Trajectories in health, long-term care and wellbeing in old age

A longitudinal study in the context of the Dutch 2015 Long-term Care Reform

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Authors’ contributions, acknowledgements and funding

For the first, second, and fifth chapter all authors made substantial contributions to conception (Maura Gardeniers (MG), Marjolein Broese van Groenou (MB), Martijn Huisman (MH), and Erik Jan Meijboom (MB)), design (MG, MH, MB, EM), interpretation of the data (MG, MH, MB, EM), and preparation of the manuscript (MG, MH, MB, EM). MH and MB were involved in the design of the Longitudinal Aging Study Amsterdam and were responsible for the data collection. MG prepared the data, performed statistical analyses, and wrote the first and final drafts of the manuscript. All authors (MH, MB, EM, MG) contributed to and approved the final versions.

For the third and fourth chapter, Emiel Hoogendijk (EH) contributed as well. For these chapters the contributions were as follows: conception (Maura Gardeniers (MG), Marjolein Broese van Groenou (MB), Martijn Huisman (MH), Erik Jan Meijboom (MB), and Emiel Hoogendijk (EH), design (MG, MH, MB, EH, EM), interpretation of the data (MG, MH, MB, EH, EM), and preparation of the manuscript (MG, MH, MB, EH, EM). MH and MB were involved in the design of the Longitudinal Aging Study Amsterdam and were responsible for the data collection. MG prepared the data, performed statistical analyses, and wrote the first and final drafts of the manuscript. All authors (MH, MB, EM, EH, MG) contributed to and approved the final versions.

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Chapter 1 Synthesis

Introduction

Western societies are ageing rapidly, with a significant increase in both the number of young older adults (aged 65 to 75) and the oldest-old (aged 75 and over) (WHO, 2015). This growth is projected to continue, with the population aged 65 and over expected to double, and those aged 80 and over expected to triple by 2050 (He et al., 2016). By 2050, it is anticipated that one in four people in the Netherlands will be 65 or older (Van Duin et al., 2015). This trend is partly attributable to advances in medical treatments that have rendered once-fatal diseases manageable, enabling individuals with chronic conditions to live longer (Crimmins et al., 2019; Deeg et al., 2013). Additionally, the substantial size of the baby boom generation, born shortly after World War II, who are now 65 years or older, contributes to this demographic shift.

One consequence of population ageing is the increasing burden of disability, as the extension of lifespan is not accompanied by a corresponding increase in disability-free life (Chatterji et al., 2015; Crimmins & Beltrán-Sánchez, 2011). Consequently, the prevalence of chronic diseases has risen both in absolute and relative terms. However, this trend does not impact all older adults uniformly. There is considerable variation in health among older individuals (Kok et al., 2017). Men, younger-old adults, and those with higher levels of education tend to experience more successful ageing trajectories (Kok et al., 2017; Pruchno, Wilson-Genderson, & Cartwright, 2010; Pruchno, Wilson-Genderson, Rose, et al., 2010). Given that health issues are key determinants of care utilisation, care trajectories in later life also exhibit substantial diversity. This variability is evident in both acute healthcare, such as that provided by GPs and hospitals, and in long-term care, whether delivered at home or in residential facilities.

Long-term care can be provided by either an unpaid informal carer or a paid formal carer (OECD, 2011). Unlike acute care, which is designed to treat diseases and acute conditions, long-term care aims to alleviate the chronic adverse effects of health issues. As such, long-term care serves as a means to restore wellbeing when it is compromised by health problems. Wellbeing includes the concept of eudaimonia, which refers to a state of vitality and full functioning (Deci & Ryan, 2008).

It is well established that different types of care have varying effects on wellbeing. For instance, the use of publicly paid care has been negatively associated with wellbeing (Abbing, Suanet, & Broese van Groenou, 2022; Boumans & Deeg, 2011; Pot et al., 2005; Swinkels et al., 2024). However, the evidence regarding the impact of informal care on wellbeing is more mixed. Some studies have identified a negative relationship between informal care and wellbeing (Ouyang et al., 2019; Zwar et al., 2019), while others have found a positive relationship, particularly in the context of spousal care (Abramowska-Kmon, Łątkowski, and Rynko 2023; Swinkels et al. 2024). Nonetheless, further understanding is needed regarding how different aspects of care, such as the amount of care provided or the perceived control over care, influence the relationship between health and wellbeing.

Given that health, care utilisation, and wellbeing are interconnected, the interaction between these factors is likely to result in a diversity of trajectories, both between and within individuals. The varied and dynamic nature of health and the resulting care trajectories may also be reflected in their relationship with wellbeing. The dynamic associations between health, care, and wellbeing highlight the importance of a longitudinal approach to better understand the interplay between these processes. Therefore, to gain deeper insight into the determinants and outcomes of care utilisation, it is crucial to examine the determinants, utilisation and outcomes of care within a longitudinal framework.

The associations between health, care utilisation, and wellbeing are crucial to study at any time, but the ageing population makes this particularly urgent. As the demand for long-term care rises, it places increasing pressure on long-term care systems. Gaining a deeper understanding of who will require which types of care is essential for future care planning. To manage costs, many countries, including the Netherlands, have reformed their long-term care systems by tightening restrictions on the use of publicly paid care and promoting ageing in place (Maarse & Jeurissen, 2016; Ministry of Health Welfare and Sport, 2013; Pavolini & Ranci, 2008; WHO, 2015).

Since the early 2000s, several reforms have been implemented in the Dutch long-term care system, focusing on reducing residential care, reorganising eligibility for publicly funded care, and establishing support programmes for informal carers (Cohu et al., 2006; Maarse & Jeurissen, 2016). However, the most significant change occurred in 2015 with the introduction of a new law regulating long-term care.

Although changes in long-term care policy are likely to impact the care utilisation of older adults, studying causal effects in this area is challenging due to the lack of experimental data. Nevertheless, a careful analysis of observational data, which describes developments in health and care utilisation, may contribute to causal theories regarding the potential consequences of care reforms. Thus, descriptive research on the changes during and after the 2015 reform may provide valuable insights into this complex causal puzzle. The 2015 reform of long-term care presents an interesting context for studying the longitudinal associations between health, care, and wellbeing, particularly because data from both before and after the reform will be utilised.

Our study thus aims to investigate the associations between health, care use and wellbeing in the context of the 2015 reform in the Netherlands, by answering the question: *What are the trajectories of health and care among Dutch older adults and how are health and care utilisation related to wellbeing, in the period of 2012-2021?*

Elaboration of the context

The 2015 long-term care reform in the Netherlands

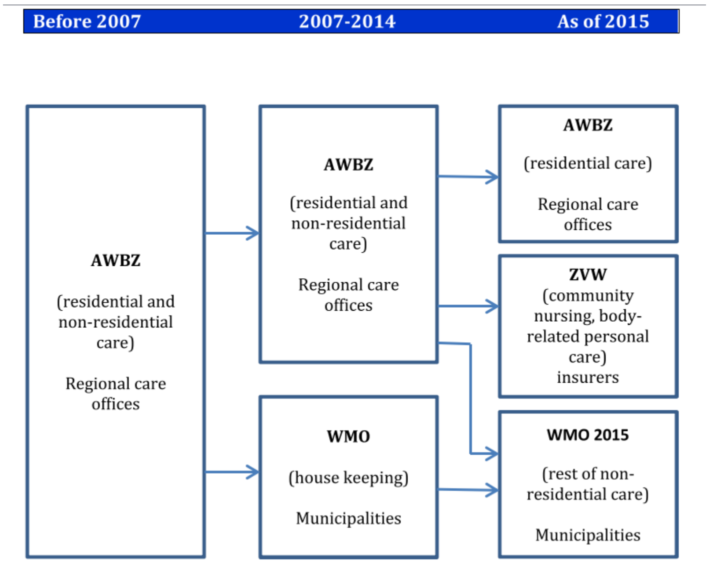
Although the Dutch population is relatively young compared to other Western countries, healthcare expenditure has been steadily rising since the 1990s (CBS, 2023; OESO, 2019). In 2013, 4% of Dutch government spending was allocated to long-term care, the highest proportion among all EU countries (OESO, 2019). To curb this increasing expenditure, the Dutch long-term care system underwent a significant reform in 2015. As a result of this reform, eligibility criteria for residential care were tightened, and home care and social assistance services were more decentralised (Alders & Schut, 2019; Ministry of Health Welfare and Sport, 2013).

Before 2015, the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten: AWBZ*) governed both home care and institutional care, placing them under the responsibility of the national government. The 2015 reform led to the transformation of the AWBZ into three distinct acts: the Long-Term Care Act (*Wet langdurige zorg: Wlz*), the Health Insurance Act (*Zorgverzekeringswet: Zvw*), and the Social Support Act (*Wet maatschappelijke ondersteuning: Wmo*) (Alders & Schut, 2019; Maarse & Jeurissen, 2016), see Figure 1. Under the new structure, only 24-hour care continued to be reimbursed through the Long-Term Care Act, remaining under the jurisdiction of the national government. Meanwhile, the reimbursement of home care was transferred to the Health Insurance Act, and the scope of the Social Support Act was expanded to include subsidies for daily activities and personal guidance.

Municipalities had already been responsible for the Social Support Act since 2007, but the reform increased their role, requiring them to provide all forms of support for daily living more efficiently. Therefore, the budget for executing the tasks of Social Support Act was significantly reduced, by 35% compared to the budget previously spent on it by the national government (Alders & Schut, 2019). The increased eligibility criteria for institutional care went hand in hand with a greater emphasis on other types of care. In the run-up to the reform, the government suggested early on that citizens should make more use of their own resources, such as own imbursement of privately paid care, and informal care from their own social network (Ministry of Health Welfare and Sport, 2013).

Figure 1

Changes in long-term care laws (Maarse & Jeurissen, 2016)



Scheme 1. The old and new regulatory framework for LTC (including service package and implementing agency).

Consequences for the utilisation of care

The reform has led to significant shifts in both the organisation and provision of long-term care. Given the extensive changes introduced by the reform, it is crucial to examine which aspects of care have been most affected. We hypothesise that the reform has influenced care by altering its accessibility, type, quantity, and quality.

Initially, there was a considerable lack of understanding among municipal implementers regarding the new long-term care regulations. Previous studies have highlighted several challenges faced by municipalities, including legal difficulties in constructing housing with integrated care services (de Klerk et al., 2019), confusion over whether care should be provided by municipalities (under the Social Support Act) or by health insurance funds (under the Health Insurance Act) (Kromhout et al., 2018), and inadequate information for older adults on where to access care (Kromhout et al., 2018) or obtain assistive devices (Esch et al., 2018)

These issues may have exacerbated barriers to accessing care. Institutional care became less accessible, with some older adults who were eligible under the previous regime no longer qualifying under the new criteria (van Klaveren et al., 2017). Additionally, waiting lists for long-term care grew, and there was a shortage of care providers (Plaisier & den Draak, 2021). As a result, more older adults with very high care needs were living at home, likely relying on publicly funded home care. However, budget cuts also meant that some municipalities were providing less publicly funded care than before (Pommer et al., 2018).

The reduced availability of institutional and publicly funded care (Plaisier & den Draak, 2021) likely led to a greater reliance on informal and privately paid care. However, these alternatives may not have been accessible to everyone. Individuals with lower incomes had fewer resources to pay for private care (Woittiez et al., 2015), and privately paid care was not always considered sufficient (Plaisier & den Draak, 2019). Regarding informal care, older adults faced various challenges, such as (Linders, 2010; Vermeij, 2016), overburdened caregivers (de Klerk et al., 2018) or simply a lack of available caregivers (de Jong & Kooiker, 2018). Moreover, there is the question of willingness to provide informal care, as two-thirds of the population believe that the state, rather than family members, should bear primary responsibility for the care of older adults (de Boer et al., 2020).

The reform likely altered the balance between informal, publicly funded, and privately paid care, as well as the overall quantity of care received. Some individuals may have experienced a reduction in the total hours of care, while others may have seen a shift in the type of care they received. A simulation study projected that reductions in publicly funded care could lead to an increase in the use of all other forms of care (Woittiez et al., 2019). However, other studies have shown a decline in care utilisation following the reforms, across all types of care, particularly among older adults with higher levels of education (Abbing, Suanet, and Broese Van Groenou 2022). This trend of declining long-term care utilisation had already begun before the reforms were implemented (Aaltonen et al. 2024).

Regarding care quality, the increased workload on publicly paid carers (Vermunt et al., 2023) may have resulted in rushed care, with essential but non-urgent tasks—such as building personal relationships—being neglected (Kleinman, 2012). Implementers also lacked the resources to focus on preventative care, which led to preventable health issues (de Klerk et al. 2019). Coordination problems among multiple carers resulted in care gaps, as carers sometimes assumed that certain tasks had already been completed (Kromhout et al. 2018). Furthermore, increased reliance on informal care potentially compromised care quality due to overburdened and untrained caregivers (de Boer et al., 2020; de Klerk et al., 2019).

In conclusion, the long-term care reform may have affected older adults' ability to access care of specific types, intensity, and quality, which, in turn, could have influenced the wellbeing of care recipients. This dissertation presents the results of analyses on longitudinal data, which are essential for examining individual-level changes within this particular long-term care context. All studies are underpinned by a comprehensive theoretical framework.

Theoretical framework of the study

When older adults experience declining health, this often leads to a reduction in their overall wellbeing. To mitigate this loss, restore previous levels of functioning, or support individuals in managing diminished capacities, older adults frequently receive various forms of care. The process of care utilisation is explained by the Andersen-Newman model, which identifies determinants of individual-level healthcare usage (Andersen & Newman, 1973). This model highlights three key factors that influence care utilisation.

Firstly, the *need* for care, indicated by the degree of illness or health status, is the primary driver of care use. Secondly, *predisposing* factors, such as demographic characteristics, socio-structural conditions, and attitudes, shape an individual's propensity to seek care. Examples of these factors include gender, age, and education. Thirdly, *enabling* factors, such as the availability of a social network with informal carers, determine whether, what type, and how much care is utilised.

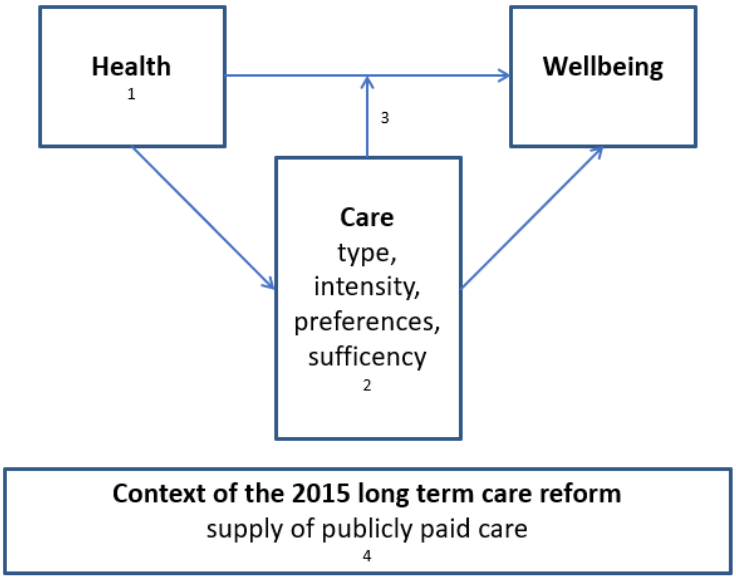
These three factors together result in the actual use of care. Older adults living in the community may rely on a mix of informal care, publicly funded care, privately paid care, or a combination of these types. Institutional care is also an option, which can be funded either publicly or privately. While the Andersen-Newman model primarily focuses on the utilisation of care, a comprehensive view of the care process should also consider the outcomes of care. Since the primary aim of care is to alleviate the impact of health issues on wellbeing, wellbeing itself can be seen as a significant outcome of care.

To hypothesise the impact of care on wellbeing, we refer to Self-Determination Theory (SDT) (Deci & Ryan, 2000), which outlines the determinants of psychological wellbeing. According to SDT, wellbeing is primarily influenced by three factors: relatedness, autonomy, and competence. Relatedness refers to the sense of connection and support from significant others. Autonomy and competence involve the ability and willingness to organise one’s experiences independently and ensure that these activities align with one’s self-concept (Deci & Ryan, 2000). This theoretical framework is particularly relevant in the context of long-term care, as health issues and care utilisation can affect these fundamental determinants of wellbeing. Given that care varies in terms of provider, amount, and alignment with the care recipient’s preferences, the mechanisms of relatedness, autonomy, and competence likely interact differently depending on these aspects of care. Empirical studies applying SDT to the care context have demonstrated that care received from strong personal relationships, sufficient levels of care, and maintaining control over care decisions, all contribute to enhanced wellbeing (Abbing, Suanet, & Broese van Groenou, 2022; Broese van Groenou, 2020; Swinkels et al., 2024).

Our study employs a longitudinal design to investigate how changes in health and care utilisation influence changes in wellbeing. Since a care trajectory begins with health problems, it is essential to first explore the various health trajectories of older adults, followed by an examination of how health affects care trajectories and how care utilisation impacts wellbeing. Figure 2 illustrates the model and the four sub-studies included in this dissertation, which are further detailed below. The figure also includes the context of the 2015 long-term care reform, which serves as the general backdrop for our studies, though it is not directly addressed in the empirical analyses.

Figure 2

Conceptual model



1. Trajectories of health
2. Trajectories of care
3. Care features moderating the health-wellbeing association
4. Care sufficiency as outcome of health, care use, and wellbeing

Four sub-studies

Health trajectories

Health plays a crucial role in triggering both care needs and wellbeing, making it essential to understand who develops health problems requiring care, especially in the context of long-term care reform. Since 1992, there has been a noticeable trend in the Netherlands: while the severity of functional limitations among older adults has decreased, the prevalence of multimorbidity has increased (Timmermans et al., 2019). In 2019, the Netherlands had 1.4 million older adults aged 75 and above, with 93% living independently (de Klerk et al., 2019). Over 60% of these individuals had some form of functional limitation, and both the number and severity of these limitations tend to increase with age (Timmermans et al., 2019; Woittiez et al., 2015).

The ability to perform activities of daily living (ADL) and instrumental activities of daily living (iADL) serves as key indicators of health and are primary drivers of long-term care needs. A decline in these abilities reflects the loss of independence, caused by either physical or cognitive decline. Functional limitations arise when ADL and iADL decline. These limitations are significant predictors of an increasing need for care, including the likelihood of requiring institutional care (Hirdes et al., 2008; Hoogerduijn et al., 2014; Sjölund et al., 2015). Furthermore, an increase in functional limitations is associated with rising care costs (Guralnik et al., 2002). In the Dutch context, there is also evidence that older adults with cognitive impairments are more likely to have unmet care needs, highlighting the importance of studying cognitive functioning trajectories as well (De Groot et al., 2018).

Previous research has explored the trajectories of functional limitation development. Most studies have identified four or fewer distinct trajectories (Jonkman et al., 2018; Kingston et al., 2015; Kok et al., 2017; Lee & Jun, 2023; Lunney et al., 2003; Martin et al., 2017), although some studies have reported a greater number of trajectories (Deeg & Zarit, 2005; Gill et al., 2013; Han et al., 2013; Kok et al., 2017; Nusselder et al., 2005; Rundell et al., 2022; Saito et al., 2022; Taylor & Lynch, 2011). The four most commonly identified trajectories are: continuously good functioning, moderately good functioning, declining functioning, and continuously low functioning.

Cognitive functioning is often assessed using various measures, such as expert evaluations of cognitive status, the Mini-Mental State Examination (MMSE), and combinations of tests like the Modified Mini-Mental State (3MS) for global cognitive function, the Controlled Oral Word Association Test (COWAT-F) for verbal fluency, the Hopkins Verbal Learning Test-Revised (HVLT-R) for episodic memory, and the Symbol-Digit Modalities Test (SDMT) for psychomotor speed. Most studies have identified three or four cognitive trajectories (Du et al., 2023; Han et al., 2022; Liew, 2020; Lobo et al., 2021, 2024; Mose et al., 2023; Su & Xiao, 2022; Wilkosz et al., 2010; Wu et al., 2022, 2020, 2021), though some have reported more than four trajectories (Baker et al., 2017; Xie et al., 2011). The three most commonly identified cognitive trajectories are: stable and high cognitive functioning, steep decline in cognitive functioning, and gradual decline in cognitive functioning.

There is a pressing need to re-evaluate the trajectories of functional and cognitive limitations among Dutch older adults, particularly in the context of and following the recent long-term care reforms, and to employ more sophisticated research methodologies in this process. Previous studies have highlighted a significant diversity in health trajectories among older adults (Enβle & Helbrecht, 2021; Kok et al., 2017). However, the types of trajectories identified often depend on various study design aspects, such as sample characteristics and time frame.

Studies with shorter time intervals have identified more dynamic trajectories in functioning, occasionally even showing signs of recovery. Conversely, some research has incorporated mortality data into their trajectory estimates to account for biases in group sizes caused by non-selective attrition due to mortality (Haviland et al., 2011). Mortality-related attrition is influenced by previous health status, making it a crucial factor for accurately classifying individuals into broader functioning categories. This approach leads to more precise classifications compared to studies that assume death occurs at random, which implies no association between death and health trajectories—a premise that seems unlikely and may introduce bias in previous findings (Haviland et al., 2011).

Our study introduces a methodological advancement by combining shorter time intervals with mortality correction, addressing this gap in the literature. Additionally, continued descriptive research is essential for modelling health trajectories among older adults. Such research is valuable for monitoring health development in the context of significant long-term care reforms, estimating future care burdens, and understanding the distribution of health and health declines in the older population. Furthermore, it is crucial to identify which need factors and predisposing characteristics—such as aspects of health and demographic factors—are associated with these health trajectories.

Therefore, the research questions of the first sub-study are as follows:
What trajectories in functional limitations and cognitive functioning can be identified in Dutch adults aged 75 and older in a period of three years during and after the long-term care reform? And how are age, sex, socioeconomic status, and chronic diseases associated with these trajectories?

Care networks

Studies on care utilisation can be broadly categorised into two main approaches. The first approach involves longitudinal analyses of care types, distinguishing between formal care, informal care, or a combination of both (Bonsang, 2009; Geerts et al., 2012; Hlebec, 2015; Hlebec & Filipovic Hrast, 2016; Kjaer & Siren, 2019a; Pinquart & Sörensen, 2002; Tennstedt et al., 1996). These studies have generally found that older adults often receive a blend of informal and formal care towards the end of their care trajectory, before transitioning to residential care. However, what types of caregivers tend to co-occur in these mixes remains unknown in these longitudinal approaches.

The second approach zooms in on these, often mixed, care arrangements that form the care network around an older adult (Bijnsdorp et al., 2018; Broese van Groenou et al., 2016; Wenger, 1991; Fret et al., 2017; Jacobs et al., 2018; Keating et al., 2003; Keating & Dosman, 2009; Lin, 2024; Savla et al., 2016; Wenger, 1997). Since there are different types of informal caregivers such as spouse, children, relatives, friends and neighbours, zooming in on the composition of the care network gives a more detailed picture of these mixed care networks and the differences between them. It also sheds light on how different types of formal and informal care tend to co-occur. This information is particularly valuable in the context of care reforms, where reductions in institutional care have shifted responsibilities to a diverse array of both formal and informal caregivers.

However, there remains a gap in understanding how these care networks evolve over time. To date, only one study has examined longitudinal changes in care networks. Lin (2024) identified five distinct care networks among American older adults, with transitions between networks driven by factors such as the loss of a spouse, co-residence with a child, and declining health. It is likely that transitions between care networks occur relatively frequently, as studies suggest that between 30% and 50% of older adults experience changes in their care arrangements over a two-year period (Allen et al., 2012; Sandra Geerlings et al., 2005). Health, age, partner status, and income were identified as significant drivers of these transitions (Allen et al., 2012; Sandra Geerlings et al., 2005).

A longitudinal study of the composition of care networks may help with getting a clear view of the diversity of the possible care trajectories, during the time of the long-term care reform. In addition we will also investigate how health relates to care use, as it precedes care but is not the sole requirement for care. For instance, social resources and economic resources also form requirements for certain types of care (following the Andersen-Newman model). Therefore, the research questions of the second sub-study are as follows:
Which care network types exist, which transitions occur between these care network types and which health and socioeconomic characteristics of care recipients are associated with changes in these care network types, in the period of the long-term care reform?

Wellbeing

Wellbeing encompasses various dimensions of psychological functioning, including life satisfaction, a sense of meaning, positive and negative affect, and social interpersonal functioning (Willroth, 2023). Empirical studies on care and wellbeing often use depressive symptoms as indicator of wellbeing.

These studies consistently show that users of publicly funded care report a higher level of depressive symptoms (Abbing et al. 2022; Boumans and Deeg 2011; Pot et al. 2005; Swinkels et al. 2024). This negative impact might be attributed to insufficient quantity of care, limited control over the care process, or a lack of emotional connection with the caregiver, as suggested by the Self-Determination Theory (SDT). In contrast, spousal care often correlates positively with wellbeing, as it typically involves a strong emotional bond that mitigates feelings of loneliness (Swinkels et al., 2024). However, the effects of informal care on wellbeing are mixed: some studies report negative associations (Ouyang et al., 2019; Zwar et al., 2019), while others highlight positive outcomes (Abramowska-Kmon et al., 2023). This variability suggests that reliance on non-spousal informal caregivers can both hinder and support feelings of autonomy and competence, depending on the context.

A fundamental assumption is that care which aligns with the needs and preferences of the recipient may alleviate the adverse effects of health deterioration on wellbeing. Key elements of care to consider include the identity of the caregiver, the amount of care provided, and whether the care meets the recipient's preferences. Although the primary aim of care is to enhance wellbeing, it is not yet known how conducive these elements of care are to wellbeing, and if they differ in the extent in which they improve wellbeing. It may be the case that these elements of care moderate the effect of functional limitations on wellbeing, potentially through the SDT mechanisms of relatedness, autonomy, and competence. Understanding these moderating effects could provide valuable insights for policymakers, guiding them in prioritizing elements of care that most effectively enhance wellbeing.

In this study, we will use the CES-D scale (Radloff, 1977) as an indicator of wellbeing. The CES-D measures depressive symptoms and includes items that reflect positive affect, negative affect, social functioning, and psychosomatic complaints, thus offering a spectrum from wellbeing to depression (Siddaway et al., 2017).

We will investigate the moderating effects of various elements of care on the relationship between health and wellbeing through a longitudinal analysis of data spanning from 2012 to 2022. Therefore, the research question of the third sub-study is as follows:
Do type of caregiver, quantity of care, sufficiency of care, and experienced control over care have a moderating effect on the relationship between functional limitations and depressive symptoms, during the period of the long-term care reform?

Care sufficiency

In the context of long-term care reform, care sufficiency, in particular, may reflect the quality of care organisation and reception—elements potentially altered by the reform. The fourth sub-study, therefore, focuses on care sufficiency as an outcome of care needs, care utilisation, and preferences for care. Perceived care sufficiency is frequently used as an indicator of care quality, particularly when assessing the intended effects of health policies (Al-Abri & Al-Balushi, 2014; Applebaum, Straker & Geron, 1999; Brady et al., 2002; Donabedian, 1988; Fatima et al., 2019; Joling et al., 2018; Pascoe, 1983; Rea & Rea, 2002). Given that the reform is likely to have influenced care utilisation, care sufficiency may also have been affected.

There are also indications that the reform has led to variations in care sufficiency over time and between regions. Regarding overall satisfaction with healthcare, Dutch citizens appeared to become increasingly satisfied between 2004 and 2012, with satisfaction rising from 5.5 to 6.5 (Dekker et al., 2016). However, this trend seems to have been interrupted after 2012 (Dekker et al., 2016). In 2018, care appeared to be sufficient for most individuals aged 75 and older, yet there are indications that some required more care than they received (de Klerk et al., 2019). For certain older adults, particularly those experiencing severe loneliness, care appeared to be insufficient following the reform (De Groot et al., 2018), possibly because they received fewer total hours of publicly funded care, resulting in less social interaction. Many older adults reported issues with the new long-term care system, such as difficulties in accessing care and identifying which organisation was responsible for specific types of care (Harnas & Schout, 2017). Some older adults requiring institutional care were deemed ineligible under the new system, whereas they would have been eligible under the previous system, leaving them to remain living independently with unmet care needs (De Groot et al., 2018). Furthermore, the reform and decentralisation may have led to regional disparities in care utilisation. For instance, older adults in rural areas have fewer caregivers available nearby due to age-related urbanisation trends (Das, 2018). Additionally, municipalities varied in the financial resources available for implementing long-term care.

This raises the question of how care sufficiency has changed during the reform. To our knowledge, changes in care sufficiency over time and across regions have not yet been studied within the Dutch long-term care context. Addressing this question contributes to the existing literature in two ways. Firstly, many previous studies on the level and determinants of care sufficiency have focused on the sufficiency of acute care (Bogner et al., 2015; Choi et al., 1989; Chumbler et al., 2016; Cleary et al., 1989; Crow et al., 2002; Johnson et al., 2016; Naidu, 2009; Pitrou et al., 2020). Fewer studies have been conducted in the context of long-term care (Kajonius & Kazemi, 2016; Kazemi & Kajonius, 2017, 2016; Knight et al., 2010; Wang et al., 2022). Secondly, this study adds to our understanding of care sufficiency and its determinants during the long-term care reform.

We aim to investigate whether care sufficiency has changed during and after the long-term care reform, as well as to identify which elements of the conceptual model are related to care sufficiency. The research questions of the fourth sub-study are therefore as follows:
To what extent has the perceived care sufficiency changed in the period after the reform (2012 - 2022) and to what extent does this differ by region and degree of urbanization?'. In addition: 'To what extent do care needs, characteristics of care use (intensity, types), and wishes regarding care (preferences and perceived control) contribute to the perception of receiving sufficient care?'

Description of the data

The Longitudinal Aging Study Amsterdam

For all four sub-studies we used data from the Longitudinal Aging Study Amsterdam (LASA). LASA is an ongoing longitudinal population-based study of older adults (aged 55+) in the Netherlands (Hoogendijk et al., 2016). The baseline sample was drawn from eleven municipal registries in 1992, stratified by age and sex, and contained 3107 men and women aged 55-84 years (born between 1908 and 1937). In 2002 an additional cohort was sampled of 1002 men and women aged born between 1938 and 1947, and in 2012 another additional cohort of 1023 older adults was sampled. For all cohorts additional measurement waves were conducted every three years, in which data was mainly collected by trained interviewers in face-to-face, computer-assisted interviews. In cases where respondents refused or were not able to complete the full interview, either an abbreviated face-to-face interview, or a 15-minutes telephone interview (with a proxy or the respondent) was conducted. Further details concerning data collection are described in cohort profile papers (Hoogendijk et al., 2020; Huisman et al., 2011). In 2015 the LASA 75-PLUS-study was conducted, an ancillary study for which three additional nine-monthly measurement waves were conducted between measurement wave 2015/16 and measurement wave 2018/19. All LASA-participants who were born before 1941 were asked to participate in the ancillary study (N=686), of whom 601 eventually participated in 75-PLUSI. In all waves data was collected on physical and cognitive health, various features of care use, social and economic resources, and depressive symptoms as indicator of wellbeing.

Study designs and main findings

Chapter 2 – Health trajectories

To address the first research question on trajectories in functional and cognitive limitations, we utilised data from the LASA 75-PLUS study (75-PLUSI, 75-PLUSII, and 75-PLUSIII), alongside data from the preceding (2015/16) and subsequent (2018/19) regular LASA waves. These measurement waves occurred at shorter intervals than the regular waves (every nine months), thereby increasing the likelihood of capturing fluctuations. We employed Group-Based Trajectory Modelling (Nagin, 2005b; Nagin & Odgers, 2010) and jointly modelled mortality to prevent bias in estimated group sizes due to non-selective attrition caused by mortality (Haviland et al., 2011).

We identified similar trajectory patterns to those observed in previous studies. For functional limitations, five trajectories were identified: 'high', 'moderate', 'steeply declining', 'gradually declining', and 'continuously low'. For cognitive functioning, four trajectories were identified: 'high', 'moderate', 'declining', and 'low'. Multimorbidity was associated with functional limitations but was not related to most cognitive functioning trajectories. Despite the use of shorter time intervals, a recovery trajectory was not identified. The co-modelling of mortality resulted in a higher estimated proportion of older adults in the adverse trajectories. Living in an institution was strongly associated with both low cognitive functioning and low functional limitations, yet nearly half of the respondents in the worse trajectories resided at home, likely with very high care needs. These adverse trajectories were associated with advanced age and lower educational attainment, suggesting that older adults with the highest care needs tend to be both older and less educated.

Chapter 3 – Trajectories in care networks

To address the second research question concerning transitions between care networks, we expanded the study sample used in the first research question to include adults aged 65 and older. We included a younger cohort for this question to capture older adults who had recently begun to receive care. Additionally, we extended the study period to examine developments in care utilisation prior to the recent decentralisation of care. Consequently, we included data starting from 2012 and utilised three triennial measurement waves: 2012/13, 2015/16, and 2018/19. To map care networks and transitions between them, Latent Transition Analysis (Sterba, 2016), with co-modelled missing states, was employed. We also investigated the characteristics associated with membership in each care network using descriptive analyses.

We identified five types of care networks: 1) no-care, 2) privately-paid, 3) mixed-informal, 4) mixed-publicly paid, and 5) co-residential. Once individuals began receiving care, they did not revert to not receiving any care. Older adults in the 'no-care' network predominantly remained within that network, with comparable transition probabilities between 2012-2015 and 2015-2018, all showing similarly low transition probabilities to other network types. Older adults in the privately-paid network exhibited significant differences in transition probabilities between 2012-2015 and 2015-2018. Between 2015 and 2018, a substantial proportion of this group passed away (approximately 40%), and transitions to mixed-public networks became very unlikely. The mixed-informal, mixed-publicly paid, and co-residential care networks had the highest probabilities of either death or transitioning to a nursing home. These three networks appear to be endpoints before either institutionalisation or death, with transitions between them being uncommon.

Notably, between 2012 and 2015, some participants transitioned from mixed-informal to mixed-public care, but none did so between 2015 and 2018. During the latter period, participants in the mixed-informal network either remained, died, or transitioned to a care facility. Between 2012 and 2015, no participants moved from the co-residential network to mixed-public, although some transitioned to privately-paid care. However, between 2015 and 2018, none moved to privately-paid care, with some transitioning to publicly-paid care instead. Participants in the mixed-publicly paid network had the highest likelihood of staying in the same network, dying, or moving to a care facility, with rare transitions to other networks. These transition rates were consistent across the waves, although the mortality rate was notably higher between 2015 and 2018. Transitions appeared to be primarily driven by deteriorating health, rather than by the loss of a spouse.

Chapter 4 – The moderating effect of care on wellbeing

To address the third research question regarding the moderating factors of care in the relationship between care and wellbeing, we utilised the same time period and age criteria as in the second study. Specifically, we employed a longitudinal design involving older adults aged 65 and above who participated in the following three waves: 2012/13, 2015/16, and 2018/19. Using a multilevel linear regression model, we estimated both between-effects (differences in wellbeing due to the differences between individuals in specific characteristics) and within-effects (the effect of a change in caregiving elements over time, indicating intra-individual change).

We found no moderating effect for control over care or type of caregiver. However, beginning to receive informal care was associated with a slight increase in depressive symptoms. This suggests that certain aspects of informal care may be less conducive to wellbeing. Interestingly, this effect does not appear to stem solely from the fact that care is provided by a member of one's social network, as there was no observed difference in depressive symptoms between respondents receiving no care and those receiving co-residential care. Our findings support previous assertions that when support evolves into caregiving by someone other than a spouse, informal care may become overly burdensome for the caregiver. Additionally, this dynamic may result in overinvolvement and miscarried helping (Coyne et al., 1988).

Regarding publicly funded care, we found evidence of a moderation effect related to the quantity of care provided. While more hours of publicly funded care contributed to more depressive symptoms when functional limitations were low, they resulted in the lowest levels of depressive symptoms when functional limitations were high. Care sufficiency also exhibited a moderating effect: there were fewer depressive symptoms when care was sufficient and functional limitations were low, but this difference diminished when limitations were high. The buffering effect of sufficient care appears to weaken as the need for care increases.

Chapter 5 – Care sufficiency

To address the fourth research question on care sufficiency, we included all older adults aged 65 and above who were receiving or started to receive care during the period of 2012-2022. This study utilised data from four waves: 2012/13, 2015/16, 2018/19, and 2021/22. Using a multilevel logistic regression, we examined the characteristics associated with perceived care sufficiency, with respondents nested within time.

A large proportion of Dutch older adults (85%) perceived their care as sufficient. However, care sufficiency was somewhat lower in 2015/16 and 2018/19 compared to 2012/13, which may suggest that the reform had a negative impact on care provision. By 2021/22, care sufficiency had returned to levels comparable to those seen before the reform, indicating that the initial decrease was more likely due to implementation issues rather than the new care system being inherently less effective at delivering quality care.

There appeared to be no regional differences in care sufficiency, but older adults in rural areas perceived their care as more sufficient than those in urban areas. This difference, however, was more pronounced before the reform, with disparities based on the level of urbanisation diminishing during and after the reform. Publicly funded care was consistently and negatively associated with care sufficiency. Educational level also influenced perceptions of care sufficiency, with older adults possessing higher levels of education perceiving their care as more sufficient.

Description of the four chapters

	Question	Data	Method	Main findings
1	What trajectories in functional limitations and cognitive functioning can be identified in Dutch adults aged 75 and older in a period of three years? And how are age, sex, socioeconomic status, and chronic diseases associated with these trajectories?	LASA 75-PLUS-study (75-PLUSI, 75-PLUSII, 75-PLUSIII), LASA 2015/16, LASA 2018/19 Aged 75+	Group Based Trajectory Modelling with mortality jointly estimated	For functional limitations five trajectories were identified: 'high', 'moderate', 'steeply declining', 'gradually declining', and 'continuously low'. For cognitive functioning four trajectories were identified: 'high', 'moderate', 'declining', and 'low'. Multimorbidity was related to functional limitations, but not to most cognitive functioning trajectories. Despite the use of shorter time intervals, a recovery trajectory was not identified. The co-modelling of mortality resulted in a higher estimated proportion of older adults in the adverse trajectories. Living in an institution associated highly with both low cognitive functioning and low functional limitations, almost half of the respondents in the worse trajectories lived at home. These adverse trajectories associated with old age, and being lower educated.
2	Which care network types can be identified, and which transitions between these care network types occur? Which health and socioeconomic characteristics of care recipients are associated with these care networks?	LASA 2012/13, LASA 2015/16, LASA 2018/19 Aged 65+	Latent Transition Analysis with co-modelled missing states	We identified five types of care networks: 1) no-care, 2) privately-paid, 3) mixed-informal, 4) mixed-publicly paid, 5) co-residential. Older adults in the no care network mostly remained in that network. The transition probabilities between 2012-2015 and 2015-2018 were comparable, with very similar (low) transition probabilities to all other network types. Older adults in the privately paid network differed strongly in terms of transitions probabilities between 2012-2015, and 2015-2018. In 2015-2018 a high proportion deceased (~40%), and transitions to mixed-public became very unlikely. The mixed-informal, mixed-publicly paid, and co-residential care networks had the highest probabilities of either death or transitioning to a nursing home. These three networks appear to be end-points before either a care facility or death, and transitions between these networks were not likely. Between 2012-2015 some participants transitioned from mixed-informal to mixed-public, but none between 2015-2018. Between 2012-2015 no participants moved from the co-residential network to mixed-public, but some moved to privately paid care. Between 2015-2018 none moved to privately paid care, but some transitioned to publicly paid care. Participants in the mixed-publicly paid network had the highest chance of staying, dying, or moving to a care facility, and rarely transitioned to other networks. These transition rates were comparable between waves, although the decease rate was much higher between

				2015-2018. Transitions appeared to be strongest induced by deteriorating health, but did not appear to be linked with loss of a spouse.
3	Do the four elements of caregiving (type of caregiver, quantity, sufficiency, experienced control) have a moderating effect on the relationship between functional limitations and wellbeing?	LASA 2012/13, LASA 2015/16, LASA 2018/19 Aged 65+	Mixed-modelling	We found no moderation effect for control over care and type of caregiver. However, starting to receive informal care resulted in a decline in wellbeing. This suggests that some aspects of informal care, are less conducive to wellbeing. Interestingly, this aspect appears not to lie solely in the fact that care is given by a member of one's social network, as there appeared to be no difference in wellbeing between respondents receiving no care, and respondents receiving coresidential care. Our findings corroborate previous notions that when support turns into caregiving for caregivers that are not the spouse, informal care might become too much of a burden to caregivers. In addition, this caregiver might result in miscarried helping and overinvolvement (Coyne et al., 1988). For publicly paid care we found evidence of a moderation effect by quantity of public care. Although more hours of publicly paid care did not contribute to wellbeing when functional limitations were low, they led to the highest levels of wellbeing when functional limitations were high. Care sufficiency displayed a moderating effect: there was more wellbeing when care was sufficient and functional limitations low, but this difference vanished when limitations were high. The buffering effect of sufficient care appears to weaken as the need for care increases.
4	To what extent has the perceived care sufficiency changed in the period after the reform (2012 - 2022) and to what extent does this differ by region and degree of urbanization? To what extent do care needs, characteristics of care use (intensity, types), and wishes regarding care (preferences and perceived control) contribute to the degree of perceived sufficiency of care?	LASA 2012/13, LASA 2015/16, LASA 2018/19, LASA 2021/22 Care-receiving	Bivariate analyses and multilevel logistic regression	Our main finding was that a big proportion of Dutch older adults (85%) perceived their care to be sufficient. However, care sufficiency was lower in 2015/16 and 2018/19, compared to 2011/12. This might be an indication that the reform negatively impacted the provision of care. In 2021/22 care sufficiency had raised to comparable levels as pre-reform, so it is more likely that this decrease was due to implementation issues, than that it was caused by the new care system being worse at providing quality care. There appeared to be no differences in care sufficiency based on region of living, but older adults in rural areas perceived their care to be more sufficient than in urban areas. This difference was however starker before the reform, and during and after the reform differences based on level of urbanization became smaller. Publicly paid care consistently and negatively associated with care sufficiency. Education level also associated with care sufficiency, with older adults with higher education levels perceiving their care as more sufficient.

What this study contributes

Main Conclusion

Our study found that health was the most important determinant of care utilisation, with between 10% and 20% of Dutch older adults consistently exhibiting a high level of care need. Following the reform, this care need was increasingly met by mixed-informal care networks. Older adults in mixed-informal care networks were similar to those in mixed-publicly paid care networks and spousal care networks in terms of need factors. This similarity in need factors, despite differences in care networks, highlights the significant role of enabling factors (such as having a spouse) in determining the type of care that older adults use.

The type of care utilised by older adults was linked to their wellbeing, with most forms of care (publicly paid, informal, or privately paid) being associated with lower levels of wellbeing, except for co-residential care. Starting to receive informal care was particularly associated with reduced wellbeing. Although receiving publicly paid care was also negatively associated with wellbeing, this effect was reversed when the amount of publicly paid care increased, leading to higher levels of wellbeing among older adults who received extensive publicly funded care.

Both perceiving control over care and receiving sufficient care were beneficial for wellbeing, but neither could buffer the adverse effects of functional limitations on wellbeing. After the reform, care sufficiency initially declined on average, which we suggest may have been due to implementation challenges with the new care policies, as care sufficiency returned to its 2012 baseline level by 2021.

Theoretical reflection

We applied the Andersen-Newman model (Andersen & Newman, 1973) to identify the factors associated with care utilisation. Consistent with the model, there was a strong correlation between care use and need factors, such as functional limitations, chronic diseases, and low cognitive functioning. Predisposing factors, such as sex and education, were also linked to the types of care networks. Women with lower levels of education were more likely to be part of mixed-informal and mixed-public care networks, while men with higher levels of education had a greater likelihood of being in co-residential or no-care networks. We also considered the enabling factor of partner status, which was a strong predictor of being in a partner care network, although the loss of a partner was not significantly associated with transitioning to another care network.

The determinants we used from the Andersen-Newman model provided explanations at the individual level and accounted for much of the variation in care utilisation. While we focused on education, income could also have served as a valuable enabling factor, although these two determinants often exhibit similar associations (Abbing, Suanet, & Broese Van Groenou, 2022). Additionally, enabling factors that consider the caregiver's perspective are likely to be strong predictors of care use as well. Examples of such factors include the distance the caregiver lives from the older adult, the caregiver's working hours, the presence of children who require care, and the willingness to provide care (Saraceno, 2013).

Determinants at the macro level are also likely to hold explanatory power for care utilisation. Although effects of these macro factors at the individual level are hard to assess, they are still likely to provide valuable insights into the observed transitions between care networks. Macrosystems and societal values partly shape enabling factors through norms on: the provision of informal care, working hours of potential informal carers, co-residence with family members, whether care is provided by the family or the state, geographical rootedness, the age of childbearing, and the decision to live in a nursing home. Consequently, changes in these norms are likely to be reflected in alterations to the enabling factors influencing care use. Furthermore, other societal influences may have impacted health, care, and wellbeing, including the Great Recession of 2008-2012, increasing digitalisation, the COVID-19 pandemic, and growing labour market shortages.

To elucidate the relationship between care use and wellbeing, we applied the Self-Determination Theory (Deci & Ryan, 2000) within the care context. The SDT has been applied in care contexts several times before, consistently showing relationships between its three central concepts—autonomy, competence, and relatedness—and wellbeing (Huang et al. 2022; Ng et al. 2012, Swinkels et al. 2024).

Relatedness proved to be a particularly useful concept within the context of care, as it can have both positive and negative effects on wellbeing in long-term care scenarios. For example, relatedness may diminish wellbeing if the utilisation of informal care makes older adults feel they are burdening their social environment (Nieuwenhuis et al., 2018). Conversely, receiving care from a spouse appeared to enhance wellbeing, likely reflecting the strength of the bond and the expression of love and commitment. Similarly, formal care was negatively associated with wellbeing, presumably due to a lack of relatedness or strong bonds with these caregivers. However, it is possible for some individuals to develop strong bonds with formal caregivers, leading to higher levels of wellbeing.

Enhancing relatedness can be achieved by actively listening, providing social support, and adopting an empathetic stance (Christakou & Lavallee, 2009; Kleinman, 2012). Our data did not capture feelings of relatedness with different types of caregivers. Therefore, future research should seek to gain greater insight into how relatedness functions across various caregiving contexts.

The indicators chosen to reflect autonomy and competence appeared to have a less pronounced impact on wellbeing. While care sufficiency was a strong predictor of wellbeing, it may also reflect the capability of the care network to deliver care in a manner that meets the needs and desires of the recipient, rather than the care recipient's own ability to arrange care. It is advisable to use concepts that more directly indicate care-specific autonomy, such as the extent to which one feels like they are allowed to make their care decisions.

Methodological reflection

The trajectory approach that examined health and care networks while co-modelling mortality was a methodological strength of our study, as it allowed for the inclusion of a significant proportion of the oldest old, who would typically have been excluded. Additionally, the use of the 75PLUS data, which included nine-monthly measurement waves, was a novel addition to previous Dutch longitudinal studies due to the relatively short intervals between measurements. Given the close link between health problems and mortality, this approach enabled us to study older adults with the most severe limitations and the highest care needs. Through this method, we demonstrated that approximately a quarter of older adults either had or developed high care needs over a three-year period. Moreover, it allowed us to show that older adults with mixed-informal, mixed-publicly paid, or co-residential care networks had higher probabilities of transitioning to a nursing home. This finding supports the general notion that nursing homes represent a final stage in the care trajectory, with various types of care being utilised at home before this option is pursued.

However, further insight is needed into the significance of the specific period under study. Ideally, a comparison with a study covering similar nine-monthly intervals during the period of 2009 to 2012 would have allowed us to draw more definitive conclusions about whether the trends observed were likely influenced by the recent reform of the long-term care system. A comparison with age-peers from an earlier time period would also have provided insight into whether the trajectories in functional and cognitive limitations we reported were time-specific or generation-specific. Future research utilising broadscale population data from the *Centraal Bureau voor de Statistiek* (Central Bureau of Statistics) might compare individual-level changes across specific periods, employing cohort-sequential designs, for example.

A larger sample size in the 75PLUS study would have enabled a more detailed analysis of the oldest participants. Estimating a model that used age as a predictor, as done in studies such as Zimmer et al. (2012), was unfeasible due to excessive extrapolation among the oldest age groups. Shorter time intervals, such as monthly measurements, might have also revealed more fluctuations in functioning, as reported in studies by Gill et al. (2006) and Stolz et al. (2019). Additionally, such intervals might have allowed for stronger inferences about the causal relationships between health, care, and wellbeing. Monthly data on these concepts could potentially reveal patterns in the order in which changes occur.

Given that certain aspects of care (such as personal care, household care, or nursing care) are sometimes funded through different care laws, distinguishing between these types of care might have been beneficial in identifying where the most significant obstacles in care provision are encountered. This could have been achieved either by measuring these distinctions ourselves or by linking data from the *Centrum Indicatiestelling Zorg* (Centre for Care Indications) and *Centraal Bureau voor de Statistiek* to our dataset. Previous studies suggest that due to higher additional payments required for care delivered through the Long-Term Care Act, some older adults chose to reduce their use of homecare following the care reform (De Groot et al., 2018; Kromhout et al., 2018). Differentiating the types of care might have provided insights into possible interaction effects between the type of care and the type of caregiver. For instance, if wellbeing was found to be lower when individuals received nursing care (but not household care) from informal caregivers, this might indicate a shortfall in the provision of necessary formal care. It might also have helped to explain how certain types of care networks develop, as some tasks are more easily performed by informal carers, while others are perceived as more appropriate for formal carers.

Wellbeing is a multifaceted concept (Willroth, 2023) encompassing various dimensions of psychological functioning, including both positive and negative affect as well as interpersonal social functioning. Our primary focus was on the psychological aspects of wellbeing, incorporating both affective and cognitive elements. We employed a multidimensional scale, the CES-D, which spans the continuum from wellbeing to depression (Siddaway et al., 2017). However, this may have constrained our ability to draw specific conclusions.

Exploring other indicators of wellbeing, such as quality of life or life satisfaction, could provide a more comprehensive understanding of the determinants of positive and negative outcomes. Additionally, measuring wellbeing through the lens of eudaimonia might have offered a valuable and pertinent operationalization of the concept. Eudaimonia, with its focus on positive psychological growth and fulfilment (Sirgy, 2012), could reveal potential positive effects of care that were not captured by our current measures. Such positive effects might arise from aspects of care that include physical touch, empathic witnessing, and the provision of emotional and moral support (Kleinman, 2012).

Implications for policy and practice

In terms of health trajectories, the findings detailed in Chapter Two reveal that between 10% and 20% of older adults exhibited severely impaired functioning. Notably, between 5% and 10% of the oldest old who lived at home had care needs that were comparable to those residing in nursing homes. This represents a substantial segment of the population requiring near-continuous home care. Given the projected increase in the number of oldest old in the Dutch population over the coming decades, this 5% to 10% group will likely expand, resulting in a growing demand for extensive home-based care.

Chapter Three describes how these care needs are addressed through various types of care networks. Older adults with poorer health were more likely to be in publicly paid care networks, mixed-informal care networks, or spousal care networks. Notably, the proportion of individuals in mixed-informal care networks increased following the 2015 reform. This network type may be advantageous from a financial sustainability perspective, as it incurs minimal public expenditure. However, informal care, like publicly funded care, faces limitations, such as the potential overburdening of informal carers (de Klerk et al., 2018) or the unavailability of such carers for some older adults (de Jong & Kooiker, 2018). Our findings, which indicate a negative impact of informal care on wellbeing, underscore the importance of supporting informal carers. Ensuring that their responsibilities remain manageable and do not diminish the quality of their relationships with care recipients is crucial. These findings are consistent with the objectives of the *Mantelzorgagenda* (Informal Carers Policy) (Ministry of Health Welfare and Sport, 2023), which aims to provide greater support for informal carers, such as through increased flexibility in work or educational commitments.

The older adults in mixed-informal care networks exhibited similar demographic characteristics—such as age, health, and education—to those in mixed-publicly funded care networks. However, it is probable that these groups differ in terms of social capital. Policy initiatives that enhance social capital, such as programmes linking older adults with community members or fostering long-term community development, may become increasingly significant for sustaining the new care system.

The emergence of inequalities in the new care system is a significant concern. As public care spending is reduced, lower socioeconomic groups may experience reduced access to formal care compared to higher socioeconomic groups (Abbing, Suanet, et al. 2022; Albertini & Pavolini 2017). The perpetuating existence of care networks with publicly paid care also underscores the need for some people to have their care delivered by the state.

Our study reveals the unintended negative consequences of recent care policies, highlighting disparities that may become more pronounced under the current system. For instance, after the 2015 reform, more affluent older adults were observed to use less or no publicly funded care, as indicated by the reduced likelihood of transitions from privately paid to mixed-public care networks. The high mortality rates in the privately paid care network—rising to 40% in the years following the reform—suggest that some older adults who developed high care needs rapidly might not have received adequate care. This supports the concept of the *zorgval* (Kromhout et al., 2018). The *zorgval* describes a situation in which older adults that were either on waiting lists for nursing homes, or with increasingly high care needs, were transferred from care laws with low contribution payments, to care laws without a cap on the contribution payment (Long-Term Care Act). In these situations, for some older adults, the costs of care became so high that they received less care than they needed.

Despite the current discourse emphasizing older adults' desire to live independently (Schuldink et al., 2024), our findings reveal frequent transitions to nursing homes, underscoring the persistent need for institutional care. This need is also highlighted in the *Wonen en Zorg Ouderen* program (Housing and Care for Older adults) which advocates for home care "if possible", thereby acknowledging that, in some cases, nursing homes remain the only viable option.

Health status continues to be the primary driver for transitions between care networks. This underscores the importance of focusing on preventative healthcare strategies, as articulated in the *Gezond en Actief Leven Akkoord en Wonen*, *Ondersteuning en Zorg voor Ouderen Ouderen* (Healthy and Active Living Agreement and Housing, Support, and Care for Older Adults) (Schuldink et al., 2024). For municipalities and health insurers, this means placing greater emphasis on fall prevention and promoting healthy lifestyles to mitigate the need for more intensive care and support later in life.

Conclusion

Given the context of the 2015 Dutch care reform, this dissertation shows that there was no evidence of major differences in health, care use, wellbeing, and care sufficiency after the reform. However, care sufficiency appeared to be slightly lower following the reform, older adults began to use more informal care, and informal care was negatively associated with wellbeing. These results raise important questions about how to organise care in the future. Several societal changes will place increasing pressure on the Dutch long-term care system, including labour market shortages, a growing ageing population, and rising care costs. The increasing population ageing also means there will be fewer younger people available for informal caregiving, and older adults may simultaneously become both caregivers and care receivers.

To ensure that the care system remains viable under this pressure, several strategies should be considered. First, strengthening social networks within communities can help create the foundation for future informal care. Programmes aimed at building social capital and promoting community engagement will be essential. Second, supporting informal carers through policies that provide greater flexibility in work and educational settings is crucial. This support will help maintain a balance of caregiving responsibilities and prevent caregiver burnout. Third, emphasising preventive health through health promotion and early intervention can help reduce the demand for intensive care and improve overall wellbeing. Fourth, facilitating access to privately paid care options and integrating assistive technologies can help meet the growing needs of older adults as demand for care increases.

In conclusion, while the 2015 reform has led to an increase in informal care use and a slight decrease in care sufficiency, these findings highlight the need for comprehensive strategies to address future challenges. By combining efforts to support informal carers, promote preventive health, and expand care options, the Dutch care system can better adapt to the evolving needs of its ageing population.

Chapter 2

Title: Three-year trajectories in Functional Limitations and Cognitive Decline among Dutch 75+ year olds, using nine-month intervals.

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Abstract

Background Using longitudinal panel data, we aimed to identify three-year trajectories in cognitive and physical functioning among Dutch older adults, and the characteristics associated with these trajectories.

Methods We used Group-based Trajectory Modelling with mortality jointly estimated to identify trajectories, using a scale composed of 6 Activities of Daily Living (ADL) as a measure of physical functioning, and the short mini mental status examination (sMMSE) or the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) as a measure of cognitive functioning. Data came from 574 Dutch adults aged 75+, collected in five nine-month measurement waves (2015–2018) for the Longitudinal Aging Study Amsterdam.

Results For physical functioning five trajectories were identified: 'high', 'moderate', 'steeply declining', 'gradually declining', and 'continuously low'; and for cognitive functioning: 'high', 'moderate', 'declining', and 'low'. Living in an institution, and being lower educated increased the probability of the two continuously low functioning trajectories, whereas old age and multimorbidity increased the probability of low physical functioning, but multimorbidity decreased the probability of low cognitive functioning. Associations for steeply declining physical functioning were absent. Being older and having multimorbidity increased the probability of gradually declining physical functioning and declining cognitive functioning. A higher prevalence of lung- and heart disease, cancer, and rheumatic disease was found in the gradually declining physical functioning group; and a higher prevalence of diabetes, cerebrovascular accidents, and cancer was found in the declining cognitive functioning group. High and moderate physical functioning and high cognitive functioning were characterized by being younger, community-dwelling, and higher educated. Having multimorbidity negatively predicted high and moderate physical functioning, but was not associated with high and moderate cognitive functioning.

Conclusion This study identified trajectories comparable to studies that used longer time intervals, showing the consistent presence of heterogeneity in both physical and cognitive trajectories. Co-modelling mortality resulted in bigger group sizes for the more adverse trajectories. The favourable trajectories, containing most of the participants, were mostly characterized by absence of disease. The prevalence of chronic diseases differed between the declining trajectories, suggesting that certain diseases tend to induce cognitive decline rather than physical decline, and vice versa.

Background

Western societies are ageing rapidly, showing both an increase in the number of young older adults (aged 65 to 75) and the number of oldest-old (aged 75 and older) (WHO, 2015). For some older adults this increased longevity goes hand in hand with chronic disease, functional limitations, and cognitive decline (Centraal Bureau voor de Statistiek, 2019; Crimmins & Beltrán-Sánchez, 2011; Deeg et al., 2018; Heger & Kolodziej, 2016; Hoeymans et al., 2011). But ageing does not appear to be debilitating to all, and some older adults reach high age while maintaining good physical and cognitive functioning (Kok et al., 2017). In other words, there is considerable heterogeneity in health and functioning in old age. Exploring this heterogeneity is a fundamental task of gerontological research.

Since levels of functioning are known to be dynamic and not static, information about trajectories of functioning is key for understanding how functioning is associated with ageing. Depending on various aspects of study design- such as the chosen indicator of functioning, the density of observation points, and the age of the population studied- previous studies identified between two and nine trajectories of physical or cognitive functioning (Comijs et al., 2004; Deeg, 2005; Gill et al., 2013; Han et al., 2013; Hu et al., 2019; Kingston et al., 2015; Kok et al., 2017; Martin et al., 2017; Min, 2018; Nusselder et al., 2005; Proust & Jacqmin-Gadda, 2005; Taylor & Lynch, 2011; Terrera et al., 2010; Timmermans et al., 2018). Despite this wide variety in the number of trajectories observed, the trajectories consistently differed based on age. So, the studies that focussed on older populations tend to be consistent in that they often report trajectories with high levels of functioning, mostly report trajectories with decline, but do not report trajectories reflecting recovery of functioning (Kingston et al., 2015; Lafortune et al., 2009; Van Houwelingen et al., 2014). Studies focussing on younger populations (~55-75 years) sometimes report recovery or fluctuating trajectories (Bolano et al., 2019; Botoseneanu et al., 2016; Deeg, 2005; Range, 2010), whereas studies that focus on older populations (75+) tend to report no recovery (Kingston et al., 2015; Lafortune et al., 2009; Van Houwelingen et al., 2014).

Because these previous trajectory studies vary in key aspects of study design, the best approach to gain a more comprehensive understanding of the heterogeneity in trajectories of functioning in older adults may be to combine several design aspects of these studies. Existing studies of functional limitations in Dutch older adults focused on relatively young samples (~mean age 70) and used relatively long time intervals of 3 years to assess trajectories of limitations (Deeg, 2005; Kok et al., 2017; Timmermans et al., 2018; Van Houwelingen et al., 2014). In the current study, we investigate heterogeneity in functional limitations and cognitive functioning among Dutch older adults. Our approach stands out from previous work on a number of aspects of study design. Firstly, we examine changes in functioning across relatively short time intervals of nine months, which may be more sensitive to meaningful change than longer follow-up periods. Secondly, we focus on a sample of participants aged 75 years and older, which is where we expect relatively many changes in functioning to occur. Thirdly, we measure functional limitations as a continuous variable. This allows for more accurate descriptions than dichotomization, which severely compresses the range of the severity of functional limitations. Finally, we incorporate information on mortality risk in our estimates of trajectories to account for bias in estimated group sizes caused by nonselective attrition caused by mortality (Haviland et al., 2011). This approach builds on the assumption that attrition due to mortality is related to the participant's previous health status and provides relevant information for classifying individuals into broader functioning categories, leading to more accurate classifications. Studies that did not account for mortality in their models implicitly made the assumption that decease occurred at random (Haviland et al., 2011). In addition, we explore differences in several key characteristics of older adults between each of the observed trajectories. Our research question is as follows: What trajectories in functional limitations and cognitive functioning can be identified in Dutch adults aged 75 and older in a period of three years? And how are age, sex, socioeconomic status, and chronic diseases associated with these trajectories?

Methods

Design and study sample

This study used data from the LASA 75-PLUS-study, an ancillary study of the Longitudinal Aging Study Amsterdam (LASA). LASA is an ongoing longitudinal population-based study of older adults (aged 55+) in the Netherlands (Hoogendijk et al., 2016). The baseline sample was drawn from eleven municipal registries in 1992, stratified by age and sex, and contained 3107 men and women aged 55-84 years (born between 1908 and 1937). In 2002 and 2012 additional cohorts were sampled of respectively 1002 and 1032 men and women born between either 1938 and 1947, or 1948 and 1957. The baseline cooperation rate was 62% for the first cohort, and 62% and 63% for the second and third cohort (Hoogendijk et al., 2016, 2020). The data were mainly collected by trained interviewers in face-to-face, computer-assisted interviews. In cases where respondents refused or were not able to complete the full interview, either an abbreviated face-to-face interview, or a 15-minute telephone interview (with either a proxy or the respondent) was conducted. Further details concerning data collection are described in cohort profile papers (Hoogendijk et al., 2016, 2020).

Although previous studies excluded demented and institutionalized people (Comijs et al., 2004; Kok et al., 2017), we did not exclude participants based on these criteria. We included participants whose scores were low on the cognitive tests, which might indicate the presence of dementia. However, we did not check the presence of a formal diagnosis of dementia. Participants with low cognitive scores were included in the sample because we also aimed to study whether the trajectories in functional limitations and cognitive decline showed overlap. For comparability reasons we wanted the samples in both the analyses to be as comparable as possible. Participants that were censored due to other reasons than death (N=34) were excluded from the analysis because of two reasons. First, this was a very small number compared to the participants that dropped out due to decease (N=139). And second, a similar study conducted by Zimmer et al. (Zimmer et al., 2012) showed that the trajectories estimated for the sample including participants that were censored due to other reasons than death looked similar to the trajectories estimated when dropout was solely modelled for deceased participants. This suggests that this data is usually probably missing not at random as well. It seems quite likely that participants refuse an interview due to health issues, but it is also possible that participants missed an interview because of reasons related to exquisite health (such as going on vacation). Because of this uncertainty, and because the number of participants that had missing data for other reasons than death was quite low (N=34), we excluded these people from the analysis. Results might have been less generalisable if we also modelled these people, where the missingness-mechanism would have been rather different, together with people for whom the missingness-mechanism was due to decease.

For the ancillary 75-PLUS-study, three additional nine-monthly measurement waves were conducted between the regular measurement waves of 2015/16 and 2018/19. All LASA-participants born before 1941 were asked to participate in the ancillary study (N=686), of whom 601 eventually participated in the LASA 75-PLUS study. For this study we used these three nine-monthly measurements: 75-PLUSI, 75-PLUSII (N=550) and 75-PLUSIII (N=507), together with data from the preceding (2015/16) and subsequent (2018/19) regular LASA waves (N=473). Table 1 shows the number of participants included in each wave.

Dependent Variables

Functional Limitations

Functional limitations are restrictions in performing physical or mental tasks, that usually result in limitations in the performance of activities of daily living (ADL). We used ADL-indicators of respondents’ ability to perform the following six tasks: 1) dressing or undressing themselves, 2) standing up from or sitting down in a chair, 3) cutting own toenails, 4) using own or public transport, 5) climbing a flight of stairs, and 6) walking 5 minutes outdoors without resting. The response categories ranged from ‘1’ not able at all, to ‘5’ very able. The responses to the ADL-items were summed to the ‘functional-limitations-scale’, that ranged from 6 to 30, with higher scores indicating higher levels of functioning.

Cognitive Decline

The degree of cognitive decline was assessed using either the sMMSE, a short 8-item version of the Mini-Mental State Examination (MMSE) (Folstein et al., 1975; Tombaugh & McIntyre, 1992), in which functioning in the following domains was tested: orientation in time and place, registration of words, attention and calculation (measured by either subtraction or spelling), and recall of three words . For participants that were unable to perform the test, cognition was assessed by interviewing a proxy, if possible. For these interviews an abbreviated form of the IQCODE (Jorm, 2004) was used: a 6-item scale ranging from 18 to 30 concerning the decline in the last 10 years on remembering 1) conversations, 2) addresses, and 3) phone numbers, and handling 4) domestic appliances, 5) money for groceries, and 6) finances. Higher scores indicated worse decline. For those participants who switched to the IQCODE at some point during the study, we imputed sMMSE data based on the IQCODE-scores.

Table 1

Description of the 5 LASA measurement waves conducted between 2015 and 2019

	Wave 2015-16	*Wave 75PLUS I*	*Wave 75PLUS II*	*Wave 75PLUS III*	*Wave 2018-19*
Invited	686	686	601	550	473
Participated. n (%)	601	601 (87.6)	550 (91.5)	507 (92.2)	473
Age. mean (SD)	82.2 (5.4)	83.0 (5.4)	83.4 (5.2)	83.8 (4.9)	84.1 (4.8)
Female. n %	368 (61.2)	368 (61.2)	338 (61.5)	311 (61.3)	295 (62.4)
Functional limitations. mean (SD)	23.9 (6.3)	22.7 (6.9)	23.1 (6.3)	22.3 (6.4)	22.4 (6.5)
Cognitive functioning. mean (SD)	14.3 (1.9)	14.6 (1.7)	14.6 (1.8)	14.6 (1.8)	14.2 (2.1)
Face-to-face interview. n	453 (78.0)	442 (73.5)	410 (68.2)	364 (66.2)	326 (68.9)
Telephone interview proxy	53 (8.8)	61 (10.1)	55 (10)	59 (11.6)	50 (10.3)
Telephone interview respondent	86 (14.3)	98 (16.3)	85 (15.5)	84 (16.6)	93 (17.0)

No guidelines have been published on how to harmonize the IQCODE with the sMMSE. Therefore we tried various ways of harmonizing the two, based on two studies that used both scales and reported which scores indicated similar levels of cognition (Chiriboga et al., 2008; Van Den Kommer et al., 2018). Since these values differed between these two studies, we estimated the trajectories using these two ways of harmonizing the two scales, to assess whether this affected the shapes of the estimated trajectories. This did not affect the shapes substantially (see figure S1 in additional file 1). Because different cut-off points did not rigorously affect the trajectory shapes, we chose the cut-off points based on a previous LASA-study (Van Den Kommer et al., 2018), since this would likely reflect our sample best. The values of the IQCODE and sMMSE are reported in Table 2. Because an IQCODE-score of 18 indicated no change in the last years, this value either corresponded with the participants' previous sMMSE-score, or if that score was not available, an sMMSE-score of 16. The eventual 'cognition-scale' was constructed by summing all the points scored on the 8 sMMSE items (or by harmonizing the IQCODE to an sMMSE-score), resulting in a scale that ranged from 0 to 16, with 16 indicating the highest level of cognitive functioning.

Table 2

Values used to harmonize IQCODE-scores with sMMSE-scores, based on cut-off values provided by van den Kommer et al. (2018)

IQCODE	sMMSE
18	16, or previous sMMSE-score
19	16
20-21	15
22-23	14
24-25	13
26-27	12
28-29	11
30	10

Despite there being indications of the IQCODE and MMSE not entirely measuring the same construct (Mackinnon et al., 2003), we argue that keeping the participants that were assigned the IQCODE at some point during the study in the analyses is better than excluding them. Since our study focusses on cognitive decline, and the IQCODE is more likely to be assessed when participants experience considerable decline, excluding these participants would have likely resulted in missing a considerable portion of the trajectories showing cognitive decline. Since the model aims to be descriptive and not explanatory, we decided that the occurrence of decline was more informative than the rate of decline. Even if the imputed data based on IQCODE-scores is an under- or overestimation of the "true" sMMSE-score, we expect the direction of cognitive decline to still be in accordance with the "true" direction.

Mortality

Mortality-data (date of decease) were obtained through the registration of municipalities (GBA), and were last updated in February 2020. It was included as a dichotomous variable, with '0' indicating being alive and '1' indicating being deceased, per wave.

Independent Variables

Age, sex, partner status (partner/ no partner), educational level, and chronic disease status (number of diseases) were used to give a description of respondents in the identified trajectories. This selection of characteristics was chosen because they represent some of the main vectors of social and economic disadvantage in older populations and reflect vulnerable groups. They were all measured at baseline (2015/16). Educational level was divided into three categories: low (primary school), middle (secondary school or lower vocational training), and high (higher vocational training or higher). For chronic disease we grouped ten diseases into five categories: 1) heart- and lung disease (coronary-, pulmonary-, and vascular disease), 2) rheumatic disease (arthritic and osteopathic), 3) diabetes, 4) cancer, and 5) cerebrovascular accidents (CVA), we used these five diseases to construct a variable that measured the number of chronic diseases.

Sensitivity and Missing Data

Data was either missing at the item level (e.g. one of the six ADL-items missed), or at the wave level (e.g. not participating in one wave). When a respondent had less than ~50% missing at the item level, data were imputed with the respondent's mean of the non-missing items at that wave. When more than 50% of the items of the outcome was missing, the outcome variable at that wave was imputed with the mean of the preceding and subsequent wave. Data that was missing at the wave level was only imputed when data for the previous and subsequent wave was available. This linear interpolation imputation method used for imputation of the waves tends to provide a good fit for longitudinal missing data (Noor et al., 2014), and it has been suggested this is even the case if the data are missing not at random (Genolini et al., 2013). For a more in depth review on the rationale for the mean-imputation method see: Halpin (2012). Data were imputed for 73 participants. Of the initial sample of 601 4.7% (N=34) dropped out for other reasons than decease, and were thus excluded from the analysis. We conducted sensitivity checks, by estimating the models 1) stratified by sex, 2) only for survivors, and 3) for deceased (see figures S2, S3, and S4 in additional file 2).

The models stratified for sex did not differ substantially in terms of shapes of the trajectories, so we performed the main analyses unstratified. The models only for survivors and deceased participants were comparably different, as expected, yet showing the importance of including the deceased participants in the analysis by jointly modelling mortality.

Method of Analysis

The analyses were conducted using the STATA package Proc Traj (Jones et al., 2001). As suggested by Nagin (Nagin, 2005a) we started with estimating an unconditional model, in which even chronological age was not included. This approach has the advantage of not allowing one covariate to have a disproportionately big influence on the model. The independent variable in the model was the time of the measurement waves. We fitted two group-based trajectory models with mortality jointly estimated, for physical and cognitive functioning. Because the dependent variables were continuous scales, we used the Tobit model, assuming a censored normal distribution (Jones & Nagin, 2013). First, we determined the number of identified trajectories that fitted the data best, by using the Bayesian Information Criterion (BIC) and the posterior probabilities, shown in table S1 and S2 in additional file 3 (Jones et al., 2001; Raftery, 1995). We also assessed whether an extra trajectory group revealed a relevantly different trajectory. After having identified the optimal number of trajectories, cognitive or physical limitations were estimated in a trajectory model, with the dropout-function accounting for dropout due to decease (Haviland et al., 2011; Jones & Nagin, 2007). This dropout-function is explained in more detail in additional file 4. The 27 participants who had missing data due to other reasons than death and could not have their data imputed, were excluded from the analysis, using the obsmar-function (Jones, n.d.).

Subsequently we calculated the average marginal effects (AME). The AME are a variation on a multinomial logistic regression, and show the association between a certain characteristic (i.e. age) and a trajectory for a one-unit change of that characteristic. The AME’s main advantage over the estimates of multinomial logistic regression lies in the fact that their provided estimates are more intuitive in terms of interpretation since they don’t require a reference group during interpretation (Jann, 2013).

Results

Descriptive Statistics

The baseline (wave 2015/16) characteristics of the 567 participants are shown in table 3. The average age was 82.20 years, with 61% being female, 50% currently having a partner, and respectively 48%, 30%, and 22% having had low, middle, and high education. Over the three years of follow-up 24% (N=139) deceased. For each wave, data was collected by proxy for 12.3% to 15.3% of the sample.

Most participants suffered from rheumatic diseases (63%) and heart- and lung disease (49%), whereas less people had diabetes (16%), CVA (10%), or cancer (23%). The average number of diseases was 1.71, 53% had two or more chronic diseases.

Functional limitations

A model with five trajectories proved to be the best fit for the data (see additional file 3 table S1 and S2). The descriptive statistics per trajectory and the multivariate estimates are shown in tables 3 and 4, and the trajectory plot and estimated mortality probability are shown in figure 1. The mortality probabilities at wave 5 in Figures 1 and 2 should not be the same as the mortality probabilities in Table 3, since the mortality probabilities shown in figures 1 and 2 are probabilities of dying prior to the next survey wave based on the current survey wave.

Figure 1

Trajectories in functional limitations (left, and mortality probability (right) by age (N=567). Dotted lines show 95%-CI.

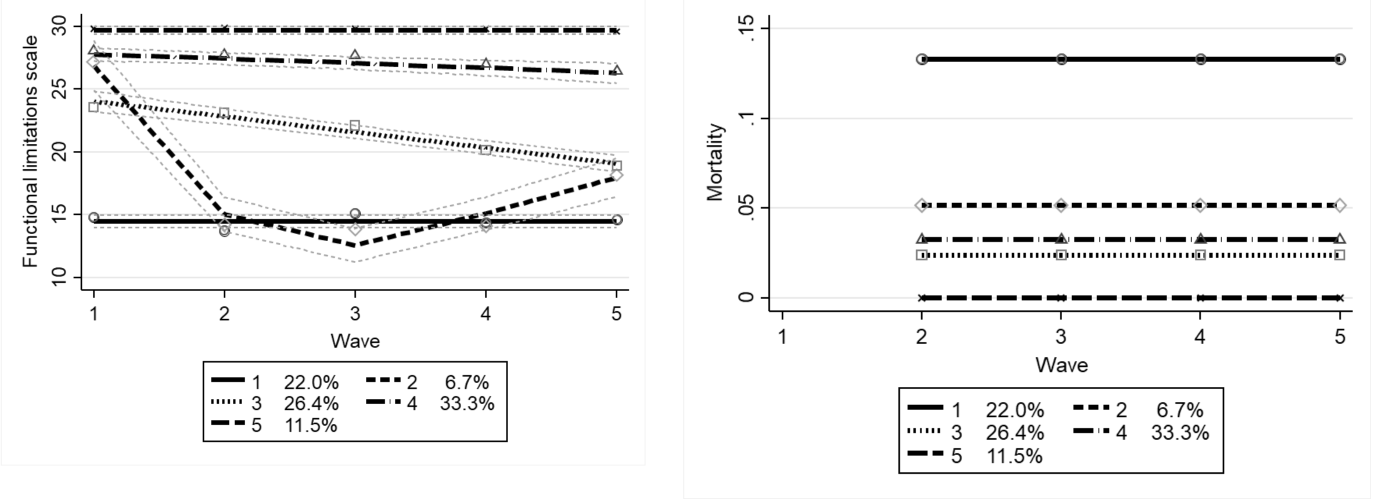


Table 3

Descriptive statistics per trajectory type of 567 Dutch adults aged 75+

		Functional Limitations					Cognitive functioning			
	Total sample *(N=567)*	***1:*** *Continuous low functioning. high mortality (N=127)*	***2:*** *Steep decline in functioning. low mortality (N=36)*	***3:*** *Gradual decline. low mortality (N=149)*	***4:*** *Moderately high functioning. low mortality (N=189)*	***5:*** *Continuous high functioning. low mortality (N=66)*	***1:*** *Continuous low functioning. high mortality (N=60)*	***2:*** *Declining functioning. moderate mortality (N=113)*	***3:*** *Moderately high functioning. low mortality (N=222)*	***4:*** *Continuous high functioning. low mortality (N=172)*
% of total	100	22.0	6.7	26.4	33.3	11.5	10.9	19.5	39.0	30.6
Age range	74.86 – 102.86	75.09 – 102.86	75.20 – 94.31	75.07 – 97.59	75.05-98.23	74.86 – 85.88	75.26 – 95.73	75.07 – 102.86	75.00 – 98.23	74.86 – 93.25
Mean (sd)										
Age	82.20 (5.32)	85.43 (5.80)	82.89 (5.36)	83.25 (5.14)	80.42 (4.15)	78.28 (2.71)	84.92 (5.08)	84.01 (6.04)	81.60 (5.13)	80.82 (4.18)
Comorbidity	1.71 (1.19)	1.97 (1.31)	1.44 (1.11)	2.05 (1.25)	1.53 (0.99)	1.12 (0.98)	1.42 (1.36)	2.04 (1.24)	1.74 (1.22)	1.58 (0.98)
% in group										
Female	61.02	71.65	58.33	67.11	55.03	45.45	63.33	60.18	60.81	61.05
Low education	48.15	62.20	38.89	53.02	47.62	16.67	61.67	60.18	52.25	30.23
Middle education	29.63	25.98	33.33	29.53	26.98	42.42	18.33	23.89	30.63	36.05
High education	22.22	11.81	27.78	17.45	25.40	40.91	20.00	15.93	17.12	33.72
Has a partner	50.62	33.86	50.00	46.31	60.32	65.15	35.00	46.90	50.90	58.14
Institutionalized	7.58	25.20	11.11	3.36	1.06	0.00	35.00	10.62	3.15	1.74
Lung/heart/vascular disease	49.03	51.18	38.89	55.03	50.26	33.33	33.33	53.98	54.05	44.77
Diabetes	15.34	22.05	16.67	18.12	12.17	4.55	18.33	23.01	14.86	9.88
CVA	9.88	18.11	2.78	12.75	5.29	4.55	6.67	18.58	11.26	3.49
Cancer	22.75	18.11	25.00	30.87	21.69	15.15	18.33	30.09	18.92	24.42
Rheumatic disease	62.61	71.65	58.33	71.14	56.08	46.97	55.00	58.41	63.51	66.86
Deceased	24.65	56.00	22.22	18.24	17.99	0.00	61.67	41.59	17.12	10.06
Posterior probability		0.94	0.91	0.91	0.92	0.90	0.95	0.83	0.86	0.90

Table 4

Multivariate predicted probabilities for the functional limitation trajectories (N=567)

	1: Continuous low functioning, high mortality (N=127)				*2: Steep decline in functioning, low mortality (N=36)*				*3: Gradual decline, low mortality (N=149)*				*4: Moderately high functioning, low mortality (N=189)*				*5: Continuous high functioning, low mortality (N=66)*			
	dy/dx (se)	*p-value*	*95% CI LL*	*UL*	*dy/dx (se)*	*p-value*	*95% CI LL*	*UL*	*dy/dx (se)*	*p-value*	*95% CI LL*	*UL*	*dy/dx (se)*	*p-value*	*95% CI LL*	*UL*	*dy/dx (se)*	*p-value*	*95% CI LL*	*UL*
Age	**0.02 (<0.01)**	**<0.001**	**0.010**	**0.021**	<0.01 (<0.01)	0.204	-0.001	0.006	**0.01 (<0.01)**	**<0.001**	**0.007**	**0.020**	**-0.01 (0)**	**0.001**	**-0.021**	**-0.005**	**-0.02 (<0.01)**	**<0.001**	**-0.025**	**-0.011**
Female	0.04 (0.04)	0.220	-0.026	0.113	-0.01 (0.02)	0.802	-0.053	0.041	0.06 (0.04)	0.131	-0.018	0.141	-0.05 (0.04)	0.263	-0.134	0.037	-0.05 (0.03)	0.081	-0.107	0.006
Low education (ref.)																				
Middle education	-0.05 (0.04)	0.138	-0.127	0.018	0.02 (0.02)	0.382	-0.026	0.068	-0.01 (0.04)	0.886	-0.088	0.076	-0.07 (0.04)	0.129	-0.151	0.019	**0.11 (0.03)**	**<0.001**	**0.050**	**0.162**
High education	**-0.13 (0.04)**	**0.001**	**-0.200**	**-0.050**	0.03 (0.03)	0.266	-0.024	0.089	-0.03 (0.05)	0.483	-0.126	0.060	<0.01 (0.05)	0.929	-0.095	0.104	**0.12 (0.03)**	**<0.001**	**0.058**	**0.186**
Has a partner	-0.04 (0.04)	0.227	-0.113	0.027	<0.01 (0.02)	0.998	-0.046	0.046	0.02 (0.04)	0.708	-0.065	0.095	0.04 (0.04)	0.297	-0.039	0.128	-0.02 (0.03)	0.57	-0.074	0.040
Comorbidity	**0.03 (0.01)**	**0.011**	**0.007**	**0.056**	-0.01 (0.01)	0.206	-0.030	0.007	**0.06 (0.01)**	**<0.001**	**0.033**	**0.088**	**-0.03 (0.02)**	**0.043**	**-0.066**	**-0.001**	**-0.05 (0.01)**	**<0.001**	**-0.071**	**-0.023**
Lives in an institution	**0.46 (0.08)**	**<0.001**	**0.300**	**0.613**	0.06 (0.06)	0.291	-0.054	0.180	**-0.14 (0.06)**	**0.018**	**-0.262**	**-0.025**	**-0.26 (0.06)**	**<0.001**	**-0.378**	**-0.134**	**-0.12 (0.01)**	**<0.001**	**-0.144**	**-0.096**

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit; UL = Upper Limit
Statistically significant associations in bold

The first group, containing 22.0% of the respondents, showed stable low levels of physical functioning: The trajectory started at a mean ADL-score of 15, and stayed at that level for the following waves. Such scores usually indicate that respondents were unable to perform 3 ADL-indicators, but were still able to perform 2 without help, although for some it meant that they had much difficulty performing all of the five ADL-indicators, and needed help with at least one of them. This group had the highest mortality probability per year: 13% at each wave. Older people dy/dx=0.02 [0.01 ; 0.02] and people who lived in an institution dy/dx=0.46 [0.30 ; 0.61] were relatively likely to follow this trajectory, as were people who suffered from multiple diseases, with each extra disease increasing the probability of this trajectory with 0.03 [0.01 ; 0.06]. When comparing the sample averages to the percentage of people that has a certain disease (see Table 3), the prevalence of diabetes, CVA, and rheumatic disease is markedly higher (>5% or more) than average in this group. People with a high education were 13% [-0.20 ; -0.05] less likely compared to those with a low level of education to have a stable level of many ADL disabilities.

The second group showed a decline in functioning, followed by a slight recovery in which some of the initial functioning was regained. The decline was steep: over the course of nine months the ADL-score declined from 26 to 15, which is indicative of gaining two severe limitations. At the end of the observation period, the average ADL-score was 17. This decline might reflect the slow regaining of functioning after function loss caused by falling or an accident. The recovery is however quite small and we did not check whether participants in this trajectory experienced falls or accidents. Relatively few participants followed this trajectory (6.7%), and the mortality probability was stable at 5%. None of the included covariates were significantly associated with this trajectory, but this might be due to the small number of participants in this group. Compared to the whole sample this group had a lower percentage of CVA and lung- and heart disease.

The third trajectory showed slight decline, and gradually decreased from an average ADL-score of 24 to 19. This trajectory contained 26.4% of the participants, and had a stable mortality probability of 3%. Older people were more likely to follow this trajectory, with 1% [0.01 ; 0.02] extra for each life year. Participants who suffered from more diseases were 6% [0.03; 0.09] more likely to follow this trajectory, this trajectory had a higher prevalence of lung- and heart disease, cancer, and rheumatic disease. Living in an institution decreased the probability of this trajectory with dy/dx=0.014 [-0.26 ; -0.03].

The fourth trajectory was stable, with an average ADL-score of 27, which indicated being able to perform all ADL-indicators with only a little or no help. The mortality probability was stable at 3%, and 33.3% of the participants followed this trajectory. Age decreased the probability of following this trajectory with 1% [-0.02 ; -0.01] per year, as did having more diseases: dy/dx= -0.03 [-0.07 ; -0.00]. Living in an institution was statistically significantly associated with this trajectory as well dy/dx=-0.26 [-0.38 ; -0.13].

The fifth trajectory was stable as well, and the participants (11.5%) in this trajectory experienced no ADL-limitations at all. Older people were less likely to follow this trajectory (dy/dx=-0.02 [-0.03 ; -0.01], as were people that suffered from more diseases, with an decrease in the probability of following this trajectory of 5% [-0.07 ; -0.02]. The prevalence of all diseases was markedly lower than average in this trajectory. Living in an institution decreased the probability of this trajectory as well, with 12% [-0.14 ; -0.10]. Education seemed to increase the probability of this favourable trajectory: the probability of this trajectory was respectively 0.11 [0.05 ; 0.16] and 0.12 [0.06 ; 0.19] higher for people with a middle education and a higher education, compared to people with a lower education.

Sensitivity analyses showed that not jointly modelling mortality resulted in different group sizes: 14% in the low (F1), 6.5% in the rapid declining (F2), 28.2% in the gradually declining (F3), 35.8% in the moderately high (F4), and 15.5% in the high (F5) trajectory (see S4 additional file 2). This resulted in overestimations of 4%, 2.5%, and 1.8% of respectively the highest (F5), moderate (F4), and gradual decline (F3) physical functioning trajectories, and a -0.2% and 8% underestimation of the rapid decline (F2) and the low physical functioning trajectory (F1), compared to the solutions of the models that included mortality.

Cognitive limitations

For cognitive limitations a four-trajectory model, shown together with the mortality plot in figure 2, proved to be the best fit. The descriptive statistics per trajectory and the multivariate estimates are shown in tables 3 and 5.

The first group showed very low cognitive functioning across time, the trajectory started at the threshold for dementia (11) with a mean sMMSE of 11. The trajectory showed no further decline, but it could be argued that given the low baseline scores, there was little further decline possible for this group. Containing 10.9% of the sample, this group was the smallest of the four trajectories. The mortality probability was continuously high at 14%. Age, although showing a very slight positive direction, was not significantly statistically associated with this trajectory dy/dx<0.01 [0.00 ; 0.01], which might be explained by the low power of this study, or by the fact that diseases such as Alzheimer's usually start between age 65-75. It appears that low educated people were most likely to follow this trajectory, and this difference was significant between low and middle educated people, with middle educated people being 6% [-0.11 ; -0.01] less likely to have continuous low cognitive functioning. Suffering from more diseases decreased the probability of this trajectory with 3% [-0.05 ; -0.01], and the people in this trajectory on average had less diseases: the prevalence of lung- and heart disease, diabetes, CVA, and rheumatic disease was lower (>5%) than the sample average. Living in an institution increased the probability with 34% [0.19 ; 0.50].

Figure 2

Trajectories in cognitive decline (left, and mortality probability (right) by age (N=567). Dotted lines show 95%-CI.

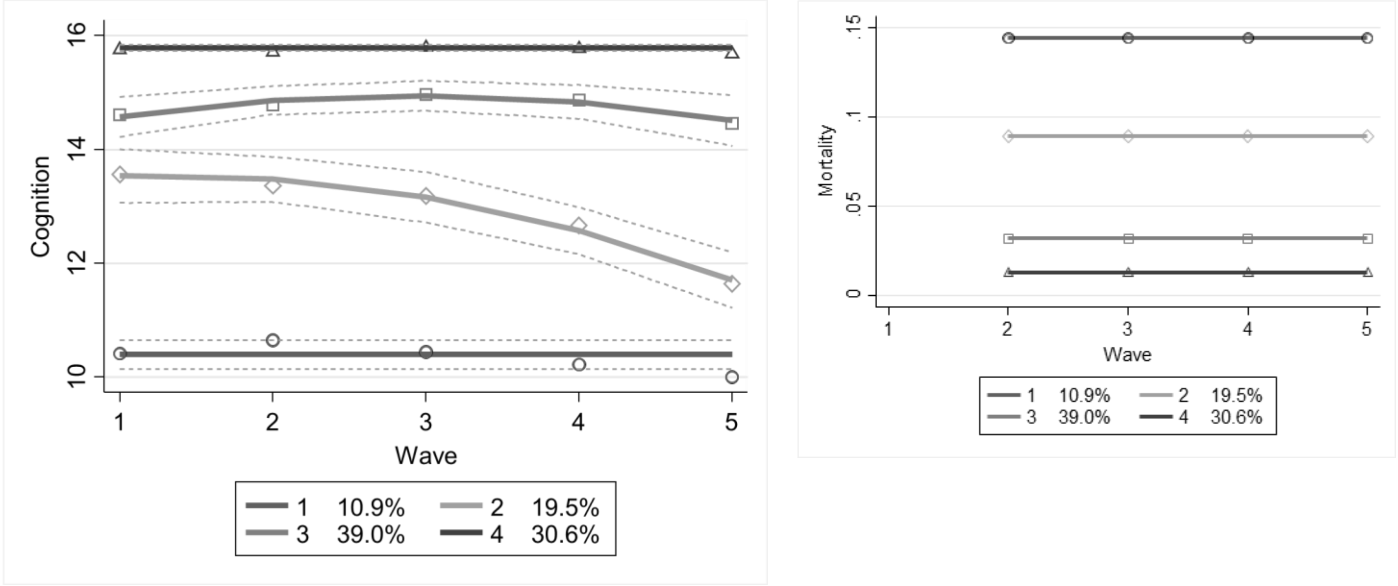


Table 5. Multivariate predicted probabilities for the cognitive functioning trajectories (N=567)

	1: Continuous low functioning. high mortality (N=60)				*2: Declining functioning, moderate mortality (N=113)*				*3: Moderately functioning, low mortality (N=222)*				*4: Continuous high functioning. low mortality (N=172)*			
			95% CI				95% CI				95% CI				95% CI	
	dy/dx (se)	*p-value*	*LL*	*UL*	*dy/dx (se)*	*p-value*	*LL*	*UL*	*dy/dx (se)*	*p-value*	*LL*	*UL*	*dy/dx (se)*	*p-value*	*LL*	*UL*
Age	<0.01 (<0.01)	0.063	0.000	0.008	**0.01 (<0.01)**	**<0.001**	**0.005**	**0.017**	-0.01 (<0.01)	0.113	-0.015	0.002	**-0.01 (<0.01)**	**0.027**	**-0.016**	**-0.001**
Female	-0.03 (0.03)	0.359	-0.083	0.030	-0.02 (0.04)	0.558	-0.097	0.052	-0.03 (0.05)	0.552	-0.118	0.063	0.08 (0.04)	0.061	-0.003	0.156
Low education (ref.)																
Middle education	**-0.06 (0.03)**	**0.021**	**-0.114**	**-0.009**	-0.07 (0.04)	0.057	-0.147	0.002	-0.03 (0.05)	0.557	-0.122	0.066	**0.16 (0.04)**	**<0.001**	**0.077**	**0.247**
High education	-0.04 (0.03)	0.204	-0.099	0.021	**-0.09 (0.04)**	**0.04**	**-0.167**	**-0.004**	**-0.14 (0.05)**	**0.007**	**-0.237**	**-0.037**	**0.26 (0.05)**	**<0.001**	**0.162**	**0.361**
Has a partner	-0.04 (0.03)	0.104	-0.098	0.009	0.01 (0.04)	0.734	-0.062	0.087	-0.03 (0.05)	0.525	-0.120	0.061	0.06 (0.04)	0.148	-0.022	0.144
Comorbidity	**-0.03 (0.01)**	**0.01**	**-0.049**	**-0.006**	**0.04 (0.01)**	**0.004**	**0.012**	**0.063**	0.01 (0.02)	0.642	-0.026	0.041	-0.02 (0.02)	0.256	-0.049	0.013
Lives in an institution	**0.34 (0.08)**	**<0.001**	**0.187**	**0.497**	0.05 (0.07)	0.449	-0.083	0.187	**-0.19 (0.07)**	**0.011**	**-0.337**	**-0.045**	**-0.20 (0.06)**	**0.001**	**-0.326**	**-0.080**

Notes: LL = Lower Limit; UL = Upper Limit

The second trajectory (19.5%) showed decline, decreasing from probable mild cognitive impairment (sMMSE= 13) to probable dementia (sMMSE= 11). The mortality probability was quite high: 9%. Being older increased the probability of this trajectory dy/dx=0.01 [0.01 ; 0.02], as did having more diseases dy/dx= 0.04 [0.01 ; 0.06]. On average, this group had a higher prevalence of diabetes, CVA, and cancer. Having had a high education decreased the probability of this trajectory with 9% [-0.17 ; <-0.01].

The third group, containing 39% of the participants, started at a mean sMMSE of 14, slightly increased to 15, and then decreased to 14. It had a stable mortality probability of 4%. People with a high education, or people that lived in an institution were respectively 14% [-0.24 ; -0.04] and 19% [-0.34 ; -0.05] significantly less likely to follow this trajectory. The prevalence of lung- and heart disease was 5% higher than the sample average.

The last trajectory showed continuous high cognitive functioning combined with a low mortality probability (2%), and contained 30.6% of the participants. Older age decreased the probability of this trajectory dy/dx=-0.01 [-0.02 ; < -0.01], as did living in an institution dy/dx=-0.2 [-0.33 ; -0.08]. People with a middle or high education respectively had a 16% [0.08 ; 0.25] and 26% [0.16 ; 0.36]. Although the association for morbidity was not significant, the prevalence of diabetes and CVA was >5% higher than the sample average.

Not jointly modelling mortality resulted in the following group sizes: 5.4% in the low (C1), 15.4% in the declining (C2), 43.8% in the moderate (C3), and 35.5 in the high (C4) trajectory. The high (C4) and moderate (C3) cognitive functioning trajectories would have been overestimated with 4.9% and 4.8%, while the declining (C2) and low (C1) trajectories would have been underestimated with 4.1% and 5.5%.

Overlap between the trajectories

Figures 3 and 4 show overlap between the trajectories of functioning. A certain coherence is visible: people in the adverse physical functioning trajectories experience low cognitive functioning more often, and people experiencing high physical functioning often experience high cognitive functioning. However, there is also still substantial variation, since 22% of people with high cognitive function experience a trajectory with severe ADL-limitations. The picture for the declining physical trajectory shows little correlation with cognition: the percentages of the cognitive trajectories are distributed almost evenly over this group.

Figure 3

Overlap between functional limitations trajectories and cognitive trajectories:

percentage of people in cognitive functioning trajectory per functional limitations trajectory.

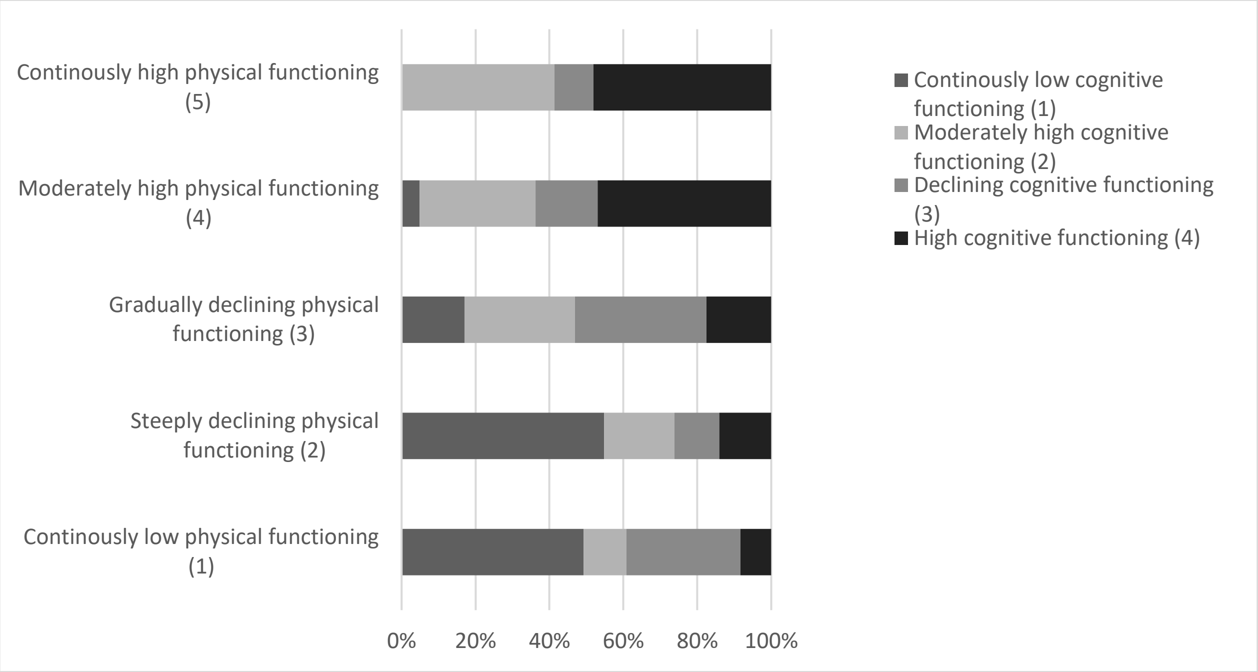
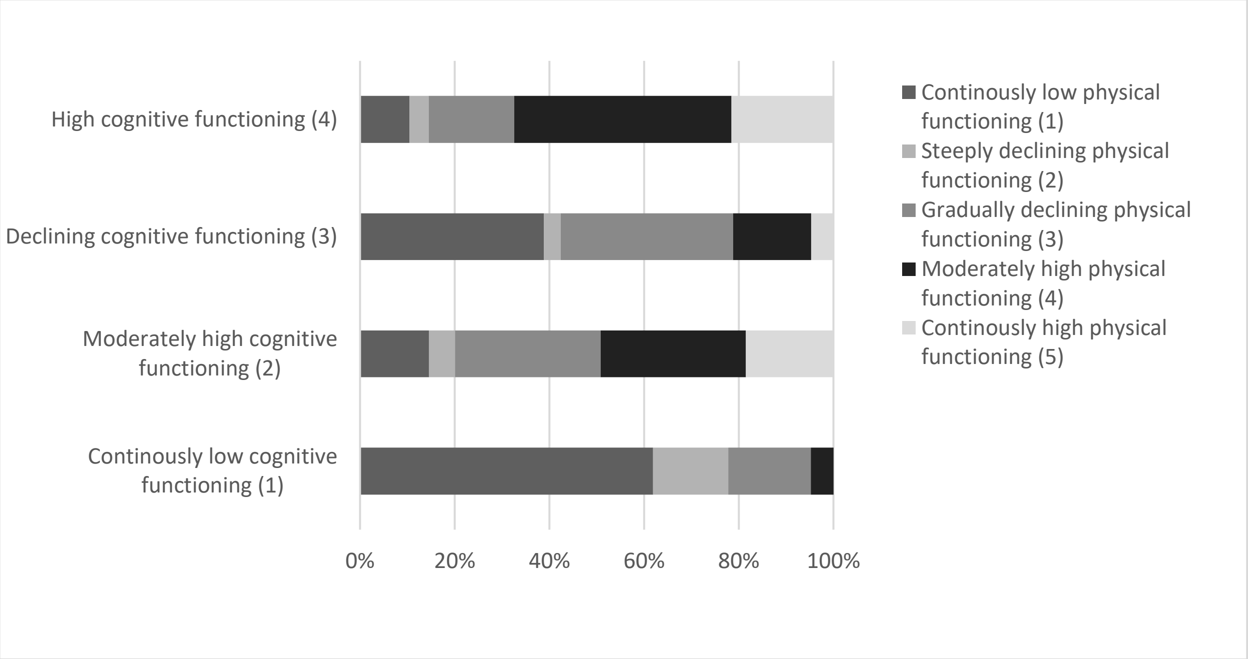


Figure 4

Overlap between functional limitations trajectories and cognitive trajectories:

percentage of people in functional limitations trajectory per cognitive functioning trajectory



Discussion

This study identified trajectories in both physical and cognitive functioning among Dutch older adults aged 75 and older. Using the innovative methodology of Group-Based Trajectory Modelling, modelling trajectories jointly with mortality, we were able to estimate more precise group sizes of the trajectories. We identified five trajectories in functional limitations and four trajectories in cognitive decline. A considerable proportion of the Dutch 75+ experienced high levels of functioning over the course of three years. For physical functioning, 11.5% of the sample experienced continuous high levels of physical functioning, and 33.3% of the sample experienced high moderate physical functioning. As for cognitive functioning, 30.6% of the sample experienced high cognitive functioning and 39% experienced moderately high cognitive functioning. But, adverse trajectories were present as well. For the physical functioning trajectories, 26.4% of the participants experienced gradual decline and 6.7% experienced steep decline followed by slight recovery. For cognitive functioning 19.5% experienced rapid cognitive decline. The most adverse trajectories showed continuous low physical functioning with at least 2 severe ADL-limitations (22%), and continuous low cognitive functioning (10.9%) with probable dementia. These trajectories had high mortality levels (~14%). The declining and low functioning trajectories are the trajectories where the requirement for care is probably highest.

Despite our study using shorter time intervals, examining older participants, and incorporating mortality risk, the trajectories seem to reflect patterns that were also identified in previous studies on trajectories of functioning in old age. Among populations of the same age group similar trajectories were identified (Gill et al., 2013; Kingston et al., 2015). Whereas our relatively old study sample resulted in a low trajectory for cognition, that is not identified among younger study samples (Comijs et al., 2004; Kok et al., 2017), but is also identified among older study samples (Han et al., 2014; Hu et al., 2019). It can be concluded that our study corroborates that there is considerable diversity in health trajectories among the 75-plus.

Taking mortality into account resulted in bigger group sizes for the more adverse trajectories, while it led to smaller group sizes for the more favourable trajectories, which is in line with what could be expected based on the studies conducted by Haviland et al. (2011) and Zimmer et al. (2012), who used the same methodology. However, although we expected that modelling mortality would result in bigger group sizes for the trajectories that showed decline, this was only the case for cognitive decline, but not modelling mortality only resulted in a negligibly small (0.2%) underestimation of the steeply declining physical functioning trajectory and a slight overestimation of the gradually declining physical functioning. This is in line with previous studies reporting very low mortality probabilities for people with increasing functional limitations (Taylor & Lynch, 2011).

The second aim of our study was to explore how the trajectories varied for several background variables (sex, age, level of education and partner status) and disease status. What is clear from these results is that the persons following the three most favourable trajectories (with either high or high moderate levels of physical functioning, or high levels of cognitive functioning) had rather favourable characteristics. They were younger, middle or high educated, lived independently, and had less diseases on average.

Yet, there appeared to be no common denominator between the people following the three declining trajectories. Both the gradually declining physical functioning trajectory and the gradually declining cognition trajectory shared some characteristics: higher age and a higher number of diseases increased the probability of these trajectories, they also had a higher prevalence of cancer than the sample average (>5%), which is understandable as these chronic diseases in more advanced stages limit mobility.

The gradually declining functional limitations trajectory had more people who were living in an institution, and the gradually declining cognition trajectory had a higher diabetes and CVA prevalence. Although none of the associations for the gradually declining physical functioning trajectory were significant, these people appeared to have more favourable characteristics than the sample average: they were higher educated, had less diseases: specifically lower rates of lung- and heart disease, and CVA. This shows the severe debilitating effects of CVA, since it reduces the level of functioning in such a severe way that the chance of following a trajectory that starts with high functioning is rather low (Taylor & Lynch, 2011). The finding that the prevalence of CVA is highest with in the gradually declining cognitive functioning is in line with previous findings that CVA does not necessarily lead to dementia, but reduces cognitive functioning, thereby resulting in mild cognitive impairment for most (Levine et al., 2015; Tham et al., 2002). Since CVA was measured at baseline, this is in line with the starting point of this trajectory, which indicates mild cognitive impairment.

While the prevalence of rheumatic diseases was high among the gradually declining physical functioning trajectory and low for the high physical functioning trajectory, a finding also reported by for example Botes et al. (2018), the prevalence was also lower for the low cognitive functioning trajectory. This relation between rheumatic diseases and cognition has been widely studied, and despite the growing body of evidence suggesting that aspirin does not have a protective effect on cognition (Ryan et al., 2020; Veronese et al., 2017), studies do indicate that non-steroidal anti-inflammatory drugs (NSAIDs) decrease the risk of cognitive decline (Wang et al., 2016).

As expected based on previous studies, older age, lower education, and living in an institution, were significantly associated with the two trajectories of poor functioning: with severe functional limitations, and with severe cognitive problems (Botes et al., 2018; Comijs et al., 2009; Marengoni et al., 2011). Although both trajectories had much lower prevalence of a partner, these associations were not significant. The pattern for diseases was different from what we expected, for functional limitations more diseases was positively associated, with higher prevalence of diabetes, CVA, and rheumatic disease, which was as expected. The link with diabetes can be explained by the adverse effects of hyperglycaemia, inflammatory cytokines, and neuropathic processes (Chiu et al., 2011). For cognitive functioning the more diseases was negatively associated with the low trajectory, with lower prevalence of lung- and heart disease, and rheumatic disease. This might be because lung- and heart disease result in death before continued cognitive functioning can occur. All in all, these trajectories seem to contain persons that experienced the deleterious effects of chronic diseases, and about half of them had to be taken into residential care due to the resulting limitations.

Associations for sex were not present. Because male brains atrophy quicker than female brains do (Gur et al., 1991), most studies stratify by sex a priori (Kok et al., 2017; Zimmer et al., 2012). However, stratifying by sex would have greatly reduced our statistical power substantially due to our small sample. And, sensitivity analysis stratified by sex showed comparable trajectories for men and women (see figures S2 and S3 in additional file 2). The absence of sex differences might be explained by the finding that these differences are most pronounced in the level of functional impairment, while rates of change are similar for men and women (Liang et al., 2008). It could be possible that due to our shorter measurement intervals the rate of change has had a bigger impact in defining the trajectories than differences in the intercept. On the other hand, the absence of sex differences is not entirely anomalous; for functional limitations Bolano et al. (2019) and Holstein et al. (2007) do not report any statistically significant sex differences, and Comijs et al. (2004) do not always identify sex differences for trajectories in cognition. In addition, a study on the differences in cognitive decline between men and women did not find these differences (Aartsen et al., 2004). Moreover, our analyses included mortality, number of chronic diseases, age and level of education, which are all factors that differ by sex, which may have decreased the effect of sex itself.

Other studies focusing on the role of education have found that education may be important for onset of functional and activity limitations but not for progression (Taylor & Lynch, 2011; Zimmer et al., 1998; Zimmer & House, 2003). Low education being associated with low levels of physical functioning is a finding also reported by Boyd et al. (2009) and Kingston et al. (2015). The finding that a higher education is negatively associated with moderate or declining levels of cognitive functioning, and positively associated with high cognitive functioning, corroborates the link between education and cognition. Furthermore, it is partly in line with the MMSE being less sensitive for cognitive decline among higher educated people (Aevarsson & Skoog, 2000), but also in line with education having a protective effect on cognitive decline (Anstey & Christensen, 2000), and people with higher cognitive ability having pursued more education.

Associations for partner status were absent. This might have been caused by not differentiating between coresident and non-coresident partners. Second, it is possible that the protective effect of having a partner diminishes with age, since this usually results in the partner requiring more care as well. Lastly, studying a population that could be either institutionalized or community-dwelling might have resulted in absent associations for partner status.

Strengths and Limitations

The main strength of this study was the use of the 75PLUS LASA-data, containing a representative sample of the Dutch oldest old: the study has a high response and cooperation rate, and enabled for studying both community dwelling and institutionalized people. Accounting for attrition by jointly modelling mortality is a strength as well, enabling us to estimate more precise group sizes. Third, defining ADL as a scale forms a strength in opposition to previous studies that compressed the range of the severity of ADL-limitations by dichotomizing ADL. Because the overall degree of functional limitations decides the need for care, it is precisely this degree that is of vital importance for policymakers, and by measuring ADL as a scale we were better at capturing the existence and the range of need for care that follow from functional limitations.

The first limitation of the study was not being able to conduct a multi-trajectory model to study the interconnectedness between cognitive decline and ADL-limitations that is implied by previous studies (Braungart Fauth et al., 2007; Mansbach & MacE, 2019). We instead decided to report the estimates of the trajectories separately, since jointly modelling mortality in a multi-trajectory model was not possible, and accounting for decease is necessary in a very old population. Second, although the use of proxy data allowed us to also include severely cognitively impaired respondents, this resulted in two different measurements for cognition (the sMMSE and the IQCODE) (Mackinnon et al., 2003). Although different ways of harmonizing did not affect the trajectories much, the absence of guidelines on how to harmonize the sMMSE and IQCODE leaves some uncertainty on whether the eventual scores are an accurate reflection of cognitive functioning among our participants. Although we did not have a considerable amount of missing items for ADL or sMMSE, we are mindful of the slight overestimation of both cognitive and ADL-levels in which the imputation of these items might have resulted. On the flip side, not including these participants in the analysis would have likely resulted in an overestimation of favourable trajectories as well. Third, although our sample size was sufficient for performing analyses, analysing a bigger sample size would have allowed for performing all of the analysis stratified by sex, and would have increased statistical power. Because the dropout-function we used was pre-specified in Proc Traj, this might be a limitation. Future research could use mixed effect models with a well-specified jointly modelled missingness mechanism (Tsonaka et al., 2009), to produce unbiased estimates, and thereby also investigate further whether the prespecified dropout function from Proc Traj produced unbiased estimates. In addition, excluding the 34 participants that dropped out due to other reasons than decease might have resulted in a selection bias, since these participants were probably less likely to experience health problems than the ones that deceased.

This study shows that age is associated with the trajectories. However, since our study design did not allow for stratifying by birth cohort, future research should focus on whether the trajectories are similar among different birth cohorts.

Implications

This study has implications for policymakers in health and long-term care. Despite this study showing that a considerably large group experiences little to no functional limitations and/ or cognitive decline, this study also identifies groups that, based on their low or declining levels of physical and cognitive functioning, have a high or increasing care need. The trajectories corresponding to the highest requirements of care are the two stable low trajectories (11-22%), and part of those groups are already living in residential care. This simultaneously shows how half of these people apparently have a high requirement of care, but do still live in independent housing, probably with a large demand on care from informal and formal caregivers. The declining trajectories (7%, 20%, 26%) are of most interest due to the increasing care need over time. This increase makes this group vital for policies aimed at future care planning, since they require more adjustments in care provision than the stable trajectories do. Our study does not provide one indicator to target all these groups, but shows old age, low education, a higher number of chronic diseases, as the best indicators for targeting risk groups, with cancer and rheumatic disease for functional limitations, and CVA and diabetes for cognitive decline. Future studies and policymakers should aim at finding indicators to identify the people that experience declines in functioning, and in particular rapid declines in functioning.

Conclusion

Our study underscores the diversity in health trajectories among the older old. Most Dutch 75-plus had high levels of functioning. Yet, about a quarter of the respondents experienced moderate functional decline, while 31% and 20% experienced functional and cognitive decline. A small part experienced very low levels of functioning: 22% and 11% experienced severe functional limitations or cognitive limitations with probable dementia and high mortality probabilities. The findings show that chronic disease prevalence is different for physical and cognitive functioning, with only cancer having a high prevalence among both the functional and the cognitive decline trajectories. Older age, low education, a higher number of chronic disease. Because cancer is the most likely predictor for decline, this should be the predictor policymakers use for future care planning and identifying people at risk for adverse functioning. A small percentage of the Dutch oldest old lives independently while having a high care requirement, and a considerable number of people has an increasing care need. It is important to identify whether the groups with currently high and an increasing care requirement get the care they need.

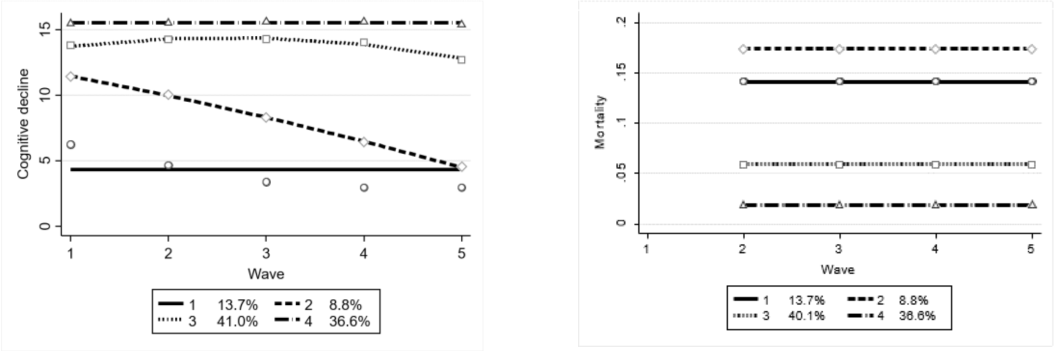
Additional File 1 Harmonizing the IQCODE and the MMSE

Figure S1

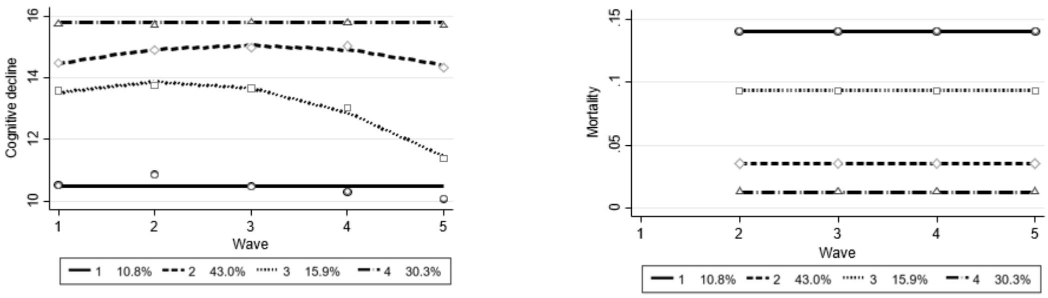
Trajectories in cognition based on two different ways of harmonizing the IQCODE and the MMSE

MMSE-scores per wave | Mortality-probability per wave

Based on Chiriboga, McHugh, and Sweeney (2008)



Based on van den Kommer et al. (2018)



One of the main problems in harmonizing the IQCODE and the MMSE lies in the fact that both scales have a different time-axis; the IQCODE asks for changes in the past ten years, whereas the MMSE measures cognitive abilities in the present. However, when looking at the individual IQCODE-scores over time, there was much more variation than one might expect to be present. Since the IQCODE asks about changes in the past ten years, we would have expected that these scores would not vary substantially over the course of nine months, but for many, it did. This variation didn’t solely show decreasing cognitive abilities, but recovery as well. This seems to imply that most proxies answering the IQCODE have the respondent’s cognitive ability of the past year most vividly in mind when answering the question. With this assumption in mind, we argue that harmonizing the two is in some way justified.

There were two decisions to be made, the first one was whether we chose a conversion from the IQCODE to the MMSE at each wave, or whether we treated the IQCODE-score as a score that had to be interpreted as a change of the respondent’s previous cognitive ability score. So, in other words: whether we decided someone’s MMSE-score would be the previous MMSE-score minus a certain amount of points (based on the IQCODE, that either indicated no/ a little/ or drastic decline), or whether we calculated the MMSE-score based on the current IQCODE-score (so without the cognitive-ability-score of the previous wave in mind). Although the option of using the IQCODE to calculate the MMSE based on the previous cognitive score seemed more correct (since it asks about cognitive change), this lead to a small group of respondents ending up with extremely low or even negative scores. In addition, because an MMSE-score below 11 indicates dementia, we assume that the difference between an MMSE-core of 8 and a score of 6 is less meaningful than the difference between a score of 16 (no cognitive decline) and 14 (where mild cognitive impairment is likely to be present). Therefore we decided to harmonize the IQCODE and the MMSE without treating the IQCODE as a measure of change compared to previous cognitive statuses, but instead treating it as an indication of the respondents’ current cognitive abilities.

When looking at the trajectories that are estimated based on the two possible ways of converting the IQCODE-scores to the MMSE-scores, shown in figure 1, they do not seem to substantially differ from one another. The conversion based on the research conducted by Chiriboga, Mchugh, and Sweeney (2008) is almost similar to the one based on the research conducted by van den Kommer et al. (2018).

Additional File 2 Sensitivity checks

1.1 Stratified by gender (Figure S2 and S3)

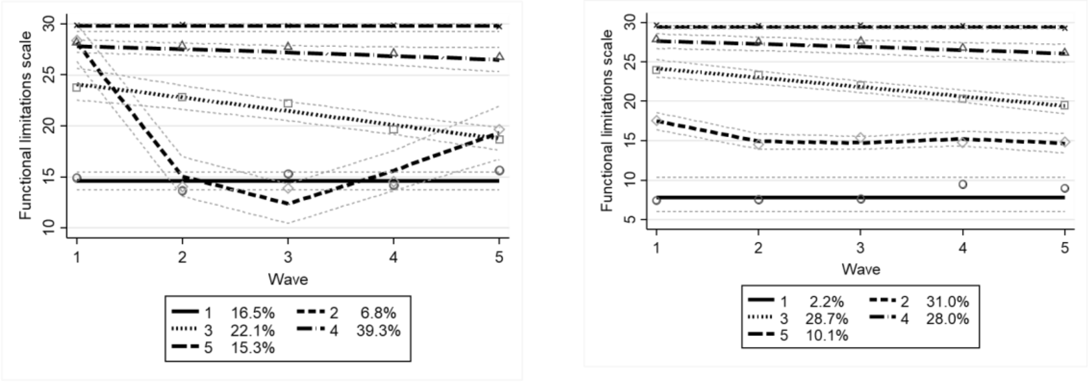
The first sensitivity check we conducted was estimating the models stratified by gender, these trajectories are shown in figures S2 and S3. It has to be noted that for functional limitations the second group for men is not present among the women’s trajectories. However, it is only the first wave in which these two trajectories differ substantially, since they hoover around a mean ADL-score of 15 from the second wave onwards. Because this group is small, it is also likely that a similar pattern is present for women but cannot be detected due to the small sample size. Since the other trajectories for functional limitations and all the trajectories for cognitive decline are similar for men and women, we decided that the power of performing the analyses on a non-stratified sample, outweighed the fact that there was one trajectory among men and women that was not entirely comparable.

Figure S2

Trajectories in functional limitations estimated stratified by gender (N=567). Dotted lines show 95%-CI.

Men (N=221) Women (N=346)

Trajectories in functional limitations



Estimated mortalityprobabilities for the functonal limitations trajectories

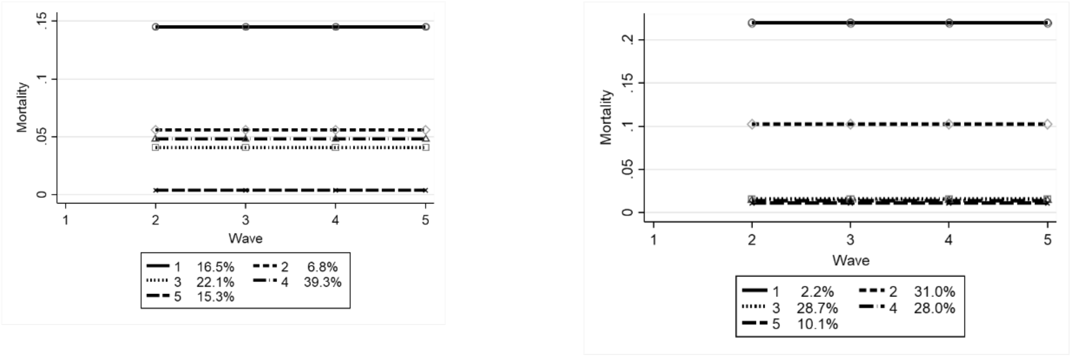
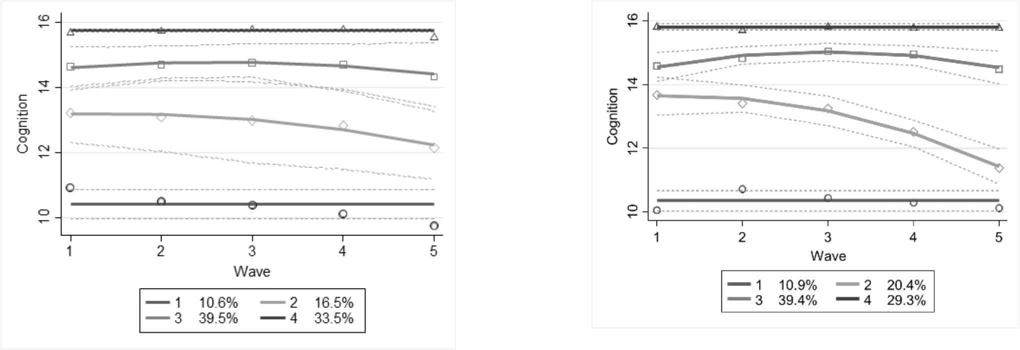


Figure S3

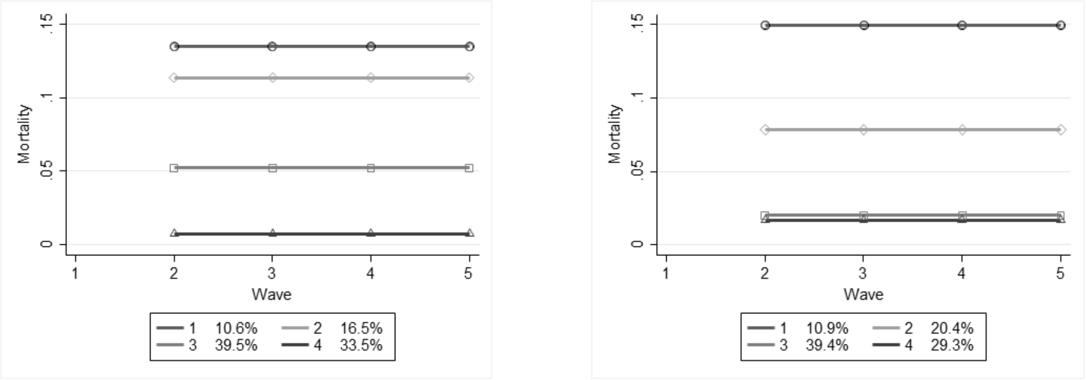
Cognitive decline trajectories estimated stratified by gender (N=567). Dotted lines show 95%-CI.

Men (N=221) Women (N=346)

Trajectories in cognitive decline



Estimated mortalityprobabilities for the cognitive decline trajectories



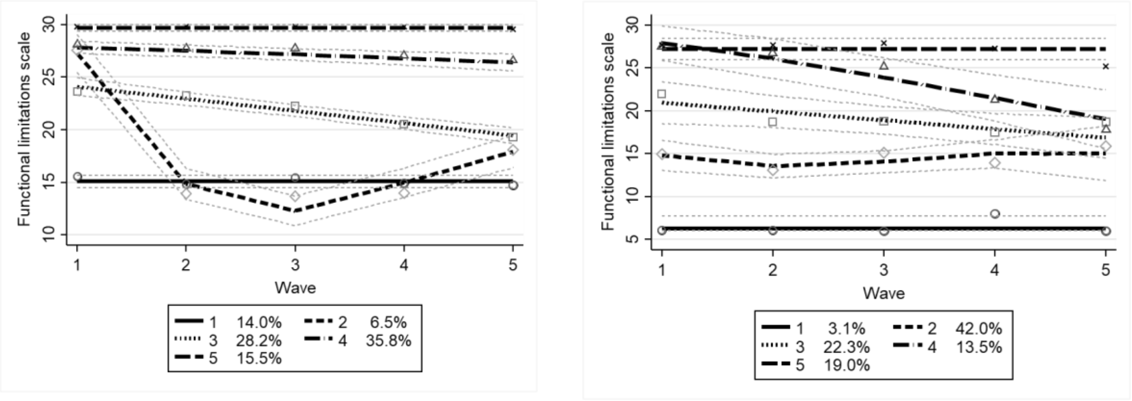
1.2 Stratified based on mortality

Figure S4

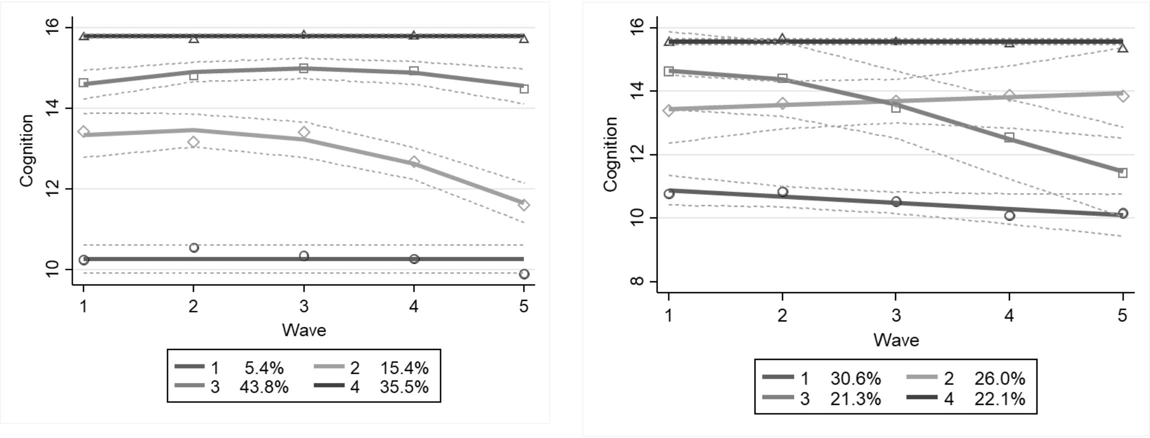
Trajectories in functional limitations and cognitive decline, for survivors or deceased participants. Dotted lines show 95%-CI

Survivors (N=425) Deceased (N=139)

Trajectories in functional limitations



Trajectories in cognitive decline



Additional File 3 Measures of fit for different number of groups

Table S1

BIC Scores for different numbers of trajectories, selected model in bold

N. Of groups	Functional limitations		Cognitive decline	
	N=567 Subjects	N= 2626 Observations	N=567 Subjects	N=2625 Observations
3	-7569.02	-7578.22	-4647.63	-4656.83
4	-7470.78	-7483.81	**-4604.83**	**-4617.09**
5	**-7392.96**	**-7408.29**	-4611.16	-4627.26
6	-7395.52	-7413.15	-4619.42	-4637.81

Table S2

Posterior probabilities for separate analysis for different numbers of trajectories, selected number of groups in bold

Functional limitations												
	1	N	2	N	3	N	4	N	5	N	6	N
3 groups	.95	176	.90	187	.95	204						
4 groups	.95	157	.89	157	.90	184	.87	69				
5 groups	**.94**	**127**	**.90**	**36**	**.91**	**149**	**.92**	**188**	**.90**	**67**		
6 groups	.98	6	.94	157	.87	132	.83	18	.91	188	.90	66
Cognitive decline												
	1	N	2	N	3	N	4	N	5	N	6	N
3 groups	.95	80	.89	242	.94	245						
4 groups	**.95**	**60**	**.84**	**113**	**.86**	**222**	**.90**	**172**				
5 groups	.95	56	.76	42	.75	124	.83	184	.83	161		
6 groups	.96	56	.71	45	.76	93	.74	199	.86	117	.57	57

Additional File 4 Dropout function

We used the dropout function provided in Proc Traj, described in further detail as equation 3, in the article written by Haviland, Jones, and Nagin (2011) on page 372 (26), and as equation 4 in Zimmer et al. (2012) on page 302 (29). Dropout was described by the following probability function:

$$P(Y_i|time_i, j; \beta^j, \Theta^j_\tau) = \left[\prod_{t=1}^{\tau_i - 1} p(y_{it}|w_{it} = 0, time_i; j; \beta^j)(1 - \Theta^j_t)\right] \theta^j_{\tau_i}$$

The distribution of the outcome was denoted by $P(Y_i|time_i)$, with Y_i capturing the longitudinal sequence of the participant’s ADL-score or MMSE-score*,* and $time_i$ representing the wave these scores were recorded. The vector β^j determined the shape of the trajectory of group *J,* and θ^j_τ the dropout probability of group *J* over the τ periods of measurement. The part of the equation between brackets denoted the probability of Y_i for each period given group J, until the moment of dropout τ_i. This was multiplied by the probability of the dropout θ^j_τ of group J, at time τ_i. And where *p(*)* was the distribution of y_{it} conditional on group *j* and the wave of the data of individual *i* at time *t*, with y_{it} being the participants ADL-score or MMSE-score, or in the case of dropout a value indicating dropout. The dropout indicator was w_{it}, having the value 1 if the individual dropped out.

Chapter 3

Title: Transitions between care networks: A prospective study among older adults in the Netherlands

This Chapter is published as:

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Abstract

As health impairment increases, older adults utilize care from different types of caregivers, but little is known about changes in the composition of care networks. We mapped the transitions between different care networks to gain insight into which people develop care networks that include informal, privately and publicly paid care. We used three waves (2012–2015–2018) of the Longitudinal Aging Study Amsterdam with 1413 Dutch community-dwelling adults, aged 64–100. Network types were identified using six types of caregivers: (1) co-resident, (2) non-co-resident children, (3) other kin, (4) neighbours/friends/acquaintances, (5) publicly paid, (6) privately paid, in a latent transition analysis with mortality and moving to a care facility as missing states. Five types of care networks were identified: (1) no care, (2) privately paid, (3) mixed informal, (4) mixed publicly paid, (5) co-resident. The co-resident network was the most unstable and had a high transition rate to nursing homes. Participants from the privately paid care network often transitioned to a mixed informal network and rarely transitioned to a mixed publicly paid network. Transitions out of the no-care network were mostly to the privately paid network. The two mixed care networks were the most stable. Transitions appeared to be most triggered by deteriorating health. Transitions to institutional care were most likely in the mixed informal, mixed publicly paid and the co-resident network. Thus, these networks appear to require additional support to facilitate ageing in place.

Introduction

With increasing life expectancy and care policies aimed at 'ageing in place', more older adults with complex health needs will require care at home for a considerable number of years (Böcker et al., 2017; WHO, 2015). As the need for care increases, a network usually develops around the person in need of care, consisting of different types of caregivers. The caregivers can be informal caregivers from the social network (e.g. spouses, relatives, friends and neighbours or volunteers) or formal caregivers (professionals) who are either publicly or privately paid. The ratio between the number of informal, publicly and privately paid caregivers can vary over the course of the care trajectory.

Previous research on care arrangements can be broadly divided into two traditions. The first tradition examines care arrangements longitudinally and divides caregivers into the rather broad categories of formal, informal or a mixture of formal and informal care (Bonsang, 2009; Geerts & Bosch, 2012a; Kjaer & Siren, 2019b; Tennstedt et al., 1996). These studies show that most older adults receive a mixed care arrangement in the later stages of their care trajectory.

The other tradition uses a network approach (Wenger 1991, 1997; Jacobs et al. 2018; Keating et al. 2003; Keating and Dosman 2009), and distinguishes the different constellations of care arrangements in more detail, usually at a specific point in time. This network approach has the advantage that it makes it possible to zoom in on these mixed care arrangements and generate ideal-typical networks in which the simultaneous occurrence of formal and informal care is made visible. These ideal-typical networks generally have different needs; for example, in networks in which formal and informal caregivers are present, communication between the caregivers should be facilitated (Jacobs et al., 2016). Networks involving only informal caregivers can be facilitated by various ways of supporting caregivers. If these needs can be linked to demographic characteristics, it will be easier for policy makers to promote the appropriate forms of support when needed.

Previous studies on care networks (CNs) have identified between four and eight types of CNs (Bijnsdorp et al., 2018; Broese van Groenou et al., 2016; Fret et al., 2017; Jacobs et al., 2018; Keating & Dosman, 2009; Savla et al., 2016), which differ in terms of size and the ratio of formal and informal caregivers. These network types generally included: a co-resident or spousal network, an informal network without a co-resident caregiver, a network consisting mainly of publicly paid caregivers, a CN with only (one) privately paid caregiver(s), and mixed networks containing both informal and formal caregivers in varying proportions (e.g., largely informal or largely formal). In general, the differences between these types of CNs are related to the individual determinants of care use: the need for care (health impairment), the willingness to use care (related to gender, age and education) and the ability to access certain types of care (e.g. the presence of a spouse for spousal care) (Jacobs et al., 2018).

These cross-sectional findings suggest that transitions in CNs are largely determined by changes in health and/or social resources. Cross-sectional findings can shed light on the relationships between determinants and transitions, as they shed light on what conditions need to be in place for a certain type of CN to form. We know from previous studies that the presence of a partner is highly associated with the coresidential network (Jacobs et al., 2018; Keating & Dosman, 2009), that higher levels of education are more common in privately paid CNs (Bijnsdorp et al., 2018; Broese van Groenou, 2020; Jacobs et al., 2018) and that older age and more severe health impairment are found in the publicly paid network due to eligibility requirements for publicly paid care.

From a policy perspective, it is important to gain insights into which CNs are likely to include publicly paid carers over time. However, to date, neither transitions in CNs nor the associated determinants have been investigated, as all studies on CNs used a cross-sectional design (e.g. Jacobs et al. 2018; Keating and Dosman 2009). In addition, the Dutch healthcare system was reformed in 2015, with a shift from institutional care to facilitating ageing in place. The 2015 reform entailed decentralisation to municipalities, which were expected to provide this type of care more efficiently. As a result, funding for the provision of long-term home care was significantly reduced, by 35% compared to the funding that central government had previously spent on it (Alders and Schut, 2019). Eligibility criteria for institutional care were raised and initially payment for care was income-related, with higher incomes paying more for care (Alders & Schut, 2019). In the run-up to the reform, politicians were quick to suggest that citizens should make more use of informal care from their own social network (Ministry of Health Welfare and Sport, 2013).

A look at the welfare state also sheds light on what factors might enable certain CNs and transitions. Before the reform, the Dutch long-term care system for older adults had a high degree of defamilisation (Saraceno & Keck, 2010), so that responsibility for care lay primarily with the state. However, the transition involved a shift to a system with a higher degree of familialisation and marketization, as it was pointed out that older adults are increasingly dependent on informal and privately paid care. Considering this, one would expect fewer transitions to publicly paid care after 2015. At the same time, the increased eligibility criteria for institutional care following the reform may have led to more people making use of publicly paid care at home.

In this study, we examine CNs using a prospective design covering an observation period of (2x3) six years. We investigate what types of CNs exist, what transitions between types of CNs take place, which CNs are most stable and what health and socioeconomic characteristics of care recipients are associated with these CNs.

Materials & Methods

Study sample and design

We used data from the Longitudinal Aging Study Amsterdam (LASA), an ongoing population-based longitudinal study of older adults (aged 55+) in the Netherlands (Hoogendijk et al., 2016, 2020). The baseline sample was stratified by age and gender from urban and rural regions of the Netherlands in 1992/93 and comprised 3107 respondents aged 55 to 84 years. In 2002 and 2012, two additional cohorts of 55-64 year olds were added with 1002 and 1023 respondents respectively from the same sample but later birth cohorts. The baseline cooperation rates were 62% for the first and second cohorts and 63% for the third cohort. Data were collected through face-to-face interviews and self-completed questionnaires. If respondents refused or were unable to participate in the standard interview, they (or a proxy) were interviewed by telephone or in an abbreviated face-to-face interview. Additional measurement waves were conducted every three years. The present study included all participants living in a community at baseline who were 65 years or older in the 2012/13 wave (N=1413), and covered the three measurement waves 2012/13, 2015/16 and 2018/19. The survey was administered in person to 871, 842 and 742 respondents in the first, second and third waves, by telephone to 34, 43 and 86 respondents, and by proxy to 17, 37 and 92 respondents.

Dependent variables

Care Network

Respondents were asked whether and from whom they receive help in the following areas: personal care, home care, nursing care, transportation, and administrative tasks. We categorised six types of caregivers: 1) co-resident (spouse, co-resident children and/or others), 2) non-co-resident children, 3) other relatives, 4) neighbours/friends/acquaintances, 5) publicly paid (community nurse, help at home), 6) privately paid (private help or in-home staff). For the follow-ups, we included two absorbing states: 1) moved to a care facility, 2) deceased, for which we used data from the municipal register (GBA).

Independent variables

We selected potential determinants based on the three dimensions of Andersen and Newman (1973; 2005) behavioural model of health service use: Need, predisposing, and enabling factors. Need factors include all factors that increase the need for care, such as chronic illness, functional limitations and cognitive decline. Predisposing factors are factors such as demographic characteristics and attitudes towards care that indicate a willingness to ask for help. Enabling factors facilitate the use of care, e.g. the presence of potential caregivers in the social network.

Need variables

Functional limitations

Functional limitations are measured as the respondents’ ability to perform the following six activities of daily living: 1) dress or undress themselves, 2) get up from a chair or sit down, 3) cut their own toenails, 4) use their own or public transportation, 5) climb stairs, and 6) walk outside for five minutes without resting. Responses were summed and ranged from 6 to 30, with higher scores indicating a higher level of functioning (Pluijm et al., 2005).

Cognitive functioning

Cognitive functioning was measured using a shortened version of the Mini-Mental State Examination (sMMSE) (Folstein et al., 1975; Tombaugh & McIntyre, 1992). The scale ranges from 0 to 16, with higher scores indicating better cognitive functioning. For respondents who were unable to complete this questionnaire, cognitive functioning was assessed in a proxy interview and measured using a shortened version of the IQCODE (Jorm & Korten, 1988). To make the measures of cognition comparable over time, IQCODE scores were converted to sMMSE scores using cut-off points based on an earlier LASA study by Comijs, Dik, Deeg, and Jonker (2004).

Chronic diseases

Chronic diseases were recorded as the sum of seven types of chronic diseases (range 0-7): Lung disease, heart disease, arterial disease, diabetes, cardiovascular accidents, rheumatic diseases, and cancer. The change scores for these variables were calculated by subtracting the previous wave's score from the current wave's score, resulting in one baseline score and two change scores per variable.

Predisposing factors

These include age at baseline (in years), sex (1=female) and education level, which was categorised into three groups: low (elementary school), medium (secondary school or lower vocational education) and high (higher vocational education or higher). We did not include income as a determinant because in our dataset the income variable contained a lot of missing values. Moreover, a previous study on LASA data showed that income often has similar associations as education

(Abbing, Suanet, & Broese Van Groenou, 2022). We did not include information on working lives, as the Dutch pension age was 65 at the time of our study, so almost all of our respondents were retired. We did not include information on number of children since the proportion of people who were childless was rather stable between cohorts.

Enabling factors

Partner status with three categories (partner/no partner/lost partner compared to previous wave) was assessed at each wave to differentiate between the effects of losing a partner and not having a partner.

Method of data analysis

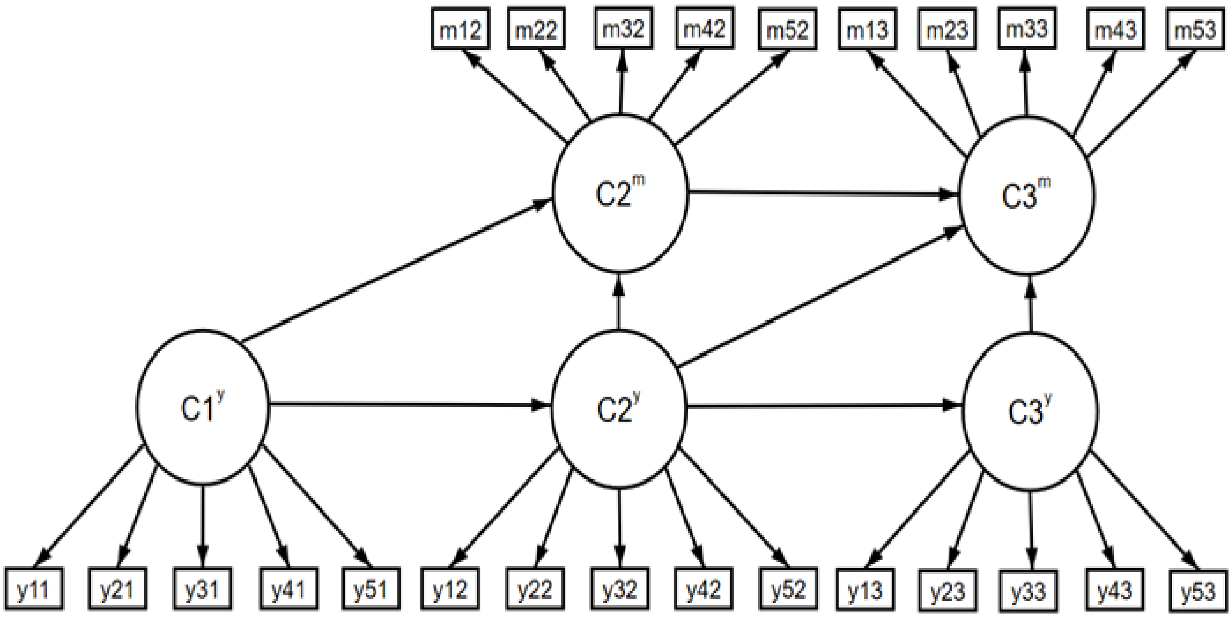
We calculated descriptive statistics using SPSS 27. We used a method that allowed for co-modelling of non-random dropouts such as death and moving to a care facility. This is important in longitudinal studies of older adults, as there is a strong association between high care needs and dropping out due to mortality or moving to a care facility. The exclusion of these departed respondents likely leads to the exclusion of respondents with high care needs. Thus, this co-modelling led to more accurate estimates of the groups that are typically of most interest to policy makers. We conducted a latent transition analysis (LTA) using MPLUS 8.6 (Muthén and Muthén, 1998-2020), together with the extension provided by Sterba (2016) in the form of a late-state-dependent nonignorable missingness LTA model (MNAR-PP LTA), which allows for co-modelling of censoring due to death and moving to a nursing facility. LTA is a longitudinal form of Latent Class Analysis (LCA) in which the classes (called states in LTA) consist of the CNs that form around an older adult. In this model (see Figure 1 for the conceptual representation), the probability of moving into one of the identified latent states or missing states is assessed at each time point.

Using the paper by Sterba (2016) as a guide, we tested several LTA models with different numbers of states for the outcome variables and missingness. We chose the appropriate number of states based on the lowest Bayesian information criterion (BIC), lowest log-likelihood, entropy, and qualitative assessment of an additional state that is structurally different from the states identified in the N-1 state solution, favouring the simplest number of latent states.

Because of power issues, we did not model the predictors and provided the descriptives instead.

Figure 1

Conceptual view of the parallel-process missing-not-at-random (MNAR-PP) Latent Transition Analysis (LTA). Shown for Time=3, and number of groups J=5.



Note. Circles represent latent classifications variables, arrows represent regression paths, squares represent measured variable indicators of the latent classification variables (Sterba, 2016)

Table 1

Descriptive statistics of sample total and CN types at each wave

		Wave 2012/2013 (T1) (N=1413)					*Wave 2015/2016 (T2) (N=1182)*					*Wave 2018/2019 (T3) (N=1027)*				
	Total	*No care*	*Private*	*Mixed informal*	*Mixed Public*	*Cores-idential*	*No care*	*Private*	*Mixed informal*	*Mixed Public*	*Cores-idential*	*No care*	*Private*	*Mixed informal*	*Mixed Public*	*Cores-idential*
N	1413	837	156	108	213	99	629	188	120	180	65	484	175	172	140	56
% of total	100	59.24	11.04	7.64	15.07	7.00	53.21	15.91	10.15	15.23	5.50	47.13	17.04	16.75	13.63	5.45
Female %	0.56	0.48	0.63	0.7	0.72	0.62	0.48	0.61	0.79	0.65	0.68	0.44	0.59	0.78	0.67	0.68
Age in years	74.92	71.56	76.89	81.76	82.38	76.73	70.29	75.13	78.1	79.61	75.18	69.50	73.16	75.75	77.37	74.15
	(0.76)	(5.61)	(7.09)	(7.76)	(6.25)	(7.23)	(4.65)	(6.24)	(6.53)	(6.37)	(6.59)	(4.11)	(5.79)	(5.96)	(6.51)	(5.85)
Partner at T1 %	0.67	0.79	0.60	0.27	0.34	0.92	0.81	0.68	0.49	0.43	0.95	0.83	0.74	0.58	0.52	0.91
Partner at T2 %	0.63	0.74	0.50	0.13	0.29	0.94	0.79	0.60	0.30	0.29	0.95	0.82	0.69	0.44	0.43	0.91
Partner at T3 %	0.60	0.70	0.49	0.11	0.18	0.79	0.75	0.54	0.24	0.18	0.84	0.81	0.65	0.32	0.26	0.94
Moved to a care facility at T2 %	0.04	0.01	0.03	0.16	0.14	0.08										
Moved to a care facility at T3 %	0.05	0.03	0.06	0.11	0.19	0.15	0.03	0.06	0.11	0.19	0.15					
ADL-score at T1[a]	25.59	27.7	26.13	22.11	21.15	20.15	27.97	26.66	23.41	22.62	22.89	28.06	26.72	26.43	23.76	23.73
	(5.82)	(4.46)	(5.08)	(6.11)	(5.90)	(6.05)	(4.36)	(5.06)	(4.28)	(6.18)	(5.90)	(4.31)	(5.06)	(5.83)	(5.97)	(6.03)
ADL-score at T2	25.11	27.06	25.17	20.65	19.48	18.57	27.82	26.43	25.35	20.84	19.45	28.14	26.82	24.69	22.92	21.98
	(6.15)	(4.83)	(5.73)	(6.46)	(6.04)	(6.85)	(4.13)	(4.77)	(5.11)	(5.77)	(6.73)	(3.96)	(5.17)	(5.41)	(5.76)	(6.87)
ADL-score at T3	24.12	25.62	23.75	19.66	18.5	18.05	26.3	24.66	22.92	19.35	18.66	26.96	25.5	22.34	20.38	20.36
	(6.48)	(5.77)	(6.35)	(6.75)	(5.45)	(7.06)	(5.46)	(5.88)	(5.95)	(5.78)	(6.51)	(5.17)	(5.60)	(6.15)	(5.82)	(6.08)
sMMSE-score at T1[b]	14.82	15.15	15.17	14.36	14.05	13.63	15.19	15.23	20.78	14.68	14.09	15.23	15.25	15.12	14.93	14.34
	(1.69)	(1.24)	(1.32)	(1.94)	(2.13)	(2.68)	(1.19)	(1.19)	(6.28)	(1.71)	(2.44)	(1.14)	(1.12)	(1.21)	(1.45)	(2.07)
sMMSE-score at T2	14.44	14.94	14.38	13.57	12.83	12.85	15.04	14.91	15.08	13.60	13.45	15.11	15.07	14.87	14.41	13.70
	(2.23)	(1.53)	(2.17)	(2.81)	(3.21)	(3.46)	(1.26)	(1.51)	(1.22)	(2.68)	(3.19)	(1.16)	(1.49)	(1.34)	(1.82)	(2.76)
sMMSE-score at T3	14.29	14.71	14.37	13.05	12.42	12.62	14.89	14.59	14.41	12.97	12.87	15.05	14.88	14.2	13.79	12.89
	(2.51)	(1.91)	(2.36)	(3.61)	(3.60)	(3.87)	(1.57)	(1.90)	(1.93)	(3.43)	(3.90)	(1.28)	(1.83)	(2.09)	(2.52)	(3.62)
N Chronic diseases at T1[c]	1.49	1.25	1.55	1.71	2.11	1.81	1.18	1.44	13.65	1.86	1.74	1.09	1.39	1.55	1.76	1.5
	(1.16)	(1.04)	(1.09)	(1.22)	(1.22)	(1.36)	(1.00)	(1.09)	(2.75)	(1.15)	(1.14)	(0.97)	(1.00)	(1.12)	(1.17)	(1.03)
N Chronic diseases at T2	1.53	1.41	1.55	1.81	1.99	1.64	1.35	1.49	1.59	2.02	1.75	1.25	1.42	1.65	1.88	1.71
	(1.13)	(1.07)	(1.09)	(1.16)	(1.29)	(1.23)	(1.043)	(1.07)	(1.16)	(1.23)	(1.14)	(1.03)	(1.01)	(1.17)	(1.17)	(0.92)
N Chronic diseases at T3	1.63	1.54	1.67	1.85	2.12	1.76	1.48	1.65	1.68	2.00	1.82	1.4	1.67	1.76	2.05	1.9
	(1.18)	(1.16)	(1.12)	(1.22)	(1.22)	(1.18)	(1.15)	(1.13)	(1.19)	(0.46)	(1.11)	(1.11)	(1.17)	(1.14)	(1.21)	(1.09)
Deceased at T2 %	0.13	0.05	0.17	0.24	0.29	0.32										
Deceased at T3 %	0.24	0.11	0.28	0.42	0.51	0.45	0.03	0.07	1.86	2.12	1.77					

Note. · [a]Activities of Daily Living, 6-30, with 30 indicating no problems in performing Activities of Daily Living, [b]short Mini Mental State Examination, 0-16, with 16 indicating no cognitive decline, [c]Number of chronic diseases, 0-7

Results

In the first wave, the average age was 74.9 years, 56% were female and 67% had a partner. In the second wave, 4% had moved into a nursing home and 13% had died. In the third wave, 5% of all participants had moved into a care home and 24% had died.

The adjustment statistics of our LTA models were inconclusive. A five-state solution with two states for missingness in wave 2 and wave 3 fit the data best, for several reasons: The BIC between models did not differ substantially, the entropy was lowest for this number, and the five-state solution identified the coresidential network as one of the networks, i.e., a network we expected based on previous studies. The details of this procedure can be found in Additional File 1.

Figure 2 shows the item response probabilities for each response category within the five-state solution. It is assumed that the types of CNs are similar across all waves. Table 2 also shows the overall probabilities for each status at each time point (columns) and the transition probabilities given latent status membership at each time point (rows). Figure 3 shows these transition probabilities in an alluvial plot.

Figure 2

Percentages of types of caregivers in the five identified care network states, among 1413 Dutch older adults aged 65 and older. Care network types were assumed to be measurement invariant, and were assessed at T1 (2012/13), and held constant for 2015/16, and 2018/19.

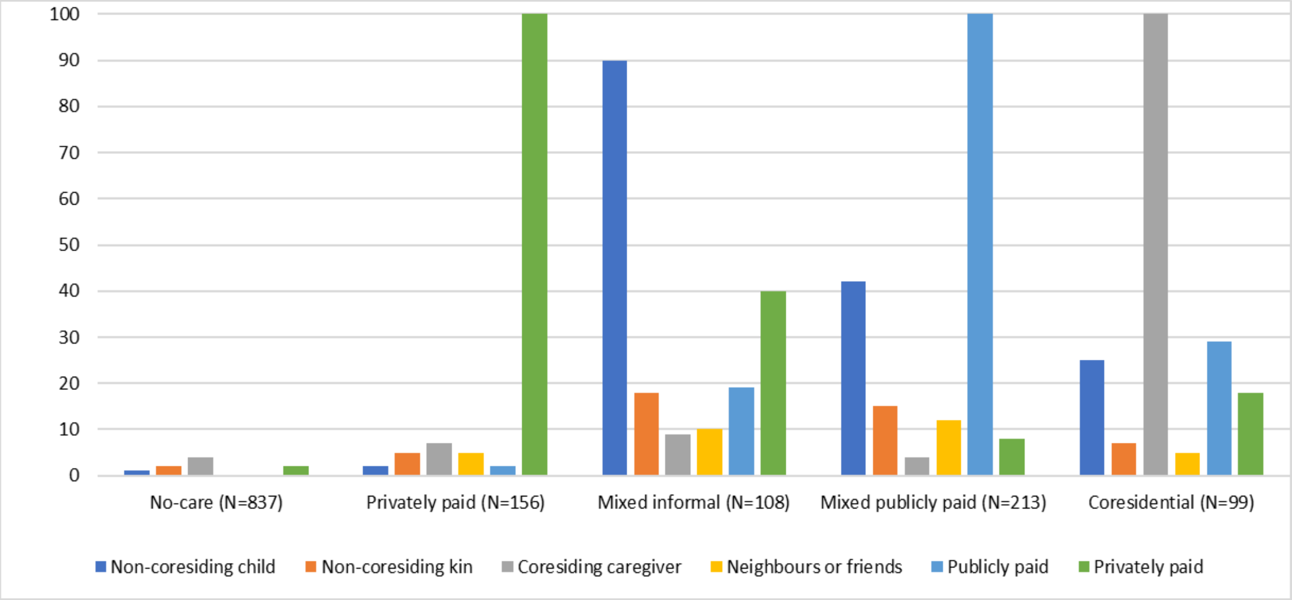


Table 2

Transition probabilities between the five CN types, identified among 1413 Dutch older adults aged 65 and older. Rows show CN types at Time 1 (2012/13) and Time 2 (2015/16), and columns show CN types at Time 2 and Time 3 (2018/19)

CN in 2012/2013 Time 1 (rows), CN in 2015/16 Time 2 (columns)

	No-care	*Private*	*Mixed informal*	*Mixed public*	*Coresidential*	*Care facility*	*Deceased*
No-care	.751	.069	.053	.054	.018	.005	.050
Private	.000	.596	.122	.090	.000	.026	.167
Mixed informal	.000	.028	.481	.139	.000	.111	.241
Mixed public	.000	.080	.023	.498	.019	.089	.291
Coresidential	.000	.172	.000	0.00	.465	.040	.323

CN in 2015/16 Time 2 (rows), CN in 2018/19 Time 3 (columns)

	No-care	*Private*	*Mixed informal*	*Mixed public*	*Coresidential*	*Care facility*	*Deceased*
No-care	.717	.065	.064	.034	.013	.009	.098
Private	.000	.426	.108	.010	.030	.030	.397
Mixed informal	.000	.000	.758	.000	.000	.067	.175
Mixed public	.000	.004	.012	.423	.000	.093	.468
Coresidential	.000	.015	.031	.138	.569	.062	.185

No care

Respondents in the first state 'No-CN' (59%$_{T1}$) received hardly any care. As shown in Table 1, respondents in this state were the youngest, with relatively high levels of functioning and few chronic diseases. There were slightly more men in this network (52%), and respondents had a higher level of education than the overall sample, 79% had a partner.

Most of these respondents remained in the network at time 2 (75%), and 5% died. Around 20% moved to another network, with the largest proportions transitioning to the privately-paid (7%), mixed-informal-CN (5%) and mixed-publicly-paid-CN (5%). At Time 3, these transition rates were similar. Participants who transitioned to another network experienced function losses: ADL-scores decreased on average by -2.7, sMMSE decreased by -0.5, and chronic conditions increased by 1.64, compared with -0.5 ADL, -0.2 sMMSE, and 1.35 chronic conditions among those who remained (calculations not shown). 13% of those who transitioned lost a partner, compared to 3% of those who remained in the group.

Privately paid

These participants all received privately paid care (11%$_{T1}$) and generally no other forms of care. There were relatively many men in this group (37%). They had an average age, were less likely to have a partner, and had a medium or high level of education, with high levels of functioning. At Time 2 most of these respondents remained in the privately-paid-CN (59.6%), 16.7% died, and about 25% transitioned: 12% to a mixed-informal, 9% to a mixed-publicly-paid, and 3% to a nursing home. About 11% transitioned to mixed-informal-CN, indicating that informal caregivers supplemented the care already provided. The transition to a mixed-informal-CN was associated with a loss of function, as the average decline among participants that made this transition was -4.3 ADL score and -4.3 sMMSE points. Of those who transitioned at T2, 8% lost a partner compared to 6% of those who remained in the group. Mortality was high in this group at time 3: 40%.

Mixed-informal

The mixed-informal-CN (7.6%$_{T1}$) shows a wide variety of caregivers: 90% received help from non-resident children, 40% from a privately paid caregiver, and between 20% and 10% received help from non-resident kin, a co-resident caregiver, neighbours or friends, and/or a publicly paid caregiver. The care recipients were relatively old, women, with no partner, a lower level of education and moderately good physical and cognitive functioning.

At T2, 48.1% remained in this network and mortality was moderately high (24%), while 13.9% transitioned to a mixed-publicly-paid-CN and 11% to a nursing home. This was likely due to severe loss of function, as the mean decline in ADL and sMMSE for these participants were 10 and 2.8 points, respectively. Of all participants who transitioned, 9% lost their partner, compared to 12% of participants who remained in this network. In the last wave, 76% of participants remained in the network, 17.5% died, and 7% moved to a care facility. This network appears to be relatively stable, although it is not known whether more or different informal caregivers joined the CN. Of the participants who made a transition, 9% lost a partner at T2 and 0% at T3.

Mixed-publicly-paid

In the mixed-publicly-paid-CN (15%$_{T1}$), 100% of older adults were cared for by a publicly paid caregiver. They also received help from non-resident children (43%) and from co-resident caregivers (5%), neighbours or friends (10%), privately paid caregivers (8%) and non-resident kin (15%). Respondents in these network were: women, older, single, with a low level of education, and poor health (ADL=21.15, sMMSE=14.05, 2.11 chronic diseases).

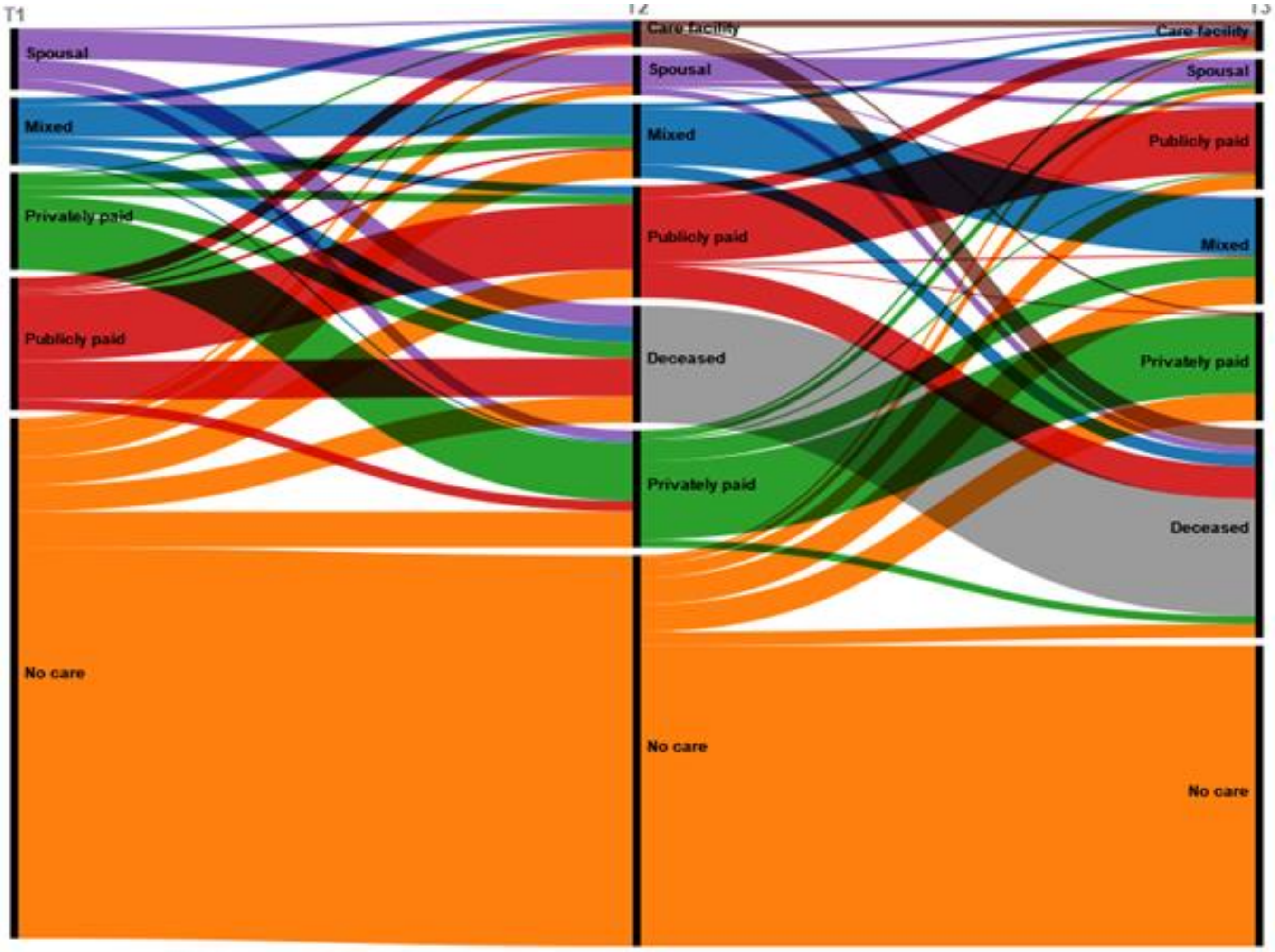
Half of these participants remained in this state at time 2 (50%), and 29% died. Almost 9% moved to a nursing facility and 8% to a privately-paid-CN. The participants who moved to a nursing facility had severe functional decline (mean -5.7 ADL, -2.6 sMMSE), while the participants who moved to a privately-paid-CN had mild functional decline (mean -2.6 ADL, -1.2 sMMSE). At Time 3, participants were most likely to die (47%), and 42% remained in the network. The proportion of participants who moved to a care facility was highest in this group: 9%.

Co-resident

In the co-resident network (7%$_{T1}$), all respondents received help from a co-resident partner or kin. Some also received care from non-coresident children (25%), as well as from publicly paid (28%) or privately paid (20%) caregivers. The network consisted of 62% women who were not very old (76.7 years), often had a partner (92%) and had a lower level of education. The participants had a low level of physical and mental functioning (ADL=20.15, sMMSE=13.6). Most participants remained at time 2 (46.5%), relatively many died (32.3%), and 17.2% moved into privately-paid-CN. Of those who moved to privately-paid-CN 24% lost a spouse. Only 4% moved to a nursing home. At T3, 56.9% remained and 19% died. 13.8% transitioned to the mixed-publicly-paid-CN. Looking at this group in more detail, we find that none of them lost a partner, but all of them experienced a deterioration in their functioning (-3.6 ADL, -0.6 sMMSE). At T3, 6.2% moved to a nursing home.

Figure 3

Transitions between the five CN types, from 2012/13 (T1), to 2015/16 (T2), and from 2015/16 to 2018/19 (T3). Colours represent the possible states, and the sizes are the proportions of participant in these states.
The states are: the spousal or co-resident-CN, Mixed or Mixed-informal-CN, Privately paid or privately-paid-CN, Publicly Paid or mixed-publicly-paid-CN, No care or no-CN.



Discussion

To our knowledge, this study was the first to use CN typology among older adults in a longitudinal perspective. We identified the following five types of CNs: the no-CN (59%$_{T1}$), the privately-paid-CN (11%$_{T1}$), the mixed-informal-CN (8%$_{T1}$), the mixed-publicly-paid-CN (15%$_{T1}$), and the co-resident network (7%$_{T1}$). By accounting for non-random attrition we were able to include meaningful information, such as transition rates to care facilities, and include deceased participants who were likely to have the highest care needs. The mixed-publicly-paid-CN and the mixed-informal-CN had relatively high numbers of deceased respondents, and were relatively stable. This seems to indicate that these networks are only present in the late stages of the care trajectory. In addition, the low transition rates between these two networks may indicate the existence of two separate and distinct care trajectories, with either the mixed-publicly-paid-CN or the mixed-informal-CN serving as the end point.

Both network types contained more older women with low levels of education and low functioning. Differences between them could be due to social or psychological resources (Jacobs et al., 2018), which were not considered in this study. Mortality was lower in the privately-paid-CN and the no-CN, but also not negligibly low. Although most participants in the no-CN and privately-paid CN were likely to be at the beginning of their care trajectory, some of them died before ever using any form of publicly paid care. It is likely that these participants suffered a sudden unexpected death, which is related to the fact that more men are represented in these groups and men have a higher risk of sudden death (Lewis et al., 2016; van Campen et al., 2013).

As the Dutch care reform mainly entailed overall budget cuts for publicly paid care and reduced availability of institutional care, we assume that other types of care, including informal and privately paid care, became more prominent after the care reform. After the care reform, a significantly lower percentage of older adults transitioned into a publicly paid network or care facility. Our results show what has changed over time, but as our study design did not include comparisons with other cohorts or time periods, it is possible that these results are due to changes caused by other processes.

Looking at transitions between the different types of CNs and neglecting transitions due to death, the more unstable networks (for survivors) were the privately-paid-CN (18%$_{T1}$) and the no-CN (19%$_{T1}$). In these two networks, the need for care was rather low to begin with. Their instability can therefore be attributed to an increasing need for care. Both network types contained more men, participants who were relatively young, had a medium or high level of education, and had high levels of cognitive and physical functioning, all of which are indicators of low care needs (Keating et al., 2003a). Privately paid care is usually a (preferred) substitute for publicly paid care (Geerts et al., 2012; Swinkels et al., 2016). Therefore, previous studies also report that a medium or high level of education, which is associated with higher affluence, contributes to the use of privately paid care (Kemper, 1992; Pinquart & Sörensen, 2002).

The co-resident network (25%$_{T1}$) was the least stable network and fell between the other four network types in terms of characteristics. It contained more men and younger participants, but also more participants with low and medium levels of education than the network without care and privately-paid-CN. The need for care was high, and the levels of functioning were equal to or worse than that of the mixed-publicly-paid-CN. This high need for care probably led to the higher transition rates. These high transition rates can probably also be explained by the fact that the co-resident network is highly dependent on a single caregiver, who also often tends to become frail or prefrail (Potier et al., 2018). As our descriptive study showed, the main reason for leaving the co-resident network was not the loss of a spouse, but was deteriorating health. It should be noted that we only considered whether the spouse was still alive or not, so this may not capture the full picture, as spouses can also become ill and no longer be able to act as a potential caregiver.

Our results are highly dependent on the structure of the Dutch healthcare system and the political context. As the healthcare systems in the various countries are very different (Geerts & Bosch, 2012b), we cannot make any statements about the generalizability of the results. Our study took place in a policy context in which the eligibility criteria for transition to a care facility were very high (round-the-clock care needs). If these thresholds had been lower, the rate of transition to a care facility would very likely have been significantly higher (Alders et al., 2019). This notion is also supported by the fact that the level and type of care utilization in the Netherlands differs between decades (Abbing et al., 2021).

In countries where the healthcare system is organized differently and where people have different norms regarding the use of care services, CNs are likely to look different from those identified in this study. The formation of CNs is also influenced by living arrangements, for example Velkoff (2001), report that women in industrialized countries are more likely to live alone than men. This is consistent with our mixed-publicly-paid-CN and mixed-informal-CN containing more women, and the spousal CN containing more men. However, in non-industrialized countries, older adults tend to live with children (Velkoff, 2001), so the relative proportions of the different types of CNs are likely to differ significantly from those in industrialized countries. In the Dutch context in particular, the proportion of older adults living alone or with a spouse is relatively high (United Nations, Department of Economic and Social Affairs, 2017). The proportion of older adults living with children is the lowest compared to other European countries (5%) (United Nations, Department of Economic and Social Affairs, 2017). It is therefore likely that informal CNs involving children are more prevalent in Mediterranean countries, where around 30% of older adults live with children (United Nations, Department of Economic and Social Affairs, 2017).

Similarly, it is likely that studies that have measured other types of care (e.g. without help with administrative tasks or transportation) also find different CNs with lower levels of informal care. These differences in both the data and the socio-cultural context could explain why a study looking at CNs in Belgium found more people with informal CNs (Fret et al., 2017). It could also explain that a Canadian study found an informal network consisting mainly of non-kin (Savla et al., 2016), while we did not identify such a network.

Our results shed light on which CNs fit into a financially sustainable care system in which care for older adults includes low public expenditure alongside the use of informal and privately paid care. With this in mind, the No-CN, Privately-paid-CN, Co-resident-CN, and Mixed-informal-CN are likely to be the most financially sustainable when less publicly paid care is available. For these people, using only informal and/or privately paid care appears to be sufficient, even for those with high care needs. Some of them may move into CNs with publicly paid care in the future, as we only followed participants for six years. However, a sizable group never uses publicly funded care in their lifetime: these are the participants from the privately-paid-CN and the no-CN that died.

In terms of a financially sustainable care system, the policy aims for aging in place. This enables older adults to maintain social connections, a sense of independence and identity (Iecovich, 2014; Kendig et al., 2017). Secondly, aging in place is a policy goal because it is less costly than institutional care (Maarse & Jeurissen, 2016). Transitions to a care facility appear to occur from all CNs for those experiencing the most severe functional decline, which is consistent with the eligibility criteria for institutional care. These transitions occurred mostly from the networks with a high care need: the mixed-informal-CN, the mixed-publicly-paid-CN, and co-resident-CN.

Consistent with other studies, the likelihood of transitioning to a nursing home were higher when informal care was provided by children than by spouses (Witvorapong, 2011). Nursing homes, especially with increased eligibility requirements, are a "final destination" where a large proportion of older adults never arrive. Transitions to a nursing facility were most likely for older women with low levels of education and poor health which were the characteristics associated with mixed-informal and the mixed-publicly paid-CN. This finding has been reported previously (Algera et al., 2004). However, other studies put this into perspective, as informal care delays institutionalization and leads to a (relatively) lower level of formal care (Van Houtven & Norton, 2004). In addition Carvalho et al. (2019) report gender differences in the point where older adults consider their disability too severe to live at home and be cared for by a spouse, with women tending to prefer institutionalization at lower levels of disability.

We demonstrated the robustness of the determinants of care use (Ronald Andersen & Newman, 2005; Babitsch et al., 2012) in a longitudinal perspective. Our longitudinal design showed that need factors, including declining functional and cognitive limitations and the number of chronic diseases, appear to have the strongest influence on transitions. This is similar to findings from studies on care arrangements (Dostie & Léger, 2005; Soldo et al., 1990; Witvorapong, 2011). The use of CN typologies in a longitudinal setting was not only novel, but linking them to determinants provides information for policy makers to anticipate what support is needed to promote the right CNs. Loss of a spouse did not often occur at the time when participants transitioned to another network, which could be explained by the fact that the spouse was already unable to provide care in the year before death.

However, the methods we used were mainly descriptive. In addition, the determinants we examined were not theoretically exhaustive. We used longitudinal data with three-year waves, which had the limitation that certain significant transitions that occurred over a shorter period of time may not have been captured. As the frailest older adults move to a care facility, this may have led to an underestimation of the number of older adults who move to a care facility and an overestimation of those who die without ever moving to a care facility. Future studies could include determinants such as social capital, mastery and attitudes towards care, income, the type of formal and informal care available in the region (Blomgren et al., 2008; Broese van Groenou, 2020; Jacobs et al., 2018).

Conclusion

To learn more about the stability of CNs, we mapped transitions between CN types. We identified the following five types of CNs: 1) no care, 2) privately-paid, 3) mixed-informal, 4) mixed-publicly-paid, 5) co-resident. The co-resident network was the most unstable and had a high transition rate to nursing homes. The privately-paid-CN was moderately stable, with participants often transitioning to a mixed-informal, but rarely to a mixed-publicly-paid-CN. There were also moderately frequent transitions from the no-CN, with transitions to the privately-paid-CN being the most likely, but other transitions also occurred. The two mixed CNs were the most stable, and transitions to a care facility were most likely for these types. For all types of CNs, transitions appeared to be strongest induced by a deterioration in health.

The no-care, privately-paid-CN, co-resident-CN, and Mixed-Informal-CN were the least likely to use publicly paid care, and participants in the privately-paid-CN and the no-CN sometimes never used publicly paid care in their lives. Transitions to a care facility were highest in the co-resident-CN and ranged around 10% in the two mixed CNs.

Additional File 1 Model Selection

For the model selection we tested which model was best fit at every wave by using LCA. In accordance with the three step model (Vermunt, 2010) we compared the models without covariates, and concluded which were the most appropriate number of classes per wave. Because co-modelling missingness should not change the number of defined classes (only the sizes of these classes) (Haviland et al, 2011), we did not model missing states in the LCA’s.

Table S1

Model fit statistics for latent class analysis per wave

Wave 1	Bootrst LRT	BIC	Entropy	Size smallest class	N
1		5756.570			1413
2	2856.525	5576.701	0.578	403	1413
3	-2741.203	5587.563	0.719	53	1413
4	-2721.247	5629.228	0.645	45	1413
5	-2716.692	5673.253	0.829	10	1413
Wave 2					
1					
2	-2395.220	4697.681	0.542	344	1095
3	-2303.350	4701.902	0.750	83	1095
4	-2280.966	4743.544	0.883	35	1095
5	-2277.292	4783.227	0.896	24	1095
6	-2272.639	4827.518	0.741	15	1095
7	-2270.261	4872.290	0.735	8	1095
8	-2268.181	4916.991	0.830	6	
Wave 3					
1		4398.226			872
2	-2178.800	4270.616	0.643	334	872
3	-2091.298	4291.238	0.713	117	872
4	-2077.911	4320.351	0.770	19	872
5	-2068.770	4353.938	0.735	13	872
6	-2061.866	4392.757	0.804	8	872
7	-2057.577	4431.996	0.822	4	872
8	-2053.560	4473.424	0.909	4	872

Although the BIC was lowest for the two-class solution at every wave, we decided to choose the five class solution, because it relatively had the best entropy and a reasonably sized smallest class. In addition, it was most in accordance with what we expected based on previous studies.

Then we checked whether measurement invariance was applicable, by first checking whether the distributions and means of the dependent variables varied greatly across time (which was not the case), and then comparing the log-chi2-tests of a model with and a model without measurement invariance (for this comparison, we compared both the LTA without the missing and the LTA with the missingness indicators included).

Eventually we decided a model with five classes at each wave, and two forms of missing states (deceased, moved to a care facility).

Table S2

Latent Transition Analysis (all with 2 classes for missing and time invariant)

N of classes	Highest loglikelihood	BIC	AIC
3	-7693.406	15923.568	15534.811
4	-7539.936	15812.472	15281.871
5	-7432.365	15822.187	15128.729

Chapter 4

Title: The moderating role of care in the association between functional limitations and wellbeing among Dutch older adults

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Abstract

We investigated how various aspects of care moderate the relationship between functional limitations and wellbeing in older adults aged 65 and above. Using mixed models, we analysed data from three waves (2012/13, 2015/16, 2018/19) of the Longitudinal Aging Study Amsterdam (N=1,341). Our findings revealed no moderating effect for either control over care or the type of caregiver. However, the number of hours of publicly funded care acted as a moderator: wellbeing was lower when functional limitations were minimal, and higher when limitations were more severe. Additionally, care sufficiency moderated wellbeing; greater wellbeing was observed when care was sufficient and limitations were low, but this difference diminished as limitations increased.

Background

Numerous studies have demonstrated that functional limitations adversely affect various aspects of wellbeing, including depressive symptoms (Gayman et al., 2008), quality of life (Andersen et al., 2004; Lam & Wodchis, 2010), and life satisfaction (Khodabakhsh, 2022). It is also well-established that functional limitations often lead to increased use of long-term care, as informal and formal caregivers provide assistance to those with health impairments (OECD, 2011). The use of long-term care may, in turn, mitigate the negative impact of functional limitations on wellbeing. Specifically, high-quality long-term care that aligns with the needs and preferences of the individual could potentially lessen the decline in wellbeing caused by functional limitations. Empirically, this suggests that certain aspects of long-term care might serve as moderators in the relationship between functional limitations and wellbeing.

However, evidence on the association between care use and wellbeing is (Abbing, Suanet, & Broese van Groenou, 2022; Pot et al., 2005). The type of caregiver appears to be significant, with informal care generally associated with higher levels of wellbeing (Pot et al., 2005), while formal care is often linked to lower wellbeing (Broese van Groenou, 2020; Pot et al., 2005). This implies that care can only buffer the negative effects of functional limitations on wellbeing if it meets certain criteria. Yet, the extent to which these criteria—or elements of care—can buffer the loss in wellbeing remains unclear.

These elements of care can be categorised as either objective or subjective. The objective elements include the type of care (whether informal, publicly provided formal care, or privately paid formal care) and the amount of care received, measured in hours. Subjective elements encompass perceived care sufficiency—whether the individual feels the care they receive is adequate—and perceived control over care, which refers to the extent to which the care recipient feels they have control over their care.

Wellbeing is a broad concept encompassing various aspects of psychological functioning, including life satisfaction, leading a meaningful life, positive and negative affect, and interpersonal social functioning (Willroth, 2023). Different aspects of care may be relevant to many of these dimensions of wellbeing. Therefore, studies examining the potential moderating role of long-term care on the relationship between functional limitations and wellbeing should consider employing measurement instruments that cover various aspects of wellbeing. In this study, we use the CES-D (Radloff, 1977), a measure typically associated with depressive symptoms. However, the CES-D includes items that reflect positive affect, negative affect, social functioning, and psychosomatic complaints, thereby providing a continuum from wellbeing to depression (Siddaway et al., 2017). This study aims to enhance our understanding of how various aspects of care moderate the relationship between functional limitations and depressive symptoms.

These insights may prove valuable to policymakers seeking to promote more efficient care within long-term care systems, which are under increasing strain due to population ageing (Calvó–Perxas et al., 2018). Ageing societies are currently facing multiple challenges: the growing burden of disease, with formerly deadly diseases becoming chronic conditions (Chatterji et al., 2015; Crimmins & Beltrán-Sánchez, 2011; WHO, 2015), leading to a greater number of individuals requiring long-term care. Simultaneously, there is a decline in the working-age population available to provide care and contribute taxes to finance care. It is argued that one way to alleviate this pressure is by delivering more efficient care, which could help curb the increase in overall public care spending (Ewijk et al., 2013). Consequently, a significant part of the current discourse on long-term care focuses on how to deliver care more efficiently. Efficient care is defined as high-quality care that effectively buffers the negative impact of functional limitations on wellbeing.

In this study, we explore the moderating effect of four caregiving elements—type of caregiver, quantity, sufficiency, and perceived control—on the relationship between functional limitations and wellbeing. While previous research by Abramowska-Kmon et al. (2023) has examined the role of informal care as a moderator in this relationship, our study is the first to consider such a comprehensive range of caregiving aspects. We make a crucial distinction between spousal care and other forms of informal care and utilise a longitudinal design. This design enables us to capture the impact of changes in caregiving elements on wellbeing over time.

By employing a longitudinal approach, we analyse data from three waves (2012/13, 2015/16, 2018/19) of the Longitudinal Aging Study Amsterdam. This allows us to estimate both between-effects (differences in wellbeing between groups) and within-effects (the impact of changes in caregiving elements over time). This methodology offers a nuanced understanding of how various aspects of caregiving influence the wellbeing of older adults, providing valuable insights into the dynamics of care and its implications for wellbeing.

Theoretical background

To understand why different elements of care might influence wellbeing, we apply the Self-Determination Theory (Deci & Ryan, 2000), which posits that relatedness, autonomy, and competence are the three primary determinants of psychological wellbeing. These concepts can be linked to the four elements of care discussed earlier by Broese van Groenou (2020).

Relatedness refers to the sense of being connected to and supported by significant others (Deci & Ryan, 2000). Since informal care is typically provided by members of one's social network, it is reasonable to expect higher feelings of relatedness in informal care contexts compared to formal care settings. This expectation aligns with findings that informal caregivers are more likely to offer care when they feel a strong connection to the care recipient (Dombestein et al., 2020). Informal carers often provide emotional support, which is likely to enhance wellbeing (Landau & Litwin, 2001; Levy et al., 2017).

Moreover, studies indicate that the use of formal care may negatively impact wellbeing(Broese van Groenou, 2020; Pepin et al., 2017; Pot et al., 2005). For instance, research shows that older women who receive formal care experience greater loneliness and lower life satisfaction compared to those receiving informal care or no care at all (Boumans & Deeg, 2011), likely reflecting a deficit in relatedness (McCamish-Svensson et al., 1999). Consequently, we hypothesise that the use of (more) informal care will mitigate the negative impact of functional limitations on wellbeing, as opposed to relying more heavily on publicly or privately funded formal care (H1).

Autonomy and competence refer to the ability and desire to self-organise experiences and ensure that activities align with one’s self-concept (Deci & Ryan, 2000). In the context of caregiving, these concepts manifest through receiving care that is both sufficient to meet one’s needs and subject to one’s control. When care is sufficient and individuals feel they have control over it, the limitations in daily living due to functional impairments can be alleviated, thereby enhancing the sense of being able to manage one's own life and care.

Higher levels of autonomy and competence are thus likely to mitigate some of the adverse effects that functional limitations have on wellbeing. Previous studies have found positive correlations between wellbeing and both care sufficiency (Abbing, Suanet, & Broese van Groenou, 2022), and control over care (Broese van Groenou, 2020). Based on these findings, we hypothesise that the negative impact of functional limitations on wellbeing will be less pronounced among older adults who perceive their care as sufficient and feel in control of it, compared to those who consider their care to be insufficient and lack control over it (H2).

Methods

Design and Study sample

Data were sourced from the Longitudinal Aging Study Amsterdam (LASA), an ongoing population-based longitudinal study focusing on older adults (aged 55 years and above) in the Netherlands (Hoogendijk et al., 2016, 2020). The initial sample, established in 1992/93, consisted of 3,107 respondents aged 55 to 84 years, drawn from both urban and rural regions in the Netherlands. Additional cohorts were introduced in 2002 and 2012, comprising 1,002 and 1,023 respondents, respectively, from different birth cohorts but the same sampling frame. The baseline cooperation rates for the first two cohorts were 62%, and 63% for the third cohort. Subsequent waves of data collection have occurred every three years.

Given that wellbeing data were unavailable for most older adults residing in nursing homes, we focused on participants living in the community who were 65 years or older during the 2012/13 wave (N=1,341) and had valid data on both functional limitations and wellbeing at that time. Data for 1,243 participants were collected through face-to-face interviews during the 2012/13 wave, while 98 participants completed an abbreviated telephone interview. The sample sizes in the analyses varied as certain independent variables were not measured in the telephone interviews. To account for the possibility of participants beginning to receive care during the follow-up period, we included those who were not receiving care at the time of the first wave of measurement.

For the subsequent waves in 2015/16 and 2018/19, data were collected from 948 face-to-face and 63 telephone interviews in the second wave, and from 694 face-to-face and 82 telephone interviews in the third wave. Since hours of care and perceived control over care were only assessed during face-to-face interviews, analyses involving these variables had a smaller sample size.

Dependent variable: psychological wellbeing

Psychological wellbeing was assessed using the Centre for Epidemiologic Studies Depression Scale (CES-D) (Radloff, 1977), a 20-item instrument designed to measure the presence of depressive symptoms over the past week. Participants responded to each item on a scale from 0 ("rarely or never") to 3 ("most of the time or always"). After reverse coding certain items to ensure consistency, the scores for all 20 items were summed, with higher scores indicating more depressive symptoms. The scale ranged from 0 to 48, where a score of 48 represents the highest level of depressive symptoms (low wellbeing), and a score of 0 indicates no depressive symptoms (high wellbeing).

Independent variables (time varying)

Functional Limitations

Functional limitations were assessed on a scale from 0 to 24 by summing the responses to six activities of daily living, where a score of 1 indicated the inability to perform the activity and a score of 5 indicated the ability to perform it without assistance. The activities were: 1) dressing or undressing themselves, 2) getting up from a chair or sitting down, 3) cutting their own toenails, 4) using their own or public transport, 5) climbing stairs, and 6) walking outside for 5 minutes without resting. Higher scores indicated a lower level of functioning (Pluijm et al., 2005).

Type of caregiver

Participants were asked if they received help (no, yes) from: 1) a co-residential caregiver (spouse, co-residential child, and/or others), 2) other informal caregivers (non-co-residential children, other relatives, neighbours/friends/acquaintances), 3) a publicly paid caregiver (community nurse, help at home), or 4) a privately paid caregiver (private help or staff at home) with at least one of the following tasks: personal care, housekeeping, nursing, transportation, and administrative tasks. For example, respondents were asked: "Do you receive help with personal care, such as washing, bathing, dressing, going to the toilet, or getting up and sitting down?" and if so, by whom and for how many hours per caregiver.

Quantity of care

The quantity of care was measured by asking how many hours per week respondents received either informal, privately paid, or publicly paid care for administrative tasks, guidance, nursing, personal care, and home care. The total hours were summed. We applied winsorisation (Tukey, 1962) to the highest values, adjusting them to the 97.5th percentile of respondents receiving that type of care. This yielded 27 hours for publicly paid care, 10 hours for privately paid care, and 50 hours for informal care.

Care sufficiency

Care sufficiency was evaluated by asking whether the amount of care received was sufficient, with a response of 1 indicating 'sufficient' and a response of 0 indicating 'not sufficient'. The latter was indicated if respondents rated their care as either insufficient or 'between sufficient and insufficient'.

Control over care

Control over care was measured on a scale from 3 to 9 and consisted of three questions: "To what extent can you decide what kind of help is given, who gives the help, and when the help is given?" A higher score indicated a higher level of control. Information on control was only available for respondents who completed the face-to-face questionnaire, resulting in a lower sample size for analyses including control over care as an independent variable and moderator (N=840).

Control variables

To account for factors that could influence both care networks and wellbeing, several control variables were included in the analysis. Gender differences in care networks and depressive symptoms have been documented, with women generally reporting higher levels of depressive symptoms (Andersson & Monin, 2018). Health problems are also associated with increased depressive symptoms and reduced wellbeing (Steptoe et al., 2015). Additionally, higher educational attainment is linked to fewer depressive symptoms (Smith & Wesselbaum, 2024).

Control variables were age at baseline (in years), sex (1=female), and education level, which was categorised into three groups: low (primary school), medium (secondary school or lower vocational education), and high (higher vocational education or higher). Chronic diseases was a scale ranging from 0 to 7, and was calculated as the sum of the seven major chronic diseases: Lung disease, heart disease, arterial disease, diabetes, cardiovascular accidents, rheumatic diseases and cancer.

Methods of Analysis

Using the *xtreg* function in STATA 16, we estimated five mixed models with functional limitations as the primary independent variable and depressive symptoms as the dependent variable. In the first model, we examined the effect of functional limitations on depressive symptoms. Since the Hausman test was significant, we applied time-varying fixed effects for functional limitations (Hausman, 1978).

In the subsequent four models, we explored the effect of functional limitations on depressive symptoms in conjunction with one of the following caregiving elements: 1) type of caregiver, 2) amount of care, 3) perceived care sufficiency, and 4) perceived control over care. Each model also included an interaction term between functional limitations and the caregiving element central to that model.

The between-person effects captured the impact of functional limitations and the four caregiving elements on depressive symptoms, while the within-person effects reflected the influence of changes in these caregiving elements on depressive symptoms over time. This approach provided valuable insights into the effects of changes in caregiving elements within an individual's life and highlighted differences between individuals based on these elements of care.

In all models, age, sex, education, and the number of chronic diseases were controlled for. These control variables were included to better understand the relationship between functional limitations and depressive symptoms.

Table 1

Descriptive statistics at three measurement waves (2012/13, 2015/16, 2018/19) among 1293 Dutch older adults aged 65 and older

	Wave 2012/13			*Wave 2015/16*			*Wave 2018/19*			*Total*	
	N	*Mean*	*SD*	*N*	*Mean*	*SD*	*N*	*Mean*	*SD*	*Min*	*Max*
Female	1341	0.57		1011	0.57		776	0.57		0	1
Age	1341	75.67	7.68	1011	73.97	6.65	776	72.56	5.75	65.01	102.0
Education	1341			1011			776				
Low	626	0.47		427	0.42		308	0.40		0	1
Middle	415	0.31		326	0.32		259	0.33		0	1
High	200	0.22		258	0.26		209	0.27		0	1
Chronic diseases (N)	1240	2.16	1.31	963	1.42	1.07	747	1.36	1.06	0	7
Depressive symptoms[a]	1341	8.30	7.30	1009	8.48	6.94	776	8.35	6.74	0	48
Functional Limitations[b]	1341	4.58	5.93	1011	4.33	5.58	776	4.95	5.76	0	24
Coresiding caregiver	1341	0.09	0.29	1067	0.09	0.29	859	0.12	0.32	0	1
Informal caregiver	1341	0.21	0.41	1341	0.18	0.38	1341	0.20	0.40	0	1
Publicly paid caregiver	1341	0.19	0.39	1067	0.19	0.39	859	0.20	0.40	0	1
Privately paid caregiver	1341	0.13	0.34	1067	0.24	0.43	859	0.27	0.44	0	1
Hours of Informal Care	1243	1.45	8.71	948	1.07	6.15	694	1.89	9.89	0	168
Hours of Publicly paid Care	1243	1.15	7.17	948	1.24	8.94	694	1.38	10.33	0	168
Hours of Privately paid Care	1243	0.41	1.44	948	0.57	1.36	694	1.18	7.13	0	22
Perceived Care Sufficiency	1211	0.90	0.30	940	0.89	0.32	692	0.87	0.33	0	1
Control over Care	582	6.68	2.18	495	6.92	2.02	390	6.95	1.99	3	9
Importance Control over Care	1243	0.81	3.07	948	1.16	3.09	694	1.41	3.14	0	5
Has a Partner	1341	1.08	0.28	1067	1.07	0.26	859	1.11	0.31	1	2

Note. [a] Measured using the CES-D, [b] Functional Limitations measured as pooled Activities of Daily Living

Results

The descriptive statistics are summarised in Table 1. In the 2012/13 wave, the sample comprised 57% females, with an average age of 75 years. On average, respondents reported 2 chronic conditions, scored 8 on the depressive symptoms scale, and 5 on the functional limitations scale.

Table 2 presents the between-person and fixed effects of functional limitations on depressive symptoms, adjusted for time. The crude effect of functional limitations was 0.41 [-0.47; -0.35], indicating that each additional unit increase in functional limitations corresponded to a 0.41-point increase on the 48-point depressive symptoms scale. After adjusting for education, age, sex, and the number of chronic diseases, the effect size of functional limitations increased to 0.47 [0.39; 0.55]. The fixed effect of functional limitations was 0.09 [0.03; 0.15], suggesting that a one-unit increase in functional limitations over time was associated with an average increase of 0.09 points in depressive symptoms.

Table 2

Multilevel analyses with wellbeing as the dependent variable and functional limitations as independent variable. Data were gathered at three measurement waves among 1341 Dutch older adults aged 65 and older

	Model 1 *Between*			Model 2 *Between*			Model 3 *Fixed*		
	B (se)	*95% CI* *LL*	*UL*	*B (se)*	*95% CI* *LL*	*UL*	*B (se)*	*95% CI* *LL*	*UL*
Functional Limitations	**0.41** **(0.03)**	**0.35**	**0.47**	**0.47** **(0.04)**	**0.39**	**0.55**	**0.09** **(0.03)**	**0.03**	**0.15**
Wave 2015/16	0.57 (1.08)	-1.56	2.69	0.75 (1.09)	-1.38	2.88	**0.83** **(0.19)**	**0.45**	**1.20**
Wave 2018/19	**-2.59** **(1.17)**	**-4.88**	**-0.30**	**-2.20** **(1.22)**	-4.59	0.20	**1.10** **(0.22)**	**0.66**	**1.54**
Female				**0.91** **(0.35)**	**0.23**	**1.60**			
Age				-0.02 (0.03)	-0.07	0.04			
Low education (ref.)				-0.29					
Middle education				(0.39)	-1.06	0.48			
				-0.49					
High education				(0.45)	-1.36	0.39			
				1.13					
Chronic diseases (N)				**(0.16)**	**0.82**	**1.44**			
Constant	**6.95** **(0.45)**	**1.56**	**11.21**	**6.02** **(2.18)**	**1.74**	**10.31**	**7.42** **(0.16)**	**7.10**	**7.74**
Observations	3,126			2,948			3,126		
R-squared	0.14			0.24			0.03		
Number of respondents	1341			1240			1341		

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit; UL = Upper Limit
Statistically significant associations in bold

Table 3

Multilevel analyses with wellbeing as the dependent variable and functional limitations, caregiver types, and interaction terms between functional limitations and caregiver types as independent variables. Data were gathered at three measurement waves among 1240 Dutch older adults aged 65 and older.

	Model 1			Model 2			Model 3			Model 4		
	Between			*Between*			*Fixed*			*Fixed*		
	B (se)	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*	
		LL	*UL*		*LL*	*UL*		*LL*	*UL*		*LL*	*UL*
Functional Limitations	**0.40**	**0.31**	**0.48**	**0.51**	**0.37**	**0.65**	**0.11**	**0.04**	**0.17**	**0.12**	**0.03**	**0.20**
	(0.05)			**(0.07)**			**(0.03)**			**(0.04)**		
Wave 2015/16	0.62	-1.49	2.74	0.57	-1.55	2.68	**0.54**	**0.15**	**0.94**	**0.54**	**0.14**	**0.94**
	(1.08)			(1.08)			**(0.20)**			**(0.20)**		
Wave 2018/19	**-2.36**	-4.75	0.03	**-2.37**	-4.76	0.02	**0.58**	**0.10**	**1.06**	**0.55**	**0.07**	**1.04**
	(1.22)			**(1.22)**			**(0.24)**			**(0.25)**		
Female	0.57	-0.13	1.26	0.53	-0.16	1.23						
	(0.35)			(0.36)								
Age	**-0.08**	**-0.14**	**-0.02**	**-0.09**	**-0.15**	**-0.03**						
	(0.03)			**(0.03)**								
Low education (ref.)				-0.12								
Middle education	-0.17	-0.94	0.61	(0.40)	-0.90	0.66						
	(0.40)			-0.49								
High education	-0.59	-1.50	0.33	(0.47)	-1.41	0.43						
	(0.46)			**1.04**								
Chronic diseases (N)	**1.07**	**0.76**	**1.38**	**(0.16)**	**0.74**	**1.35**						
	(0.16)			0.67			0.61			1.03		
Coresiding caregiver	-0.24	-1.58	1.10	(1.11)	-1.51	2.84	(0.46)	-0.29	1.51	(0.68)	-0.31	2.37
	(0.68)			**1.66**			**1.04**			**1.39**		
Informal caregiver	**1.16**	**0.07**	**2.26**	**(0.82)**	**0.06**	**3.25**	**(0.32)**	**0.41**	**1.68**	**(0.47)**	**0.48**	**2.30**
	(0.56)			**3.10**			0.61			-0.06		
Publicly paid caregiver	**2.28**	**1.18**	**3.38**	**(0.87)**	**1.39**	**4.81**	(0.46)	-0.29	1.52	(0.67)	-1.37	1.25
	(0.56)			**1.56**			0.63			0.77		
Privately paid caregiver	**1.64**	**0.58**	**2.70**	**(0.73)**	**0.12**	**3.00**	(0.40)	-0.15	1.40	(0.49)	-0.20	1.74
	(0.54)			-0.15						-0.06		
Functional Limitations * Coresiding caregiver				(0.11)	-0.38	0.07				(0.08)	-0.21	0.09
				-0.08						-0.05		

Functional Limitations * Informal caregiver				(0.09)	-0.25	0.10				(0.05)	-0.16	0.06
				-0.12						0.08		
Functional Limitations * Publicly paid caregiver				(0.09)	-0.30	0.06				(0.06)	-0.04	0.21
				-0.00						-0.03		
Functional Limitations * Privately paid caregiver				(0.10)	-0.20	0.19				(0.06)	-0.15	0.08
Constant	**10.69**	**6.08**	15.30	**11.18**	6.54	**15.82**	**7.12**	**6.77**	**7.47**	**7.08**	**6.70**	**7.47**
	(2.35)			**(2.36)**			**(0.18)**			**(0.19)**		
Observations	2948			2948			2948			2948		
R-squared	0.26			0.26			0.04			0.04		
Number of respondents	1240			1240			1240			1240		

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit; UL = Upper Limit
Statistically significant associations in bold

Caregiver types

Table 3 presents the effects of caregiver types, functional limitations, and the interaction between functional limitations and caregiver types on depressive symptoms. In Models 1 and 3, which exclude interaction terms, the effect of functional limitations on depressive symptoms was statistically significant and positive. Specifically, Model 1 revealed significant positive between-person effects for three types of caregivers compared to other caregiver types: informal caregivers (B=1.16 [0.07; 2.26]), publicly paid caregivers (B=2.28 [1.18; 3.38]), and privately paid caregivers (B=1.64 [0.58; 2.70]). This suggests that care provided by informal, publicly paid, or privately paid caregivers was associated with more depressive symptoms than care provided by co-residential caregivers or no care. In Model 3, which focuses on fixed effects, starting to receive care from an informal caregiver was associated with an increase in depressive symptoms (B=1.04 [0.74; 1.35]). However, given that a clinically relevant change in depressive symptoms is approximately 7 points (Radloff, 1977), these observed differences appear relatively modest.

Interaction effects were examined in Models 2 and 4. The data did not support significant interactions between functional limitations and caregiver types for either between-person or fixed effects models. This indicates that the relationship between functional limitations and depressive symptoms does not significantly vary based on the type of caregiver, contrary to our initial hypothesis in H1.

Table 4

Multilevel analyses with wellbeing as the dependent variable and functional limitations, hours of care, and interaction terms between functional limitations and hours of care as independent variables. Data were gathered at three measurement waves among 1240 Dutch older adults aged 65 and older

	Model 1: *Between*			Model 2: *Between*			Model 3: *Fixed*			Model 4: *Fixed*		
	B (se)	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*	
		LL	*UL*		*LL*	*UL*		*LL*	*UL*		*LL*	*UL*
Functional Limitations	**0.51** **(0.05)**	**0.42**	**0.60**	**0.59** **(0.05)**	**0.49**	**0.70**	**0.31** **(0.05)**	**0.22**	**0.41**	**0.32** **(0.05)**	**-0.22**	**-0.43**
Wave 2015/16	-0.00 (1.01)	-1.99	1.99	0.15 (1.01)	-1.83	2.13	**0.53** **(0.20)**	**0.14**	**0.91**	**0.52** **(0.20)**	**-0.14**	**-0.91**
Wave 2018/19	-1.39 (1.16)	3.66	0.89	-1.41 (1.15)	-3.67	0.85	**0.65** **(0.23)**	**0.19**	**1.10**	**0.65** **(0.23)**	**-0.19**	**-1.10**
Female	**0.94** **(0.35)**	**0.25**	**1.63**	**0.84** **(0.35)**	**0.15**	**1.52**						
Age	-0.04 (0.03)	-0.09	0.02	**-0.07** **(0.03)**	**-0.12**	**-0.01**						
Low education (ref.)												
Middle education	-0.44 (0.40)	-1.22	0.34	-0.35 (0.39)	-1.12	0.43						
High education	-0.71 (0.46)	-1.62	0.20	-0.65 (0.46)	-1.56	0.25						
Chronic diseases (N)	**0.97** **(0.16)**	**0.65**	**1.28**	**0.92** **(0.16)**	**0.61**	**1.23**						
Hours of Informal Care	**0.07** **(0.04)**	**-0.01**	**0.14**	0.08 (0.08)	-0.08	0.23	**0.07** **(0.03)**	**0.02**	**0.12**	0.07 (0.04)	0.01	-0.14
Hours of Publicly paid Care	-0.03 (0.07)	-0.17	0.11	**0.59** **(0.16)**	**0.28**	**0.90**	0.03 (0.06)	-0.08	0.14	0.00 (0.11)	0.21	-0.22
Hours of Privately paid Care	0.15 (0.14)	-0.13	0.42	0.35 (0.19)	-0.03	0.73	0.05 (0.11)	-0.17	0.26	0.12 (0.14)	0.16	-0.40
Functional Limitations* Hours of Informal Care				-0.00 (0.01)	-0.01	0.01	0 0			0.00 (0.00)	0.01	-0.01
Functional Limitations * Hours of Publicly paid Care				**-0.04** **(0.01)**	**-0.06**	**-0.02**	0 0			0.00 (0.01)	0.01	-0.02
Functional Limitations * Hours of Privately paid Care				-0.03 (0.02)	-0.08	0.02	0 0			-0.01 (0.02)	0.05	-0.02
Constant	**7.91** **(2.19)**	**3.62**	**12.20**	**9.67** **(2.22)**	**5.32**	**14.01**	**6.76** **(0.18)**	**6.41**	**7.12**	**6.74** **(0.20)**	**7.13**	**6.35**
Observations	2850			2850			2883			2883		
R-squared	0.25			0.27			0.06			0.06		
Number of respondents	1240			1240			1267			1267		

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit UL = Upper Limit. Statistically significant associations in bold

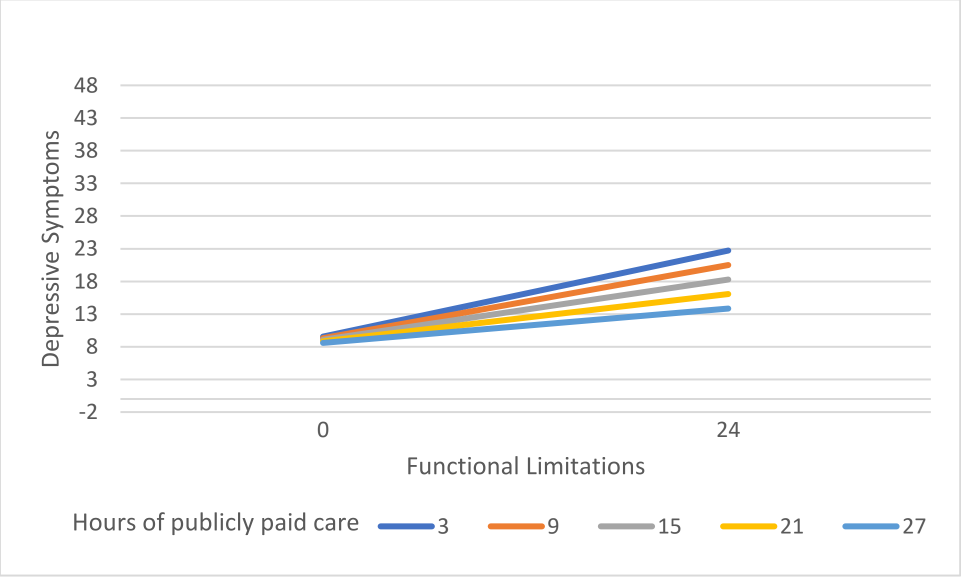
Quantity of care

Table 4 presents the effects of the number of hours of different types of received care, functional limitations, and the interaction between functional limitations and hours of care on depressive symptoms. Model 1, which does not include interaction terms, found that the quantity of care did not have a statistically significant between-person effect on depressive symptoms. However, Model 3, which examines fixed effects, revealed a statistically significant positive relationship between the number of hours of informal care received and depressive symptoms (B=0.07 [0.02; 0.12]). Given that we winsorised the maximum number of hours of informal care to 50 hours, the maximum effect of receiving full-time informal care compared to no informal care was 3.5 points on the 48-point CES-D scale. Thus, a shift from zero to full-time informal care corresponds to an average increase of 3.5 points in depressive symptoms.

In Model 2, the interaction effect of hours of publicly paid care was statistically significant (B=-0.04 [-0.06; -0.02]), as was the main effect (B=0.59 [0.28; 0.90]). This suggests that for individuals with fewer functional limitations, an increase in publicly paid care was associated with more depressive symptoms, while for those with more functional limitations, additional hours of publicly paid care were linked to fewer depressive symptoms (see Figure 1). Model 4 did not reveal statistically significant fixed effects for either the main effects or interaction terms. These results do not support our first hypothesis. Instead, they indicate that, contrary to expectations, more hours of formal care can act as a buffer in cases of poor health, whereas more hours of informal care do not.

Figure 1

Interaction effect of hours of publicly paid care (between effects) on the association between depressive symptoms (CES-D) and functional limitations (ADL), for -1SD (0 hours) to max (27 hours), based on the analyses reported in Model 2, Table 4.



Care sufficiency

Table 5 presents the effects of care sufficiency, functional limitations, and the interaction between functional limitations and care sufficiency on depressive symptoms. In Models 1 and 3, we observed that both the between-person and fixed effects of care sufficiency were negative and statistically significant. Specifically, individuals who perceived their care as sufficient experienced depressive symptoms that were, on average, 4.78 points [-6.05; -3.52] lower compared to those who perceived their care as insufficient. Furthermore, Model 3 indicates that respondents who initially viewed their care as insufficient but later perceived it as sufficient had, on average, 1.01 [-1.80; -0.22] fewer depressive symptoms.

The interaction effect in Model 2 (B=0.23 [0.04; 0.43]) suggests that the impact of functional limitations on depressive symptoms based on care sufficiency was absent at low levels of functional limitations but pronounced at high levels of functional limitations (see Figure 2). At the highest level of functional limitations, there was no noticeable difference in depressive symptoms based on perceived care sufficiency. Model 4 did not reveal significant moderation effects for fixed effects. Hence, the second hypothesis must be revised, as the buffering effect of care sufficiency is only evident under conditions of relatively good health.

Figure 2

Interaction effect of care sufficiency (between effects) on the association between depressive symptoms (CES-D) and functional limitations (ADL), based on the analyses reported in Model 2, Table 5

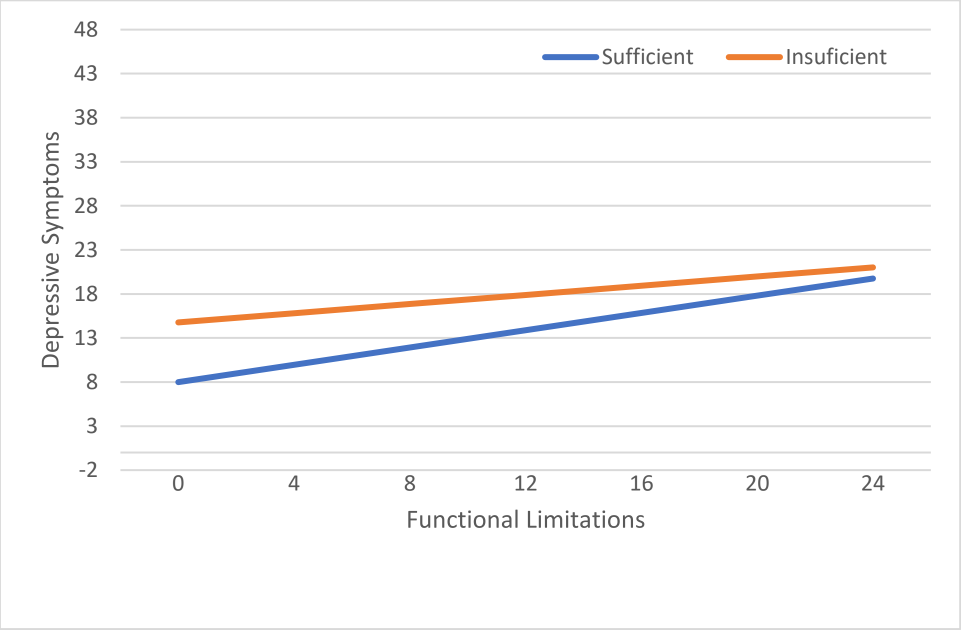


Table 5

Multilevel analyses with wellbeing as the dependent variable and functional limitations, care sufficiency, and an interaction term between functional limitations and perceived care sufficiency as independent variables. Data were gathered at three measurement waves among 1236 Dutch older adults aged 65 and older.

	Model 1: *Between*			Model 2: *Between*			Model 3: *Fixed*			Model 4: *Fixed*		
	B (se)	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*	
		LL	*UL*		*LL*	*UL*		*LL*	*UL*		*LL*	*UL*
Functional Limitations	**0.45** **(0.04)**	**0.36**	**0.53**	**0.26** **(0.09)**	**0.08**	**0.44**	**0.34** **(0.05)**	**0.25**	**0.43**	**0.35** **(0.07)**	**0.21**	**0.49**
Wave 2015/16	-0.03 (0.93)	-1.86	1.80	-0.06 (0.93)	-1.89	1.77	**0.48** **(0.20)**	**0.09**	**0.87**	**0.48** **(0.20)**	**0.09**	**0.87**
Wave 2018/19	-1.58 (1.10)	-3.73	0.57	-1.62 (1.10)	-3.77	0.53	**0.61** **(0.23)**	**0.15**	**1.06**	**0.61** **(0.23)**	**0.15**	**1.07**
Female	**0.98** **(0.34)**	**0.31**	**1.65**	**1.00** **(0.34)**	**0.33**	**1.66**						
Age	-0.04 (0.03)	-0.09	0.02	-0.04 (0.03)	-0.10	0.01						
Low education (ref.)												
Middle education	-0.21 (0.39)	-0.96	0.55	-0.17 (0.39)	-0.93	0.58						
High education	-0.31 (0.44)	-1.17	0.55	-0.28 (0.44)	-1.14	0.58						
Chronic diseases (N)	**0.89** **(0.16)**	**0.59**	**1.20**	**0.87** **(0.16)**	**0.57**	**1.18**						
Perceived Care Sufficiency	**-4.78** **(0.64)**	**-6.05**	**-3.52**	**-6.78** **(1.08)**	**-8.89**	**-4.67**	**-1.01** **(0.40)**	**-1.80**	**-0.22**	-0.91 (0.59)	-2.07	-0.25
Functional Limitations * Perceived Care Sufficiency				**0.23** **(0.10)**	**0.04**	**0.43**	0 0			-0.02 (0.07)	-0.16	0.12
Constant	**12.46** **(2.18)**	**8.18**	16.74	**14.77** **(2.40)**	**10.07**	**19.47**	**7.77** **(0.42)**	**6.94**	**8.60**	**7.68** **(0.58)**	**6.55**	**8.82**
Observations	2809			2809			2841			2841		
R-squared	0.29			0.29			0.06			0.06		
Number of respondents	1236			1236			1262			1262		

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit UL = Upper Limit, Statistically significant associations in bold

Control over care

Table 6 presents the effects of the number of control over care, functional limitations, and the interaction between functional limitations and control over care on depressive symptoms. Model 1 indicates that respondents who felt they had control over their care experienced, on average, 0.35 [-0.61; -0.08] fewer depressive symptoms compared to those who felt they lacked control, with a maximum potential effect of -2.1 points. However, Model 3 reveals that changes in perceived control over time did not significantly affect depressive symptoms, with a fixed effect of B=0.01 [-0.23; 0.25].

The interaction terms in both Model 2 (between effects) and Model 4 (fixed effects) did not provide substantial evidence of a differential impact of functional limitations on depressive symptoms based on the respondent's level of perceived control over care. Thus, the second hypothesis regarding control over care is not supported.

Table 6

Multilevel analyses with wellbeing as the dependent variable and functional limitations, control over care, and an interaction term between functional limitations and control over care as independent variables. Data were gathered at three measurement waves among 840 Dutch older adults aged 65 and older.

	Model 1			Model 2			Model 3			Model 4		
	Between			*Between*			*Fixed*			*Fixed*		
	B (se)	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*		*B (se)*	*95% CI*	
		LL	*UL*		*LL*	*UL*		*LL*	*UL*		*LL*	*UL*
Functional Limitations	**0.38** **(0.05)**	**0.28**	**0.48**	**0.26** **(0.13)**	**-0.01**	**0.52**	**0.34** **(0.06)**	**0.21**	**0.46**	0.24 (0.14)	-0.04	0.51
Wave 2015/16	-0.20 (0.79)	-1.76	1.36	-0.22 (0.79)	-1.77	1.34	0.20 (0.37)	-0.51	0.92	0.21 (0.37)	-0.51	0.92
Wave 2018/19	-0.57 (0.81)	-2.16	1.02	-0.57 (0.81)	-2.16	1.01	0.14 (0.44)	-0.73	1.00	0.11 (0.44)	-0.75	0.98
Female	0.65 (0.49)	-0.31	1.61	0.65 (0.49)	-0.31	1.61						
Age	**-0.09** **(0.04)**	**-0.16**	**-0.02**	**-0.09** **(0.04)**	**-0.16**	**-0.02**						
Low education (ref.)												
Middle education	0.12 (0.54)	-0.93	1.17	0.15 (0.54)	-0.91	1.20						
High education	-0.48 (0.62)	-1.69	0.74	-0.40 (0.62)	-1.62	0.83						
Chronic diseases (N)	**1.12** **(0.21)**	**0.72**	**1.53**	**1.12** **(0.21)**	**0.71**	**1.53**						
Control over care	**-0.35** **0.14**	**-0.61**	**-0.08**	**-0.48** **(0.19)**	**-0.85**	**-0.11**	0.01 (0.12)	-0.23	0.25	-0.10 (0.18)	-0.46	0.25
Functional Limitations * Control				0.02 (0.02)	-0.02	0.06				0.02 (0.02)	-0.02	0.06
Constant	**15.19** **(3.29)**	**8.73**	**21.65**	**16.05** **(3.40)**	**9.38**	**22.72**	**8.31** **(0.97)**	**6.39**	**10.22**	**9.08** **(1.35)**	**6.42**	**11.73**
Observations	1445			1445			1465			1465		
R-squared	0.19			0.19			0.06			0.06		
Number of respondents	840			840			858			858		

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit UL = Upper Limit, Statistically significant associations in bold

Discussion

In this study, we explored whether specific elements of care moderate the relationship between functional limitations and wellbeing. Our findings reaffirm the well-established negative impact of functional limitations on wellbeing (Braam et al., 2005; Geerlings et al., 2000; Hilderink et al., 2012; Luo et al., 2020; Na & Streim, 2017), as measured through depressive symptoms in our study. Consistent with previous studies using data from LASA (Abbing, Suanet, & Broese van Groenou, 2022; Pot et al., 2005), and other studies (Abramowska-Kmon et al., 2023; Brown, 2007; Kwak et al., 2014), we found that care use generally correlates negatively with wellbeing. Our study adds new insights by demonstrating that both the quantity and sufficiency of care moderate the impact of functional limitations on wellbeing. Contrary to our expectations, we found no evidence that the type of caregiver or perceived control over care significantly moderates this relationship.

Specifically, our findings indicate that an increase in hours of publicly paid care can buffer the adverse effects of functional limitations on wellbeing. Conversely, starting to receive informal care was associated with a slight decline in wellbeing, though this effect was relatively minor. Notably, aspects of informal care that may be less beneficial to wellbeing do not appear to overlap with those of co-residential care, as no significant differences in wellbeing were observed between respondents receiving no care and those receiving co-residential care.

Informal care can generate ambivalence in the recipient, particularly through the lens of relatedness. Numerous studies have highlighted feelings of burden experienced by those receiving informal care (Bredewold et al., 2019; Ford, 2012; Martire et al., 2003; Nieuwenhuis et al., 2018). Our findings indicate that this ambivalence is particularly pronounced with care provided by children, as opposed to co-residential care, which often involves spouses. This aligns with previous research showing that spousal care is generally associated with higher levels of wellbeing (Allen & Wiles, 2014; Carr et al., 2017), whereas care from other informal sources, particularly children, correlates with lower levels of wellbeing (Lee et al., 2018; Ouyang et al., 2019; Swinkels et al., 2024; Thomas, 2010; Zwar et al., 2019). Expectations and preferences play a significant role, with individuals typically expecting and preferring to receive care from their spouse (Byrne et al., 2009; Li & Dai, 2019). In contrast, the dynamics of care provided by adult children might be perceived differently, resulting in the recipient feeling like a burden.

This dynamic is also connected to the concept of reciprocity, where the nature of the caregiving relationship influences expectations and emotional responses (Fyrand, 2010). Our results suggest that receiving care from children can lead to a sense of ambivalence and the feeling of being a burden. Research by Carr, Cornman, and Freedman (2017) indicates that social connectedness fosters higher levels of wellbeing, and Ashida and Heaney (2008) propose that this may be even more significant than the support received. However, the positive effects of relatedness through daily interactions with a loved one might be counterbalanced by another side of relatedness, namely the desire to be able to contribute to one's social environment.

Relatedness also helps explain why an increase in publicly paid care does not contribute to wellbeing when functional limitations are low but does enhance wellbeing at high levels of functional limitations. It is possible that the more publicly paid care someone receives, the stronger the attachment becomes. The high degree of differentiation among publicly paid caregivers in the Netherlands—often resulting in multiple caregivers with narrowly defined roles— often results in a variety of caregivers with very narrowly defined job descriptions. An increased number of caregiver hours increases the chance of the development of positive social interactions between these caregivers and the care recipient, potentially enhancing wellbeing.

Furthermore, the professional nature of formal care might mitigate the feeling of being a burden, as these caregivers are less likely to elicit such feelings. The observed contrast between the effects of informal and formal care on wellbeing—where formal care is associated with better wellbeing, particularly when care needs are high—could indicate a gap filled by the need for supplementary formal care. In our sample, many individuals with extensive functional limitations received only informal care, suggesting that the lower wellbeing in this group might reflect a lack of formal care. A combination of both formal and informal care can offer greater control and a sense of mastery among recipients (Wylie et al., 2024), potentially enhancing overall wellbeing.

Care sufficiency and control over care, the subjective elements of care, seemed to be most significant when functional limitations were relatively minimal. The primary between-effect of care sufficiency was substantial, and the initial perception of care as sufficient led to enhanced wellbeing, a finding corroborated by other studies (Hsu, 2010; Kadowaki et al., 2015; Swinkels et al., 2024). Additionally, we observed a moderating effect indicating that average levels of wellbeing tended to converge with increasing levels of functional impairment, although sufficient care maintained a strong positive effect on wellbeing.

Consequently, the buffering effect of sufficient care appears to diminish as the demand for care increases. It is possible that, at lower levels of functional limitations, sufficient care enhances autonomy by mitigating functional limitations, whereas this level of autonomy becomes less achievable as functional limitations intensify. As functional limitations rise, sufficient care may still improve functioning, but the likelihood of not meeting all needs increases when functional limitations are severe (Spiers et al., 2022). The notion that needing care adversely affects wellbeing, despite the care being deemed sufficient, is supported by Abramowska-Kmon et al. (2023), who reported that older adults not requiring care exhibited higher levels of wellbeing compared to those in need of care who perceived their care as sufficient.

Despite anticipating that control over care would have a positive moderating effect on wellbeing, we found only a positive main effect, in line with Morgan and Brazda (2013). Previous research also suggests that control over care does not serve as a mediator in the relationship between receiving care and wellbeing (Kwak et al., 2014). This implies that older care recipients might consider having control over care to be less important than receiving sufficient care. A prior study demonstrated that only care recipients who valued having control over care as significant reported a negative association between using formal care and wellbeing (Broese van Groenou, 2020).

Strengths & Limitations

To our knowledge, this study is the first to examine care within a longitudinal framework while differentiating between various care constellations, such as spousal versus other informal care, and privately paid versus publicly paid care. Additionally, we accounted for both the amount of care received and subjective elements of care use, offering more detail than previous research. Utilising a representative sample of the Dutch older population from the LASA study, our research benefited from a high number of follow-up visits and low missingness due to factors other than death or relocation to a nursing facility. The use of multiple follow-up waves and the estimation of within-person effects enabled us to evaluate the impact of changes in care, providing insights into which elements of care are beneficial to wellbeing and should be encouraged by policy.

However, this study also has several limitations. Firstly, despite a sufficient sample size, a larger sample could have increased statistical power, potentially altering the results for fixed effects, as fixed effects analyses require data from at least two time points. A larger sample would also have permitted gender-stratified analyses, which might be valuable for future research given the reported gender differences in the relationship between functional limitations, care, and wellbeing (Abramowska-Kmon et al., 2023; Carr et al., 2017; Hajek & König, 2016; Zwar, König, van der Leeden, et al., 2022).

Secondly, there are concerns about biases inherent in multilevel analyses of non-experimental data across multiple time points, which limits our ability to draw causal conclusions (Dedrick et al., 2009). However, our analyses did not reveal significantly different results across the various waves. The capacity to assess the effects of caregiver changes on wellbeing provides meaningful insights. Given that the CES-D is highly sensitive to change, with notable shifts possible within a few weeks (Radloff, 1977; Vilagut et al., 2016), future studies with shorter intervals between waves could further elucidate the impact of caregiver changes on wellbeing. Lastly, not all respondents had data on all variables: control over care was assessed only in face-to-face interviews, which means that respondents likely receiving the highest levels of care were not queried about their perceptions of control.

Implications

Our study reveals that high levels of informal care may adversely impact wellbeing, despite its current popularity in policy frameworks. As care needs increase, older adults' wellbeing seems to be less adversely affected by functional limitations when they receive more hours of publicly paid care. These findings challenge the general assumption that informal care is beneficial for wellbeing, while formal care is detrimental. Our research provides a nuanced perspective on both types of care and suggests that the relationship between care and wellbeing is more intricate than previously understood. Bonding with formal caregivers can offer positive outcomes, whereas excessive care from adult children or relatives may lead to feelings of ambiguity and dependency, potentially lowering self-esteem (Zwar, König, & Hajek, 2022).

Our results indicate that receiving substantial amounts of formal care during periods of high care needs significantly helps manage severe health issues. Therefore, policymakers should aim to ensure that care teams provide the necessary level of care, especially during times of severe functional impairment.

The study also highlights the importance of tailoring care to the needs of the recipient, as both too much and too little care can impact wellbeing. Assessing the ‘goldilocks-zone’ where the amount of care is just enough, could offer valuable insights for policymakers seeking to enhance the wellbeing of older adults through care interventions. Additionally, while subjective elements of caregiving, such as perceptions of sufficient care and control over care, are important for wellbeing, their impact diminishes as functional limitations increase. Therefore, interventions aimed at enhancing the quantity of care are likely to be more effective in improving wellbeing than those focused on subjective aspects. Given the ageing population and the current shortage of home care services, it is crucial to address how to ensure that older individuals living at home will receive the necessary care in the near future.

Conclusion

This study offered more nuanced insights into the role of caregiving in the relationship between functional limitations and wellbeing. Drawing on the Self-Determination Theory, the concepts of relatedness and autonomy proved useful in understanding the associations between health, care, and wellbeing. We identified a moderating effect in the health-wellbeing relationship related to the quantity of care, and the sufficiency of care. Specifically, the impact of functional limitations on wellbeing varied according to the amount of publicly paid care received, particularly when functional limitations were severe. Conversely, care sufficiency and control over care seemed to be less effective in enhancing wellbeing at this stage. Nonetheless, further research is required to clarify the mechanisms underlying these findings.

Chapter 5

Title: Trends in the sufficiency of long-term care as perceived by older care recipients between 2012 and 2022 in the Netherlands

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Abstract

Due to population ageing and rising healthcare costs, Dutch long-term care was reformed in 2015. Important measures were stricter admission requirements for nursing homes and decentralization of homecare to municipalities. The consequences of these changes for the perceived quality of care are still unknown. We examined to which extent the sufficiency of care as experienced by older people has changed during this period. We also examined the relationship with individual characteristics, such as care needs, care use, and wishes regarding care.

Data from older care recipients at four observations from the Longitudinal Aging Study Amsterdam (LASA) between 2012 and 2022 (N=1316) were used. Multilevel logistic regression analysis were performed.

Perceived care sufficiency decreased a little after the healthcare reform in 2015 and 2018, but recovered in 2022. There appeared no difference based on living region, but care sufficiency was higher in less urban areas (OR=0,89). In addition, functional limitations (OR= 0,94), chronic diseases (OR=0,80), use of public care (OR= 0,67), and higher education level (OR=1,53) were strongly associated with care sufficiency. However, use of publicly paid care appeared to be the type of care that contributed least to care sufficiency; a lack of perceived control over care may be an explanatory factor.

Keywords

Long-term care, care sufficiency, Longitudinal Aging Study Amsterdam

Introduction

When older people develop health problems, they are not only dependent on acute medical care, but often also on long-term care. Here one would expect different care needs, consisting for example of help with personal care, nursing or household care. Long-term care can mitigate the negative impact of health problems on the wellbeing of the person in need of care if the care is of high quality and tailored to the needs of the person in need of care. One indicator of the quality of care is the perceived sufficiency of care, i.e. the extent to which people consider the care they receive to be sufficient. This sufficiency of care is an important element in the relationship between health, care utilisation and wellbeing (Abbing, Suanet, & Broese van Groenou, 2022; Hsieh & Kenagy, 2020; Q. Wang et al., 2022).

The factors that determine the sufficiency of care have mainly been studied in the context of medical care. This requires a better understanding of the factors that determine the sufficiency of long-term care. These factors can be broadly categorised into individual factors that determine demand, such as age, health and care preferences, and structural factors that reflect supply, such as care policy, time and place. A mismatch between supply and demand could contribute to care being perceived as insufficient. The supply of care changes frequently, in part due to the rising cost of long-term care. The biggest adjustment took place in 2015 when the legal framework for long-term care was drastically changed. Using longitudinal research, we aim to better understand the extent to which the care reform was associated with a change in older people's perceived level of care sufficiency and the extent to which this was related to structural and individual characteristics.

Structural factors of care sufficiency

In 2015, the General Care Provision Act (AWBZ) was replaced by the Long-Term Care Act (*Wet Langdurige Zorg: Wlz*) and the Health Insurance Act (*Zorgverzekeringswet: Zvw*) and the Social Support Act (*Wet maatschappelijke ondersteuning: Wmo*) was extended. The aim of this reform was to make care better and more efficient, also in order to save costs (Alders & Schut, 2019). For this reason, home care was decentralised, with responsibility for the provision and financing of care and support being transferred from the state to the municipalities in the Social Support Act and Health Insurance Act. Intensive care at home or residential care was regulated by the Long-Term Care Act , for which responsibility remained primarily with the national government. The Health Insurance Act regulated and organised the financing of district nursing care. With the Social Support Act, assistance for independent living and participation in society was regulated by the municipalities. Municipalities were assumed to be able to provide this care efficiently and therefore the total budget for financing care was lower than the total national expenditure on long-term care in previous years. For example, the budget for home care was 11% lower and for nursing home care it was 35% lower than the previous budget (Alders & Schut, 2019). In addition, citizens were encouraged to organise care themselves, from their own network (informal) or self-paid (private).

This reform raises the question of the extent to which care has remained sufficient. On the one hand, concerns have been expressed as to whether the new care system can still guarantee sufficient care (de Klerk et al., 2022; Raad Volksgezondheid & Samenleving, 2023). On the other hand, the aim of the reform was to provide care tailored to the specific needs of patients (customised care), which may have made care more sufficient than before the reform (Janssen et al., 2016). In addition, decentralisation would have led to differences in care provision between municipalities. As ageing in the Netherlands varies by region and degree of urbanisation, municipalities in different parts of the Netherlands face different challenges. In particular, municipalities with a higher degree of urbanisation tend to have a larger number of structural healthcare facilities (Centraal Bureau voor de Statistiek, 2022), as well as more potential formal and informal care providers in the neighbourhood. In contrast, rural areas may be more reliant on informal care. The first research question of this study is: 'To what extent has the perceived sufficiency of long-term care by older people changed in the post-reform period (2012 - 2022) and to what extent does this differ by region and degree of urbanisation?

Individual factors of care sufficiency

At the centre of the concept of care sufficiency is the question of whether a person considers the care they receive to be sufficient. From this perspective, the sufficiency of care is primarily determined by what one needs (need for care), what one receives (type of care, quantity) and what one wants for care (preferences, perceived direction). For the first factor, care needs, it is easier to perceive care as sufficient if the needs are lower and less complex. Previous studies have shown that poorer health status is related to lower perceived care sufficiency (Naidu, 2009; Spiers et al., 2022). In particular, the sufficiency of care was lower in older people with functional limitations (Bogner et al., 2015).

The second factor of care sufficiency concerns the care received, whereby both the intensity of care (in hours) and the type of care provider (informal, formal or privately paid help) are important. With more intensive care, we expect less care sufficiency. The organisation of intensive care is more complex; sometimes care is subject to different laws and there are often several care providers. This complexity increases the risk of coordination problems between care providers (Jacobs et al., 2014), and this fragmentation of care often leads to problems (Raad Volksgezondheid & Samenleving, 2023). We distinguish between three types of care providers, which are likely to differ in the extent to which they can provide sufficient care. For publicly paid care, there are limitations in terms of available time and flexibility, as well as the fact that care is not aways provided by the same individuals. These time constraints also apply to informal carers. At the same time, there may be more flexibility as informal carers often make time somewhere out of duty. At the same time, older people often fear being a burden on their informal carers (Nieuwenhuis et al., 2018). In the case of private help, this can theoretically be highly individualised, making it more likely that care will be sufficient.

A third factor concerns a person's wishes regarding care. It is more likely that care will be perceived as insufficient if one does not receive the preferred care. Older people may be more favourable towards informal care than formal care (Boumans & Deeg, 2011; Pot et al., 2005), so formal care may be more likely to be perceived as insufficient. Similarly, the utilisation of care in general may contribute to a sense of dependency and thus a lack of perceived control over care, which may also lead to lower sufficiency of care. In this case, perceived control is also related to the sufficiency of care.

The second research question of this study is: 'To what extent do care needs, characteristics of care utilisation (intensity, types) and wishes regarding care (preferences and perceived direction) contribute to the degree of perceived sufficiency of care?

Consideration of personal characteristics

In addition to these determinants, there is empirical evidence that age, gender, level of education and partner status are associated with both health and care utilisation as well as perceived care sufficiency. Several studies show that men (Abramowska-Kmon et al., 2023; Naidu, 2009; Spiers et al., 2022), single people (Rabiner, 1992), and younger people (Spiers et al., 2022) experience lower perceived sufficiency of care. Therefore, it is necessary to control for these person characteristics in this study.

Method

Research design and respondents

We used data from the Longitudinal Aging Study Amsterdam (LASA, www.lasa-vu.nl). This is a population-based longitudinal study of older people aged 55 years and older in the Netherlands

(Hoogendijk et al., 2016, 2020). In 1992/93, a baseline sample of 3107 respondents aged between 55 and 85 years was drawn in 11 municipalities in three regions. The three regions were Amsterdam, Oss and Zwolle and the villages surrounding them. 1002 and 1023 respondents aged between 55 and 64 were selected as additional cohorts from the same sampling frame in 2002 and 2012 respectively. For the first and second cohorts, the baseline co-operation rate was 62% and for the third cohort 63% (Huisman et al., 2011). In order to collect the LASA data, respondents were generally interviewed face-to-face. If they were unable to do so, they took part in a telephone interview or an interview was conducted with a proxy (e.g. a family member).

The measurement waves took place approximately every three years and included measurements of respondents from all three different cohorts. We chose 2011/12 as the 'baseline year' as five (rather than two) forms of care were asked about and the perceived control over care since this observation was measured. We selected respondents who were receiving or were going to receive care at each of the four observation points 2011/12-2015/16-2018/19-2021/22 and were aged 65 or older.

The study had a longitudinal design with time-varying predictors. We used data from face-to-face and telephone surveys of LASA from the four observations. The total N was 1316 (individual respondents), although only a few respondents had data at all time points. The total N after the selections was 2011/12 (N=628), 2015/16 (N=615), 2018/19 (N=620) and 2021/22 (N=562), although there was overlap in respondents between these time points. Of these, we had data from 482 respondents at four measurement points, data from 299 respondents at three measurement points, data from 257 respondents at two measurement points and data from 278 respondents at one measurement point.

Dependent variables

We measured the sufficiency of care by asking the question: Overall, is the help you receive insufficient, allright or sufficient? Respondents who rated their care as 'insufficient' or 'allright' received a score of 0 'insufficient care', and respondents who rated their care as sufficient a score of 1 'sufficient care'.

Independent variables

Time

The historical point in time was included in the model as the year in which the measurement took place. This variable had four values: 2011-2015-2018-2021.

Region

Information on region of residence (time variable) was included based on postcode. Respondents whose first two postcodes were between 10 and 19 were assigned to the Amsterdam region, between 50 and 65 to the Oss region and between 72 and 90 to the Zwolle region. For respondents who had moved to another region, we added the category 'Other'.

Urbanisation

The degree of urbanisation was determined by the number of addresses per km2 of the postcodes in which the respondents lived [21]. This scale ranged from '1' non-urban (<500 addresses), '2' somewhat urban (500-1000 addresses), '3' fairly urban (1000-1500), '4' urban (1500-2500), '5' very urban (>=2500).

Care type and intensity

Respondents could indicate whether, from whom and for how many hours they received help with at least one of the following tasks: personal care, household tasks, caring tasks, transport outside the home and administration. Three types of carers (time-varying) were distinguished: informal (partner, housemates, other housemates, children living away from home, other family members, neighbours/friends/acquaintances), publicly paid (community nurse, home help, care home staff) or privately paid.

The number of hours (time variable) was also known for these three types. These were three separate variables that were not mutually exclusive: for example, it was possible to receive both publicly paid and informal care.

Incongruence between actual and preferred caregiver

The incongruence between desired and actual care (time variable) was measured with two statements: 'Care by children or family members/by a professional is at the expense of your independence', with response categories ranging from '1' strongly agree to '5' strongly disagree. This information was combined with the use of (in)formal care. If the respondent received help from a non-desired (agree or strongly agree) carer, the variable incongruence between desired and actual carer was '1', and if the respondent was only cared for by a desired carer, the value was '0'. This variable was created for informal and formal care (private and publicly paid).

Control over care

Experienced control over care (time variable) was measured for three aspects of care. Experienced control over: who provided the care, what type of care was provided and when the care was provided. The response scale ranged from '1' I leave everything to others, '2' I decide a little myself, '3' I decide everything myself. The answers to these questions were added together to form a scale ranging from '3' little control to '9' a lot of control. For telephone respondents there was no information available on perceived control.

Functional limitations

The functional limitations (time variable) were based on the OECD questionnaire on physical limitations (Boshuizen et al., 2000). First, respondents were asked whether they could not perform the following six daily activities with '1' or '5' without assistance: dressing or undressing themselves, getting up from a chair or sitting down, cutting their own toenails, using their own or public transport, climbing stairs and walking outside for 5 minutes without resting. These scores were summed and re-scored to give a scale of 0-24, with higher scores reflecting a lower level of functioning (Pluijm et al., 2005).

Chronic diseases

We counted the number of chronic diseases (time variable) by asking respondents whether they suffered from lung disease, heart disease, arterial disease, diabetes, stroke, rheumatic disease or cancer. The total score ranged from 0 to 7 chronic diseases. Although self-reported chronic diseases may be under- or over-reported, previous research shows that this method of measurement is reasonably accurate for most chronic diseases with the exception of arterial and rheumatic diseases (Kriegsman et al., 1996).

Control variables

Age was determined at each measurement and measured in years. Gender was either '1' female or '0' male. Educational level was categorised into three groups: '1' low (primary school), '2' medium (high school or lower vocational training) and '3' high (higher vocational training or higher). Partner status was a dichotomous variable indicating that a respondent had '0' no partner or '1' a partner.

Methods of analysis

We ran multiple multilevel logistic regressions with care sufficiency and the independent variables, via the GENLINMIXED command in SPSS 27.0. In these, respondents formed the first level and time formed the second level. The models included a random intercept and fixed effects. Associations were considered significant if the 95% confidence interval did not contain 1. Six models were estimated that first tested subcomponents and then the entire research questions. Variables were tested for multicollinearity; we found no correlations above 0.5 and no variable had a Variance Inflation Factor (VIF) greater than 10. The method of analysis used allowed for missing values, so these were not imputed.

As sensitivity analyses, the analyses were also carried out with 2009 as the reference year and with only personal care and home care as forms of care. The results of the sensitivity analyses can be requested from the author. We also analysed whether a cohort that was newly included in the dataset in 2012 influenced the results. This was not the case.

Results

Differences in care sufficiency by observation

The descriptive statistics can be found in Table 1. Figure 1 shows the percentage of perceived care sufficiency by time of measurement and region. By far the majority of respondents considered care sufficiency, and this high percentage hardly differed between observations or by region.

Figure 1

Percentage of care sufficiency over time by region

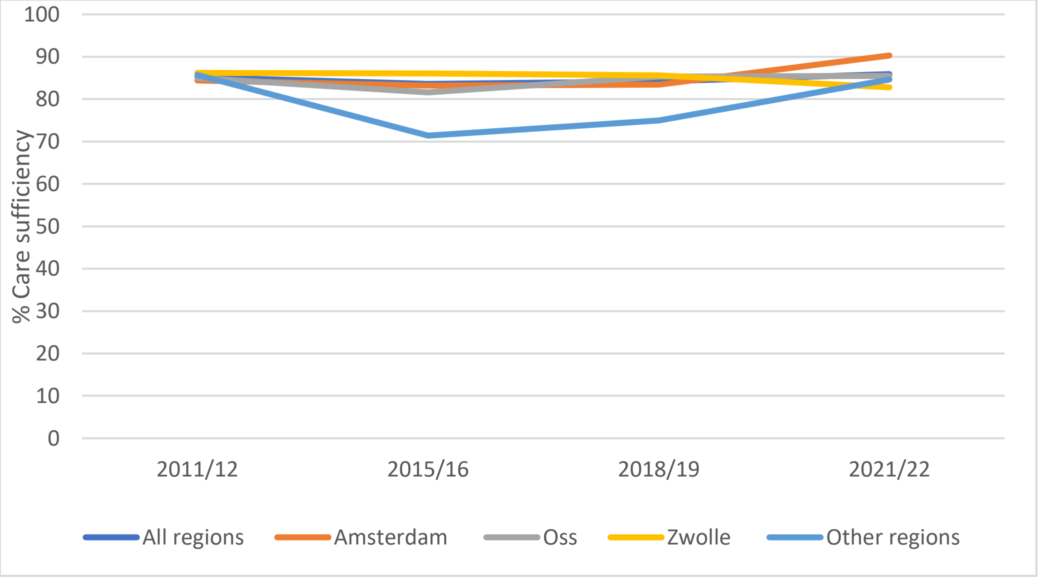

Table 1

Percentage of caregivers that considers care as sufficient per wave

		Wave 2012/13	Wave 2015/16	Wave 2018/19	Wave 2021/22
Total		85.2	83.6	84.2	85.9
	p	*0.734*			
Region	Amsterdam	84.4	83.2	83.4	90.3
	Oss	85.0	81.6	85.3	85.5
	Zwolle	86.2	86.1	85.6	82.8
	Other	85.7	71.4	75.0	84.6
	p	*0.966*	*0.406*	*0.738*	*0.457*
Degree of urbanisation	Non urban	85.2	83.3	89.7	84.8
	Somewhat urban	87.9	87.9	84.3	88.2
	Fairly urban	83.1	83.0	83.3	100.0
	Urban	89.5	82.4	80.3	82.4
	Very urban	77.3	79.0	86.7	93.0
	p	*0.070*	*0.353*	*0.380*	*0.415*
Use of informal care)	No	**89.3**	85.8	88.3	85.9
	Yes	**82.3**	81.9	82.1	85.9
	p	***0.023***	*0.249*	*0.064*	*1.00*
Use of publicly paid care	No	**89.4**	**89.4**	**89.6**	**91.5**
	Yes	**80.1**	**73.3**	**70.4**	**75.0**
	p	***0.003***	***<0.001***	***<0.001***	***<0.001***
Use of privately paid care	No	**82.2**	**78.0**	81.6	**81.5**
	Yes	**91.4**	**90.2**	87.1	**91.4**
	p	***0.004***	***<0.001***	*0.079*	***0.002***
Incongruence informal care	No	**82.8**	81.6	82.2	83.9
	Yes	**89.4**	86.7	87.2	89.0
	P	***0.037***	*0.128*	*0.122*	*0.144*
Incongruence formal care	No	83.9	83.5	84.0	84.5
	Yes	88.0	83.7	84.6	88.2
	p	*0.249*	*1.000*	*0.905*	*0.288*
Sex	Man	89.0	85.8	85.4	88.7
	Female	83.5	82.4	83.5	84.1
	p	*0.096*	*0.340*	*0.628*	*0.186*
Education	Low	**81.2**	**78.0**	**78.5**	82.9
	Middle	**87.4**	**87.8**	**85.6**	83.9
	High	**91.9**	**88.1**	**90.2**	91.4
	p	***0.012***	***0.007***	***0.007***	*0.059*
Partnerstatus	No	83.8	82.4	**78.3**	83.8
	Yes	86.7	84.7	**89.2**	87.6
	p	*0.408*	*0.494*	***0.001***	*0.246*

Note. Statistically significant associations in bold

Table 2

Average number of functional limitations (0-24), chronic diseases (0-7), hours of care. control over care (3-9), and age per wave, for respondents that experienced care as sufficient and respondents that experienced care as insufficient

		Wave 2012/13	Wave 2015/16	Wave 2018/19	Wave 2021/22
Functional limitations	Total	**6.28**	**5.27**	**4.81**	**4.76**
	Insufficient	**9.62**	**8.12**	**8.13**	**6.29**
	Sufficient	**5.69**	**4.71**	**4.19**	**4.50**
	p	***<0.001***	***<0.001***	***<0.001***	***0.006***
N chronic diseases	Total	**1.90**	**1.66**	**1.80**	**1.78**
	Insufficient	**2.52**	**1.99**	**2.33**	**2.29**
	Sufficient	**1.80**	**1.59**	**1.70**	**1.70**
	p	***<0.001***	***0.002***	***<0.001***	***<0.001***
Total hours of care	Total	4.62	4.36	**5.11**	4.35
	Insufficient	6.50	5.26	**8.44**	4.36
	Sufficient	4.29	4.19	**4.48**	4.35
	p	*0.057*	*0.394*	***0.019***	*0.994*
Control over care	Total	**6.66**	**7.03**	**7.16**	**7.12**
	Insufficient	**6.22**	**6.37**	**6.14**	**6.50**
	Sufficient	**6.74**	**7.16**	**7.36**	**7.22**
	p	***0.049***	***0.001***	***<0.001***	***0.004***
Age	Total	79.75	**79.12**	**78.15**	**78.21**
	Insufficient	80.03	**80.95**	**80.90**	**80.13**
	Sufficient	79.69	**78.76**	**77.64**	**77.89**
	p	*0.722*	***0.018***	***<0.001***	***0.023***

Note. Statistically significant associations in bold

In Table 2, Models 1 and 2 examined the first research question: To what extent has perceived care sufficiency changed by region and degree of urbanisation? Model 1 estimated the effect of year of observation, region and degree of urbanisation on sufficiency of care, adjusted for person characteristics. Time and region were not significantly related to care sufficiency. For each additional unit of urbanisation level, the odds ratio (OR) was 0.88, indicating a 0.88-fold probability of receiving sufficient care. The 95% confidence interval (95% BI) ranged from [0.80; 0.98], so this OR was between 0.8 and 0.98 when repeated 100 times 95 times. Model 2 tested for an interaction effect between time and region or level of urbanisation, but this was not the case.

In Models 3 to 5, we examined the second research question: to what extent do care needs, characteristics of care use (intensity, types) and wishes regarding care (preferences and perceived direction) contribute to care sufficiency? Model 3 estimated the effect of time together with health, adjusted for person characteristics. In 2015/16, people were significantly less likely to experience sufficiency of care than in 2011/12 OR: 0.72 [0.53; 0.98]. Experiencing one more point on the disability scale made people 0.93 [0.90; 0.95] times more likely to experience insufficient care. Having another chronic illness increased the odds of having sufficient care by 0.78 [0.70; 0.87] times, suggesting that higher care needs decrease the odds of having sufficient care.

Aspects of care were added in model 4. Using 2011/12 as year of reference, it was found that 2015/16 OR: 0.69 [0.50; 0.94] and 2018/19 OR: 0.66 [0.47; 0.94] had substantially lower odds of care sufficiency. In 2021/22, the OR of 0.79 was no longer statistically significant. However, the confidence interval, which ranged from 0.54 to 1.15, showed that both a positive and negative odds were consistent with our data. An effect in which one experienced lower odds of having sufficient care in 2021/22 than in 2011/12 fitted our data, and an effect in which one had higher odds of having sufficient care sufficiency in 2021/22 than in 2011/12 fitted the data. Receiving publicly paid care was negatively associated with care sufficiency. Recipients of publicly paid care had 0.62 [0.43; 0.88] times the odds on care sufficiency as non-publicly paid care recipients. Model 5 shows that both incongruence for receiving informal care and control over care were almost not associated with care sufficiency. Model 6 includes all variables in the model. The following associations with care sufficiency were significant: time, degree of urbanisation, functional disability, chronic diseases, publicly paid care and education level.

Considering only two instead of five forms of care had no significant influence on the results. Models using 2008/9 as the reference year showed no time effect. Health and publicly paid care showed a strong association with care sufficiency, and therefore the effect of time was significant only when the time difference in these two factors was taken into account. Sensitivity analysis showed that the time difference in both factors was not as large in the 2009 comparison as in the 2012 comparison. This did not appear to be due to cohort differences.

Table 3 part 1

Multilevel analyses with care sufficiency as the dependent variable, models 1, 2 and 3

	Model 1			*Model 2*			*Model 3*		
		95% CI			*95% CI*			*95% CI*	
	OR	*LL*	*UL*	*OR*	*LL*	*UL*	*OR*	*LL*	*UL*
2015/16	0.81	0.60	1.10	0.42	0.13	1.35	**0.72**	**0.53**	**0.98**
2018/19	0.82	0.59	1.14	0.45	0.08	2.65	0.73	0.52	1.03
2021/22	0.90	0.62	1.29	0.52	0.08	3.57	0.82	0.57	1.20
Amsterdam	1.79	0.76	4.25	1.26	0.34	4.69			
Oss	1.65	0.68	4.01	1.15	0.29	4.53			
Zwolle	1.88	0.78	4.53	1.10	0.28	4.24			
Degree of urbanisation	**0.88**	**0.80**	**0.98**	0.86	0.72	1.03			
Female	0.84	0.62	1.14	0.83	0.61	1.13	0.88	0.65	1.20
High education	**2.38**	**1.62**	**3.49**	**2.41**	**1.64**	**3.54**	**1.64**	**1.12**	**2.39**
Middle education	**1.63**	**1.20**	**2.23**	**1.65**	**1.21**	**2.25**	**1.39**	**1.02**	**1.90**
Has a partner	1.13	0.84	1.51	1.12	0.83	1.51	1.08	0.80	1.46
Age	**0.98**	**0.96**	**0.99**	**0.98**	**0.96**	**0.99**	0.99	0.98	1.02
Functional limitations							**0.93**	**0.90**	**0.95**
N of chronic diseases							**0.78**	**0.70**	**0.87**
2015 * Amsterdam				2.08	0.58	7.43			
2015 * Oss				2.28	0.61	8.44			
2015 * Zwolle				1.71	0.46	6.36			
2018 * Amsterdam				1.50	0.24	9.27			
2018 * Oss				2.03	0.31	13.32			
2018 * Zwolle				2.33	0.35	15.33			
2021 * Amsterdam				1.71	0.23	12.52			
2021 * Oss				1.81	0.23	14.15			
2021 * Zwolle				1.67	0.22	12.78			
2015 * Degree of urbanisation				1.08	0.81	1.44			
2018 * Degree of urbanisation				1.08	0.85	1.38			
2021 * Degree of urbanisation				0.95	0.75	1.22			

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit; UL = Upper Limit. Statistically significant associations in bold

Table 3 part 2

Multilevel analyses with care sufficiency as the dependent variable, models 4, 5 and 6

	Model 4			*Model 5*			*Model 6*		
		95% CI			*95% CI*			*95% CI*	
	OR	*LL*	*UL*	*OR*	*LL*	*UL*	*OR*	*LL*	*UL*
2015/16	**0.69**	**0.50**	**0.94**	**0.68**	**0.50**	**0.94**	**0.70**	**0.51**	**0.96**
2018/19	**0.66**	**0.47**	**0.94**	**0.64**	**0.45**	**0.91**	**0.67**	**0.47**	**0.96**
2021/22	0.79	0.54	1.15	0.79	0.54	1.16	0.81	0.55	1.20
Amsterdam							1.40	0.58	3.35
Oss							1.28	0.52	3.12
Zwolle							1.45	0.59	3.52
Degree of urbanisation							**0.89**	**0.80**	**0.99**
Female	0.84	0.61	1.15	0.82	0.60	1.13	0.82	0.59	1.13
High education	1.45	0.98	2.15	1.37	0.93	2.03	**1.53**	**1.02**	**2.29**
Middle education	1.32	0.97	1.81	1.28	0.93	1.75	1.36	0.99	1.87
Has a partner	1.01	0.75	1.36	0.98	0.73	1.33	0.94	0.69	1.27
Age	1.00	0.98	1.02	1.00	0.98	1.02	1.00	0.98	1.02
Functional limitations	**0.94**	**0.91**	**0.96**	**0.94**	**0.91**	**0.97**	**0.94**	**0.92**	**0.97**
N of chronic diseases	**0.79**	**0.71**	**0.88**	**0.80**	**0.71**	**0.89**	**0.80**	**0.71**	**0.89**
Receives informal care	1.14	0.82	1.59	1.12	0.80	1.55	1.08	0.78	1.51
Receives privately paid care	1.28	0.92	1.78	1.27	0.91	1.77	1.23	0.88	1.72
Receives publicly paid care	**0.62**	**0.43**	**0.88**	**0.67**	**0.46**	**0.97**	**0.67**	**0.46**	**0.97**
Total hours of care	1.00	0.99	1.01	1.00	0.99	1.01	1.27	0.95	1.68
Incongruence informal care				1.27	0.96	1.69	1.00	0.99	1.01
Control over care				1.07	0.99	1.15	1.07	0.99	1.15
2015 * Amsterdam									
2015 * Oss									
2015 * Zwolle									
2018 * Amsterdam									
2018 * Oss									
2018 * Zwolle									
2021 * Amsterdam									
2021 * Oss									
2021 * Zwolle									
2015 * Degree of urbanisation									
2018 * Degree of urbanisation									
2021 * Degree of urbanisation									

Note. Standard errors in parentheses. 95% Confidence Interval, LL = Lower Limit; UL = Upper Limit. Statistically significant associations in bold

Discussion and conclusion

The motivation for the study was the reform of long-term care and the resulting potential changes in the perceived sufficiency of care. The results showed that the percentage of older people in need of care who perceived care to be sufficient was very high (over 85%) and that this percentage did not change significantly over time. However, when we held care needs, care utilisation and person characteristics constant, the percentage of older people who felt care was sufficient appeared to decrease in 2015/16 and 2018/19 compared to 2011/12. This suggests a decline in the perceived sufficiency of care in the early years following the reform, among people with the same care needs and care utilisation. However, this could also be a specific difference to 2011/12, as the sensitivity analyses with 2008/9 as the reference year showed no time effect. Care sufficiency went back towards 2011/12-levels in 2021/22, which could mean that people have learnt to cope with the changes caused by the long-term care reform.

We found no difference by region, but older people from non-urban areas were relatively more likely to consider care as sufficient than older people from highly urbanised areas. However, the differences appear to have decreased since decentralisation, as urbanisation had the strongest influence on care sufficiency in 2011/12. Moreover, the difference was only a few per cent and there did not appear to be a moderating effect of time on the degree of urbanisation. Therefore, it cannot be concluded that the effect of urbanisation rate on care sufficiency has changed as a result of the care reform. Furthermore, the results showed that the need for care, the utilisation of public care and the level of education were strongly correlated with the perceived sufficiency of care. The greatest influence was the need for care - those with health problems perceived care as less sufficient. This is consistent with previous findings (Naidu, 2009; Spiers et al., 2022). Care may feel more sufficient if it is better able to restore the negative effects of health loss on wellbeing, and restore daily functioning to the original level (Haex et al., 2022). For many health conditions, care no longer appeared to mitigate the negative impact of health loss on wellbeing (Abramowska-Kmon et al., 2023).

The negative association between publicly paid care and care sufficiency was consistent over time. The model without public care (in the sensitivity analysis) showed that this effect was partly due to the experienced control over care. These results suggest that the way care is provided is not sufficient. It is possible that the workload in publicly paid care leads to care being provided less well or frequently (Vermunt et al., 2023), which may also contribute to loss of control over care in older people (Vermunt et al., 2023). In the current care system, problems such as scarcity, accessibility and workload for care professionals have not yet been solved even after the reform (De Groot et al., 2018; Vermunt et al., 2023). As a key component of sufficient care in the general care system is publicly paid care, there are still concerns about how best to organise this form of care. A key recommendation is that care should be designed in such a way that older people have a lot of control over their care, which is one of the key determinants of care sufficiency. At the same time, a shift to other forms of care can also have disadvantages. Overburdening informal carers (De Groot et al., 2018) can lead to problems for informal carers such as burnout and other health issues.

Public care does not appear to have been fully replaced by informal and private care. Although informal and private care can have a positive impact on care sufficiency, an increase in informal or privately paid care does not seem to explain the recovery in care sufficiency. Perhaps by 2021 the initial implementation problems had been resolved, publicly paid care was more accessible again or people were receiving better tailored care than before anyway.

In addition, of all the personal characteristics analysed, the level of education had the strongest influence on care sufficiency. People with higher levels of education experienced care as more sufficient, possibly because they received relatively more privately paid care and experienced more control over care (Galenkamp et al., 2012). The effect of education was actually greater in a model without privately paid care (in the sensitivity analyses). However, this effect also persisted in a model with privately paid care. This suggests that people with a higher level of education are better able to organise care according to their wishes, and not only in relation to privately paid care.

The results suggest that both the supply of and demand for long-term care are important for the degree of perceived care sufficiency. We conclude this from the importance of the degree of urbanisation and the time of observation on the one hand and the importance of the demand for long-term care and the use of public long-term care services on the other. The degree of match between supply and demand is reflected in the utilisation of care types, hours of care and the perceived direction of care, but the multivariate analyses show that there is still unexplained variance for the time difference in care sufficiency. This requires an explanation that incorporates even more characteristics of supply and demand. The number of hours available in relation to the number of hours required is an important supply characteristic. Several studies on acute and long-term care report that procedural characteristics explain more variance in care sufficiency than structural characteristics (From et al., 2009; Kajonius & Kazemi, 2016). Examples of these procedural characteristics are: Information about the availability of care and care facilities, degree of flexibility in the provision of care, relationship with the carer, influence, respect, autonomy (From et al., 2009; Kajonius & Kazemi, 2016).

Strengths and limitations

A larger sample size would have allowed us to use postal code as a predictor rather than the global regional classification currently used. A GIS analysis between postal code and care sufficiency would perhaps also provide more insight into the relationship between region and care sufficiency. The strengths of this study lie in the use of representative and up-to-date data and in filling a gap in our knowledge of what determines long-term care sufficiency.

Conclusion

Our study shows that there was a slight decline in perceived care sufficiency after the long-term care reform, but it recovered to 2012 baseline by 2022. Care sufficiency did not differ by region; however, older people living in less urbanised areas experienced higher care sufficiency. Care utilisation tailored to care needs can lead significantly to perceived care sufficiency. However, the use of publicly paid care appears to be the form of care that contributes least to perceived care sufficiency. One possible explanatory factor for this is the lack of control over care.

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Summary

Western societies, particularly in countries like the Netherlands, are experiencing significant demographic shifts as their populations age. However, this rise in longevity is not paralleled by an increase in disability-free life years, leading to a greater burden of chronic diseases among older adults. Diversity in health outcomes among older adults is significant, with factors such as gender, age, and educational background influencing successful aging trajectories. Health issues are a primary driver of care needs, resulting in varying care trajectories for older individuals. These care needs can be met through either informal (unpaid family caregivers) or formal (paid professional caregivers) long-term care options. Unlike acute care, which addresses immediate health concerns, long-term care aims to manage chronic health conditions and restore wellbeing. Wellbeing is influenced by the different types of care older adults use. Research indicates a negative correlation between publicly funded care and wellbeing, while the relationship between informal care and wellbeing is mixed. Understanding the dynamics of health, care, and wellbeing necessitates a longitudinal approach, particularly as the aging population significantly impacts long-term care systems.

In response to steadily rising health care expenditures, significant reforms to the Dutch long-term care system were enacted in 2015. This restructuring aimed to tighten eligibility for institutional care and decentralize home care and social assistance. Municipalities faced a 35% reduction in funding, which resulted in increasing pressure to deliver care efficiently. The government encouraged older adults to utilize personal resources and informal care from their social networks. The 2015 reform resulted in significant shifts in care organization and delivery. The changes brought about by the reform potentially affected the ability of older adults to access and receive quality care. This, in turn, has implications for their overall wellbeing. Understanding these dynamics is critical for future care planning, especially as countries like the Netherlands grapple with increasing demands on their long-term care systems.

This study aims to investigate the relationships between health, care use, and wellbeing among older Dutch adults from 2012 to 2021, particularly in light of the 2015 long-term care reform. It seeks to explore the following questions:

Chapter 2: What are the trajectories in functional limitations and cognitive functioning can be identified in Dutch adults aged 75 and older in a period of three years? And how are age, sex, socioeconomic status, and chronic diseases associated with these trajectories?

Chapter 3: Which care network types can be identified, and which transitions between these care network types occur? Which health and socioeconomic characteristics of care recipients are associated with these care networks?

Chapter 4: Do the four elements of caregiving (type of caregiver, quantity, sufficiency, experienced control) have a moderating effect on the relationship between functional limitations and wellbeing?

Chapter 5: To what extent has the perceived care sufficiency changed in the period after the reform (2012 - 2022) and to what extent does this differ by region and degree of urbanization?
To what extent do care needs, characteristics of care use (intensity, types), and wishes regarding care (preferences and perceived control) contribute to the degree of perceived sufficiency of care?

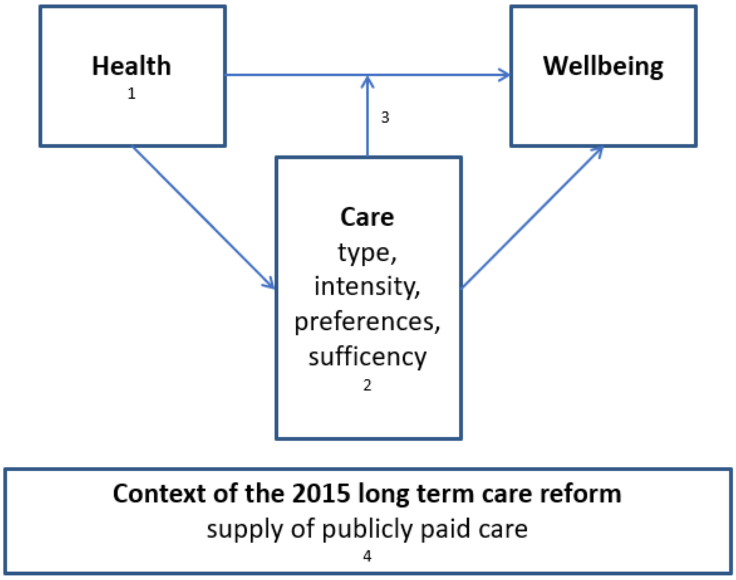
By analysing longitudinal data, the research aims to shed light on the interplay between health, care use, and wellbeing, thus contributing valuable insights into the effects of long-term care policy changes on older adults.

Theoretical model

The process of care use is explained by the Andersen-Newman model (Andersen & Newman, 1973), which identifies three primary determinants of health care utilization: the need factors (health status), predisposing factors which influence the likelihood of seeking care (e.g. gender, age, and education), and enabling factors, which influence the availability of resources (e.g. social network, income). While the Andersen-Newman model focuses primarily on care utilization, the study extends this by considering the outcomes of care, particularly its impact on wellbeing.

To understand how care affects wellbeing, the study refers to the Self-Determination Theory (Deci & Ryan, 2000), which posits that psychological wellbeing is driven by three key factors: relatedness, autonomy, and competence. These determinants of wellbeing are influenced by the nature of care—who provides it, how much is provided, and whether it aligns with the preferences of the care recipient. Studies applying the Self-Determination Theory in care contexts suggest that wellbeing is higher when care is provided by close relations, when the care is sufficient, and when recipients maintain control over their care.

The study adopts a longitudinal approach to explore how changes in health and care use affect wellbeing over time. It examines different health trajectories in older adults and how these impact their care trajectories and wellbeing. A conceptual model (figure 1) visualizes the relationships between health, care use, and wellbeing, with the 2015 long-term care reform in the Netherlands serving as the broader context for these studies. The reform, though not directly analysed in the empirical part, provides an important backdrop for understanding the dynamics of health, care, and wellbeing.



1. Trajectories of health
2. Trajectories of care
3. Care features moderating the health-wellbeing association
4. Care sufficiency as outcome of health, care use, and wellbeing

Methods

Data

In all chapters we used data from The Longitudinal Aging Study Amsterdam (LASA), which is a comprehensive, ongoing study that tracks the ageing process in older adults (aged 55+) in the Netherlands. Initiated in 1992, LASA originally sampled 3,107 men and women aged 55-84 from 11 municipal registries, stratified by age and sex. Additional cohorts were added in 2002 and 2012, bringing in new participants aged 55 and older. The study collects data every three years through face-to-face interviews conducted by trained interviewers. If participants are unable or unwilling to complete a full interview, shorter alternatives, such as a telephone or a proxy interviews, are offered. For chapter 2 we also used the LASA 75-PLUS study, focusing specifically on older participants born before 1941. This ancillary study involved three additional measurement waves over nine months, with 601 out of 686 eligible participants taking part. These additional measurement waves were conducted between the regular LASA measurement cycles of 2015/16 and 2018/19.

Analyses and main findings

Chapter 2 – Health Trajectories

In chapter 2 we examined trajectories in functional and cognitive limitations among older adults using data from the LASA 75-PLUS study. Using Growth-Based Trajectory Modelling, with mortality jointly estimated, we identified five functional limitation trajectories and four cognitive functioning trajectories. Multimorbidity was related to functional limitations but not to most cognitive trajectories. Adverse trajectories were more common among older, lower-educated individuals. The study found that older adults with the highest care needs often lived at home with significant care support, especially those in the worst trajectories.

Chapter 3 – Trajectories in Care Networks

This chapter explored the transitions between different care networks among older adults over time, using data from LASA between 2012 and 2019. We used a Latent Transition Analysis, with a nursing home and decease as missing states. Five types of care networks were identified: no-care, privately-paid, mixed-informal, mixed-publicly paid, and co-residential. Once older adults began receiving care, they typically did not revert to no-care. Transitions between networks were often driven by deteriorating health. The study found that certain care networks, particularly mixed-informal and mixed-publicly paid, served as endpoints before transitioning to a care facility or death.

Chapter 4 – The Moderating Effect of Care on Wellbeing

This chapter investigated how different aspects of care affect the relationship between functional limitations and wellbeing. Using LASA data between 2012 and 2019, we estimated both the between and within effects in a multilevel linear regression. No moderation effect was found for control over care or type of caregiver. However, starting to receive informal care was linked to increased depressive symptoms, suggesting that some informal care may negatively impact wellbeing. Publicly paid care showed a moderation effect: while more hours of care increased depressive symptoms when functional limitations were low, it led to the lowest levels of depressive symptoms when limitations were high. Sufficient care buffered against depressive symptoms but this effect weakened as the need for care increased.

Chapter 5 – Care Sufficiency

In this chapter we analysed levels of perceived of care sufficiency among older adults from 2012 to 2022. We included all older adults that were 65 or older, that received or started to receive care between 2012 and 2022. Using a multilevel logistic regression we assessed which characteristics associated with perceived care sufficiency. Respondents were nested in time.

A high proportion (85%) of Dutch older adults perceived their care as sufficient, although there was a dip in care sufficiency during the 2015-2019 period, likely due to care reform implementation issues. By 2021/22, care sufficiency levels had returned to pre-reform levels. Publicly paid care was consistently associated with lower perceptions of care sufficiency. Higher education levels correlated with higher perceived care sufficiency. Regional differences in care sufficiency were not noted. But there were differences based on degree of urbanisation, with rural residents generally perceiving their care as more sufficient than urban residents, though these differences lessened over time.

Main Contributions and Conclusions

The study reveals that health is the primary determinant of care use among older adults, with 10-20% of Dutch seniors consistently having high care needs. Post-reform, these needs were increasingly met by mixed-informal care networks. The type of care network used by older adults (informal, publicly paid, or privately paid) was found to negatively impact wellbeing, except for co-residential care. Starting to receive informal care, in particular, was linked to lower wellbeing. However, more hours of publicly paid care seemed to improve wellbeing when functional limitations were high. Control over care and care sufficiency were both important for wellbeing, but they did not fully counterbalance the negative effects of functional limitations. After initial decreases post-reform, care sufficiency returned to pre-reform levels by 2021. Making it likely that the initial decrease was due to implementation issues rather than systemic failure.

Theoretical Reflection

The study utilized the Andersen-Newman model to explore factors influencing care use, confirming that health (need factors), demographic characteristics (predisposing factors), and enabling factors like having a spouse significantly determine care utilization. Enabling factors from caregivers' perspectives, such as their proximity, working hours, and willingness to provide care, were not directly considered but are likely important predictors. Macro-level influences, including societal norms and events like the Great Recession, digitalization, the COVID-19 pandemic, and labour market shortages, might also have been potential influences on care use and transitions between care networks.

To explain the relationship between care use and wellbeing, the Self-Determination Theory (SDT) was applied, showing mixed effects of relatedness on wellbeing. Informal care, particularly when perceived as a burden, could reduce wellbeing, while care from a spouse often enhanced it due to the strong emotional bonds. Formal care was generally associated with lower wellbeing, possibly due to weaker bonds with caregivers. The concepts of autonomy and competence were less strongly linked to wellbeing, suggesting that future research should explore care-specific autonomy and the perceived burden of care in greater detail.

Methodological Reflection

The methodological approach of this study, which tracked trajectories in health and care networks while co-modelling mortality, represents a significant strength. This co-modelling of missing states allowed for the inclusion of a substantial proportion of the oldest old, a demographic often excluded from similar studies. The use of the 75PLUS dataset, with its nine-monthly measurement waves, provided a novel and robust longitudinal framework, enabling the examination of health and care needs over relatively short intervals. This methodology was particularly effective in capturing the dynamics of older adults with significant limitations and high care needs, demonstrating that around a quarter of older adults developed substantial care needs over a three-year period.

The trajectory approach also highlighted that older adults in mixed-informal, mixed-publicly paid, or co-residential care networks had higher probabilities of transitioning to nursing homes. This finding supports the idea that nursing homes often represent a final stage in the care trajectory, with multiple types of care typically utilized at home before this transition occurs.

However, the study's temporal scope limits broader conclusions about the effects of the 2015 long-term care reform. A comparison with similar studies from the period of 2009 to 2012 would have provided more definitive insights into whether observed trends were due to the reform or were part of broader temporal shifts. Further research, perhaps utilizing broadscale population data from the *Centraal Bureau voor de Statistiek* (Central Bureau of Statistics), could explore these dynamics over different time periods using cohort-sequential designs.

A larger sample size in the 75PLUS study would have enabled a more detailed examination of the oldest old. The inability to estimate a model using age as a predictor—due to excessive extrapolation among the oldest ages—suggests that this demographic remains underrepresented. Additionally, shorter intervals between measurements (e.g., monthly) could have provided more granular insights into fluctuations in functioning and allowed for stronger inferences regarding causal relationships between health, care, and wellbeing.

Distinguishing between types of care (e.g., personal care, household care, nursing care) would have been beneficial, particularly in understanding obstacles in care provision. This distinction could have been achieved through direct measurement or by linking data from the *Centrum Indicatiestelling Zorg* (Centre for Care Indications) and *Centraal Bureau voor de Statistiek* to our dataset. Understanding the interaction effects between care type and caregiver type could have illuminated how certain care networks develop and the potential mismatch between care needs and available care resources.

The study's focus on psychological wellbeing using the CES-D scale may have limited specific conclusions. Exploring other wellbeing indicators, such as quality of life or life satisfaction, might have revealed different determinants of wellbeing outcomes. Furthermore, operationalizing wellbeing as eudaimonia could have highlighted the potential positive effects of care, such as emotional support and empathic witnessing, which were not fully captured by the CES-D scale.

Implications for Policy and Practice

The study's findings underscore the importance of addressing the needs of older adults with high care requirements, particularly as the Dutch population ages and the proportion of the oldest old increases. With 5-10% of older adults requiring near-constant home care, there is a growing demand for sustainable care solutions.

The increase in mixed-informal care networks post-reform suggests that this care network may align with a financially sustainable care system. However, the negative impact of informal care on wellbeing highlights the need for policies that support informal caregivers, such as those outlined in the *Mantelzorgagenda*. Enhancing social capital and fostering long-term community building could be crucial for sustaining these care networks.

The study also raises concerns about inequalities in care access, particularly for lower socioeconomic status groups. The decline in publicly paid care usage among more affluent older adults post-reform suggests that some may not be receiving the care they need, a situation exacerbated by the "*zorgval*" phenomenon. The *zorgval* describes the situation in which older adults that were either on waiting lists for nursing homes, or with increasingly high care needs, were transferred from care laws with low contribution payments, to care laws without a cap on the contribution payment (Long-Term Care

Act: Wlz). In these situations, for some older adults, the costs of care became so high that they received less care than they needed. This underscores the importance of ensuring equitable access to care and addressing unintended negative consequences of care policies.

The observed transitions to nursing homes, despite a policy focus on independent living, suggest that nursing homes remain a necessary option for many older adults. This finding aligns with the in the *Wonen en Zorg Ouderen* program’s (Housing and Care for Older adults) emphasis on providing care at home "if possible," while acknowledging that nursing home care is sometimes the only viable option.

The study highlights the need for preventative healthcare to reduce the burden on the long-term care system. Municipalities and health insurers may need to place greater emphasis on fall prevention and promoting healthy lifestyles among older adults to mitigate the rising demand for care.

Conclusion

In conclusion, this dissertation reveals no major differences in health, care use, wellbeing, and care sufficiency after the 2015 Dutch care reform. However, there was a slight decline in care sufficiency, increased reliance on informal care, and a negative relationship between informal care and wellbeing. The findings raise important questions about the future of care provision in the Netherlands, particularly in light of societal changes such as labour market shortages, population aging, and the rising costs of care. To ensure the sustainability of the care system, efforts must focus on supporting informal care networks, fostering social capital, and emphasizing preventative health measures.

Samenvatting

Westerse samenlevingen, vooral in landen zoals Nederland, ondergaan aanzienlijke demografische verschuivingen nu hun bevolkingen vergrijzen. Deze toename in levensduur gaat echter niet gepaard met een toename van het aantal jaren zonder beperkingen, wat leidt tot een grotere last van chronische ziekten onder oudere volwassenen. Er is een aanzienlijke diversiteit in gezondheidsuitkomsten onder ouderen, waarbij factoren zoals geslacht, leeftijd en opleidingsachtergrond invloed hebben op het verloop van het verouderingstraject. Gezondheidsproblemen zijn een belangrijke drijfveer voor zorgbehoeften, wat resulteert in uiteenlopende zorgtrajecten voor ouderen. Deze zorgbehoeften kunnen worden vervuld door verschillende vormen van langdurige zorg: informele verzorgers (onbetaalde mantelzorgers) of formele verzorgers (betaalde professionele zorgverleners). In tegenstelling tot acute zorg, die gericht is op onmiddellijke gezondheidsproblemen, heeft langdurige zorg tot doel chronische gezondheidsaandoeningen te beheersen en het welzijn te herstellen. Welzijn wordt beïnvloed door de verschillende soorten zorg die ouderen gebruiken. Onderzoek toont een negatieve correlatie aan tussen door publiek gefinancierde zorg en welzijn, terwijl de relatie tussen informele zorg en welzijn zowel positieve als negatieve correlaties heeft. Het begrijpen van de dynamiek van gezondheid, zorg en welzijn vereist een longitudinale benadering, vooral omdat de vergrijzing een aanzienlijke impact heeft op systemen voor langdurige zorg.

In reactie op de gestaag stijgende zorguitgaven werden in 2015 aanzienlijke hervormingen doorgevoerd in het Nederlandse langdurige zorgsysteem. Deze herstructurering was gericht op het aanscherpen van de toegang tot institutionele zorg en het decentraliseren van thuiszorg en sociale bijstand. Gemeenten kregen te maken met een vermindering van 35% in financiering, wat leidde tot een toenemende druk om zorg efficiënt te leveren. De overheid moedigde ouderen aan om gebruik te maken van persoonlijke middelen en informele zorg uit hun sociale netwerken. De hervorming van 2015 leidde tot aanzienlijke verschuivingen in de organisatie en levering van zorg. De veranderingen als gevolg van de hervorming hadden mogelijk invloed op de toegang tot kwalitatieve zorg. Dit heeft op zijn beurt implicaties voor hun algehele welzijn. Het begrijpen van deze dynamiek is cruciaal voor toekomstige zorgplanning, vooral omdat landen zoals Nederland worstelen met toenemende druk op hun langdurige zorgsystemen.

Deze studie heeft tot doel de relaties tussen gezondheid, zorggebruik en welzijn onder oudere Nederlandse volwassenen van 2012 tot 2021 te onderzoeken, met name in het licht van de hervorming van de langdurige zorg in 2015. Het richt zich op de volgende vragen:

Hoofdstuk 2: Welke trajecten in functionele beperkingen en cognitief functioneren kunnen worden geïdentificeerd bij Nederlandse volwassenen van 75 jaar en ouder over een periode van drie jaar? En hoe zijn leeftijd, geslacht, sociaaleconomische status en chronische ziekten geassocieerd met deze trajecten?

Hoofdstuk 3: Welke typen zorgnetwerken kunnen worden geïdentificeerd, en welke overgangen tussen deze zorgnetwerken vinden plaats? Welke gezondheids- en sociaaleconomische kenmerken van zorgontvangers zijn geassocieerd met deze zorgnetwerken?

Hoofdstuk 4: Hebben de vier elementen van zorgverlening (type zorgverlener, hoeveelheid, voldoende zorg, ervaren controle) een modererend effect op de relatie tussen functionele beperkingen en welzijn?

Hoofdstuk 5: In hoeverre is de ervaren zorgtoereikendheid veranderd in de periode na de hervorming (2012 - 2022) en in hoeverre verschilt dit per regio en mate van verstedelijking? In hoeverre dragen zorgbehoeften, kenmerken van zorggebruik (intensiteit, typen) en wensen met betrekking tot zorg (voorkeuren en ervaren controle) bij aan de mate van ervaren zorgtoereikendheid?

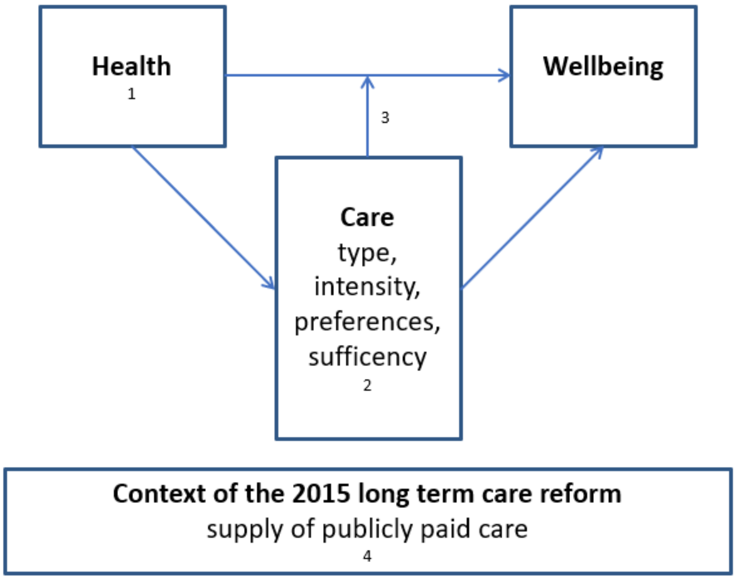
Door het analyseren van longitudinale gegevens streeft het onderzoek ernaar inzicht te bieden in de wisselwerking tussen gezondheid, zorggebruik en welzijn, en zo waardevolle inzichten te leveren in de effecten van veranderingen in het beleid voor langdurige zorg op oudere volwassenen.

Theoretisch model

Het proces van zorggebruik wordt verklaard door het Andersen-Newman model (Andersen & Newman, 1973), dat drie primaire determinanten van zorggebruik identificeert: de behoeftefactoren (gezondheidsstatus), predisponerende factoren die de kans op het zoeken naar zorg beïnvloeden (bijvoorbeeld geslacht, leeftijd en opleiding) en faciliterende factoren, die de beschikbaarheid van middelen beïnvloeden (bijvoorbeeld sociaal netwerk, inkomen). Hoewel het Andersen-Newman model zich voornamelijk richt op zorggebruik, breidt deze studie dit uit door de uitkomsten van zorg, met name de impact ervan op welzijn, te beschouwen.

Om te begrijpen hoe zorg het welzijn beïnvloedt, hebben we gebruik gemaakt van de Zelfdeterminatietheorie (Deci & Ryan, 2000), die stelt dat psychologisch welzijn wordt gedreven door drie kernfactoren: verbondenheid, autonomie en competentie. Deze determinanten van welzijn worden beïnvloed door de aard van de zorg - wie deze verleent, hoeveel er wordt verstrekt, en of deze overeenkomt met de voorkeuren van de zorgontvanger. Studies die de Zelfdeterminatietheorie toepassen in zorgcontexten suggereren dat welzijn hoger is wanneer zorg wordt verleend door naaste relaties, wanneer de zorg voldoende is, en wanneer ontvangers controle behouden over hun zorg.

Onze studie hanteert een longitudinale benadering om te onderzoeken hoe veranderingen in gezondheid en zorggebruik het welzijn in de loop van de tijd beïnvloeden. Het onderzoekt verschillende gezondheidstrajecten bij ouderen en hoe deze hun zorgtrajecten en welzijn beïnvloeden. Een conceptueel model (figuur 1) visualiseert de relaties tussen gezondheid, zorggebruik en welzijn, met de langdurige zorghervorming van 2015 in Nederland als bredere context voor deze studies. De hervorming, hoewel niet direct geanalyseerd in het empirische deel, biedt een belangrijk kader voor het begrijpen van de dynamiek van gezondheid, zorg en welzijn.



1. Trajectories of health
2. Trajectories of care
3. Care features moderating the health-wellbeing association
4. Care sufficiency as outcome of health, care use, and wellbeing

Methoden

Data

In alle hoofdstukken hebben we gebruik gemaakt van gegevens uit de Longitudinal Aging Study Amsterdam (LASA), een uitgebreide, doorlopende studie die het verouderingsproces bij oudere volwassenen (55+) in Nederland volgt. De studie, die in 1992 werd gestart, omvatte oorspronkelijk 3107 mannen en vrouwen van 55-84 jaar uit 11 gemeentelijke registers, gestratificeerd naar leeftijd en geslacht. Extra cohorten werden toegevoegd in 2002 en 2012, waarbij nieuwe deelnemers van 55 jaar en ouder werden betrokken. De studie verzamelt om de drie jaar gegevens door middel van face-to-face interviews door getrainde interviewers. Als deelnemers niet in staat of niet bereid zijn om een volledig interview af te leggen, worden kortere alternatieven, zoals een telefonisch of proxy-interview, aangeboden. Voor hoofdstuk 2 hebben we ook gebruik gemaakt van de LASA 75-PLUS studie, die zich specifiek richtte op oudere deelnemers geboren voor 1941. Deze aanvullende studie omvatte drie extra meetgolven over negen maanden, waarbij 601 van de 686 in aanmerking komende deelnemers deelnamen. Deze extra meetgolven werden uitgevoerd tussen de reguliere LASA meetcycli van 2015/16 en 2018/19.

Analyses en belangrijkste bevindingen

Hoofdstuk 2 – Gezondheidstrajecten

In hoofdstuk 2 onderzochten we trajecten in functionele en cognitieve beperkingen bij oudere volwassenen met behulp van gegevens uit de LASA 75-PLUS studie. Met behulp van Growth-Based Trajectory Modelling, waarbij mortaliteit gezamenlijk werd geschat, identificeerden we vijf trajecten van functionele beperkingen en vier trajecten van cognitief functioneren. Multimorbiditeit was gerelateerd aan functionele beperkingen, maar niet aan de meeste cognitieve trajecten. Ongunstige trajecten kwamen vaker voor bij oudere, lager opgeleide individuen. De studie toonde aan dat ouderen met de hoogste zorgbehoeften vaak thuis woonden met aanzienlijke zorgondersteuning, vooral degenen in de slechtste trajecten.

Hoofdstuk 3 – Trajecten in Zorgnetwerken

Dit hoofdstuk onderzocht de overgangen tussen verschillende zorgnetwerken onder oudere volwassenen in de loop van de tijd, met behulp van gegevens van LASA tussen 2012 en 2019. We gebruikten een Latent Transition Analysis, met een verpleeghuis en overlijden als ontbrekende staten. Vijf typen zorgnetwerken werden geïdentificeerd: geen-zorg, particulier-betaald, gemengd-informeel, gemengd-publiek betaald, en co-residentieel. Zodra ouderen begonnen met het ontvangen van zorg, keerden ze meestal niet terug naar geen-zorg. Overgangen tussen netwerken werden vaak gedreven door verslechterende gezondheid. De studie vond dat bepaalde zorgnetwerken, met name gemengd-informeel en gemengd-publiek betaald, fungeerden als eindpunten voordat ze overgingen naar een zorginstelling of overlijden.

Hoofdstuk 4 – De Modererende Effecten van Zorg op Welzijn

Dit hoofdstuk onderzocht hoe verschillende aspecten van zorg de relatie tussen functionele beperkingen en welzijn beïnvloeden. Met behulp van LASA-gegevens tussen 2012 en 2019 hebben we zowel de tussen- als binnen-effecten geschat in een multilevel lineaire regressie. Er werd geen modererend effect gevonden voor controle over zorg of type zorgverlener. Er werd echter een significant, zij het klein, effect gevonden voor de hoeveelheid zorg. Ouderen met functionele beperkingen ervoeren een lager welzijn wanneer ze grotere hoeveelheden informele zorg ontvingen. Dit negatieve effect werd versterkt door de aanwezigheid van formele zorg, wat suggereert dat zowel veelvuldige zorgontvangst als een gebrek aan controle over de eigen zorg schadelijk kunnen zijn voor het welzijn van ouderen.

Hoofdstuk 5 – Zorgtoereikendheid na de Hervorming van 2015

Het laatste empirische hoofdstuk onderzocht de determinanten van zorgtoereikendheid en hun veranderingen na de langdurige zorghervorming in Nederland in 2015. Met behulp van longitudinale LASA-gegevens over de periode 2012-2022 werd een multilevel model toegepast om de veranderende determinanten van zorgtoereikendheid te onderzoeken. De resultaten toonden aan dat ervaren zorgtoereikendheid sinds de hervorming van 2015 geleidelijk is afgenomen. Regionale variaties in zorgtoereikendheid werden gevonden, waarbij ouderen in meer verstedelijkte gebieden een grotere afname van zorgtoereikendheid rapporteerden. De mate van toereikendheid werd voornamelijk beïnvloed door de mate van ontvangen zorg (zowel informeel als formeel), de aanwezigheid van sociale steun, en de autonomie in zorgkeuzes.

Belangrijkste Bijdragen en Conclusies

Het onderzoek toont dat gezondheid de belangrijkste determinant is van zorggebruik onder ouderen, waarbij 10-20% van de Nederlandse senioren consequent hoge zorgbehoeften heeft. Na de hervorming werden deze behoeften steeds vaker vervuld door gemengde informele zorgnetwerken. Het type zorgnetwerk dat door ouderen wordt gebruikt (informeel, publiek betaald of particulier betaald) bleek een negatieve impact te hebben op het welzijn, met uitzondering van co-residentiële zorg. Het starten met het ontvangen van informele zorg werd in het bijzonder gekoppeld aan een lager welzijn. Echter, meer uren publiek betaalde zorg leken het welzijn te verbeteren wanneer de functionele beperkingen hoog waren. Controle over zorg en zorgtoereikendheid waren beide belangrijk voor welzijn, maar konden de negatieve effecten van functionele beperkingen niet verzachten. Na aanvankelijke dalingen in zorgtoereikendheid na de hervorming, keerde de zorgtoereikendheid in 2021 terug naar het niveau van vóór de hervorming, wat waarschijnlijk aangeeft dat de aanvankelijke daling te wijten was aan implementatieproblemen.

Theoretische Reflectie

Het onderzoek gebruikte het Andersen-Newman model om factoren te verkennen die zorggebruik beïnvloeden, waarbij werd bevestigd dat gezondheid (behoeftefactoren), demografische kenmerken (voorspellende factoren) en faciliterende factoren zoals het hebben van een partner belangrijke determinanten zijn van zorggebruik. Faciliterende factoren vanuit het perspectief van zorgverleners, zoals hun nabijheid, werktijden en bereidheid om zorg te verlenen, werden niet direct overwogen maar zijn waarschijnlijk belangrijke voorspellers. Invloeden op macroniveau, zoals maatschappelijke normen en gebeurtenissen zoals de Grote Recessie, digitalisering, de COVID-19-pandemie en tekorten op de arbeidsmarkt, hadden mogelijk ook invloed op zorggebruik en overgangen tussen zorgnetwerken.

Om de relatie tussen zorggebruik en welzijn te verklaren, werd de Zelfdeterminatietheorie (SDT) toegepast, waarbij gemengde effecten van verbondenheid op welzijn werden aangetoond. Informele zorg, vooral wanneer deze als een last werd ervaren, kon het welzijn verminderen, terwijl zorg van een partner dit vaak verbeterde vanwege de sterke emotionele banden. Formele zorg werd over het algemeen geassocieerd met lager welzijn, mogelijk door zwakkere banden met zorgverleners. De concepten autonomie en competentie waren minder sterk verbonden met welzijn, wat suggereert dat toekomstig onderzoek specifiek de autonomie in zorg en de ervaren last van zorg in meer detail zou moeten verkennen.

Methodologische Reflectie

De methodologische benadering van deze studie, waarbij trajecten in gezondheid en zorgnetwerken werden gevolgd terwijl mortaliteit mee werd gemodelleerd, maakte het mogelijk een substantieel deel van de oudste ouderen, een demografie die vaak wordt uitgesloten van soortgelijke studies, te includeren. Het gebruik van de 75PLUS-dataset, met zijn negenmaandelijkse meetgolven, bood een nieuw en robuust longitudinaal kader dat het mogelijk maakte om gezondheid en zorgbehoeften over relatief korte intervallen te onderzoeken. Deze methodologie was bijzonder effectief in het vastleggen van de dynamiek van oudere volwassenen met aanzienlijke beperkingen en hoge zorgbehoeften, en toonde aan dat ongeveer een kwart van de ouderen aanzienlijke zorgbehoeften ontwikkelde over een periode van drie jaar.

De trajectbenadering benadrukte ook dat oudere volwassenen in gemengde informele, gemengd publiek betaalde of co-residentiële zorgnetwerken een hogere kans hadden om over te gaan naar verpleeghuizen. Deze bevinding ondersteunt het idee dat verpleeghuizen vaak een laatste fase in het zorgtraject vertegenwoordigen, waarbij een mix van meerdere soorten zorg thuis wordt gebruikt voordat deze overgang plaatsvindt.

De temporele reikwijdte van de studie beperkt echter bredere conclusies over de effecten van de langdurige zorghervorming van 2015. Een vergelijking met soortgelijke studies uit de periode 2009 tot 2012 zou meer definitieve inzichten hebben gegeven in de vraag of waargenomen trends het gevolg waren van de hervorming of deel uitmaakten van bredere temporele verschuivingen. Verder onderzoek, mogelijk met behulp van grootschalige populatiedata van het Centraal Bureau voor de Statistiek, zou deze dynamiek over verschillende tijdsperiodes kunnen verkennen door cohorten te vergelijken.

Een grotere steekproefomvang in de 75PLUS-studie zou een gedetailleerder onderzoek van de oudste ouderen mogelijk hebben gemaakt. Het onvermogen om een model te schatten met leeftijd als voorspeller - vanwege overmatige extrapolatie onder de oudste leeftijden - suggereert dat deze demografie ondervertegenwoordigd blijft. Bovendien zouden kortere intervallen tussen metingen (bijv. maandelijks) meer gedetailleerde inzichten in fluctuaties in functioneren hebben kunnen bieden en sterkere conclusies mogelijk hebben gemaakt over causale relaties tussen gezondheid, zorg en welzijn.

Het onderscheid maken tussen typen zorg (bijv. persoonlijke verzorging, huishoudelijke zorg, verpleging) zou nuttig zijn geweest, vooral om obstakels in de zorgverlening te begrijpen. Dit onderscheid had kunnen worden bereikt door directe meting of door het koppelen van gegevens van het Centrum Indicatiestelling Zorg (CIZ) en Centraal Bureau voor de Statistiek (CBS) aan de studiedataset. Inzicht in de interactie-effecten tussen zorgtype en zorgverlenerstype had kunnen verduidelijken hoe bepaalde zorgnetwerken zich ontwikkelen en waar mogelijke mismatch ontstaat tussen zorgbehoeften en beschikbare zorgbronnen.

De focus van de studie op psychologisch welzijn met behulp van de CES-D-schaal kan specifieke conclusies hebben beperkt. Het verkennen van andere welzijnsindicatoren, zoals kwaliteit van leven of levensvoldoening, had mogelijk andere determinanten van welzijnsuitkomsten onthuld. Bovendien had het operationaliseren van welzijn als *eudaimonia* de mogelijke positieve effecten van zorg, zoals emotionele steun en empathisch getuigen, kunnen benadrukken.

Implicaties voor Beleid en Praktijk

De bevindingen van de studie onderstrepen het belang van het aanpakken van de behoeften van ouderen met hoge zorgbehoeften, vooral nu de Nederlandse bevolking vergrijst en het aandeel van de oudste ouderen toeneemt. Met 5-10% van de ouderen die bijna-constante thuiszorg nodig hebben, is er een groeiende vraag naar duurzame zorgoplossingen.

De toename van gemengde informele zorgnetwerken na de hervorming suggereert dat dit zorgnetwerk mogelijk aansluit bij een financieel duurzaam zorgsysteem. Echter, de negatieve impact van informele zorg op welzijn benadrukt de noodzaak van beleid dat informele zorgverleners ondersteunt, zoals uiteengezet in de Mantelzorgagenda. Het versterken van sociaal kapitaal en het bevorderen van sociale netwerken op lange termijn zou cruciaal kunnen zijn voor het in stand houden van deze zorgnetwerken.

De studie roept ook zorgen op over ongelijkheden in toegang tot zorg, vooral voor groepen met een lagere sociaaleconomische status. De afname van het gebruik van publiek betaalde zorg onder welvarender ouderen na de hervorming suggereert echter ook dat sommigen mogelijk niet de zorg ontvangen die ze nodig hebben, het *zorgval*-fenomeen. De *zorgval* beschrijft de situatie waarin ouderen die ofwel op wachtlijsten voor verpleeghuizen stonden, of met toenemende hoge zorgbehoeften, werden overgebracht van zorgwetten met lage eigen bijdragen naar zorgwetten zonder een plafond op de eigen bijdrage (Wet Langdurige Zorg: Wlz). In deze situaties werden voor sommige ouderen de kosten van zorg zo hoog dat ze minder zorg gebruikten dan ze nodig hadden. Dit onderstreept het belang van het waarborgen van gelijke toegang tot zorg en het aanpakken van onbedoelde negatieve gevolgen van zorgbeleid.

De waargenomen overgangen naar verpleeghuizen, ondanks een beleidsfocus op zelfstandig wonen, suggereren dat verpleeghuizen voor veel ouderen nog steeds een noodzakelijke optie blijven. Deze bevinding komt overeen met de nadruk van het Wonen en Zorg Ouderen-programma op het bieden van zorg thuis "waar mogelijk", waarbij wordt erkend dat verpleeghuiszorg soms de enige haalbare optie is.

Het onderzoek benadrukt de noodzaak van preventieve gezondheidszorg om de druk op het langdurige zorgsysteem te verminderen. Gemeenten en zorgverzekeraars moeten mogelijk meer nadruk leggen op valpreventie en het bevorderen van een gezonde levensstijl onder ouderen om de stijgende zorgvraag te verminderen.

Conclusie

Concluderend onthult dit proefschrift geen grote verschillen in gezondheid, zorggebruik, welzijn en zorgtoereikendheid na de Nederlandse hervorming van 2015. Er was echter een lichte daling in zorgtoereikendheid, een toenemend beroep op informele zorg en een negatieve relatie tussen informele zorg en welzijn. De bevindingen roepen belangrijke vragen op over de toekomst van zorgverlening in Nederland, vooral in het licht van maatschappelijke veranderingen zoals tekorten op de arbeidsmarkt, vergrijzing van de bevolking en de stijgende zorgkosten. Om de duurzaamheid van het zorgsysteem te waarborgen, moeten de inspanningen gericht zijn op het ondersteunen van informele zorgnetwerken, het versterken van sociaal kapitaal en het benadrukken van preventieve gezondheidsmaatregelen.