de zorg en het sociale domein op het zorggebruik van ouderen in de toekomst. Het laat zien dat samenkomende trends in patiënt- en populatiekarakteristieken (bijvoorbeeld meer ouderen die zelfstandig wonen en een afname van de *parent support ratio*) naar verwachting zal leiden tot een extra toename van zorggebruik (vooral huisartsenzorg en informele zorg), wat eerder niet was voorzien op basis van studies die keken naar het effect van de afzonderlijke trends.

Om een betrouwbare inschatting te kunnen maken van toekomstige gezondheidstrends op populatieniveau is gedetailleerde informatie over afzonderlijke beïnvloedende factoren, bijvoorbeeld de impact van een bepaalde ziekte, nodig. In **Deel 2** van dit proefschrift wordt de impact van heupfracturen onderzocht, een aandoening met een hoge incidentie die grote invloed heeft op de gezondheid en het dagelijks functioneren van ouderen. Het uiteindelijke doel hiervan is meer inzicht te geven in de impact van heupfracturen, wat meegenomen kan worden in toekomstige onderzoeken naar gezondheidstrends en -verwachtingen.

Net zoals de algemene ouderenpopulatie verandert de heupfractuurpopulatie, zowel in aantal als in complexiteit van (gezondheids)problemen. Vergeleken met patiënten die twintig jaar geleden een heupfractuur kregen zijn de huidige patiënten (i.e. de thuiswonende ouderen en patiënten uit een verpleeghuis samen genomen) ouder en met meer comorbiditeiten ten tijde van de heupfractuur. In **Hoofdstuk 3** hebben we met behulp van routinezorgdata van huisartsen en data van het Centraal Bureau voor de Statistiek (CBS) de patiëntkarakteristieken en het gebruik van huisartsenzorg in het jaar voorafgaand aan de fractuur van de huidige thuiswonende oudere heupfractuurpatiënt in kaart gebracht. Het laat zien dat thuiswonende ouderen ten tijde van de heupfractuur een mediane leeftijd van 83

jaar (IQR 76-88) hebben, 70% is vrouw, de helft heeft polyfarmacie, en de mediane kwetsbaarheidsscore (elektronische Frailty Index-Utrecht) is 0.20 (IQR 0.12-0.26). Het hoofdstuk laat ook een beperkte maar statistisch significante toename zien van het aantal contacten met de huisarts in de maanden voorafgaand aan de heupfractuur. Dit ondersteunt de eerdere bevindingen dat patiënten al voor de heupfractuur steeds kwetsbaarder worden.

De impact van een ziekte kan het beste uitgedrukt worden in bijvoorbeeld dagelijks functioneren of zelfervaren gezondheid, omdat deze uitkomsten in mindere mate beïnvloed worden door zorgbeleid dan een uitkomst als zorggebruik. Dagelijks functioneren neemt af met de leeftijd, zelfs als er zich geen (acute) ziekten voordoen. Het is bekend dat dagelijks functioneren na een heupfractuur nog sneller achteruit gaat, met een slechter niveau van functioneren zowel op de korte als de lange termijn. Om die reden wordt een heupfractuur over het algemeen gezien als het begin van achteruitgang van dagelijks functioneren op oudere leeftijd. Echter, gegeven de hoge leeftijd en het veel voorkomen van multimorbiditeit bij heupfractuur patiënten kun je je afvragen of de heupfractuur daadwerkelijk een begin van achteruitgang in functioneren inluidt, of dat het slechts één van de vele bijdragende factoren in een eerder, voor de heupfractuur, begonnen traject van achteruitgang is. **Hoofdstuk 4** van dit proefschrift onderzoekt door middel van een meta-analyse met individuele patiëntdata of de achteruitgang in dagelijks functioneren bij ouderen met een heupfractuur in het jaar voor de fractuur sneller is dan de achteruitgang in functioneren van leeftijdsgenoten zonder heupfractuur. De studie bevat vier prospectieve cohorten van 80-plussers uit Nederland, Nieuw-Zeeland (Māori en niet-Māori) en het Verenigd Koninkrijk, met 161 heupfractuur patiënten en 2196 controles. Het laat zien dat dagelijks functioneren al in het jaar voor de heupfractuur achteruit gaat. Deze achteruitgang gaat sneller dan de achteruitgang in dagelijks functioneren onder 80-plussers zonder heupfractuur, en het eindigt in een slechter niveau van dagelijks functioneren net voor de heupfractuur dan dat van leeftijdsgenoten zonder heupfractuur. **Hoofdstuk 5**, een tweede meta-analyse met individuele patiëntdata op basis van dezelfde vier cohorten, bekijkt de relatie tussen de achteruitgang in functioneren voor de heupfractuur en het niveau van functioneren na de fractuur. Het laat zien dat het pre-fractuur niveau van dagelijks functioneren geassocieerd is met het niveau van functioneren kort na de heupfractuur: patiënten met veel beperkingen voor de fractuur herstellen minder na de fractuur. Het hoofdstuk laat ook zien dat de snelheid waarmee het functioneren voor de fractuur achteruit ging niet is geassocieerd met het niveau van functioneren na de fractuur. Met andere woorden,

het traject van dagelijks functioneren na de heupfractuur is geen voortzetting van het traject van dagelijks functioneren voor de heupfractuur.

Het laatste deel van dit proefschrift (**Deel 3**) verkent verschillende aspecten van het meten van dagelijks functioneren in de kliniek en het onderzoek. Dagelijks functioneren speelt een belangrijke rol binnen de ouderengeneeskunde. Een correcte meting hiervan is daarom van belang. Vaak wordt dagelijks functioneren geoperationaliseerd met vragenlijsten over Activiteiten van het Dagelijks Leven (ADL) en Instrumentele Activiteiten van het Dagelijks Leven (IADL). Het gebruik van deze (I)ADL vragenlijsten kost veel tijd en is arbeidsintensief, wat het voor onderzoek verzamelen van deze informatie op grote schaal bemoeilijkt. Routinezorgdata is een potentiële bron van informatie over dagelijks functioneren op grotere schaal voor onderzoek, en kan ook helpen om het niveau van dagelijks functioneren van een patiënt voorafgaand aan een acute gebeurtenis of ziekte te bepalen. Echter, (I)ADL scores worden niet standaard gerapporteerd in routinezorgdata, en er zijn ook nog geen samengestelde maten voor functioneren op basis van routinezorgdata beschikbaar. Er zijn daarentegen wel (samengestelde) maten voor kwetsbaarheid op basis van routinezorgdata ontwikkeld. **Hoofdstuk 6** van dit proefschrift beschrijft een cohort studie waarin werd gekeken of een elektronische frailty index (benadering) op basis van routinezorgdata van huisartsen gebruikt kon worden om dagelijks functioneren te bepalen. Het onderliggende idee hierbij is dat frailty en dagelijks functioneren twee verschillende maar voor een groot deel overlappende concepten zijn. Het studiecohort kwam uit de ISCOPE (Integrated Systemic Care for Older People) trial, waarin zowel metingen van dagelijks functioneren (met vragenlijsten) als routinezorgdata van huisartsen, waarmee de elektronische frailty index berekend kon worden, beschikbaar waren. De studie laat zien dat een elektronische frailty index (eFI-Utrecht) gebaseerd op eerstelijns routinezorgdata niet gebruikt kan worden als een proxy voor dagelijks functioneren zoals gemeten met (I)ADL vragenlijsten. Een mogelijke verklaring hiervoor is dat dagelijks functioneren waarschijnlijk verder gaat dan de opeenstapeling van ziekten die gemeten wordt met een frailty index. Dagelijks functioneren wordt ook beïnvloedt door coping mechanismen en omgevingsfactoren, iets wat niet standaard in routinezorgdata terug te vinden is. **Hoofdstuk 7** gaat ook in op wat bijdraagt aan het dagelijks functioneren en hoe goed dat momenteel wordt gemeten. Het beschrijft een kwalitatieve interview studie, welke onderdeel was van de HIP CARE (Hip fractures: Inventarisation of Prognostic factors and Their Contribution towards Rehabilitation in older pErsons) prospectieve cohort studie, waarin ouderen met een heupfractuur werd gevraagd wat dagelijks functioneren voor hen betekent. Het laat zien dat dagelijks functioneren zoals gemeten met

(I)ADL vragenlijsten iets anders weergeeft dan het zelfervaren functioneren van ouderen met een heupfractuur. Zelfervaren functioneren omvat een breder spectrum aan activiteiten. Daarnaast hadden beperkingen in deze activiteiten een wisselend effect op zelfervaren functioneren, iets wat in (I)ADL vragenlijsten vaak niet wordt meegenomen.

Conclusie

Samenvattend, dit proefschrift laat zien dat ouderen met een heupfractuur al voor hun fractuur achteruit gaan, met een snellere pre-fractuur achteruitgang en slechter pre-fractuur niveau van dagelijks functioneren vergeleken met leeftijdsgenoten zonder heupfractuur. Het is nog niet mogelijk om deze achteruitgang in functioneren voorafgaand aan een heupfractuur bij individuele patiënten te meten, omdat dagelijks functioneren niet routinematig wordt gemeten in de klinische praktijk en omdat er momenteel geen andere manier is om het niveau van dagelijks functioneren uit routinezorgdata te halen. Het pre-fractuur niveau van dagelijks functioneren, wat vaak kort na de heupfractuur nog wel achterhaald kan worden, is echter op zichzelf al informatief voor het inschatten van de herstelkansen kort na de heupfractuur. Hoe dan ook, een heupfractuur is een teken van al ingezette achteruitgang in functioneren. Het kan zorgverleners ervan bewust maken dat hun patiënt in een traject van achteruitgang in dagelijks functioneren zit, waar de verwachtingen van de herstelmogelijkheden op afgestemd moeten worden.

Bij het meten van dit herstel in dagelijks functioneren zouden onderzoekers en zorgverleners zich bewust moeten zijn dat (I)ADL vragenlijsten slecht overeenkomen met zelfervaren functioneren van ouderen en dat ze niet zo gevoelig zijn voor kleine (maar voor oudere patiënten relevante) veranderingen in functioneren. Bij het meten van post-fractuur herstel is het daarom aan te raden om tenminste aan patiënten zelf rechtstreeks te vragen wat zij van hun functioneren en herstel vinden, en niet alleen (I)ADL vragenlijsten toe te passen.

Tot slot, dit proefschrift geeft meer inzicht in de impact van heupfracturen op het dagelijks functioneren van ouderen. Dit inzicht kan inschattingen van de gezondheid en het zorggebruik van de toekomstige ouderen verbeteren.

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CURRICULUM VITAE

Willeke Maria Ravensbergen-Roobol was born on January 7th 1994 in Rijnsburg, the Netherlands. She grew up in Valkenburg ZH, graduated from the Christelijk Lyceum Dr. W.A. Visser 't Hooft in Leiden (bilingual grammar school, International Baccalaureate Certificate English) in 2012 and in that same year started medical school at Leiden University.

During her years in medical school, she served as a board member of the International Federation of Medical Students Associations – the Netherlands (IFMSA-NL) as National Officer on Research Exchange. Furthermore, she worked as a student teaching assistant at the Department of Anatomy and Embryology at the Leiden University Medical Center (LUMC), and did a research internship at the Department of Anaesthesiology as part of her Honours Programme. She completed the Bachelor of Medicine and the Honours Programme Medicine of the Leiden University in 2015. One year later she started with the Master Vitality and Ageing at the Leiden University. In that same year she worked as a research assistant at the Center of Expertise in Palliative Care at the LUMC. She did her research internship for the Master Vitality and Ageing at the Centre for Health and Society of the National Institute for Public Health and the Environment (RIVM), after which she graduated in 2017.

Directly afterwards she started as a PhD-student at the department of Public Health and Primary Care, where she worked on her research in the period 2017-2021. During her PhD research she followed an intensive programme in epidemiology. Her PhD research project focussed on daily functioning of community-dwelling older adults with a hip fracture and was supervised by Prof.dr. J. Gussekloo, Prof. dr. A.W.M. Evers and Dr. J.W. Blom. In spring 2021, Willeke started with the Master of Medicine, from which she graduated in September 2023. Willeke is married with Steffan Roobol.